

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

SUPPLEMENT



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



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- **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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1. APPENDIX I - SEARCH STRATEGIES (PROVISIONAL VERSION)

1.1. Cochrane

Date 11/04/2023 17:35:25

Database Cochrane

Search strategy

- #1 [mh "Waiting lists"]
- #2 ((wait or waiting) NEAR/2 (time or times or list or lists)):ti,kw
- #3 #1 or #2
- #4 ((organ? or kidney? or renal or heart? or cardiac or liver? or hepatic or pancreas or lung? or pancreatic) NEAR/3 (donor? or donation? or shortage or allocation)):ti
- #5 (transplantation? or transplant?):ti
- #6 [mh "Transplants"[m]]
- #7 [mh "organ transplantation"[m]]
- #8 #4 or #5 or #6 or #7
- #9 #3 not #8
- #10 #9 with Cochrane Library publication date Between Jan 2013 and Dec 2023
- #11 #10 in Cochrane Reviews

Comments



1.2. Embase

Date 14 Jul 2023

Database Embase

Search strategy

- #1 ((wait OR waiting) NEAR/2 (time OR times OR list OR lists)):ti,kw
- #2 ((organ\$ OR kidney\$ OR renal OR heart\$ OR cardiac OR liver\$ OR hepatic OR pancreas OR lung\$ OR pancreatic) NEAR/3 (donor\$ OR donation\$ OR shortage OR allocation)):ti
- #3 transplantation\$:ti OR transplant\$:ti
- #4 'transplant'/de
- #5 'organ transplantation'/exp
- #6 #2 OR #3 OR #4 OR #5
- #7 #1 NOT #6
- #8 #7 AND [2013-2023]/py
- #9 #8 NOT [medline]/lim
- #10 #9 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)
- #11 'economics'/exp
- #12 'health economics'/exp
- #13 'pharmacoeconomics'/de
- #14 'drug cost'/de
- #15 'drug formulary'/de
- #16 'economic aspect'/de
- #17 'economic evaluation'/exp
- #18 'cost'/exp



- #19 'quality-adjusted life years'/de
- #20 'monte carlo method'/exp
- #21 #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
- #22 econom*:ab,ti,kw OR price:ab,ti,kw OR prices:ab,ti,kw OR pricing:ab,ti,kw OR priced:ab,ti,kw OR discount*:ab,ti,kw OR expenditure*:ab,ti,kw OR budget*:ab,ti,kw OR pharmaco-economic*:ab,ti,kw OR 'pharmaco economic*':ab,ti,kw
- #23 cost:ti OR costs:ti OR costing:ti OR costly:ti
- #24 'cost effective*':ab,ti,kw
- #25 (cost* NEAR/2 (util* OR efficac* OR benefit* OR minimi* OR analy* OR saving* OR estimate* OR allocation OR control OR sharing OR instrument* OR technolog*)):ab
- #26 (decision NEAR/1 (tree* OR analy* OR model*)):ab,ti,kw
- #27 (markov:ab,ti,kw OR markow:ab,ti,kw OR monte:ab,ti,kw) AND carlo:ab,ti,kw
- #28 qoly:ab,ti,kw OR qolys:ab,ti,kw OR hrqol:ab,ti,kw OR hrqols:ab,ti,kw OR qaly:ab,ti,kw OR qalys:ab,ti,kw OR qale:ab,ti,kw OR qales:ab,ti,kw
- #29 (((adjusted NEAR/2 (quality OR life)):ab,ti,kw) OR ((willing* NEAR/2 pay):ab,ti,kw) OR sensitivity:ab,ti,kw) AND analys*s:ab,ti,kw
- #30 #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29
- #31 #21 OR #30
- #32 #10 AND #31
- #33 'barriers'/exp
- #34 'facilitator'/exp
- #35 'patient attitude'/exp/mj
- #36 'attitude to health'/mj/exp



- #37 'doctor patient relationship'/mj
- #38 #33 OR #34 OR #35 OR #36 OR #37
- #39 barrier\$:ti,kw
- #40 issue?:ti,kw
- #41 issue\$:ti,kw
- #42 problem\$:ti,kw
- #43 hinder\$:ti,kw OR hindered:ti,kw OR hinders:ti,kw
- #44 facilitate\$:ti,kw OR facilitator\$:ti,kw
- #45 ease:ti,kw OR easy:ti,kw OR easier:ti,kw
- #46 difficult:ti,kw OR difficulty:ti,kw OR difficulties:ti,kw
- #47 willing:ti,kw OR willingness:ti,kw
- #48 belief\$:ti,kw OR believe*:ti,kw
- #49 preference*:ti,kw
- #50 dialog*:ti,kw OR conversation*:ti,kw
- #51 decision:ti,kw OR decide*:ti,kw OR deciding:ti,kw
- #52 motivation\$:ti,kw
- #53 acceptance:ti,kw OR acceptability:ti,kw
- #54 perception\$:ti,kw
- #55 behavior\$:ti,kw
- #56 attitude\$:ti,kw
- #57 input\$:ti,kw
- #58 experience\$:ti,kw
- #59 value\$:ti,kw
- #60 perspective*:ti,kw



- #61 expectation*:ti,kw
- #62 choice\$:ti,kw OR choose*:ti,kw OR choosing:ti,kw
- #63 empower*:ti,kw
- #64 knowledge*:ti,kw
- #65 involv*:ti,kw
- #66 engag*:ti,kw
- #67 consult*:ti,kw
- #68 interact*:ti,kw
- #69 satisfaction:ti,kw OR satisfied:ti,kw
- #70 discuss*:ti,kw OR discussion*:ti,kw
- #71 #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR
#47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR
#55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR
#63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70
- #72 #38 OR #71
- #73 #10 AND #72
- #74 #73 NOT #32

Comments



1.3. Embase

Date 11 Apr 2023

Database Embase

Search strategy

- #1 ((wait OR waiting) NEAR/2 (time OR times OR list OR lists)):ti,kw
- #2 ((organ\$ OR kidney\$ OR renal OR heart\$ OR cardiac OR liver\$ OR hepatic OR pancreas OR lung\$ OR pancreatic) NEAR/3 (donor\$ OR donation\$ OR shortage OR allocation)):ti
- #3 transplantation\$:ti OR transplant\$:ti
- #4 'transplant'/de
- #5 'organ transplantation'/exp
- #6 #2 OR #3 OR #4 OR #5
- #7 #1 NOT #6
- #8 #7 AND [2013-2023]/py
- #9 #8 NOT [medline]/lim
- #10 #9 AND ('meta-analysis'/exp OR 'meta-analysis' OR 'systematic review'/exp OR 'systematic review')
- #11 #10 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)

Comments



1.4. Medline

Date March 29, 2023

Database Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to March 29, 2023>

Search strategy

- 1 Waiting lists/
- 2 ((wait or waiting) adj2 (time or times or list or lists)).ti,kf.
- 3 1 or 2
- 4 limit 3 to yr="2013-Current"
- 5 ((systematic review or systematic literature review or systematic scoping review or systematic narrative review or systematic qualitative review or systematic evidence review or systematic quantitative review or systematic meta-review or systematic critical review or systematic mixed studies review or systematic mapping review or systematic cochrane review or "systematic search and review" or systematic integrative review).ti. not comment.pt. not (protocol or protocols).ti. not medline.st.) or (Cochrane Database Syst Rev.ja. and review.pt.) or systematic review.pt.
- 6 meta-analys*.ti.
- 7 meta-analysis.pt.
- 8 exp Technology Assessment, Biomedical/
- 9 health technology assessment.ti,kf.
- 10 HtA.ti,kf.
- 11 5 or 6 or 7 or 8 or 9 or 10
- 12 4 and 11
- 13 ((organ? or kidney? or renal or heart? or cardiac or liver? or hepatic or pancreas or lung? or pancreatic) adj3 (donor? or donation? or shortage or allocation)).ti.



14 (transplantation? or transplant?).ti.

15 exp *Transplants/

16 exp *organ transplantation/

17 13 or 14 or 15 or 16

18 12 not 17

Comments



2. APPENDIX II – OVERVIEW OF THE LITERATURE

2.1. Waiting time assessment technics

Table 1 – Overview of the primary studies on WT assessment techniques

ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
Adams 2020 ¹	USA	Outpatient Colonoscopy in veterans with positive faecal occult blood test between 2008 and 2015 in 124 facilities	Starting point Date of the lab test Endpoint Date of the outpatient colonoscopy	Retrospective analysis of data from VA administrative data from the Corporate Data Warehouse	Risk of misclassification in the administrative data No possible to generalize to the overall population
Anderson 2022 ²	New Zealand	3 treatment options: 1. Surgery 2. Medical treatment In 124 patients with biopsy-proven atypical endometrial hyperplasia from 2 hospitals between 01/01/2019 and 31/12/2021	Referral-to-treatment is defined as the difference between the date of referral acceptance or the date of the last outpatient clinic appointment and date of treatment Decision-to-treatment is defined as the difference between the date the decision for treatment and the date of treatment was made.	Retrospective analysis of the date reported in electronic clinical records using search terms specific to the two institutions to identify cases of atypical endometrial hyperplasia	Quality of data depend of the quality of coding (retrospective analysis) Interpretation of data is hampered by the lack of a national guideline. When non-surgical treatments may start before the diagnosis, decision-to-treat was considered as zero => waiting times appear shorter. In contrast, women with surgery after non-surgical treatment seem to have longer waiting times because surgery was considered as the 'treatment' end-point.
Arulanandam 2021 ³	Canada	Surgery for inguinal hernia, cryptorchidism or hypospadias in 1389 children (aged between 2 to 16y) without complex chronic medical conditions for the period 2010–2013	Time to referral: time elapsed between the most recent family physician / paediatrician visit and the patient's first surgical specialist visit and	Population-based retrospective cohort study of randomly selected children from administrative databases of the Régie de l'assurance maladie du Québec (universal coverage).	Use of proxies for time to refer and time to surgery using last visit as date of referral decision and date of surgery decision



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
			Time to surgery: time elapsed between the most recent visit to the surgical specialist and the date of surgery	Two databases were anonymously linked: the Physician Service Claims Database (physician remunerated services across all clinical settings), and the Registered Persons Database (patient demographics).	
Bilandzic 2022 ⁴	Croatia	4 treatment options: 1. Surgery (gamma knife or brain surgery) 2. Surgery + oncologic treatment 3. Oncologic treatment (radiotherapy, chemotherapy or chemoradiotherapy) 4. Symptomatic treatment In 73 patients with a brain tumour confirmed by CT or MRI. in one hospital (2016-2017)	Diagnosis-to-treatment interval: time between the date of radiological diagnosis and the date of the first treatment.	Prospective data collection in a department of neurosurgery of one hospital Data was prospectively recorded on type of surgery type of (oncologic) treatment	Risk of bias when the diagnosis was made in another institution or at an emergency neurology ward which referred these patients to other departments for further treatment
Biloglav 2020 ⁵	Croatia	WT for CT scan and MRI in public hospitals	Time between physician's decision and examination	Retrospective analysis of aggregated data from public hospitals and describing 2015 and 2018	Possible overestimation because of registration at several lists, the use of private services, patient's death, or omission to cancel the reservation The impact of misuse cannot be analysed
Blackmore 2019 ⁶	Canada (Ontario)	1 844 asymptomatic postmenopausal women with unilateral invasive breast cancer diagnosed through breast	Median WT for: • From an abnormal mammogram to definitive surgery (if several	Retrospective administrative databases (integrated client management system) from the Ontario Breast Screening Program	Potential confounders can only be addressed by adjustment for differences in patient populations.



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
		assessment centres or usual care between 2002 and 2010	surgery date of the last surgery is considered) - From surgery to chemotherapy - From surgery to radiotherapy - From chemotherapy to radiotherapy	combined with a chard abstraction using a standardized abstraction form	Patient and system factors were not captured by the data (patient beliefs and attitudes, barriers to accessing treatment (logistics, availability of physicians, appointment scheduling...)).
Bonati 2019 ⁷	Italy (Lombardy)	2 262 children and adolescents aged 5-17 years who access an attention deficit hyperactivity disorder centre for diagnostic classification and management	Time between the request for a first-time visit to the date of a completed diagnostic procedure	Retrospective analysis of centers for Attention-Deficit Hyperactivity Disorder Registry Database between 2013 and 2017. Data were anonymized and written informed consent was obtained for all patients	It was not possible to evaluate the number of patients they did not get an appointment.
Brito-Fernandes 2021 ⁸	Hungary	1 000 general population from a national representative sample	WT to get an appointment with a GP, a specialist in public sector or, a specialist in private sector. Considered WT was the WT for the last outpatient visit during the 12 months preceding the assessment. WT are reported in categories: 0 days (same day) 1 day (next day) 2–5 days (couple of days) 6–7 days (just less than a week) 8–14 days (more than a week) 15–30 days (more than two weeks)	An online, cross-sectional, self-reported WT in a survey on the national representative sample. Questions are based on a standardized set of questions forth by the OECD. ⁹	Selection bias because of survey occurred online Recall bias Participation bias (< 2% of the sample) No information about the urgency level of the visit



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
			• 31–60 days (more than one month) • 61–90 days (more than two months) • 91 days or longer (more than three month)		
Cortez 2022 ¹⁰	USA (California)	Call a randomised sample of dermatology clinics and GP practices for suspicion of melanoma between June 2017 and March 2019	WT (in days) were collected for the next available in-person visit; video visits were excluded.	GP practice and dermatology practices were called by a “mystery client” using a patient vignette (a concerning, changing, and pigmented skin lesion suggesting the need for an immediate provider evaluation for melanoma) Care providers were called a maximum of 3 times and a callback number was left after the third call. Ethical approval was granted.	Only 2 regions of the state of California were assessed Confounding factors, such as socioeconomic status, language barriers, and difficulty navigating the healthcare system were not tested.
Creadore 2021 ¹¹	USA (28 states)	Randomly selected dermatology clinics were called by a fictive new patient with a new and changing mole during 4 days in February 2020 (exclusion of academic or federal clinic)	First-available appointment (excluding same day)	Secret shopper study design: Researchers called each clinic 3 times and followed a script to decrease call variability. No appointments were scheduled during the call	Clinic not representative of the entire national dermatology clinic landscape. Seasonal trends in WT were not studied. Data collection period was short compared with previous secret-shopper studies. WT was assessed for new patient appointments only, follow-up appointments were not considered



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
De Swart 2022 ¹²	The Netherlands	4589 patients (≥ 18y) with a first-time glioblastoma surgery between 2014 and 2019 in 13 hospitals	3 WT were assessed, time from: • first MR scan to surgery • first neurosurgical consultation to surgery • first MR scan to consultation	Retrospective analysis of administrative data from the Quality Registry Neuro Surgery in which all patients with glioblastoma are mandatory registered	Lack of information that may explain WT: cause of presentation, other stages of referral, routes of referral (e.g., emergency department or outpatient clinic)
Fan 2020 ¹³	Canada (Southwestern Ontario)	225 patients with nonmelanoma skin cancer between 2015 and 2018	3 WT were assessed, time from: • referral to consultation • referral to surgical excision • consultation to surgical excision	Retrospective chart review	Referral to another physician for biopsy prior to referral to a plastic surgeon not taking into account
Feyman 2022 ¹⁴	USA	4 846 892 veterans needed an appointment in 3 care categories: primary care, mental health, and all other specialties between 2018 and 2021	WT is defined as the difference between the date of approval and the appointment date for a new clinical relationship (repeat visits for established patients were excluded)	Analysis of the administrative database of Veterans Health Administration	Not possible to identify if WT experienced by veterans were clinically appropriate. Access to care for veterans in the private sector can be impacted by their health and insurance status. No distinction between individual specialties.
Gardner 2020 ¹⁵	UK (Scotland)	62 patients with thyroid cancer (2016 – 2018) in NHS Lothian (sub-region of Scotland)	Time from GP referral to diagnosis Time from GP referral to treatment The level of referral is defined as routine, urgent, urgent – suspicion of cancer	Review of a prospectively held database of patients discussed at MDT meetings	Low numbers of patients Inability to identify all patients referred with a suspected thyroid mass



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
Jabbal 2023 ¹⁶	UK (Scotland)	Patients with total hip arthroplasty or total knee arthroplasty from 1998 to 2021	Waiting time for inpatient or day case admission (no precise definition)	Data collected through the Scottish Arthroplasty Project dataset (continuous audit monitoring the outcome of all arthroplasty procedures in all NHS Scotland) gathering data from several existing databases Data were quality-checked	No link between WT and clinical profiles
Lazzeri 2020 ¹⁷	Literature review including 8 papers from Canada (3 studies), France, UK, South Africa, Sweden and Poland	Patients with prostate cancers from 1996 to 2015	WT from cancer suspicion to treatment WT from cancer suspicion to histopathological confirmation WT from cancer diagnosis to the start of treatment	Data sources: • Questionnaire • Retrospective administrative data • Retrospective medical chart review • Semi-structured interview	Not systematic review (only one database MEDLINE) Language: Italian, English, and French
Lee 2021 ¹⁸	USA	Fictional female patient complaining of "urine leakage" between 7 th August and 2 nd October 2017	WT for a new patient appointment with an academic Female Pelvic Medicine and Reconstructive Surgery urologist or gynaecologist	Secret shopper study design: 6 callers used a standardized script to ascertain the earliest available appointment time for fictional Medicaid and Medicare patients No appointment was made and information about the study was given including the option to decline participation in the study No formal institutional review board approval.	Focus on academic institutions so no representative of the private practices nor rural and medically underserved areas Potential daily or weekly variation in wait times not taken into account No analysis of the presence or absence of a triage system No analysis of the difference in WT between resident clinic and standard provider clinics
Liddy 2020 ¹⁹	Canada	2060 referrals for patients in need of specialist visits in 22 clinics	The design of one of these studies	Retrospective chart audit of primary care practices based on extraction from the electronic medical records or from referral letters of a random sample of	Low sample size Participation of the clinics is voluntary leading to potential selection bias The level of urgency was based on keywords in the



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
				100 cases from each clinic over a 1-month period.	medical records that might not have been used consistently Patient- or provider- factors that may affect the WT were not studied Density of medical specialists may affect the WT and is not studied
Ling 2020 ²⁰	Australia	Children aged between 5 to 18 years with symptoms of isolated daytime urinary incontinence /enuresis or mixed bladder and bowel dysfunction in one institution from September 2017 to February 2018	WT, measured in a number of days, is assessed during several steps in the patient journey WT_A : time between referral written by the GP and referral received at the hospital WT_B : time between referral received at the institution and referral acknowledged by triage nurse WT_C : time between referral acknowledged by triage nurse and referral booked WT_D : time between referral booked and attendance first appointment at clinic WT_E = WT_B+WT_C WT_F = WT_B+WT_C+WT_D WT_G = WT_A+WT_B+WT_C +WT_D	Retrospective electronic medical record review	There is missing data in the electronic medical records. Therefore, sample size varies between each waiting period. There were temporal inconsistencies between dates, leading to negative WT. They were excluded from the study. In addition, there are some inconsistent administrative data entries or non-conventional methods of clinic attendance (e.g. appointment fixed due to free clinic slot cancellations). Comparability with a previous study performed in the same patient population because of variation in WT definitions.
Mahabadi 2020 ²¹	Canada (Saskatchewan)	98 adult patients with epilepsy surgery in one university hospital	WT in months: - Time from the diagnosis of epilepsy to the referral to an epilepsy center - Time from the diagnosis of epilepsy to the first	Data collected from medical records between 2007-2017	Small sample size hampering the generalisation of the results



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
			consult to the epilepsy center • Time from diagnosis to the consult of NPS • Time from diagnosis to the VEEG • Time from diagnosis to the first consult at neurosurgery • Time from diagnosis to the ES • Time from first EP consult to consult of NPS • Time from first EP consult to the VEEG • Time from first EP consult the ES <i>EP (epilepsy program) NPS (neuropsychology) VEEG (Video-electroencephalography) ES (epilepsy surgery)</i>		
Mulraney 2021 ²²	Australia	Children attending private specialists for initial mental health appointments for anxiety or attention-deficit/hyperactivity disorder	Number of days between the call and the next available appointment with the specified specialist or, if unavailable, with the first available specialist in a group practice	Prospective secret shopper study in 317 private practices of paediatricians, psychiatrists and psychologists using two clinical vignettes at random. A mobile phone was used to avoid identification of the region. If an appointment time was offered, the booking of the appointment was postponed and a call back was proposed by the caller. No appointments were booked with any provider.	Following elements were not studied: • Earlier appointment due to cancellations • Length of offered appointment • Seasonal changes in wait times to appointment.



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
Naimer 2022 ²³	Canada	Patients needed a referral from a primary care practice to any specialists in 2 primary care clinics between 1st January 2016 and 31st December 2017 (i.e. 7141 referrals for 4967 patients)	Number of days between referral date and appointment date. Level of urgency was defined by the referring physician: • as per availability • within 1 month • urgent • within 1 week	Feasibility study to assess WT from data extraction from primary care electronic medical records	Extractions of the electronic medical records did not allow to take into account: • patient preference • primary care provider preference • type of problem or diagnosis • appropriateness of the referral • time to make the referral (WT 0 before a patient was sent to the specialist) Data was not easily extractable without manual manipulation. There was a high degree of missing data because of the lack of codifiable format variables in the electronic medical records. Small sample size
Osowiecka 2019 ²⁴	Poland	123 patients treated for prostate cancer from 22 nd May 2014 to 19 th February 2015 at five oncology centres	3 WT were measured: • from the cancer suspicion to the diagnosis • from the cancer suspicion to the start of treatment • from the diagnosis to the start of treatment Cancer suspicion was defined as : • date of the first visit to a doctor, with urinary disorders;	Interviews of patients individually + data from medical records and hospital databases	No limit mention



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
			• or the date of PSA test in the case of patients without symptoms; • or the date of the control visit when the recurrence of a previously treated cancer Diagnosis was defined as the date of obtaining histopathological results. Start of treatment was defined as the date of surgery, radiotherapy (time of the first fraction), hormonal therapy, or chemotherapy.		
Palermo 2019 ²⁵	USA (Seattle)	Adolescents aged 10-18 years waiting for chronic pain clinic evaluation in a tertiary paediatric pain clinic	From time of first referral to the appointment Results are proposed in categories: see within 4 weeks, 8 weeks, 12 weeks, or after 12 weeks.	Review of medical records during 12-month period in order to fully capture appointment history including the status of the appointment (completed, cancelled, missed, rescheduled)	Generalisation of results is hampered by : • Small sample size (only in one treatment facility) • Sub-set of the adolescent population with chronic pain (only patients referred to a tertiary center) • No inclusion of patients promptly seen due to their disease condition (e.g. cancer) • Sample included predominantly non-Hispanic whites.



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
Park 2022 ²⁶	Canada	168 patients with psoriatic arthritis waiting to see by a rheumatologist in one facility in Toronto between January 2013 and May 2019	Number of days between the date of referral and the date of assessment by a rheumatologist at the Clinic.	Retrospective chart reviews of medical records including the presence of an urgent referral	The study was not able to consider the period between the date of the onset of symptoms and seeing a physician or starting an antirheumatic drug treatment.
Popovic 2023 ²⁷	Canada (Ontario)	1 138 532 people with cataract surgery	2 WT are assessed: - number of days from referral to initial visit with the surgeon (WT1) - number of days from the decision for surgery until the first eye surgery date (WT2) Referral can be done by an optometrist or a GP Date of the decision for surgery is defined as the second last visit to the cataract surgeon.	Retrospective population-based analysis of health administrative data (i.e. 2 years before the surgery for WT2 and 3 years before the first visit with the surgeon for WT1)	As no referral date was recorded a proxy was used with the billing data. That can lead to the wrong attribution of the referring provider and errors when optometrists do not use the code for cataracts. Referrals that did not include a referral from an optometrist or a GP were not considered in the WT measurement. Unclear date of diagnosis when patients were followed at baseline by a cataract surgeon. The design of the study did not allow for discussion on the appropriateness of cataract surgery for included patients, or the patients with cataracts who did not receive surgery
Povitz 2019 ²⁸	Canada (Ontario)	216 514 patients with obstructive sleep apnea and starting CPAP for the first time from 1 st January 2006 to 31 st December 2013.	Diagnostic time is defined as the period between the assessment of a sleep complaint in primary care and the diagnostic by a polysomnography. Treatment time is defined as the period between the date of polysomnography and the	Retrospective population-based cohort study using provincial health administrative data	Only patients assessed in primary care were included in the cohort. Therefore, more severe cases were not considered. WT is overestimated because a trial period of max 30 days is foreseen before purchasing a CPAP device.



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
			date of purchase of the CPAP device.		
Pozsgai 2019 ²⁹	Hungary	212 patients with colorectal cancer from 1 st January 2012 to 31 st December 2016	Time-to-diagnosis is defined as the number of days from the first patient-physician consultation (with a GP, specialist, or at emergency room) with symptoms and asking for lab tests, ultrasound, and colonoscopy... until the pathologically confirmed date of diagnosis. Time to treatment was defined as the number of days of the first patient-physician consultation with symptoms until the first day of any form of treatment (surgical or oncological (chemo-, radiotherapy) treatment).	A retrospective analysis of data extracted from 26 GP practices gathered with data from 1 hospital. Level of urgency is considered	Small sample size probably not representative Inaccuracies in the recorded data at the GP's offices Patients were diagnosed and treated in a university clinic where care may be provided more rapidly.
Rabice 2021 ³⁰	USA	New patient visit at 427 outpatient female pelvic medicine and reconstructive surgery offices women with the common and nonemergent concern of uterine prolapse (between 25 th June to 18 th July 2019)	WT for the soonest appointment available with a urologist or a gynaecologist for her 65-year-old mother, in whom uterine prolapse was recently diagnosed by her gynaecologist.	Mystery Caller Study: one caller using the same vignette for each call. No appointments were scheduled. Excluded offices are those no reachable, requesting additional information or consultation, not accepting new patients or certain type of insurance coverage. Offices were not informed of their participation but received a debriefing letter.	Participants were restricted to those reported on the research online tool of the American Urogynaecologic Society. Some information reported in this list was not accurate. No analysis was performed of the non-respondents. Data collection period of 4 months did not allow for capturing a potential seasonal effect



ID	Country	Intervention / population	Definition of WT	Assessment methods	Limits reported by the authors
Saggaf 2021 ³¹	Canada (Ontario)	7313 adult patients (≥ 18 years) with delayed traumatic peripheral nerve injury operations from April 2009 to March 2018	2 WT were measured: - the time from referral to first consultation with the surgical specialist - the time from consultation when the decision to treat is taken to the date of the surgical procedure	Retrospective analysis of data from the Wait Time Information System Four priority levels were defined and an access target in weeks was associated with each priority level	Quality of analyses of retrospective data depends on the accuracy of the recorded data. Lack of data in administrative databases such as reasons for the delay between consultation and surgery, potential confounders, clinical characteristics No linkage with hospital databases or other administrative databases
Sun 2023 ³²	USA (5 states spread in US: New York, California, North Dakota, Virginia Wyoming)	Appointments with one of the 864 psychiatrists for an English-speaking 33-year-old female with a chief complaint of depression without active suicidal ideation (from May 2022 to July 2022)	WT between the call and an in-person appointment And WT between the call and a telepsychiatry appointment	Data were collected using the mystery shopper method in a representative sample of practices according to geographical and insurance variables and type of psychiatrist. A semi-structured script was used to standardise data collection, including the provision of a name, insurance, GP referral, and an absence of active suicidal ideation to avoid A&E referral. No appointment was made during the call. An email or letter was sent to the participating practices at the end of the study.	Accessibility in counties may be overestimated because an assumption was made that patients would seek psychiatric care in another county if no psychiatrist or no psychiatrist available. A single caller using a single script did not allow to test the impact of race, age, gender, language, other types of private insurance, or chief complaint on WT. Uncertified psychiatrists and non-physician practitioners proving self-pay psychiatric care were excluded.



2.2. Impact of waiting time on health outcomes

2.2.1. Systematic reviews

Table 2 – Overview of (systematic) reviews and meta-analyses on the impact of WT on health outcomes

ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
Deslauriers 2021 ³³	Medline, CINAHL, and Embase 1990-2018	Outpatient physiotherapy services in persons with musculoskeletal disorders	5 RCTs ³⁴⁻³⁸ , 3 cohort studies ³⁹⁻⁴¹ , and 1 cross-sectional studies ⁴² UK (1 study) ³⁸ Kosovo (1 study) ⁴² Singapore (1 study) ⁴¹ South Korea (1 study) ³⁵ Sweden (3 studies) ^{34, 36, 37} USA (2 studies) ^{39, 40} ⇒ 7 other studies describing the impact of WT on cost are described in the table below	• Pain Negative effect in 5 studies^{34, 36, 39-41} No effect in 3 studies^{35, 37, 38} • Disability Negative effect in 3 studies³⁹⁻⁴¹ No effect in 2 studies^{34, 38} • QoL Negative effect in 2 studies^{38, 40} • Psychological symptoms Negative effect in 1 study³⁸ • Range of motion at the neck or elbow Negative effect in 1 study³⁶ No effect in 2 studies^{35, 37} • Rehabilitation success Negative effect in 1 study⁴²	Conclusion: Overall, seven of the nine studies found a negative effect of WT on at least one clinical outcome. A negative effect or no significant effect of WT on pain, disability, and range of motion. Negative effect was found for QoL and psychological symptoms. There was no positive effect of WT reported in any study. The review provides mixed evidence that suggests the potential detrimental effects of WT on health outcomes. Limits: • variability in the definition of WT before receiving services. • Included studies were of low to high methodological quality, with a mean moderate quality score



ID	Databases searched and search date	Patients/setting/intervention	Number and type of included studies/Countries	Effect of WT	Conclusions and limits stated by the authors
Lukacs 2019 ⁴³	PubMed, Scopus, Cochrane Database of Systematic Reviews, LISTA, and Library of Congress 2000-2017	Pancreatic cancer	15 retrospective cohorts⁴⁴⁻⁵⁸, 2 prospective studies^{59, 60}, and 1 RCT⁶¹ 14 out of 18 studies are single centred^{45-49, 51-57, 59, 60} Canada (2 studies)^{45, 52} France (1 study)⁵⁰ Germany (1 study)⁴⁶ Greece (1 study)⁶⁰ Ireland (1 study)⁴⁹ Italy (2 studies)^{48, 51} Japan (1 study)⁵⁷ Macedonia (1 study)⁵⁹ South Korea (1 study)⁵⁸ Sweden (1 study)⁵⁵ The Netherlands (1 study)⁶¹ UK (2 studies)^{44, 54} USA (3 studies)^{47, 53, 56}	Definition of WT: - from first symptom to first visit^{52, 56, 57, 60} - from first visit to diagnosis^{46, 56, 60} - from first symptom to first visit + from first visit to diagnosis⁴⁸ - from first cross-sectional imaging to treatment^{44, 45, 49, 55} - from latest cross-sectional imaging to treatment^{47, 53, 61} Effect of WT: - Significant association of shorter delays with <u>improved</u> outcomes (resectability; mortality hazard rate at 5y; survival at 1,3 and 5y) – 4 studies^{48, 54, 55, 58} - Significant paradox association of shorter delays with <u>worse</u> outcomes (presence of metastasis at diagnosis; mortality hazard rate 3 y; mortality hazard rate (FU 2 years); surgical outcomes: rate of resectability; rate of palliative bypass / exploration; rate of lymph node positivity;	Conclusion: Despite the many sources of bias, the majority of studies (that reported multivariate analyses) showed a statistically significant association between shorter delays and better clinical outcomes. However, no non-inferiority studies were available. Heterogeneity in definitions of WT and outcomes and populations included preclude meta-analysis of included studies. All the included studies suffered from one or more sources of potential methodological bias: - No control for confounders - Risk of low study power - Adjustment to intermediary outcomes in the causal chain - No control for the wait time paradox - Risk of length bias



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				rate of microscopically residual disease; rate of complications) – 3 studies^{50, 57, 61} No association statistical found between WT and outcomes – 11 studies^{44-47, 49, 51-53, 56, 59, 60}	
Nowak 2022 ⁶²	Pubmed, Embase, Cochrane Library From inception to 2022	Upper tract urothelial carcinoma (UTUC) undergoing radical nephroureterectomy (RNU)	7 retrospective series⁶³⁻⁶⁹; 3 single-centre series^{63, 65, 67} 3 multicentre series^{64, 66, 69} 1 population-based registry⁶⁸ Asia (3 studies)^{63, 64, 69} North American (2 studies)^{66, 68} Europe (1 study)⁶⁵ World (1 study)⁶⁷	Cancer-specific survival (CSS) 3 studies found a significant impact of the delay in RNU on overall cohort or a subset of patients^{64, 67, 69} No significant difference in CSS in overall cohort or subset of patients in 2 studies^{65, 66} Overall survival (OS) 3 studies found a significant impact of delay RNU on OS in overall cohort or a subset of patients^{63, 68, 69} No significant difference in OS before and after 90 days from UTUC diagnosis.⁶⁶ Recurrence-Free survival (RFS) 1 study found a significant impact of the delay in RNU on RFS in the overall cohort or a subset of patients⁶⁴	Long waiting time for RNU (especially > 3 months after diagnosis) could be considered to negatively affect oncological outcomes such as CSS, OS or RFS. Safe delay might be shorter for high-risk patients or patients with ureteral tumour(s) and/or hydronephrosis at the time of diagnosis Limitations: - High risk of bias in all included studies - Retrospective and heterogeneous study designs - Reason for RNU delay was mostly not reported - Studies carried out in different geographical regions



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				2 studies found no association ^{65, 67}	Underpowered studies to detect differences in oncological outcomes
Patten 2023 ⁷⁰	Ovid MEDLINE, EMBASE, EBSCOhost (CINAHL, MEDLINE, APA PsycInfo and SPORTDiscus) and Google Scholar Inception to 2021	People with hip or knee osteoarthritis and pain waiting to see an orthopaedic specialist	24 RCT⁷¹⁻⁹⁴ 2 non-randomised controlled trial^{95, 96} 7 observational study⁹⁷⁻¹⁰³ 15 studies included Hip osteoarthritis^{72, 77-80, 83, 85, 92, 95-97, 100-103} 20 studies included knee osteoarthritis^{71, 73, 74, 76, 82, 84-86, 88-94, 98-102} 2 studies mixed hip and knee osteoarthritis (no separated)^{75, 87} Pain was assessed by HHS (Harris hip score) HOOS (hip disability and osteoarthritis outcome score) KOOS (knee injury and osteoarthritis outcome score) KSS (Knee Society Score) NHP (Nottingham health profile) NRS (numerical rating scale) OA (osteoarthritis) P4 (4-item pain intensity measure) SD (standard deviation) SF-36 (36-item short form survey) VAS (visual analogue scale) WOMAC (Western Ontario and McMaster Universities osteoarthritis index)	No significant change in pain over time (effect size= 0.082, 95% CI = -0.009, 0.172) No significant association between the length of time spent on a waitlist and longitudinal changes in pain ($\beta=0.004$, 95% CI = -0.005, 0.012)	Patients with knee and hip osteoarthritis who were on a waiting list for consultation with orthopaedic specialist did not report a change in pain up to 1 year Limitations of included studies - Duration on the waiting list was not always reported - Duration of pain prior the enrollment was reported only in 1 study - Regular pain assessment during the waiting was missing Limitations of the meta-regression - Large variation in care provided in the control group that may affect pain levels - Some studies did not report the content of usual care - No high quality studies included - Maximum follow-up was limited to 1 year



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
Tope 2023 ¹⁰⁴	MEDLINE, EMBASE, Web of Science, and Cochrane Library of Systematic Reviews 2010-2019	Patients with brain, breast, blood, colorectal, eye, head and neck, paediatric, prostate, ovarian or multisite cancer.	20 meta-analyses ^{38, 105-124} 8 systematic reviews ¹²⁵⁻¹³²	Systematic reviews <u>Brain</u> Unclear evidence 1 SR¹³²: no association between time from surgery to chemotherapy and OS in 4 studies and improved OS in patients experiencing time from surgery to chemotherapy between 31 and 42 days compared to < 31 days <u>Colorectal</u> <i>Time between from neoadjuvant chemoradiotherapy to surgery</i> 1 SR¹²⁷ higher pathologic complete response rates (pCR) associated with tumour down-staging in patients waiting > 6-8 weeks than those waiting < 6-8 weeks. However, few studies included in this SR showed that time > 6-8 weeks conferred higher pCR rates. <i>Time from diagnosis to surgery</i> 1 SR¹¹⁰ showed no association between extended time with length, OS or disease-specific survival <u>Eye</u>	The authors concluded that there is unclear evidence for the association between lag time in cancer with the patient outcomes because either consistency or disagreement across reviews on the same lag time, cancer site, and outcome. Limitations of included studies • Evolution of treatment modality over time was not considered but can affect patient outcomes • Ambiguity in defining of lag time interval start and endpoint • Waiting time paradox (patients with more advanced-stage disease are prioritised for referral and treatment compared to patients with early-stage or less severe disease. This prioritisation leads to conclude that early referral and/or treatment is associated with higher mortality)



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				<i>Time from symptom onset to diagnosis</i> 1 SR¹¹⁴ showed that increased time is associated with an increased rate of extraocular disease, metastatic disease, and mortality in patients with retinoblastoma. <u>Head and neck</u> <i>Time from diagnostic to primary intervention</i> 1 SR¹²⁸ showed that extended time was associated with poorer OS <i>Time from surgery to radiotherapy</i> 1 SR¹²⁸ showed that shorter time was associated with improved OS and RFS <i>Time from surgery to completion of radiotherapy</i> 1 SR¹²⁸ showed that prolonged time was associated with poorer OS <u>Paediatric</u> <i>Time from symptom onset to diagnosis</i> - Retinoblastomas 1 SR¹²⁵ reported worsened OS in patients with longer time - Ewing's sarcomas	Limitations of the review: - Inclusion criteria (only review and meta-analysis from 2010 to 2019) may affect the results due to evolution in treatment - Variability in statistic reporting and timing thresholds - No inclusion of patient-level factors such as patient profiles, treatment choice, drug adherence or adverse event mangement



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				While 1 SR¹²⁹ found that longer time was associated with poorer OS, another SR¹²⁵ found no association between time and OS • CNS tumours Shorter time was associated with poorer OS and extended time was associated with improved OS in 1 SR¹¹⁶ while another SR¹²⁵ did found no association between time and OS • Osteosarcoma 2 SR^{125, 129} found no association with extended time and OS <u>Prostate cancer</u> 1 SR¹³¹ showed no association between extended time from diagnosis to surgery or to radiotherapy with worsened oncologic outcomes or OS for patients with low-risk prostate cancers but some evidence suggests that these associations may be present among patients with moderate- and high-risk prostate cancers.	



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				Meta-analyses - Blood (smoldering multiple myeloma) <i>Lag time between diagnosis and immunotherapy</i> 1 M-A¹²⁴ showed a significant association between shorter time and disease progression (HR:0.53, 95% CI 0.33,0.87) but no association between time and mortality was found - Brain <i>Time between surgery and neoadjuvant chemoradiotherapy</i> Time was not associated with an increased risk of mortality in 1 M-A¹¹³ - Breast <i>Time between surgery and adjuvant radiotherapy</i> 1 M-A¹⁰⁹ found a significant increase in risk of worsened locoregional control per 1-month increase of time but no change in risk of mortality per 1-month increase in time <i>Time between surgery and adjuvant chemotherapy</i> 3 meta-analyses^{117, 122, 123} reported a significant increase in risk of mortality	



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				per 1-month increase in time - Colorectal <i>Time from neoadjuvant radiotherapy to surgery</i> 1 M-A¹²¹ higher pCR rates were associated with time > 4 weeks but no association with mortality or risk of worsened disease-free survival (DFS) <i>Time from neoadjuvant chemoradiotherapy to surgery</i> Higher pCR rates were associated with time >6-8 weeks¹¹⁵ or >7-8 weeks¹³³ or ≥8 weeks¹⁰⁷. No association with mortality or risk of worsened DFS for surgery > 6-8 weeks¹¹⁵ or ≥8 weeks¹⁰⁷. <i>Time between surgery and adjuvant chemotherapy</i> Increased risk of mortality when time >6-8 weeks¹¹⁵ and > 8 weeks¹⁰⁶ 4-week increase was associated with a greater risk of mortality¹⁰⁵ - Head and neck <u>Oral cancer</u> <i>Time from symptom onset to (1) first being seen by a primary care provider (PCP), (2) referral to a</i>	



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
				<i>specialist and (3) diagnosis and time from first being seen by a PCP to diagnosis</i> 1 M-A ¹¹⁸ Greater risk of worsened TNM staging with any longer lag time and a greater risk of mortality when longer time for the referral to a specialist <u>Oral and oropharyngeal cancers</u> <i>Time from symptom onset and diagnosis</i> 1 M-A ¹⁰⁸ found greater odds of increased TNM staging when time is classified as long <u>All head and neck cancers</u> <i>Time from symptom onset to (1) first being seen by a primary care provider (PCP), (2) referral to a specialist and (3) diagnosis and time from first being seen by a PCP to diagnosis</i> 1 M-A ¹¹⁹ found greater risk of mortality for longer lag times <u>Esophageal cancer</u> <i>Time from neoadjuvant chemoradiotherapy to surgery</i> 1 M-A ¹¹¹ found reater odds of 2-year mortality when time > 7-8 Weeks but no	



ID	Databases searched and search date	Patients/setting/ intervention	Number and type of included studies/ Countries	Effect of WT	Conclusions and limits stated by the authors
					association with odds of 5-year mortality • Ovarian <i>Time from surgery to adjuvant chemotherapy</i> 1 M-A ¹¹² found a significantly greater risk of mortality per 1-week increase in time or with extended time while a second M-A found no association between extended time and odds of 3-year mortality ¹²⁰



2.2.2. Primary studies

Table 3 –Overview of primary studies on the effect of WT on health outcomes

ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
Anggondowati 2020 ¹³⁴	Retrospective cohort study USA	693 554 adult patients with non-small cell lung cancer	Time-to-treatment was defined as the period between diagnosis and initiation of any first-course treatment Categories: • 0 day • 1 day to 4 weeks • 4.1 days to 6.0 weeks • > 6.0 weeks	5-year OS <i>Any first-course treatment</i> Adjusted HR (95% CI)* Early-stage (n=277 245) • 0 day 0.84 (0.82-0.85) • 1 day to 4 weeks Ref • 4.1 days to 6.0 weeks 0.93 (0.91-0.95) • > 6.0 weeks 0.92 (0.91-0.94) Locally advanced disease (n=169 650) • 0 day 0.73 (0.71-0.74) • 1 day to 4 weeks Ref • 4.1 days to 6.0 weeks 0.82 (0.80-0.83) • > 6.0 weeks 0.71 (0.70-0.72) Metastatic disease (n=244 569) • 0 day 0.75 (0.74-0.76) • 1 day to 4 weeks Ref • 4.1 days to 6.0 weeks	Main conclusions Longer time-to-treatment does not have detrimental effects for patients, especially those with more advanced disease stages. Time-to-treatment longer than four weeks was associated with a lower risk of death for patients of all cancer stages. A subgroup analysis of early-stage patients who received surgery alone, showed that, compared with surgery between 1 day and 4 weeks, the risk of death was increased by 6% and 17% when surgery was performed between 4 and 6 weeks, and after 6 weeks, respectively. Limitations Usage of a National Cancer Data Base covering 70% of newly diagnosed cancer leading to a potential selection bias because hospitals including in the database have higher severity patients than the rest of hospitals across US The participating hospitals in the database are typically



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				0.75 (0.74-0.76) • > 6.0 weeks 0.58 (0.57-0.59) <i>Subgroup analysis for early-stage patients who received surgery only</i> Adjusted HR (95% CI)*\$ Early-stage (n=not reported) • 0 day 0.91 (0.89-0.93) • 1 day to 4 weeks Ref • 4.1 days to 6.0 weeks 1.06 (1.03-1.09) • > 6.0 weeks 1.17 (1.14-1.20) * for age, sex, race, urban/rural, distance to hospital, facility type, primary payer, Charlson/Deyo comorbidity score, histologic type, and treatment modalities \$ Excluding patients who died within 1 month after diagnosis	larger, located in urban locations, and provide a higher degree of oncology-related specialisation compared to non-participant hospitals Non all potential confounders affecting time-to-treatment can be taken into account such as tumour aggressiveness, performance status leading to the counter-intuitive findings
Bissonnette 2021 ¹³⁵	Multicentre prospective study gathering 5 cohorts from the US, the Netherlands, Canada and Australia	Patients with non-small cell lung cancer who were intended to receive curative-intent radiotherapy (n=181)	Number of days between diagnosis staging PET/CT scan and the subsequent treatment planning PET/CT (lapsed time)	Multivariate binary logistic regression impact of lapsed time after adjustment for age, gender, pathology type (adenocarcinoma, squamous cell, large cell or NOS), Stage (II, IIIa, IIIb), N	<u>Main conclusion:</u> Longer intervals between imaging and treatment were associated with high rates disease progression. Patients with more extensive initial nodal



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				classification (N0, N1, N2-N3) OR (95% CI), p value - T migration 1.16 (1.06 – 1.27), p= 0.001 - N migration 1.09 (1.02 – 1.71), p= 0.018 - M migration 0.97 (0.83 – 1.15), p=0.752 - Upstage 1.13 (1.06, - 1.20), p<0.001 - New nodes 1.07 (0.98 – 1.15), p=0.122	involvement and those with adenocarcinoma had the highest rates of stage migration. Dedicated RT planning PET/CT imaging is recommended, especially if >3 weeks have elapsed after initial staging.
Brenkman 2017 ¹³⁶	Population-based cohort study from the Netherlands Cancer Registry	Patients with curable gastric cancer who received neoadjuvant chemotherapy followed by gastrectomy (n=1701) or underwent primary gastrectomy (n=2077)	WT in weeks was defined as - interval between the date of diagnosis and the start date of neoadjuvant chemotherapy (neoadjuvant group) - interval between the date of diagnosis and the date of gastrectomy (surgery group) WT was categorised into 3 categories ≤ 5 weeks*, 5-8 weeks and > 8 weeks * official maximum WT from diagnosis to treatment for curative cancer treatment	OS was defined as the time elapsed from the start date of the treatment to the date of death from any cause or to the date of the last follow-up Multivariate analysis adjusted for age, gender, malignancy history, tumour differentiation, cT stage, cN stage, year of diagnosis, and referral status HR (95% CI), p <u>Neoadjuvant treatment</u> - WT ≤5 weeks Ref - WT 5-8 Weeks 0.82 (0.66–1.02), p=0.068 - WT> 8 weeks 0.85 (0.59–1.21), p=0.354 - Additional week WT	Main conclusion: WT was not associated with OS in either patients treated with neoadjuvant chemotherapy followed by a gastrectomy or primary gastrectomy (i.e. treatments with curative intent) <u>Limitations:</u> - Potential confounding factors may have been missed such as data on patients' co-morbidity, performance status, nutritional status, symptoms of the tumour or hospital factors - Retrospective nature of the study



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				0.96 (0.92–1.00), p=0.078 <u>Surgery only</u> - WT ≤5 weeks Ref - WT 5-8 Weeks 0.92 (0.81–1.05), p=0.200 - WT > 8 weeks 0.95 (0.79–1.08), p=0.314 - Additional week WT 0.99 (0.98–1.01), p=0.264	
Chidiac 2022 ¹³⁷	Retrospective study based on the Swedish Hydrocephalus Quality Registry	Patients with idiopathic normal pressure hydrocephalus (n=3007)	Waiting time was defined as the time between decision to accept a patient for surgery and the surgery procedure categorised in 3 groups : ≤ 3 months (short), 3.1-5.9 months (intermediate) and ≥ 6 months (long)	Modified iNPH scale (miNPH) assessing severity and outcome (gait, balance and incontinence). A clinical significant improvement was defined as an increment of ≥ 5 points <u>Post-operative change in miNPH scale 3 months postoperatively compared to preoperatively</u> Median (Min – Max) - Short vs Intermediate 7.0 (88.8 – -77.3) vs 5.0 (72.0 – -69.8), p=0.2565 - Short vs long 7.0 (88.8 – -77.3) vs 4.0 (61.3 – -70.3), p=0.0152 <u>Post-operative change in miNPH scale 12 months postoperatively compared to preoperatively</u> Median (Min – Max)	<u>Main conclusions:</u> Shunt surgery in patients with idiopathic normal pressure hydrocephalus should be performed within 3 months of decision to treat to attain the best outcome/ <u>Limitations:</u> 20% of the patients operated are not included in the database There were some missing data for the outcome (e.g. lack of routine clinical 12-month follow-up at some centres)



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				- Short vs Intermediate 7.5 (85.8 – -66.8) vs 5.0 (73.8 – -77.3), $p=0.1608$ - Short vs long 7.5 (85.8 – -66.8) vs 5.0 (78.8 – -86.8), $p=0.0288$	
				TUG (secondes) Median (IQR), n, p - Short vs Long at 3 months 4.0 (0.6-9.0), 428 vs 3.0 (-0.6-7.1), 248, $p=0.0246$ - Short vs Long at 12 months 5.0 (2.0-9.8), 101 vs 3.0 (-1.8-8.0), 152, $p=0.0195$	
				TUG (steps) Median (IQR), n, p - Short vs Long at 3 months 4.0 (1.0-9.0), 418 vs 3.0 (-1.0-8.0), 244, $p=0.0108$ - Short vs Long at 12 months 5.0 (2.0-10.0), 97 vs 2.0 (-2.3-8.0), 150, $p=0.0031$	
				MMSE Median (IQR), n, p - Short vs Long at 3 months -1.0 (-3.0-1), 747 vs -1.0 (-2.0-1.0), 419, $p=0.0121$ - Short vs Long at 12 months	



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				-1.0 (-3.0-0.0), 243 vs 0.0 (-2.0-2.0), 265, $p<0.0001$	
Clement 2022 ¹³⁸	Multicentre cross-sectional study including patients from 2021 to 2022 randomly selected from the waiting lists of the 4 centres (UK)	Patients who underwent a total hip arthroplasty, a total knee arthroplasty or a total or partial knee arthroplasty were contacted by telephone to assess EQ-5D-3L, CFS (Rockwood Clinical frailty scale) (n=326)	WT was defined as the time spent on a waiting list (at least 6 months) Outcomes were assessed at the time of the phone call for their current value and their probable value six months prior the call	Hip - Frailty (CFS)* 1 (not reported), $p<0.001$ - HRQoL* EQ-5D 0.196 (0.154-0.154), $p<0.001$ - EQ-vas 10.3 (7.7-12.9), $p<0.001$ - WTD# 3.00 (1.70-5.30), $p<0.001$ Knee - Frailty (CFS)* 1 (not reported), $p<0.001$ - HRQoL* EQ-5D 0.153 (0.112-0.194), $p<0.001$ - EQ-vas 6.9 (4.9-8.8), $p<0.001$ - WTD# 2.81 (1.42-5.58), $p=0.002$ * Mean difference (95%), p #WTD = state worse than death assessed by EQ-5D<0 OR (CI 95%), p	<u>Conclusions:</u> Patients waiting more than six months for total hip arthroplasty or knee arthroplasty had a statistically and clinically significant deterioration in their HRQoL and increased frailty, and an increased risk of WTD <u>Limitations:</u> - No assessment of comorbidities, joint-specific PROMs, progression of the radiological appearances, associated pain in other joints and the effect - No assessment of the effect of the prolonged waiting for surgery on the patient's mood that may influence the EQ-5D results. - Assessment by EQ-5D-3L and not EQ-5D-5L - Potential recall bias



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
De Swart 2022 ¹²	Retrospective analysis of administrative data from the Quality Registry Neuro Surgery in which all patients with glioblastoma are mandatory registered The Netherlands	4589 patients (≥ 18y) with a first-time glioblastoma surgery (biopsy or resection) between 2014 and 2019 in 13 hospitals 2 types of surgery were considered biopsy and resection	2 times were assessed: - Time from first MR scan to surgery (MTS): timely MTS < 21 days, long MTS ≥ 21 days - Time from first neurosurgical consultation to surgery (CTS): timely CTS < 14 days, long CTS ≥ 14 days	Complication grade Data reported in graph - Biopsy No significant difference between timely and long MTS (p=0.943) No significant difference between timely and long CTS (p=0.665) - Resection No significant difference between timely and long MTS (p=0.576) No significant difference between timely and long CTS (p=0.999) KPS score change Data reported in graph - Biopsy No significant difference between timely and long MTS (p=0.465) No significant difference between timely and long CTS (p=0.566) - Resection Significant difference between timely and long MTS (p=0.0005): fewer KPS score improvements were observed after long MTS No significant difference between timely and long CTS (p=0.0005): fewer KPS score improvements were observed after long CTS	<u>Main conclusions:</u> - fewer KPS score improvements are observed in patients with longer times to resection - complications are not associated with time to surgery - longer survival is observed in patients selected for longer CTS <u>Limitations:</u> Lack of information before surgery on cause of presentation, other stages of referral, and route of referral (emergency department or outpatient clinic) Lack of details on tumour characteristics (localisations, molecular classifications), other therapies or hospital details (total number of surgery, number of tumour surgeons or bed capacity)



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Survival Multivariable model • CTS <i>Binary variable</i> HR 0.90, 95% CI: 0.83-0.98, longer survival was associated with longer CTS <i>Continuous variable in days</i> HR 1.00, 95% CI: 0.99-1.00, no association with survival • MTS <i>Binary variable</i> HR 0.94, 95% CI: 0.87-1.02, no association with survival <i>Continuous variable in days</i> HR 1.00, 95% CI: 0.99-1.00, no association with survival	
Denault 2022 ¹³⁹	Multicentric retrospective analysis of the Quebec Hospitals Cancer Registries (inclusion from February to April 2017 with a 3-year follow-up)	Patients with small and non-small-cell lung cancer treated by surgery, definitive radiation, definitive chemoradiation or systemic treatment (n= 1 309)	WT was defined as the number of days between: • 1st abnormal imaging and 1st treatment (WT1) • 1st appointment with specialist to 1st treatment (WT2) • Diagnosis (date of pathology result) to 1st treatment (WT3) • Pathology result to biomarkers results (WT4)	OS Adjusted* HR (95% CI), p • WT1 (n=776) ≤ 60 days 0.98 (0.97-0.99), p=0.002 >60 days 1.00 (1.00-1.00), p=0.8 • WT2 (n=767) ≤ 60 days 0.98 (0.96-0.99), p=0.001 >60 days 1.00 (1.00-1.00), p=0.2 • WT3 (n=645) ≤ 60 days 0.93 (0.89-0.97), p=0.0002 >60 days	<u>Conclusions:</u> No detrimental effect of diagnosis and treatment delays on survival, but this should be interpreted with caution considering the missing data. <u>Limitations:</u> • Losses to follow-up • Missing data • OS based on 90% of the sample • Exclusion of negative diagnosis-to-treatment intervals and/or supportive treatment were excluded resulting in a



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				1.00 (1.00-1.00),p=0.9 WT4 (n=339) ≤ 60 days 0.95 (0.90-1.01),p=0.1 >60 days 1.00 (1.00-1.00), p=0.7 *Adjusted HR for performance status, histology, stage, and primary treatment Risk comparison of OS in the waiting group for WT3 Adjusted^{\$} HR (95% CI), p ≤ 60 days 0.93 (0.89-0.97), p=0.0002 >60 days Reference \$ Adjusted for age, gender, ECOG performance status (Eastern Cooperative Oncology Group), type of hospital, histology, type of treatment	multivariate survival model based on 761/1309 patients
Deslauriers 2020 ¹⁴⁰	Retrospective analysis of the Quebec Pain Registry Canada	Multidisciplinary pain treatment in patients with rheumatic conditions between 2004 and 2014 Baseline n= 3 230 At 6-month patient questionnaire n = 1 948	WT was defined as the period between receipt of the referral and the first patient's visit at a multidisciplinary pain treatment facility classified in 3 groups: < 2 months, 2–6 months and, > 6 months	Pain interference <i>10-items of Brief Pain Inventory (BPI) – MCID* = 1 point</i> Adjusted^{\$} change from baseline to 6 months (95% CI) <2 months -1.12 (-1.42,-0.81) 2-6months -0.70 (-0.93,-0.48)	<u>Main conclusions:</u> - Longer delays were significantly associated with less improvement in pain interference, pain intensity and HRQoL - Differences were below the minimal clinically important difference - But a significantly higher proportion of



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				>6 months -0.47 (-0.66,-0.28) $p<0.001$ (no significant difference between 2–6 months and > 6 months) - Proportion of patients reaching MCID <2 months 48.3% 2-6months 40.3% >6 months 34.9% $p<0.001$ Pain intensity <i>Numeric pain rating scale (NPRS) – MCID* = 1 point or 15% change</i> - Adjusted^s change from baseline to 6 months (95% CI) <2 months -1.3 (-1.6,-0.9) 2-6months -0.6 (-0.9,-0.4) >6 months -0.4 (-0.6,-0.2) $p<0.001$ (no significant difference between 2–6 months and > 6 months) - Proportion of patients reaching MCID <2 months 47.5% 2-6months 29.6% >6 months 28.4% $p<0.001$ HRQoL <i>12-item Short-Form Health Survey version 2 (SF-12v2)</i>	patients achieving clinically significant improvements in the group of patients waiting less than 2 months compared to patients waiting > 2 months <u>Limitations:</u> - High proportion of patients lost to follow-up (potential risk selection bias) - Restropective data (2004-2014) design lead to: - possible changes in the organisation of the multidisciplinary pain treatment facilities - coding errors or inconsistency in data collection - missing data (e.g. primary vs secondary diagnostic or data regarding period prior referral that may affect the progression of their condition) - Potential inaccuracy of self-reported data due to the data collection tools



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				– MCID* = from 3.3 to 5 points <i>Subscales Mental component scale (MCS)</i> - Adjusted[§] change from baseline to 6 months (95% CI) <2 months 3.7 (2.3,5.0) 2-6months 1.5 (0.3,2.6) >6 months 2.0 (1.0,3.0) $p < 0.001$ (no significant difference between 2–6 months and > 6 months) - Proportion of patients reaching MCID <2 months 45.4% 2-6months 39.4% >6 months 40.2% $P = 0.078$ <i>Subscale physical component scale (PCS)</i> - Adjusted[§] change from baseline to 6 months (95% CI) <2 months 3.9 (2.7,5.1) 2-6months 1.6 (0.6,2.5) >6 months 2.0 (1.2,2.8) $p < 0.001$ (no significant difference between 2–6 months and > 6 months) - Proportion of patients reaching MCID	for the clinical outcomes Usage of WT categories instead of continuous variable. It may have affected the strength of the associations with the clinical outcomes



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				<2 months 45.9% 2-6months 37.6% >6 months 39.4.4% $p=0.001$ *MCID = minimal clinically important difference \$ Adjusted for age, sex, pain duration, number of comorbidities, and income	
Elbaz-Greener 2019 ¹⁴¹	Retrospective cohort study using data extracted from the CorHealth Ontario TAVR Registry in Canada (inclusion 2010 – 2016)	Patients who underwent elective and urgent transcatheter aortic valve replacement (TAVR) (n = 2 170)	WT is defined as the number of days from the referral date to the date of the TAVR procedure	30-day mortality - All cohort Results reported in graph Non-linear relationship between time and mortality* ($p=0.002$). Increased HR with shorter WT - Additional adjustment level level of urgency Results reported in graph No relationship between time and mortality* ($p=0.58$). - Elective surgery HR (95% CI),p 0.99 (0.99-1.0, $p=0.12$) - Urgent patients HR (95% CI),p 1.0 (0.99-1.01), $p=0.40$ All-cause of readmission at 30 days - All cohort Results reported in graph	<u>Conclusions:</u> After adjusting for urgency status, there was no association between WT and postprocedural outcomes such as 30-day mortality and all-cause of readmission at 30 days. <u>Limitations:</u> - Adjusted limited to factors reported in the registry. Other confounding factors such as left ventricular function, Society of Thoracic Surgeons, and Euro score were not taken into account - Substantial evolutions in TAVR technology and care delivery were observed during the period of inclusion - Starting point was the referral and not the onset of symptoms. WT



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Non linear relationship between time and mortality* (p=0.02). Increased HR with shorter WT - Additional adjustment level level of urgency Results reported in graph No relationship between time and mortality* (p=0.98). - Elective surgery HR (95% CI),p 1.0 (0.99-1.0, p=0.52) - Urgent patients HR (95% CI),p 1.0 (0.99-1.01), p=0.16 *Mortality is assessed by HR adjusted by socioeconomic and clinical factors	before referral was not taken into account Due to the observational design of the study, the causality in the effect seen with urgency status and its influence on the relationship between WT and outcomes cannot be firmly demonstrated
Eng 2019 ¹⁴²	Retrospective analysis of electronic medical records from single academic hospital in the US (between 2014-2015)	Patients undergoing laparoscopic Roux-en-Y gastric bypass or sleeve gastrectomy (n=415)	WT was defined as the number of days from the initial consultation to the preoperative visit before surgery categorised in 3 groups: 0-3 months, 3-6 months, > 6 months	Preoperative weight loss (≥ 5% total wait lost) Adjusted* OR (95% CI), p - All cohort 0-3 months Reference 3-6 months 1.04 (0.52-2.07), ns > 6 months 1.14 (0.55-2.33), ns - Bypass 0-3 months Reference	<u>Conclusions:</u> Longer preoperative WT was not associated with improved weight loss or reduced adverse events such as complications (anastomotic or staple line leaks, gastrointestinal bleeding, bowel obstructions, myocardial infarctions, surgical site infections, and venous thromboembolisms) and readmission <u>Limitations:</u>



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				3-6 months 0.98 (0.41-2.37), ns > 6 months 1.36 (0.55-3.37), ns • Sleeve 0-3 months Reference 3-6 months 1.08 (0.34-3.40), ns > 6 months 0.77 (0.23-2.58), ns Postoperative weight loss at 3 months postop <u>Δ BMI (SD), p</u> • Bypass 0-3 months: -9.55 (2.8) 3-6 months: -9.39 (2.6) > 6 months: -9.06 (3.2) p=0.67 • Sleeve 0-3 months: -7.75 (2.0) 3-6 months: -8.5 (2.7) > 6 months: -7.29 (2.5) p=0.13 <u>% total wait lost, p</u> • Bypass 0-3 months: 20.7 (4.6) 3-6 months: 19.1 (5.2) > 6 months: 19.1 (5.6) p=0.18 • Sleeve 0-3 months: 18.5 (4.8)	• Small sample size • Lack of information on socio- demographic characteristics (including insurance type) of the patient population and on the reasons to delay treatment



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				3-6 months: 18.7 (5.6) > 6 months: 16.6 (5.4) p=0.18 Postoperative weight loss at 6 months postop <u>Δ BMI (SD), p</u> - Bypass 0-3 months: -12.28 (2.7) 3-6 months: -13.05 (3.4) > 6 months: -12.43 (4.1) p=0.47 - Sleeve 0-3 months: -9.90 (3.4) 3-6 months: -9.98 (3.4) > 6 months: -9.48 (3.9) p=0.85 <u>% total wait lost, p</u> - Bypass 0-3 months: 27.0 (5.7) 3-6 months: 27.1 (5.4) > 6 months: 25.9 (7.4) p=0.57 - Sleeve 0-3 months: 23.3 (7.6) 3-6 months: 22.7 (7.2) > 6 months: 22.5 (8.3) p=0.1893 Postoperative weight loss at 12 months postop <u>Δ BMI (SD), p</u> - Bypass 0-3 months: -15.11 (5.3) 3-6 months: -16.07 (4.3)	



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				> 6 months: -14.71 (3.8) p=0.40 - Sleeve 0-3 months: -10.4 (4.1) 3-6 months: -10.6 (4.4) > 6 months: -11.2 (5.5) p=0.89 <u>% total wait lost, p</u> - Bypass 0-3 months: 32.3 (8.6) 3-6 months: 33.2 (6.1) > 6 months: 31.2 (6.8) p=0.49 - Sleeve 0-3 months: 26.3 (9.6) 3-6 months: 24.1 (9.4) > 6 months: 25.0 (12.0) p=0.81 Postoperative weight loss at 24 months postop <u>Δ BMI (SD), p</u> - Bypass 0-3 months: -13.99 (5.8) 3-6 months: -15.26 (6.1) > 6 months: -13.80 (5.0) p=0.40 - Sleeve 0-3 months: -8.59 (4.6) 3-6 months: -10.58(6.5) > 6 months: -8.61 (5.2) p=0.33 <u>% total wait lost, p</u>	



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Bypass 0-3 months: 29.4 (9.8) 3-6 months: 31.3 (9.5) > 6 months: 29.5 (9.8) p=0.57	
				Sleeve 0-3 months: 20.6 (10.5) 3-6 months: 23.0 (12.3) > 6 months: 19.6 (11.0) p=0.57	
				Complication rate Adjusted* OR (95% CI), p	
				Bypass 0-3 months Reference 3-6 months 0.37 (0.10-1.39), ns > 6 months 0.13 (0.02-1.15), ns	
				Preoperative weight loss (≥ 5% total wait lost) Adjusted* OR (95% CI), p	
				Bypass 0-3 months Reference 3-6 months 0.56 (0.14-2.28), ns > 6 months 0.61 (0.14-2.79), ns	
				Sleeve 0-3 months Reference	



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				3-6 months 1.08 (0.04-27.78), ns > 6 months 1.60 (0.06-42.98), ns * Adjusted for age, BMI, co-morbidities	
Gacci 2022 ¹⁴³	Observational prospective study in 97 centres in Italy (2014-2015)	Patients treated for prostate cancer (n= 1466)	WT was defined as the number of days from the diagnosis by biopsy of prostate cancer to the first treatment received categorised < 90 days and ≥ 90 days	QoL <u>University of California Los Angeles-Prostate Cancer Index (Italian UCLA-PCI)</u> Mean difference between WT ≥ 90 days and < 90 days was ns for: bowel bother; bowel function; sexual bother; sexual function; urinary bother, urinary function; <u>Short-Form Health Survey (SF-12 Standard v1 scale)</u> - SF-12 physical component subscale Mean difference between from WT ≥ 90 days and < 90 days from baseline to - To 6 months 0.42 (-0.60, 1.45), p=0.8503 - To 12 months 0.40 (-0.69, 1.48), p=0.9036 - SF-12 mental component subscale Mean difference between from WT ≥ 90 days and < 90 days from baseline to - To 6 months	Main conclusion: WT might have no impact on functional and oncological outcome. Limitations: - Lack of information about the availability of different treatment in each centre - Not stratification on prostate cancer risk - Not information about volume of each centre



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				1.02 (0.07,2.12), p=0.0428 To 12 months 0.56 (-0.60, 1.72), p=0.7356 Upgrading ns when comparing WT < 90 days and WT ≥ 90 days Upstaging ns when comparing WT < 90 days and WT ≥ 90 days No positive surgical margins WT < 90 days 72.5% vs WT ≥ 90 days 73.8%, p=0.7790 PSA at 12 months follow-up <0.07 ng/mL WT < 90 days 85.1% vs WT ≥ 90 days 83.2%, p=0.5965	
Garcia-Botello 2021 ¹⁴⁴	Prospective cohort single-centre study (patients included from 2012 to 2017 followed until 2020) - Spain	Patients undergoing definitive surgery for colorectal cancer and did not receive preoperative chemoradiotherapy (n=602)	WT was defined as the time from completion of diagnosis workup to definitive surgery and categorised as follows: < 2 weeks, 2-4 weeks, 4-6 weeks, > 6 weeks	<i>Results reported in graph</i> Postoperative deaths No significant difference between WT categories (p=0.442) 2-year and 5-year disease-free survival (DFS) No significant difference between WT categories (p>0.05) 2-year DFS No difference between stages 5-year DFS For AJCC* stage II tumors, higher 5-y DFS for 2-4 and 4-6 weeks	<u>Main conclusions:</u> Time from diagnosis to definitive surgery up to 6 weeks is not associated with a decrease in 2-year or 5-year DFS in colorectal cancer patients. <u>Limitations:</u> - Low sample size - Majority of cases were treated in the first 6 weeks for ethical issues leading to difficulties to conclude regarding long term effect - No assessment of delay before referral for surgery



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				WT was not prognostic factor for DFS on Cox-regression analysis for all group (p=0.414) or by tumour stage (p=0.712) * American Joint Committee on Cancer	No assessment of patient socioeconomic level and access to health service but effect limited because of the organisation of Spanish health system
Gonzales 2021 ¹⁴⁵	Padill	Retrospective in one centre in Spain (patients included between 2017 and 2019)	Patients who underwent scheduled, unilateral, semirigid ureteroscopy for a single ureteral stone (n=219)	WT was defined as the number of days between the date of the imaging test used as the basis for inclusion of patients on the waiting list (usually performed a few days before consultation and 4–6 weeks after initial presentation of the renal colic) and the date of surgery Risk of negative ureteroscopy Adjusted* OR (95% CI), p - WT (per day) 1.005 (1.00-1.01), p=0.024 - At 30 days 1.188 (1.02-1.38), p=0.024 - At 60 days 2.176 (1.02-4.61), p=0.043 * Gender, BMI, stone characteristics (density, size, radiopaque) and preoperative DJ stent Negative ureteroscopy rates per month 1 month 10.8% 2 months 12.2% 3 months 13.1% 4 months 16.4% 5 months 16.7% 6 months 17.5% >6 months 18.7%	<u>Conclusions:</u> Patients with small (e.g. ≤6 mm) radiolucent stones and with long WT (≥ 60 days) may be offered CT re-evaluation before surgery as up to 18.7% of these patients may already have passed the stone and could avoid an unnecessary procedure. <u>Limitations:</u> - Not all patients underwent a preoperative CT scan (sensitivity of 95-100%, specificity 96-98% for the detection of ureteral stones). Rather some patient underwent KUB X-ray and urinary system ultrasound (sensitivity 96% and specificity 91%) - No standard definition of long WT
Greve 2020 ¹⁴⁶		Retrospective analysis of a nationwide cohort from Swedish Registry for Hip	Patients ≥ 65 y with (non-pathological) a cervical or a non-cervical hip fracture underwent more or less	WT was defined as the number of hours between the arrival at the hospital and the surgery grouped in 4-month mortality Adjusted* HR (95% CI) p-value not provided	<u>Conclusions:</u> No association between WT and 4-month mortality were found in patients 65-year



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
	Fracture Patients and Treatment (RIKSHÖFT)	invasive surgery within 7 days of the hospitalisation (n= 59 675)	two categories ≤ 24h and > 24h	- Men ≤ 24h - Reference > 24h 1.06 (1.00-1.14), ns - Women ≤ 24h - Reference > 24h 1.16 (1.09-1.22) - ASA 1 ≤ 24h - Reference > 24h 1.28 (0.78-2.10), ns - ASA 2 ≤ 24h - Reference > 24h 1.05 (0.94-1.17), ns - ASA 3 ≤ 24h - Reference > 24h 1.13 (1.07-1.19) - ASA 4 ≤ 24h - Reference > 24h 1.17 (1.07-1.29) - Age 65-85** - ASA 1-2	and older with hip fracture and ASA 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 for women than for men, and for patients > 85. <u>Limitations:</u> - No conclusion on causal relationships because of the observational design - No possible to control for all potential confounding factors - WT also affected by system-related factors



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				≤ 24h Reference > 24h 1.02 (0.85-1.22) ASA 3-4 ≤ 24h Reference > 24h 1.11 (1.03-1.19) • Age > 85** ASA 1-2 ≤ 24h Reference > 24h 1.09 (0.96-1.25) ASA 3-4 ≤ 24h Reference > 24h 1.22 (1.15-1.30) * Adjusted for age, type of fracture, and type of surgery ** non adjusted HR	
Hack 2022 ¹⁴⁷	Retrospective population-based cohort study using real-world data from the Netherlands Cancer Registry between 2010 and 2019	Adult women with cervical cancer underwent surgery or (chemo)radiotherapy with curative intent (n=4 653)	WT was defined as the time interval between first pathologic confirmation of carcinoma and the day of first curatively intended treatment categorised as follows: ≤ 8 weeks, >8 weeks	OS Adjusted* HR (95% CI) • Patients with surgery ○ WT as continuous variable 0.97 (0.93-1.01) ○ WT as dichotomised variable 0.93 (0.68-1.27)	<u>Main conclusion:</u> WT of up to 12 weeks from diagnosis to curatively intended treatment in cervical cancer patients has no negative impact on OS. <u>Limitations:</u> • Few patients beyond 12 weeks leading to



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				○ WT as polynomial variable ○ ns results reported in graph • Patients with (chemo)radiotherapy ○ WT as continuous variable 0.97 (0.93-1.01) ○ WT as dichotomised variable 0.91 (0.75-1.09) ○ WT as polynomial variable ○ ns results reported in graph * Adjusted for patient-, tumor-, and treatment related characteristics	insufficient statistical power • No adjustment possible for non-recorded confounding factors such as type of surgery • Other outcomes could not be evaluated (loco)regional recurrences and cancer-specific survival because not routinely collected • No information on reasons for longer WT and cause of death
Karlsson 2022 ¹⁴⁸	Retrospective cohort study based on data extracted from the National Swedish Kidney Cancer Register between 2009-2021 and followed-up until 9 December 2021	Patients with non-metastatic renal cell carcinoma at primary diagnosis treated by surgery (n=9 918)	3 WT were defined: • WRS Number of months from the date of radiological diagnosis to the date of surgery • WRT Number of months from the date of radiological diagnosis to the date of treatment decision • WTS Number of months from the date of treatment decision to the date of surgery	WT as a predictor of all-cause mortality <i>Cox regression analyses</i> Adjusted* HR (95% CI), p • WRS All: 1.03 (1.02-1.04), p<0.001 T1: 1.03 (1.01-1.04), p<0.001 T2: 1.04 (1.00-1.09), p=0.079 T3: 1.05 (1.02-1.08), p=0.003 T4: 0.98 (0.86-1.13), p=0.807	<u>Main conclusions:</u> Prolonged surgical waiting time resulted in a significant increased risk of early death among renal cell carcinoma patients. <u>Limitations:</u> • Retrospective design leading to a lack of control on the data collection process • Missing information on : ○ Reasons to delayed surgery ○ Lack of data on comorbidity



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				WRT All: 1.02 (1.01-1.04), p< 0.001 T1: 1.02 (1.01-1.04), p=0.004 T2: 1.03 (0.97-1.09), p=0.286 T3: 1.04 (1.00-1.08), p=0.034 T4: 1.00 (0.86-1.16), p=0.997 WTS All: 1.06 (1.03-1.09), p<0.001 T1: 1.05 (1.01-1.08), p=0.005 T2: 1.11 (0.98-1.26), p=0.100 T3: 1.10 (1.00-1.21), p=0.043 T4: 0.89 (0.57-1.41), p=0.626 * Adjusted for the confounding gender, incidental finding , year of surgery, age at surgery, open surgery, tumour size and renal cell carcinoma type and T substage	○ All-cause mortality was available but cancer-specific mortality would be a better outcome



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Khan 2020 ¹⁴⁹	Retrospective cohort study based on chart review in 1 centre in Canada (inclusion between 2012 and 2015)	Patients < 17y with had unprovoked seizures for suspected epilepsy who were waiting for a first clinical assessment (n=197)	Waiting time was defined as the number of months between seizure onset and the first clinical assessment	Risk of unfavourable outcome (patients continuing to have seizures) Adjusted OR (95% CI), p - At 6 months 1.13 (1.04-1.23), p<0.001 - At 12 months 1.09 (1.00-1.18), p=0.04 - At 18 months 1.11 (1.02-1.20), p=0.02	<u>Conclusions:</u> Prolonged WT for a paediatric neurology evaluation of children with new onset epilepsy may increase the risk for a poor epilepsy outcome. <u>Limitations:</u> - retrospective study restricting to the collected information. - As different physicians have been involved in the study, potential observer bias was suspected because of variation in their treatment approach leading to variation in the data collection - Misdiagnosed before referral may increase WT
Khanolkar 2021 ¹⁵⁰	Retrospective analysis of electronic medical records of 1 cancer centre in Canada (inclusion between 2003 et 2016)	Patients with intermediate-risk prostatic carcinoma treated with low-dose-brachytherapy (n=466 including favourable intermediate risk (n=296) unfavourable intermediate risk (n=170))	WT was defined as the time from biopsy to treatment procedure	Multivariate analysis Adjusted* HR (95% CI), p Cumulative incidence of recurrence - All^s 1.01 (1.00-1.03); p=0.080 - NCCN favourable intermediate-risk 1.02 (0.97-1.07); p=0.550 - NCCN unfavourable intermediate-risk 1.01 (1.00-1.03); p=0.044	<u>Main conclusion:</u> Increases in wait times for low-dose-brachytherapy were associated with an increased risk of recurrence and metastases in patients with intermediate-risk prostatic cancer. <u>Limitations:</u> Routine post-implant dosimetry was not calculated on th post-treatment CT images



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				Cumulative incidence of metastases - All[§] 1.03 (1.02-1.05); p<0.001 - NCCN favourable intermediate-risk 0.99 (0.87-1.12); p=0.820 - NCCN unfavourable intermediate-risk 1.04 (1.02-1.06); p<0.001 OS - All[§] 0.96 (0.91-1.01); p=0.126 - NCCN favourable intermediate-risk 0.98 (0.92-1.05); p=0.553 - NCCN unfavourable intermediate-risk 0.95 (0.87-1.03); p=0.220 * Adjusted presence of androgen deprivation therapy, age, and § NCCN risk	- No information on - Repeat biopsy, repeat examination or imaging - Change in management strategy - Personal patient preferences
Kirkegard 2019 ¹⁵¹	Retrospective analysis of population based cohort of patients included in the Danish Pancreatic Cancer Database from 2011 and 2016 (n=873)	Patients undergoing for pancreatic cancer (resection or palliative procedure)	WT was defined as: - From the date of entry into the National Cancer Pathway to date of the surgery (WT1) - From the last CT or PET-CT scan to the date of surgery (WT2)	Median survival, in months (95% CI) - WT1 <u>Resection</u> < 28 days 22.3 (18.1-27.3) 28-55 days 25.1 (21.0-31.3) ≥56 days 20.7 (14.0-26.1)	Main conclusion: WT to surgery did not affect survival in patients undergoing surgery for pancreatic cancer. Limitations: Potential selection bias as patients with longer WT may have smaller tumours, leading to better prognosis



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				<u>Exploration/palliation</u> < 28 days 6.7 (5.5-9.8) 28-55 days 8.1 (6.3-9.3) ≥56 days 7.6 (2.9-12.2) • WT2 <u>Resection</u> < 28 days 22.1 (19.3-25.9) 28-55 days 22.0 (17.4-26.2) ≥56 days 21.8 (16.3-26.1) <u>Exploration/palliation</u> < 28 days 6.0 (3.7-8.3) 28-55 days 8.0 (6.2-9.3) ≥56 days 6.3 (1.3-9.1)	- Missing data on: - Cancellation of surgery due to tumour progression or clinical deterioration - Factors affecting prognosis such as resection margins, lymph node status, tumour differentiation, or performance status - Reasons for WT (e.g. preoperative optimization, additional diagnostic workup, administrative reasons...)
Koire 2022 ¹⁵²	Retrospective observational study using health record data from a specialised clinic in 5 community locations in Texas (USA) between 2014 and 2019	Peripartum patients with a positive screen for peripartum depression symptoms (Edinburgh Postnatal Depression Scale – EPDS – score ≥ 10) (n=490)	WT was defined as the number of days between the initial positive EPDS screen and the patient's first appointment with the reproductive psychiatry clinic.	Adjusted* OR (95% CI), p Δ EPDS score ≥4 • WT in weeks 1.133 (1.080-1.189), p<0.0001 • WT in months 1.709 (1.391-2.099), p=0.03 Self-harm ideation • WT in weeks	<u>Conclusion:</u> Longer period between primary care referral and appointment with a specialist has a negative impact on the mental health of women as each week spent waiting for an appointment produced a 13% increase in odds of clinically meaningful worsening of peripartum



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				1.089 (1.029-1.152), p=0.003 • WT in months 1.439 (1.130-1.833), p=0.003 *Adjusted for maternal age, score at first positive EPDS screen, maternal ethnicity, marital status, medicaid status	depression scores (EPDS score increase ≥ 4) and 9% increase in odds of developing new self-harm ideation. <u>Limitation:</u> • Over-representation of white women
Kokkinos 2022 ¹⁵³	Retrospective analysis between 2015 and 2020 in one centre in London (UK-England, n=233))	Patients with basal cell carcinoma underwent Mohs micrographic surgery (MMS)	WT was defined as the time between the date of referral for MMS upon review at the outpatient specialist dermatology clinic and the date when MMS was performed	Lesion size Positive correlation between increase in lesion size and increase in WT for surgery (p=0.008, Person's correlation= 0.176)	<u>Main conclusion:</u> To reduce lesion size at surgery, WT should be decreased. <u>Limitations:</u> • No comparison of the impact of WT with patients underwent surgical excision • Retrospective design • Small sample size • One centre impairing generalibility to all UK
Kruger 2022 ¹⁵⁴	Retrospective analysis of prospectively collected data from one cancer centre in Germany (inclusion from 2002 – 2015, follow-up until February 2017)	368 patients with resectable pancreatic cancer	WT was defined as the number days between first imaging showing advanced pancreatic cancer to first receipt of chemotherapy in palliative intent (TTI) categorised according median, p75 and p90 to control lead time using a landmark analysis	Overall survival Hazard ratio (95% CI), p • TTI median ≤ 29 days 1.12(0.88-1.42); n=153 > 29 days 1;n=143 p=0.362 • TTI p75 ≤ 43 days 1.03(0.77-1.36); n=221	<u>Main conclusion:</u> Absence of a string adverse effect of prolonged TTI on prognosis after controlling for the lean effect or 'waiting time paradox' <u>Limitations:</u> • Small sample size • Imbalance in subgroup of patients with a very long TTI, it remains unclear whether a very



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				> 43 days 1;n=72 p=0.856 • TTI p90 ≤ 60 days 1.04(0.69-1.57); n=264 > 60 days 1;n=28 p=0.861 Progression-free survival during first-line chemotherapy similar results were obtained (data not showed)	longTTI negatively affects treatment outcome
Lai 2020 ¹⁵⁵	Retrospective cohort of data from Breast Cancer Cancer Agency's neoadjuvant treatment database for patients from a breast cancer Cancer Agency Vancouver centre (Canada - inclusion from 2012 to 2018)	Patients with breast cancer undergoing neoadjuvant chemotherapy followed by surgical resection (n=343)	Time to surgery (TTS) was defined the time from the date of the last dose of neoadjuvant chemotherapy to the date of surgery, catagorised as follows: < 4 weeks, 4-8 weeks, > 8 weeks	<i>Multivariable Cox model</i> 5-year OS Adjusted* HR (95% CI), p <u>4-8 weeks vs < 4 weeks</u> 1.11 (0.47-2.61), p=0.82 <u>> 8 weeks vs < 4 weeks</u> 2.82 (0.85-9.35), p=0.09 5-year DFS Adjusted* HR (95% CI), p <u>4-8 weeks vs < 4 weeks</u> 0.79 (0.41-1.51), p=0.47 <u>> 8 weeks vs < 4 weeks</u> 1.17 (0.40-3.38), p=0.78 * Adjusted for age, Charlson comorbidity score, clinical stage, surgery type, receptor type, pathologic complete response and surgical complications	<u>Main conclusion:</u> Patient outcomes were not meaningfully affected within 8-week window from the completion of neoadjuvant chemotherapy. <u>Limitations:</u> • Single institution • Median follow-up of 3.3 years



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Lo 2021 ¹⁵⁶	Retrospective cohort study using data from the National Cancer Database (USA 2010-2016)	Adult patients with stage I, II or III adenocarcinoma of colon (n=187 394)	WT was defined as the number of weeks from cancer diagnosis to surgery and categorised as follow: < 1 week, 1-3 weeks, 3-6 weeks, 6-9 weeks, 9-12 weeks, and > 12 weeks	Short-term mortality <u>30-day mortality rate</u> < 1 week: 4.4 % 1-3 weeks: 1.8% 3-6 weeks: 1.3% 6-9 weeks: 1.7% 9-12 weeks: 1.9% >12 weeks: 2.5% $p < 0.001$ <u>90-day mortality rate</u> < 1 week: 7.3 % 1-3 weeks: 3.2% 3-6 weeks: 2.3% 6-9 weeks: 2.8% 9-12 weeks: 3.3% >12 weeks: 4.3% $p < 0.001$ Similar short-term outcomes were observed after stratification by pathological stage of disease. Long-term mortality <u>Adjusted* 5-year overall survival</u> <i>HR (95% CI), p</i> < 1 week: 1.71(1.66-1.75), $p < 0.001$ 1-3 weeks: 1.12(1.09-1.15), $p < 0.001$ 3-6 weeks: <i>Reference</i> 6-9 weeks:	<u>Main conclusions:</u> - Optimal timing for colon cancer surgery is between 3 and 6 weeks after diagnosis. - All delays beyond 6 weeks are associated with worse short-term mortality, and 5-year overall survival - Worst outcomes occurring in patients undergoing surgery >12 weeks after colon cancer diagnosis - Similar trends were observed after stratification for pathological stage of disease, except for stage III, no significant difference between 5-year mortality in group 6-9 weeks and group 3-6 weeks (reference) <u>Limitations</u> - Due to retrospective design, no possibility to control for all potential confounders - Missing information: admission tpe (emergency vs elective) or individual postoperative complications, disease-free survival



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				1.10(1.06-1.15), $p < 0.001$ 9-12 weeks: 1.25(1.18-1.33), $p < 0.001$ >12 weeks: 1.43(1.35-1.52), $p < 0.001$ $p < 0.001$ Similar trend was observed for stage I and II patients. For stage III, no significant difference 6-9 weeks and 3-6 weeks (reference) * Adjusted for demographic factors (age, sex, ethnicity, education, income, insurance type, county, distance to facility), clinical/oncological factors (Charlson/Deyo score, TNM, usage of adjuvant chemotherapy, grade differentiation, nodes), margins, tumor size), hospital factors (type of facility)	
Lopez-Cedrun 2019 ¹⁵⁷	Retrospective cohort study in 1 centre between 1998 and 2008 follow-up until 2016 (Spain)	Patients diagnosed with oral/oropharyngeal squamous cell carcinoma (n=228)	WT was defined as the first specialist visit to the start of treatment (hospital interval)	Survival Multivariate Cox models Exp (β), p Time interval between 3 and 18 days 1.9180, $p = 0.05$ Time interval between 19 and 25 days Reference Time interval between 26 and 55 days	<u>Main conclusion:</u> V-shaped association, where patients with short intervals (3–18 days) and those with long intervals (26–55 days) had higher mortality than those with intermediate intervals (19–25 days) <u>Limitations:</u> Retrospective design leading



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				1.8185, p= 0.04	- o to potential selection bias, - o missing information: - on socioeconomic characteristics of patient (low impact due to universality of the Spanish health system) - factors associated to prognosis such as depth of invasion or extranodal extension • Potential lead-time bias
Marcickiewicz 2022 ¹⁵⁸	Population-based cohort study from Swedish National Cancer Registry (2010-2018)	Adult patients with histologically verified primary endometrial cancer with a histology of endometrioid-, serous-, mucinous-, clear cell carcinomas or carcinosarcoma with surgery as primary treatment (n= 7 366) classified in two risk groups: • High-risk - Non-endometrioid histology (serous, clear cell carcinoma or carcinosarcoma), endometrioid adenocarcinoma FIGO grade 3, or non-diploid tumours. • Preoperative low-risk	WT was defined as the number of days between date of diagnosis (date of biopsy by endometrial aspiration or dilation and curettage) and definitive surgery date (defined by surgery including at least a hysterectomy). WT was categorised as follows: ≤ 14 days 15-32 days 33-50 days 51-70 days > 70 days	5-year relative survival (=excess mortality in a study population due to the disease, compared to the mortality in the general population) Impact of the wait time on survival was more prominent in the high-risk tumour group than in the low-risk group (p value not provided, results reported in graph) Excess mortality rate ratio Adjusted* OR (95% CI), p • ≤ 14 days 2.10 (1.25-3.54), p=0.005 • 15-32 days	<u>Main conclusions:</u> Prolonged wait time to surgery did not seem to have a significant adverse effect on prognosis. <u>Limitations:</u> Despite a large sample size and a quality control of the data, limits were: • Potential selection bias because large number of missing data on the date of surgery (n=3 454) • Missing recording of potential confounding variables: data on adjuvant treatment, comorbidity, and BMI.



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
		Endometrioid histology Grade 1 -2 and diploid tumours.		Reference • 33-50 days 0.76 (0.59-0.99), p=0.044 • 51-70 days 1.04 (0.78-1.37), p=0.806 • > 70 days 0.90 (0.64-1.26), p=0.533 * Age, level of education, country of birth, treating hospital, FIGO stage, histology, preoperative risk group	No information about patient's preferences and extended workups due to risk factors for surgery.
Mitric 2020 ¹⁵⁹	Retrospective cohort study in one centre in Canada between 2007 and 2015	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. (n=136)	WT was defined as the time between the endometrial biopsy and surgery as categorised as follows: ≤12 weeks (84 days), > 12 weeks	Adjusted* HR (95% CI) Disease-specific survival • ≤12 weeks Reference • > 12 weeks 1.2 (0.6-2.5), p = 0.6 Overall Survival • ≤12 weeks Reference • > 12 weeks 1.1 (0.6-2.1), p = 0.7 Progression-free survival • ≤12 weeks Reference • > 12 weeks 0.9 (0.5-1.7), p = 0.8 * Adjusted for clinical factors (age, BMI, ASA score) and	Main conclusion: Prolonged surgical wait time for poorly differentiated endometrial cancer seemed to have a limited impact on clinical outcomes compared to biological factors. <u>Limitations:</u> - Retrospective design leading to selection bias - No assesement on outcomes such as stress-, anxiety- and surgery-related morbidity - Restricted statistical power due to low number of patients



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				pathological factors (stage III/IV versus I/II, non-endometrioid vs endometrioid, lymphovascular)	
Müller 2021 ¹⁶⁰	Retrospective review of electronic medical records in 12 neuro-oncological teams from the Netherlands (inclusion 2012-2013)	Adult patients with a first-time surgery for glioblastoma (n=1 033)	Time-to-surgery was defined as the number of days between the diagnostic MR scan and surgery	Adjusted* HR (95% CI), p OS 1.000 (0.999-1.001), p=0.83 Performance change 0.857 (0.811-0.906), p<0.01 Tumor volume in mL 1.005 (1.002-1.008), p<0.01 Resection vs biopsy 0.340 (0.286-0.404), p<0.01	<u>Main conclusion:</u> The extent of resection, residual tumour volume, performance change, and patient survival are not associated with time-to-surgery <u>Limitations:</u> Missing information on: • Timings of consultations • Tumour board discussions, • Capacity issues on wards and operating rooms. • the duration, severity and pace of progression of symptoms before surgery, actual parameters that led to urgent surgery. • QoL • Length of hospital stay, and the need for postoperative rehabilitation Use only Karnofsky performance changes but



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Nasioudis 2022 ¹⁶¹	Population retrospective cohort study from National Cancer Database (USA – between 2004-2015)	-based Patients with FIGO stage I epithelial ovarian carcinoma who received multiagent chemotherapy within 12 weeks from surgery and had at least 1 month of follow-up	Time to chemotherapy was defined as the interval between surgery and administration of chemotherapy categorised < 6 weeks (no delay) and 6-12 weeks (delay)	OS Adjusted* HR (95% CI), p • Delay (No vs Yes) 1.25 (1.10, 1.42), p<0.001 • Subgroup analysis ○ Patients with lymph node dissection (LND) 1.21 (1.05, 1.40) p value not provided ○ Exclusion of patients with stage IA/IB grade 1 endometrioid/serous or stage IA/IB mucinous tumors (any grade), delay in chemotherapy 1.25 (1.09, 1.42) p value not provided ○ After controlling for type of surgery (laparotomy vs minimally-invasive surgery) in addition to other factors* 1.37 (1.11, 1.70)	relevant neurological or cognitive decline due to longer time-to-surgery was missing Underestimation of the extent of glioblastoma infiltration due to the definition of enhancement with enclosed necrosis or cyst as tumour <u>Main conclusion:</u> Delay in adjuvant chemotherapy administration following staging surgery may have a detrimental impact on the overall survival of patients with FIGO stage I epithelial ovarian cancer, especially for those with high-grade serous histology or stage IC disease. <u>Limitation</u> • Potential histology and stage misclassifications due to absence of central pathology review • Reasons of no LND were not documented • Type of surgery variable (laparotomy or minimally-invasive surgery) was introduced in 2010 (half of data collection period)



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				* controlling for patient age, race, presence of comorbidities, insurance status, tumour histology and grade, performance of LND and disease substage,	- No data on tumour relapse or cause of death precluding from analysing the impact of delay in adjuvant chemotherapy administration on progression-free and cancer-specific survival. - For patients receiving a multi-agent regimen, composition of chemotherapy was not known - No information on patient functional status.
Nica 2022 ¹⁶²	Population-based retrospective cohort study from provincially funded health insurance (Canada – inclusion between 2003 and 2017)	Adult women diagnosed with high-grade endometrial cancer who underwent a hysterectomy (n= 3 518)	WT was defined as: 1) Number of days from diagnosis based on biopsy to surgery (WT D) 2) Number of days from gynaecologic oncology consultation to surgery (WT C)	OS Adjusted* HR (95% CI), p - WT D (days) 1–7 days (n = 48) 2.7 (1.61–4.51), p <0.0001 8–14 days (n = 45) 1.96 (1.50–2.57), p <0.0001 15–21 days (n = 97) 1.20 (0.87–1.66), ns 22–28 days (n = 166) 0.75 (0.56–1.01), ns 29–45 days (n= 700) Reference 46–60 days (n = 801) 0.82 (0.72–0.94), ns	<u>Main conclusion:</u> Patients who have surgery more than 45 days after surgical consultation have reduced survival. <u>Limitations:</u> Retrospective use of administrative data does not allow to control for some potential confounding factors such as patient ethnicity, performance status, FIGO staging or detailed pathological reporting. In addition, grade 3 endometrioid endometrial cancer because of lack of data on pathological grade data.



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				61–75 days (n = 599) 0.85 (0.70–1.03), ns 76–90 days (n = 353) 1.00 (0.82–1.21), ns 91–105 days (n = 161) 1.07 (0.94–1.22), ns 106–120 days (n = 79) 1.10 (0.72–1.66), ns 121–182 days (n = 84) 1.30 (0.86–1.98), ns • WT C (days) 1–7 days (n = 67) 1.33 (0.92–1.92), ns 8–14 days (n = 221) 1.07 (0.88–1.31), nS 15–21 days (n = 302) 1.04 (0.84–1.29), ns 22–28 days (n = 372) 1.14 (0.90–1.44), ns 29–45 days (n= 763) Reference 46–60 days (n = 258) 1.19 (1.04–1.36), p<0.0001 61–75 days (n = 117) 1.42 (1.11–1.83), p<0.0001 76–90 days (n = 40) 1.21 (0.72–2.05), ns 91–227 days (n = 51) 1.58 (0.83–3.02), ns	Other outcomes of interest were not studied (lack of data) such as QoL, psychological distress, healthcare system cost
				* Adjusted regionalisation period (i.e. surgery by a gynecologic oncologist and access to a multidisciplinary	



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				care team in a gynecologic oncology centre), age, comorbidities, adjuvant therapy and disease stage	
Patel 2019 ¹⁶³	Retrospective analysis of patient records between 2005 and 2014	Patients underwent a radical prostatectomy for prostatic carcinoma (n=2 310)	WT was defined as the number of day from biopsy to radical prostatectomy categorised < 2 months and then at monthly intervals of up to 6 months	Logistic regression analysis controlling for age, gland volume, number of positive cores, total core % involvement, PSA, PSAD (prostate-specific antigen density) No association found between WT and higher pathological stage, positive margin, lymph node positivity Figures not shown	<u>Main conclusion:</u> Surgical delays of up to 6 months following prostate biopsy were not associated with pathological stage, positive surgical margins or lymph node involvement. <u>Limitations:</u> • Single institution • complete data in 85% of patients • Limited number of patients with higher-risk disease • High)risk patients selected for faster surgery (waiting paradox bias) • Short follow-up • No information about patients on active surveillance vs those with de novo prostatic cancer diagnoses prior radical prostatectomy
Raphael 2020 ¹⁶⁴	Population-based retrospective study including a random sample of patients from Ontario (Canada) (inclusion from 2001-2002)	Women with early stage breast cancer (stage I or II BCA) who were treated with breast-conserving surgery and adjuvant radiotherapy with or without chemotherapy (n=1028)	WT for patients without chemotherapy was defined as the interval from the date of last surgery or biopsy to the date of first radiotherapy treatment categorised as < 12 weeks and ≥ 12 weeks	Event-free survival (composite outcome = evidence of locoregional recurrence, diagnosis of metastatic disease, or BCA-specific mortality) Adjusted* HR (95% CI), p	<u>Main conclusions:</u> In patients who received chemotherapy, delay to the initiation of adjuvant RT after breast-conserving surgery is associated with



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
			WT for patients with chemotherapy was defined as the interval from the date of last chemotherapy to the date of the first radiotherapy treatment categorised as < 6 weeks and ≥ 6 weeks	- Patients without chemotherapy 1.44 (0.98-2.11), p=0.07 Median follow-up 7.2 years - Patients with chemotherapy 1.50 (1.00-2.22, p=0.047) *Adjusted for age and stage	inferior BCA survival outcomes <u>Limitations:</u> - Baseline difference in the balance between groups of prognostic factors, comorbidities, and postoperative complications - No information on - hormone receptor status or adjuvant hormonal treatments (factors associated with improved rates of local recurrence and overall survival) - rt doses and completion rates, and whether boost radiation was applied to the tumour bed. - Low event rates limited the power to identify a statistically significant difference between waiting time groups
Roule 2022 ¹⁶⁵	Retrospective analysis of a cohort from FRANCE-TAVI or FRANCE-2 registries between 2013 and 2019 in one hospital in France	Patients with elective TAVR (n=383)	WT was defined as the number of week from referral date for valve replacement to the date of the TAVR.	Adjusted* HR (95% CI), p 30-day mortality 1.19 (0.99-1.06) p=0.47 1-year mortality 1.02 (1.002-1.04), p=0.02	<u>Conclusions:</u> WT were associated with a 2% per week increase of 1-year mortality after referral. <u>Limitations:</u>



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Re hospitalisation for cardiac event (all types of events) 1.01 (0.98-1.04), p=0.27 Bleeding (all types) 0.99 (0.96-1.007), p=0.21	• Due to the observational nature of the study, No all confounding factors can be taken into account for the adjustment • Time symptom onset was unknown and therefore the magnitude of effect of longer wait times on outcomes can be underestimated • Monocentric study leading to limitations in generalisation of the results
Scott 2019 ¹⁶⁶	Cross-section analysis in one orthopaedic teaching hospital in UK (between	Patients undergoing a primary total hip arthroplasty (n= 1 555), or a primary total knee arthroplasty (n = 1 700)	OP WT was defined as the number of weeks between primary care referral and orthopaedic review WT for surgery was defined as the number of weeks between the orthopaedic review and the surgery	Mean (±SD), p Hip • OP WT Patients reporting WTD status* at 1 year: 13.8 weeks (± 8.1) vs patients without WTD at 1 year: 15.4 weeks (± 7.5), p=0.018 • WT for surgery Patients reporting WTD status* at 1 year: 12.3 weeks (± 5.0) vs patients without WTD at 1 year: 13.6 weeks (± 5.8), p=0.001 Knee • OP WT Patients reporting WTD status* at 1 year: 15.1	<u>Conclusions:</u> Patients reporting WTD at 1 year had a shorter waiting between primary care referral and orthopaedic review and between orthopaedic review and surgery for primary total hip arthroplasty. These associations were not observed in patients who underwent primary total knee arthroplasty. <u>Limitations:</u> • Large number of loos to follow-up at 1 year • Lack of robust waiting list data



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				weeks (± 7.4) vs patients without WTD at 1 year: 15.6 weeks (± 5.7), $p=0.577$ WT for surgery Patients reporting WTD status* at 1 year: 14.2 weeks (± 6.8) vs patients without WTD at 1 year: 14.1 weeks (± 6.0), $p=0.797$	- No control of all relevant confounding covaraites - No control for anxiety and depression - Mono centric study
				* WTD = state of 'worse than death' defined as EQ-5D<0	
Sripada 2022 ¹⁶⁷	Cross-sectional study in one centre in UK. Data were collected through questionnaire	Patients waiting for anterior cruciate ligament reconstruction (n=67)	WT was defined as the number of days on the waiting list	Multivariate analysis reporting adjusted* β (95%), p HRQoL (MCID EQ-5D= 0.008 difference) 0.0004 (0.0000-0.0007), $p=0.038$	<u>Conclusions:</u> Every 200 days spent on the waiting list for anterior cruciate ligament reconstruction, a patient would have a clinically significant deterioration in the HRQoL <u>Limitations:</u> - Single centre study rising issue of generalisability of the results 75% of the respondents were male - Data collection during the COVID-19 pandemic the can affect HRQoL
Sutherland 2019 ¹⁶⁸	Prospective study in one centre based on a survey of patients at booking of elective surgery and 6	Adult patients who underwent a surgery for painful first	WT was defined as the number of weeks between the booking date at the	Adjusted* β (SE), p At 6 months Depression – PHQ-9	<u>Conclusions:</u> No association between depression and generic



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
	months postoperatively between 2013 and 2017 using PHQ-9 (patient health questionnaire), PEG (pain intensity (P), interference with enjoyment (E), of life and general (G) instrument), FOAS (Foot and ankle outcome score) (Vancouver – Canada)	metatarsophalangeal joint (n=87)	hospital and the date the date of surgery	0.02 (0.02), p=0.614 Pain – PEG 0.02 (0.01), p=0.91 Pain – FOAS -0.3 (0.1), p=0.04 Symptoms – FOAS -0.1 (0.1), p=0.30 Activities of daily living – FOAS -0.4 (0.1), p=0.01 Sport and recreation – FOAS -0.2 (0.2), p=0.28 QoL – FOAS -0.2 (0.1), p=0.15 * Adjusted by gender, age, SES index score, Charlson index	pain scores and WT for surgery. At the 6-month postoperatively, prolonged WT was associated with smaller gains for pain and activities of daily living of the foot-specific patient reported outcomes. <u>Limitations:</u> - No detailed information on pathology, operative procedure - Potential selection bias due to a low response rate - Short follow-up (at 6 months) to detect potential gains in FAOS domains
Thornton 2020 ¹⁶⁹	Secondary analysis of a randomised clinical noninferiority trial including patients from one tertiary care multidisciplinary sleep clinic in Canada between 2014 and 2017	Patients with severe sleep-disorder breathing treated with positive airway pressure (PAP) therapy (n=176)	WT was measured from date of referral to the date of PAP treatment initiation	Multivariate analysis reporting adjusted* β (95%), p Change in Epworth Sleepiness Scale -0.37 (-18.51 to -0.24), p=0.04 Visit-Specific satisfaction instrument-9 -0.024 (-0.047 to -0.0015), p=0.04	<u>Conclusions:</u> Shorter WT is associated with a greater improvement in somnolence measured by Epworth Sleepiness Scale and a higher satisfaction assessed by Visit-Specific satisfaction instrument-9 <u>Limitations:</u> Potential issue with the generalisation of the findings because monocentric study including only severe sleep-disorder breathing



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
Traylor 2021 ¹⁷⁰	Retrospective cohort study using data from electronic medical record in an academic centre in US between 2012-2018	Patients who underwent a hysterectomy for benign gynaecologic disease (n=277)	WT was defined as the number of days between the date of initial preoperative visit and the date of surgery categorised in >30 days and ≤ 30 days	Complication rate • Interoperative complications >30 days: 8% vs ≤ 30 days: 11%, p=0.482 • Postoperative complications >30 days: 26% vs ≤ 30 days: 19%, p=0.13 Health care use (risk for 4 or more phones call, messages, emergency room, or office visits) OR (95% CI) adjusted for leuprolide use • >30 days vs ≤ 30 days (reference) 5.09 (2.97-8.73) • WT as a continuous variable 1.03 (1.02-1.04) Readmission OR (95% CI) adjusted for history of hypertension • >30 days vs ≤ 30 days (reference) 3.22 (1.27-8.19)	• Small sample size leading to potential risk of underpowered study to detect association of WT with the patient reported outcomes understudy. <u>Conclusions:</u> A surgical WT >30 days in patients undergoing a hysterectomy for benign disease is associated with increased healthcare use in the interim. Patients with a longer surgical WT did not experience worse surgical outcomes but had a higher risk for readmission after surgery <u>Limitations:</u> • Retrospective design rely on accurate provider documentation • Lack of information on reason to delay surgery, healthcare use outside of the institution, WT before the decision-to-treat • Monocentric design limited the generalibility of the results



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
Van Dijk 2023 ¹⁷¹	Retrospective analysis of data from electronic patient records from multiple centres in het Netherlands	Adult patients with major depressive disorder (n=715 outpatients)	WT was defined as the interval between diagnostic workup and treatment initiation (psychotherapy or pharmacotherapy)	Δ in the score of the quick inventory of depressive symptomatology – self report score at 6 months Multivariable regression model β (95% CI), p 0.053 (0.01-0.09), p=0.01 Adjustment for severity and presence of suicidal ideation at diagnostic workup	<u>Main conclusion:</u> A longer duration of the WT was associated with a poorer treatment outcome, also after adjustment for potential clinical confounders like severity and the presence of suicidality at diagnostic work-up. An increase in WT with 1 day is associated with an increase in the difference of the QIDS-SR-scores at start of treatment and after six months follow up of 0.053, indicating less improvement. <u>Limitations:</u> • Outcome assessed at 6 months (relatively large interval) • Uncontrolled design • Lack of information on potential confounders such as education level, income, comorbidity, motivation of treatment, experience of the care provider, decision-making process or treatment (only pharmacotherapy and/or psychotherapy)



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
Vasilyeva 2020 ¹⁷²	Retrospective cohort analysis in a single tertiary referral centre in Canada (inclusion 2008-2015, follow-up until June 2018)	Patients with ductal adenocarcinoma of the head of the pancreas (n=144)	WT was defined as the time from diagnosis on imaging to surgical resection categorised as follows: < 4 weeks, 4-8 weeks 8-12 weeks > 12 weeks	Overall survival <i>Adjusted* HS (95% CI), p</i> < 4 weeks Reference 4-8 weeks 0.66(0.38-1.14) ns 8-12 weeks 0.60(0.34-1.04) ns > 12 weeks 0.49 (0.28-0.85) p<0.005 Recurrence-free survival <i>Adjusted* HS (95% CI), p</i> < 4 weeks Reference 4-8 weeks 0.59(0.32-1.09) ns 8-12 weeks 0.50(0.26-0.95) p<0.005 > 12 weeks 0.29 (0.15-0.56) p<0.001 * Age at diagnostic, comorbidity index, preoperative biliary drainage (external vs internal)	<u>Main conclusions:</u> There was an improvement in overall and recurrence-free survival in patients who waited over 12 weeks, likely due to selection bias <u>Limitations:</u> Since the cases were included based on the procedure codes, the following factors were not captured: number of patients - with resectable tumors at diagnosis who were not fit for surgery, - progressed during wait time, - refused surgery, - were never referred to see a surgeon - and without knowing these numbers a true intention to These can lead to a high risk of patient selection bias and impair the possibility of intention to treat analysis
Warren 2020 ¹⁷³	Retrospective cohort study from 1 institution from 2011 to 2017 USA – New-York	Adult patients with high-grade (WHO grade III or IV) glioma pathologically confirmed (n=291)	WT was defined as the time from surgical procedure to the first date of chemoradiation	OS Time starting at the first date of chemoradiation to the date of death or last follow-up.	<u>Main conclusion:</u> WT was not associated with OS <u>Limitations:</u> Potential selection bias



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Adjusted* HR (95% CI), p 0.994 (0.978-1.011), p=0.4924 * for demographic factors (age, gender, white/non-white, Hispanic/ non-hispanic)	Lack on information on functional status, comorbidity score, neurological status, presence or absence of insurance coverage • Questionable generalisability to other state One centre in New-York state
Yip 2019 ¹⁷⁴	Retrospective study based on survey at baseline and at 6-month follow-up using the SNOT-32 (22-item Sino-Nasal Outcome Test) Canada	Adult patients with medically recalcitrant chronic rhinosinusitis who underwent endoscopic sinus surgery (n=104)	WT was defined as the number of days between the date of consent for endoscopic sinus surgery and the date of surgery	Correlation with WT Pearson correlation coefficient, p Global SNOT-32 score -0.187, p=0.020 Symptom domain • Rhinologic -0.203, p=0.039 • Extranasal rhinologic -0.241, p=0.014 • Ear-facial -0.244, p=0.013 • Psychological dysfunction -0.143, p=0.147 • Sleep dysfunction -0.164, p=0.096 Threshold WT until SNOT-22 declines by MCID (days) • Global score 287 • Symptom domain	<u>Conclusions:</u> Less improvement in HRQoL after endoscopic sinus surgery with increasing surgical wait time. Prolonged wait times may result in less improvement in disease-specific symptoms, but do not appear to worsen psychological or sleep dysfunction. <u>Limitations:</u> Retrospective design impairing to control for potential confounders such as geography, health care reimbursement paradigms, smoking status.



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
				Rhinologic 452 Extranasal rhinologic 421 Ear-facial 381	
Zeng 2021 ¹⁷⁵	Retrospective study based on the National Cancer data base from 2004 – 2014 (USA)	Adult patients with pT3 renal cell carcinoma treated with radical and partial nephrectomy (n=22 653)	WT was defined as time from date of diagnosis imaging to date of surgery categorised as follows: ≤ 10 weeks and > 10 weeks	<i>Multivariate Cox regression</i> 5-year OS Adjusted* HR (95%CI), p ≤ 10 weeks Reference > 10 weeks 1.13 (1.04-1.24), p<0.01	<u>Main conclusion:</u> WT > 10 weeks is associated with decreased in 5-year OS <u>Limitations</u> - Retrospective review of patient records can lead to selection bias (e.g. patient with larger tumour earlier scheduled, exclusion from the analysis of all patients who had 0 day interval between diagnostic imaging and surgery but it can be reimaging on the day of surgery) - Date of imaging used as a proxy of date of definitive diagnosis - Cancer-specific-survival and recurrence data would provide more direct analysis in comparison with 5-year OS



ID	Study type / setting / Country	Intervention / population	Definition of WT	Impact on health outcomes	Conclusions and limits reported by the authors
Zumer 2020 ¹⁷⁶	Retrospective analysis of patients' data from 2 centres in Slovenia between 2004 and 2007	Patients with oral cavity, oropharyngeal, hypopharyngeal, or laryngeal squamous cell carcinoma (head and neck tumours) with curative-intent definitive RT, with or without concurrent chemotherapy (n= 262)	WT was defined as the time interval between the date of histopathologic diagnosis and the first day of the RT course	5-year OS <i>Index cancer deaths</i> Adjusted* HR (95% CI), p 1.001 (0.990-1.012), p=0.844 5-year local recurrence Adjusted* HR (95% CI), p 1.012 (0.998-1.027), p=0.094 * Adjusted for TNM, Age, Gender and therapy (radiotherapy with or without chemotherapy) Tumour growth - Median tumour volume relativ increase rate was 32% per day - Median tumour volume doubling time 19 days (range: 2-659 days) No difference between tumour stages.	<u>Main conclusion:</u> Delays in the onset of RT do not harm all patients (no statistically significant impact on disease survival or local recurrences) <u>Limitations:</u> - Retrospective design missing information on p16 or HPV tumour for oropharyngeal carcinoma - Low sample size - Technical limitation in CT scan acquisition to assess tumour volume



2.3. Impact of waiting on costs

2.3.1. Systematic reviews

Table 4 – Overview of (systematic) reviews and meta-analyses on the effect of WT on costs

ID	Databases searched and search date	Patients/setting/ intervention/definitions	Number and type of included studies/ Countries	Effects of WT	Conclusions and limits stated by the authors
Deslauriers 2021 ³³	Medline, CINAHL, and Embase 1990-2018	Outpatient physiotherapy services in persons with musculoskeletal disorders Costs: full description not available.	7 studies investigating healthcare costs, cost-effectiveness or sick leaves: 6 are retrospective cohorts from the USA (n=5) ^{39, 177-180} or Canada (n=1) ¹⁸¹ ; and 1 randomized controlled trial from Sweden ³⁴ . 9 other studies investigating the effects of waiting time on health (outcomes) or on the health system in the review. Studies on outcomes are described in the table above.	Healthcare costs Patients with low back pain with delayed physiotherapy (PT) (15–90 days) vs early (≤14 days): - at 24-month follow-up in 122.723 patients*: 3.031\$ vs 1.828\$, p<0.05¹⁷⁷ - at 18-month follow-up in 2234 patients from a primary care physician*: 5.885\$ vs 3.148\$, p<0.05¹⁷⁸ * costs for spinal injection surgery, advanced imaging, and opioid prescription during and after the waiting period £ and costs for physician visits Cost-effectiveness ³⁹ Patients with neck pain (n= 1531 patients) WT defined as symptoms duration before initiating PT categorised as follows: <4 weeks (early PT) and >4 weeks (delayed PT)	Conclusion: Evidence of higher costs for patients who wait longer before physiotherapy services. Results from included studies suggest an association between WT for PT services and longer sick leave as well as lower care efficiency. However, the studies did not differentiate whether the additional costs, healthcare utilization, and sick leave duration occurred while waiting or after receiving PT services. Limitations: - Variability in the definition of WT before receiving services. - Included studies were of low to high methodological quality, with a mean moderate quality score – higher quality evidence



ID	Databases searched and search date	Patients/setting/ intervention/definitions	Number and type of included studies/ Countries	Effects of WT	Conclusions and limits stated by the authors
				Smaller PT value per dollar and lower treatment efficiency for the delayed PT group ($p < 0.05$) Sick leave Longer for patients who waited longer before initiating PT: - Higher proportion of patients (low back pain) with prolonged sick leave (>6 months) in the delayed PT II group (>90 days before PT) vs. earlier groups (PT within 30 days of injury; 31–90 days before PT ($p < 0.01$))³⁴ - Higher proportion of patients (musculoskeletal back injury) with >90 paid lost days in the delay to PT group (>30 days before PT) vs. the no delay group (PT within 30 days of injury) ($p < 0.05$)¹⁷⁹ - Longer period of sick leave (patients with acute low back pain) in the group III (8–197 days before PT) vs earlier groups (PT within 0–1 days after	needed to confirm the results



ID	Databases searched and search date	Patients/setting/ intervention/definitions	Number and type of included studies/ Countries	Effects of WT	Conclusions and limits stated by the authors
				the injury; 2–7 days before PT) ($p < 0.05$) ¹⁸⁰ No significant difference for patients with subacute LBP consulting between early (PT initiated within 2 days) vs control group (28 days before PT)	

2.3.2. Primary studies

Table 5 – Overview of primary studies on the effect of WT on costs

ID	Perspective	Study type / setting / Country	Intervention / population	Definitions of WT and/or costs	Impact on costs	Conclusions and limits reported by the authors
Delisle 2020 ¹⁸²	Provincial universal payer (health system)	Population-based retrospective cohort study / Manitoba, Canada	6936 patients diagnosed with colorectal cancer between 2004 and 2014	<u>WT</u> = time interval from a patient's index contact to the first definitive treatment (surgery, radiation therapy, or chemotherapy) → estimated from administrative records by using an algorithm previously found to have high accuracy <u>Diagnosis/diagnostic WT</u> = time interval from the index or first contact with the health care system until the date of diagnosis of colorectal cancer available from the Manitoba Cancer Registry <u>Treatment WT</u> = time interval spanning from the diagnosis date of colorectal to the date of first definitive treatment identified from the Manitoba Cancer Registry (surgery,	Adjusted* mean cost ratio by quintile (95% CI), p • Very short: Reference • Short: 1.21; (1.10–1.32), $p < 0.01$ • Moderate: 1.30 (1.19–1.43), $p < 0.01$ • Long: 1.48 (1.33–1.64), $p < 0.01$ • Very long: 1.39 (1.26–1.54), $p < 0.01$ * Adjusted for age, sex, incomes, Charlson comorbidity index, year of diagnosis, distance from Winnipeg, cancer site, grade, stage at diagnosis	<u>Conclusions:</u> Total adjusted health care costs increased as total WT increased for both colon and rectal cancer until about 200 days, after which there was a decreasing trend in total costs. Shorter total WT were associated with significantly lower health care costs even after adjusting for patient and disease characteristics. Other significant predictors of lower costs included older age, increased comorbidities, earlier year of diagnosis, colon cancer (versus rectal), and less advanced stage at diagnosis.



ID	Perspective	Study type / setting / Country	Intervention / population	Definitions of WT and/or costs	Impact on costs	Conclusions and limits reported by the authors
				radiation therapy, or chemotherapy) <u>Total WT</u> = sum of the total diagnostic and treatment WT and categorised into quintiles (i.e. very short, short, moderate, long, and very long). <u>Costs</u>: inpatient and outpatient health care costs accrued between the index contact and first treatment. Costs were estimated by using the Manitoba Health administrative databases. All costs are reported in 2014 Canadian dollars.		<u>Limitations</u>: Small sample size limits the robustness of the conclusions; potentially limited generalizability; unable to confirm by using administrative data that shorter WT represented more urgent presentation; results could not differentiate between systemic delays from those due to patient-related preferences; even with use of adjusted health care costs, it is possible of not complete control for increases in costs related to comorbidities, which may explain part of the association between WT and health care costs and utilization.
Fanizzi 2023 ¹⁸³	National Health Service (NHS)	Cost-benefit analysis as a technology assessment method / Department of Breast Radiodiagnosis / Italy	242 oncology patients with breast cancer, grouped by metastatic and nonmetastatic patients (2019)	<u>Cost-analysis</u> considered the costs of staff, goods and services, general expenses and machinery. <u>3 strategies of WT tested</u>: Current strategy: 32-month waiting list → 40 daily screening exams; daily costs: 1468,61€ Strategy 1 (extra staff and machinery): 22-month waiting list → 60 daily screening exams; daily costs: 2715,99€ Strategy 2 (extra machinery): 16-month waiting list → 80	Revenues, costs and daily margins per strategy (current strategy vs 22-month strategy (60 patients) vs 16-month strategy (80 patients)): Daily hospital's revenues: 3.986,10€ vs 5.979,5€ vs 7.936,05€ Daily cost: 1.468,61€ vs 2.715,99€ vs 2.906,40€ Daily margin: 2.517,49€ vs 3.263,16€ vs 5.029,65€ Unit screening costs per patient (3-year screening costs):	<u>Conclusions</u>: The most cost-effective incremental ratio could be achieved by reducing current waiting lists from 32 to 16 months (the most expensive strategy is the 16-month waiting list strategy). This strategy would also allow to include more people in the screening programs (60,000 patients in 3 years). → the optimal scenario resulted to be the more expensive one, but which over the course of three years proved to be more convenient and effective.



ID	Perspective	Study type / setting / Country	Intervention / population	Definitions of WT and/or costs	Impact on costs	Conclusions and limits reported by the authors
				daily screening exams; daily costs: 2906,40€	Current: 34,42€ (€1.069.687,68) Strategy 1: 45,27€ (€ 1.978.238,64) Strategy 2: 36,33€ (€ 2.116.927,08) The Incremental Cost- Effectiveness Ratio (ICER = ratio between variation of costs and difference in effectiveness between the two new strategies each of which compared against the current one). ICER's 22- months strategy: €25614,30; ICER's 16-months strategy: 13507,31€.	<u>Limitations:</u> Result is linked to the economic-managerial situation of the Institute. Not all reductions of waiting lists would lead to cost-effective improvement
Huang-Lung 2022 ¹⁸⁴	Health system	Comparative analysis / Australia	Cataract surgery	<u>WT</u> = time elapsed from addition to a public hospital waiting list to surgical admission (do not capture time elapsed from initial diagnosis and referral by an optometrist or general medical practitioner to an ophthalmologist for confirmation of diagnosis, presurgical assessment, or subsequent addition to a surgical wait list.) <u>Estimated costs:</u> The inflation-adjusted cost of cataract surgery and three ophthalmology consultations (one pre- and two postoperative) was estimated	Reducing the WT for cataract surgery from 12 months to 3 months: \$13.4 million increase in health system costs for surgery and perioperative consultations in 2019–20 dollars. By reducing WT to 3 months: estimation = 50 679 falls avoided + increase of 141 motor vehicles crashes (higher crash rates after second eye surgery explained by age and increased exposure to more risky driving situations after both eye surgeries)	<u>Conclusions:</u> Comparative analysis: reducing waiting periods from 12 to 3 months would result in estimated public health system cost savings of \$6.6 million by preventing 50 679 falls. Investment in public cataract services to address current unmet needs would prevent avoidable vision impairment and associated negative consequences. → significant reduction in falls and modest health system cost savings. <u>Limitations:</u> Cost savings from this analysis do not account for longer-term costs to society and individuals



ID	Perspective	Study type / setting / Country	Intervention / population	Definitions of WT and/or costs	Impact on costs	Conclusions and limits reported by the authors
				at \$3713 per eye in 2020 (ref: Independent Hospital Pricing Authority) → Total costs in \$A millions (\$M) over a 3-year period presented in 2019–20 dollars: \$2967 per surgery and \$248.5b per consult (3 per eye, 1 pre-operative and 2 postoperative)		from falls and motor vehicle crashes, including loss of life, disability care, loss of income, legal system costs, property damage and reduced quality of life (they are likely to be an underestimate of the potential benefits to society overall)



2.4. Strategies to reduce waiting times

Table 6 – Strategies in primary care and their impact on waiting time

ID	Setting	Design	Type (mechanism)	Description	Impact on waiting time
Fernandez Perez 2022 ¹⁸⁵	Spain Region Madrid GP	Interrupted time series (with control) (population survey) n=109 601	Freedom of choice (demand)	Free choice of GP	Mean difference +0.7d (33%) 6y after implementation +0.8d (29%) compared to synthetic control (6y after implementation)
Govier 2023 ¹⁸⁶	USA National care	Controlled before after study n= 54 358 (EHR and database)	Increase capacity and maximum WT (mixed)	Community care networks: expanded networks of community providers (two third-party administrators instead of one) and VA instituted network new adequacy standards (the ability to provide enrollees with timely access to an adequate number of in-network providers)	Adjusted* mean difference within group CCN 39.2d (95%CI: 33.5,44.8) Control 33.7d (95%CI: 26.3,41.2) Adjusted* mean difference across group 5.4d (95%CI: -3.8,14.6)
Harding 2020 ¹⁸⁷	Australia Melbourne Primary care	RCT cluster stepped wedge N=4358	STAT (demand)	Specific timely appointments for triage model: rate of service demand is calculated and corresponding number of new appointments per week to meet demand is protected in schedules; prompt face-to-face assessment for prioritization of services based on need of the patient, context and overall demand for the service; short-term targeted intervention to reduce backlog of waiting patients prior to introduction of protected appointments.	Median difference reduction 11d (29%) adjusted IRR 0.71 (95%CI: 0.60-0.83)
Speed 2022 ¹⁸⁸	Canada Saint John Horizons health network Physiotherapy	Interrupted time series (case records) N=20 484	Open access booking (mixed)	Open-access booking model: administrative model including elements of advanced access, triage and centralised wait lists	Mean difference Before weekly increase 0.12d (95%CI: 0.06,0.18) After: jump 8.1d (95%CI: -0.45,16.65) and weekly decrease 0.27d Total is weekly decrease of 0.15d
Swami 2021 ¹⁸⁹	Australia National GP	Interrupted time series (data by survey GP)	Funding (supply)	General practice rural incentive program (GRIP): remoteness classification system to determine which geographical areas are eligible for rural incentives (between 1.4% and 6.2% of	Mean difference for new patients' reduction 4.14d (16%), p=0.01



N=8751

annual income, depending on range of factors
including how long they stay in that area).

CCN community care networks, CI confidence interval, EHR electronic health records, GP general practitioner, GRIP general practice rural incentive program, IRR incidence rate ratio, STAT specific timely appointments for triage model, VA veterans affairs, WT waiting time

*adjusted for VA facility–level clustering and age category, sex, race, ethnicity, marital status, VA copayment category, new VA enrollee status, insurance status, county-level national ADI rank of Veteran residence, Veteran residence in a primary care HPSA, Veteran residence in a mental health HPSA, rurality of Veteran residence, distance to the nearest VA primary care facility from Veteran residence, VA facility–level SHEP care coordination score, and Elixhauser index



Table 7 – Strategies in specialised healthcare (consultation) and their impact on waiting time

	Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)
Ahluwalia 2020¹⁹⁰	Canada Province of Ontario Rheumatology	Prospective cohort n=549	Task shifting (supply) and triage (demand)	Triage assessment by extended role practitioners paired with rheumatologists based on geographic proximity	Median difference Reduction 23d (40%) for expedited, Increase 39d (67%) for non-expedited patients compared to control.
Azogil-Lopez 2019¹⁹¹	Spain North of Huelva region Internal medicine	RCT cluster n=417	Telemedicine (mixed)	DETELPROG: scheduled outpatient internal medicine consultation requested by FP, integrated in both agendas; telephone consultation with internist while the patient is in the FP consultation	Median difference experimental group compared to control group. Reduction 27d (66%) (95%CI: 20.0,33.0), p<0.001
Bhavsar 2019¹⁹²	USA Tertiary hospital Virginia Hepatology	Retrospective cohort n=187	Telemedicine (mixed)	eConsults: electronic consultation between specialist and PCP; request from PCP is reviewed by hepatologist, who after additional information (if necessary) decides whether to complete eConsult and make management recommendations to PCP or see the patient FTF	Mean response time eConsult 22h (SD 28h) Mean waiting time for FTF visit 68d (SD 55)
Ciudin 2023¹⁹³	Spain Hospital Barcelona Urology	Prospective cohort n=30	Timing of diagnostics (supply)	Diagnostic model combining all the tests in a single stop consultation (ultrasound, uroflowmetry, cystoscopy, pressure-flow study)	Mean difference WT Reduction 175d (89%)
Fernandez-Perez 2022¹⁸⁵	Spain Region Madrid Specialist	Interrupted time series (with control) (population survey) n=109 601	Freedom of choice (demand)	Free choice of specialist	Mean difference Reduction 18d (22%) 2y after implementation Reduction <10% 6y after implementation



	Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)
					Compared to synthetic control 30d (30%) reduction 6y after implementation
Lewis 2020 ¹⁹⁴	Australia Melbourne Hospital Epilepsy	Before after study n=949	STAT (demand)	Specific timely appointments for triage (STAT) model	Difference in Time to next available appointment: stable for first epilepsy, difference 1d (3%) reduction for general epilepsy 15d (17%)
Li 2022 ¹⁹⁵	USA Country VHA Specialist outpatients	Before and after study N=39.5 million appointments	No-show policy (demand)	Electronic appointment reminders (VEText)	Adjusted *** mean difference -5.73d (95%CI: -7.04, -4.41) (10%)
Lonergan 2020 ¹⁹⁶	Ireland Letterkenny Hospital Urology	Before after study n=1114	Timing of diagnostics and task shifting (supply)	Direct access to diagnostics (diagnostics after referral and triage but prior to clinic, one stop, ultrasound and ambulatory flexible cystoscopy) and an ANP-led clinic	number of patients waiting > 12m reduction 76% (baseline 375))
Lu 2019 ¹⁹⁷	USA Michigan Hospital Hand surgery	Retrospective cohort n=4070	Timing of diagnostics (supply)	Pre-referral advanced diagnostic testing compared to post-referral	Median difference WT increase 19-94d (25-107%) depending on pathology p<0.05
Malcolm 2022 ¹⁹⁸	USA Duke, Texas 8 rheumatology clinics	Controlled before after study n=809	Telemedicine (mixed)	eConsults: asynchronous, consultative provider-to-provider electronic communications to replace traditional referral	Adjusted* median difference (before vs after comparison minus before vs after intervention) -17.1d (95%CI: -36.8, 2.6)
Mohammed 2020 ¹⁹⁹	Canada Ontario subregion Ocean network	Retrospective cohort N=15 503	Telemedicine (mixed)	Integrating electronic referral within musculoskeletal model: seamless flow of electronic orthopedic referrals from primary	Mean difference initial electronic referrals compared to paper-based referrals transcribed into the system



	Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)
	Hip and knee musculoskeletal problems			care to central intake, process and transcribe faxed referrals into eReferral system, detect and record missing referral information, secure and timely communication with providers, APC can accept, triage and book appointment using eReferral solution, automatic calculation of wait, outcome notes and secure messaging	Reduction 21.4d (30%), $p<0.001$ from creation referral to initial assessment (after Bonferroni correction) processing time reduction 21.76d (30%), $p<0.001$ (included in WT) (after Bonferroni correction)
Mutsekwa 2019²⁰⁰	Australia Queensland hospital Gastro-enterology	Before after study n=748	Taks shifting (supply) (And triage)	Dietician first gastroenterology clinic model: triage of referrals by gastroenterology consultant, service description sheet was mailed to patient with their appointment letter, possibility to opt-out and remain on medical specialist wait list	Mean difference Reduction 214d (76%) (for eligible patients)
Palani 2023²⁰¹	USA Country VHA Cardiology and orthopedics	RCT cluster 12 intervention and 6 comparison sites	Task shifting (supply)	Medical scribes in VAMC (Veterans affairs Medical centers): trained but clinically unlicensed professionals who can assist providers in navigating the EHR and entering patient visit information	Adjusted** difference in difference for orthopedics Reduction 8.54d (95%CI: -12.63,-4.46), $p<0.001$ (request to appointment date) Reduction 5.74d (95%CI: -8.38,-3.09), $p<0.001$ (appointment made to appointment date) and reduction 2.81d (95%CI: -5.92,0.30), $p=0.077$ (request to appointment made) Cardiology Increase 0.91d (95%CI: -2.0,3.89), $p=0.548$ (request to appointment date) increase 0.33d (95%CI: -1.7,2.36), $p=0.75$ (appointment made to



Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)	
				appointment date) and increase 0.58 (95%CI:-1.3,2.54), p=0.561 (request to appointment made)	
Patel 2020 ²⁰²	USA Hospital Texas Rheumatology positive ANA referrals	Before after study n=139 126	Telemedicine (mixed)	eConsults referring provider can select e-consult or direct in-person visit; e-consults are reviewed by rheumatologists for appropriateness of referral type and switching possible, recommendations through EHR, scheduled appointment for in-person referral if needed	Mean response time 1.7d Mean difference for FTF visit (before-after) Reduction 30d (47%), p<0.001
Pokorny 2021 ²⁰³	Australia Queensland hospital Paediatric ENT	Controlled trial (not randomized) n=131	Task shifting (supply)	Advanced audiology-led service: experienced audiologists complete extra training under supervision of ENT surgeons to provide basic ENT outpatient services; triage by ENT surgeons	Median difference First appointment (APC or specialist) Reduction 321.5d (77%), p<0.001 First appointment specialist Reduction 271.5d (65%), p<.001
Poyah 2020 ²⁰⁴	Canada Nova Scotia Nephrology clinic	Interrupted time series n= 6625	Complex combination (mixed)	New triage and booking system including intake criteria an triage guidelines, telephone reminders, waitlist reviewing, reducing follow-up, and increasing new referral clinic capacity	No significant shift of mean wait times for the elective (P3-P5) categories Only 3/18 (16.7%) data points fell within target for P3 category, 0/18 data points fell within target for P4 category, and 1/18 (5.5%) data points fell within target for P5 category.
Rabinowitz 2022 ²⁰⁵	Canada Toronto Neurology centre	Before after study n=1542	Telemedicine (mixed)	Virtual rapid access clinic (VRAC): patient centered care workflow, involving multidisciplinary staff and online administrative tools	Mean difference Reduction 15d (25%), p<0.0001 (separate data on epilepsy, headache and concussion)
Roemeling 2019 ²⁰⁶	The Netherlands Groningen Hospital	interrupted time series n=9277	Capacity increase (supply)	Expansion service: up to week 31 maximum capacity 10 person-days (2FTE), from week 33 to	Mean difference -43d (60%) p<0.001



	Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)
	Rheumatology			week 39 a resident provided a further temporary boost to capacity (similar productivity as rheumatologists, but 1/3 output due to lack of experience)	
Sakowska 2019²⁰⁷	Australia Geelong region Gastro-enterology	Before after study n=3414	Capacity increase (outsourcing) (supply)	Public private partnership endoscopy initiative (PPPEI) i.e public list for colonoscopy in private hospital Additional weekly clinic that selected new patients referred for potential endoscopy, to improve efficiency of the public referral process	Median difference WT Reduction 19d (21%) for consultation, p<0.01 For category 1 patients (urgent, diagnostic or positive faecal occult blood test) Reduction 89d (71%) for colonoscopy, p<0.01
Schettini 2019²⁰⁸	USA Duke, Texas 4 nephrology clinics	Retrospective cohort n=1319	Telemedicine (mixed)	eConsults: asynchronous, consultative provider-to-provider electronic communications to replace traditional referral	Median response time eConsults: 45% the same day, 80% within 2 days Median difference WT for FTF visit converted eConsults compared to traditional referrals Reduction 11d (22%)
Seiger 2022²⁰⁹	USA Boston (MGH) Pediatric dermatology	Retrospective cohort n=180	Telemedicine (mixed)	eConsults: asynchronous, consultative provider-to-provider electronic communications to replace traditional referral	Mean difference WT for FTF visit converted eConsults compared to traditional referrals Reduction 16.8d (31%) (Completion eConsult on average 1.8d)
Singh 2022²¹⁰	USA Chicago region Urology	Cross-sectional comparison (secret shopper)	Task shifting (supply)	Advanced practice providers: nurse practitioners and physicians assistants in urology practices	Practices with or without AP median difference first visit 8d reduction (56%), p=0.09 Practices with AP median difference First visit AP compared with specialist 10d reduction (67%), p=0.04



	Setting	Design	Type (mechanism)	Description	Impact on waiting time (consultation)
Tahhan 2020²¹¹	Australia Sydney Hospital Diabetic retinopathy	Retrospective cohort n=133	Task shifting (supply) and telemedicine	task sharing model of care collaborative community eyecare for the management of low-risk diabetic retinopathy involving community based optometrist assessment and virtual review by ophthalmologists (C-EYE-C)	Median difference between C-EYE- C and standard hospital car Reduction of 65d (55%), p<0.01

ANA anti-nuclear antibodies, ENT ear nose throat, FTE full time equivalent, MGH Massachusetts General Hospital, WT waiting time

*adjusted for age, race, clinical pair and primary payer

** adjusted for proportion of veterans over age 65, proportion of veterans between ages 35 and 65, proportion of enrollees with priority status 7 or 8, Zillow Home Value Index, Medicare Advantage penetration, NOSOS risk score, proportion of Black enrollees, proportion of American Indian enrollees, proportion of Asian enrollees, and proportion of Native Hawaiian enrollees plus clinic and pay period fixed effects

*** adjusted for the following patient-level confounders: age, age squared, sex, race, marital status, insurance status, calendar month of appointment date, day-of-week of appointment date, number of past appointments from January 1, 2018, number of distinct and appointment classes from January 1, 2018. The results also include adjustments for the following clinic-level confounders: number of completed appointments in the past week, total number of appointments in the past week, and total number of patients seen from January 1, 2018

APC ANP advanced nurse practitioner, FP family practitioner FTF face-to-face PCP primary care physician MGH Massachusetts General Hospital VHA veterans health affairs, VAMC veterans affairs medical centers EHR electronic health record



Table 8 – Strategies in specialised healthcare and effect on waiting time for surgery

Reference	Setting	Design	Type (mechanism)	Description	Impact on waiting time (surgery)
Pokorny 2021²⁰³	Australia Hospital Queensland Paediatric ENT: middle ear, hearing or speech concerns	(non-randomized) controlled trial n=131	Task shifting (capacity)	Advanced audiology-led clinic experienced audiologists complete extra training under supervision of ENT surgeons to provide basic ENT outpatient services; triage by ENT surgeons	From referral to grommet insertion Median difference -402d (64%), p=0.002
Putri 2023²¹²	UK Hospital Sheffield Cataract surgery	Before and after study n=21	Decrease general anaesthesia (demand)	Local anesthesia instead of general or local anesthesia with intravenous sedation	From referral to (cataract) surgery Mean difference -11 weeks
Quercioli 2022²¹³	Italy Hospital Tusancy Surgery	Before and after study n=1269	Operating room organization (capacity)	Multidimensional intervention Separation flow day surgery from ordinary surgery, increasing operating time by reorganizing staff, allocation sessions flexibly in proportion to waiting list using a simulator and development of an algorithm	From date placed on waiting list to surgery Mean difference in daycare General surgery depending on priority class A -2d (8%), p=0.769 B -83.3d (48%), p<0.001 C -120.7 (49%), p<0.001 Orthopaedics depending on priority class A -16d (39%), p<0.001 B -51d (33%), p<0.001 C -85d (42%), p=0.006 Obstetrics & gynaecology depending on priority class A -7d (24%), p=0.127 B -64.5d (34%), p<0.001 C -111d (47%), p=0.006 Urology depending on priority A -2d (6%), p=0.557 Mean difference in ordinary surgery General surgery depending on priority class A -2d (6%), p=0.784 B -113.1d (50%), p<0.001



C -93.7 (38%), $p<0.001$
 Orthopaedics depending on priority
 A -4d (12%), $p=0.195$
 B -31.5d (21%), $p=0.005$
 C -71d (35%), $p=0.001$
 Obstetrics + gynaecology depending on priority
 A -21d (46%), $p=0.07$
 B -85d (35%), $p<0.001$
 Urology depending on priority
 A -0.4d (1%), $p=0.952$
 B -24d (15%), $p=0.436$
 (too low amount of observations for not mentioned categories)

Table 9 – Strategies in specialised healthcare and their impact on waiting time for imaging

reference	Setting	Design	Type and mechanism	Description	Impact on waiting time
Bhullar 2021²¹⁴	New Zealand Hospital MRI	Interrupted time series n=2367	Complex combination Lean type approach (supply)	Optimisation of capacity MRI: matching capacity and demand, waiting list segmentation and redesigning the system	Mean difference Reduction 73.3d (76%) for MRI
Li 2022¹⁹⁵	USA Country VHA Radiology	Before after n=2 374 232	No-show policy (demand)	Electronic appointment reminders: two text message reminders to patient's mobile phones before their appointment	Adjusted* mean difference Reduction 3.31d (12%) for radiology
Roifman 2020²¹⁵	Canada Hospital Heart failure MRI	Before after n=451	Increase capacity by outsourcing (supply)	Combined clinical and research protocol Waitlist review, contact patient, rebooking, adding research sequences, data entered in registries	Reduction of 4m (45%) for cardiac MRI (no information on mean or median)
Rudder 2019²¹⁶	USA Hospital MRI children	Retrospective cohort n=134	Decrease general anaesthetics (demand)	MRI try without sedation programme: Child life specialist intervention preparing children with video's and pictures + support family/child	Mean difference Reduction of 30.8d (67%) for MRI

*adjusted for patient-level confounders

MRI magnetic resonance imaging VHA veterans' health affairs



Table 10 – Strategies in cancer care and their impact on waiting time intervals

Reference	Setting	Design	Type (mechanism)	Description	Impact on waiting time
Alvarenga 2022²¹⁷	USA Hospital Yale Breast cancer	Before study after n= 1523	Administrative efficiency (supply)	reflex testing RefT: patient navigator, expedition of scheduling additional work-up, elimination written orders	From abnormal result (unclear) to resolution definite categorization mean difference -15.3d (65%), median difference -13d (65%), p<0.01
Blackmore 2019²¹⁸	Canada Province of Ontario Breast cancer	Retrospective cohort n=5260	Rapid access clinic (mixed)	Breast assessment clinic: providing all abnormal mammographic work-up, radiological, surgical and pathologic consultation with experts and providing a navigator for patient support and referral coordination	Only surgery endpoint From abnormal screen to surgery (time to treatment) AOR* 0.63 (37%)(95%CI: 0.52,0.77) compared to usual care
Cha 2020²¹⁹	Canada Vancouver hospital BC surgery	Before study after n=1216	Triage (demand)	Centralized intake and triaging of breast patient referrals: intake coordinator; complete work-up; nurse navigator triage tool; referral either to breast physician or to breast surgeon and specialised programmes	mean difference WT from diagnosis to surgical consult -4d (19%), p=0.0013 mean difference from diagnosis to definite surgery (time to treatment) -6d (20%), p=0.0008 (median difference -1d)
Cotton 2020²²⁰	Canada Southlake hospital Lung cancer	Before study after n= unknown	Rapid access clinic (mixed)	Diagnostic assessment program (DAP): centralized system with MDT, nurse navigator, increase capacity to meet demand	Diagnostic interval meets target 28d increase with 88% (from 47% to 88.4% meets target)
Ewart 2023²²¹	Canada Hospital Kamloops Breast cancer	Retrospective cohort n=539 3 groups pre BHC after BHC control (after BHC)	Breast health clinic (rapid access clinic?) and timing diagnostics (mixed)	Rae Fawcett Breast Health clinic (BHC), centralized delivery of comprehensive breast cancer diagnostic and treatment services; triple assessment in one day model TAM (nurse and physician assessment, breast diagnostic imaging and ultrasound guided core needle breast biopsy), nurse navigator to coordinate patient care, family physicians with extra training in breast disease, referrals to surgery or oncology team	Overall waiting time before/after: -29.8d (38%), p<0.001 control/intervention: -24d (33%), p<0.001 Diagnostic interval Before/after: -21.3d (47%), p<0.001 Control/intervention: -12.5 (34%), p=0.004 Time to treatment Before/after: -8.5d (26%), p=0.0037 Control/intervention: -11.5 (32%), p=0.007 From presentation to imaging Before/after: -12.4d (49%), p<0.001 Control/intervention: -9d (41%), p<0.001



Reference	Setting	Design	Type (mechanism)	Description	Impact on waiting time
					Before/control reduction diagnostic interval: -8.8d, p=0.004, other intervals not significant
Gulak 2019 ²²²	Canada Ottawa hospital lung cancer	Interrupted time series n=2990	Timing of diagnostics (supply)	Navigation day programme: single day visit with nurse-led teaching, social work, smoking cessation counseling, symptom control and dedicated test slots for PET/CT, pulmonary function tests and MRI of the brain	Only imaging endpoint WT from abnormal result to imaging Mean difference -6.3d (40.7%) for PET/CT, p<0.0001 Mean difference -5.8d (36.3%) for MRI brain p<0.0001
Habbous 2021 ²²³	Canada Province of Ontario Lung cancer	Retrospective cohort n=22 049	Rapid access clinic (mixed)	Diagnostic assessment program (DAP): centralized system with MDT, nurse navigator, increase capacity to meet demand	Diagnostic interval adjusted** median difference -0.8d (95%CI: -2.7,1.1) Time to treatment adjusted** median difference -8.5d (95%CI: -9.7,-7.3)
Hartley 2021 ²²⁴	UK Birmingham hospital Bone or soft tissue malignancy	Before after study n=236	Triage (demand)	Daily diagnostic multidisciplinary meeting (DMDT) : stratification of resources (rapid access to those felt to be at greatest risk of malignancy)	From referral to first management decision interval mean difference -6d (55%), p<0.05 (median difference -5d)
Lim 2023 ²²⁵	UK Hospital greater Glasgow and Clyde NHS Head neck cancer MDT	Retrospective cohort n=187	Decrease general anaesthetics (demand)	Local anaesthetic biopsy (n=45) compared to general anaesthetic (n=142) in urgent suspicion of cancer pathway	WT from referral to first visit (consultation) mean difference -1d (6%), p=0.29 From consultation to treatment decision mean difference -24.8d (56%), p<0.05 From referral to treatment decision mean difference -24d (40%), p<0.05
McKevitt 2019 ²²⁶	Canada Vancouver hospital Breast cancer surgery	Controlled before after n=2428	Operating room organization (supply)	Immediate reconstruction swing room program: two concurrently running operating rooms to combine mastectomy with immediate reconstruction	Only surgery endpoint From biopsy to surgery Mean difference -18d (26%), p<0.0001
Nilssen 2019 ²²⁷	Norway Country Colorectal, lung,	Interrupted time series n=235 971	Rapid access clinic and max waiting time (mixed)	Cancer patient pathway: set of max days between referral and first visit, clinical decision and treatment also coordinator	Time to treatment (radiotherapy) median difference -14 to -15d, p<0.001, for colorectal, lung and prostate cancer Time to treatment (surgery)



Reference	Setting	Design	Type (mechanism)	Description	Impact on waiting time
	breast and prostate cancer				median difference stable at 21d for colorectal and breast cancer, reduction of 7d for lung cancer and reduction 36d for prostate
Papp 2023 ²²⁸	Hungary Hospital Cancer	Retrospective cohort n=900	Funding (supply) (linked to a target max WT)	HBP funding (versus NHI funding): agreement imaging performed within 7 days (compared with 14 days target)	Only imaging endpoint Reduction of 13d (76%) for CT/MRI
Prang 2021 ²²⁹	Australia Victoria hospital Cancer surgery	Before after study n=199 885	Maximum waiting time (supply)	Time based targets and public performance reporting: National elective surgery targets waiting times by urgency category (i.e. urgent - within 30 days, semi-urgent - within 90 days and non-urgent – within 12 months; PPR is voluntary for private hospitals. The indicators publicly reported for breast, bowel and lung cancer at the time of the study included elective surgery waiting times by urgency and the number of patients treated within recommended elective surgery waiting times by urgency.	Only surgery endpoint From date placed on waiting list to admission for surgery (not urgent (90d) +2.97d (SE 2.67), p=0.27
Webber 2020 ²³⁰	Canada Province of Ontario Breast cancer	Retrospective cohort n=62 333	Rapid access clinic (mixed)	Breast assessment sites: Provide expedited and coordinated care: single access point for all diagnostic and staging services, streamlined coordination of imaging and specialist consultation and patient navigation	Diagnostic interval (from first healthcare visit to diagnosis) adjusted ***median difference -4.0d (95%CI: -3.2,-4.9) for symptomatic and median difference -5.4d (95%CI:-4.7,-6.1) for screening Time to treatment adjusted*** median difference 4.2d (95%CI:3.8,4.7) for symptomatic and median difference 4.2d (95%CI:3.7-4.8) for screening



Reference	Setting	Design	Type (mechanism)	Description	Impact on waiting time
Zonderland 2023²³¹	Denmark Hospital Aarhus Neurosurgery cancer	Before study n=142	after Operating room organization (supply)	Allocating operating room capacity to non-elective neurosurgical patient based on mathematical model	Only surgery endpoint From request to elective surgery Before 7.69d (95%CI: 6.91-8.47) After 6.81d (95%CI: 6.05-7.56) No significant difference

AOR adjusted odds ratio, BHC breast health clinic, CI confidence interval, CT computerized tomography, DAP diagnostic assessment programme, DMDT **daily diagnostic multidisciplinary meeting**, HBP healthy Budapest programme, NHI national health institute, MDT multidisciplinary team, MRI magnetic resonance imaging, NHS national health service, PPR public performance reporting, RefT reflex testing, TAM triple assessment in one day model

*adjusted for assessment pathway, age, period of diagnosis, treatment centre region, stage and definitive surgery type

**adjusted for age, sex, urban/rural residence, neighborhood income quintile, neighborhood immigrant density, region of residence at the level of Local Health Integration Network (LHIN), Euclidean distance to the nearest DAP, Charlson Comorbidity Index, stage, histology, emergency visit within 7 days of diagnosis, and hospital admission on the diagnosis date.

*** adjusted for stage at diagnosis, first presentation in ED, age group, number of comorbidities (minor and major), neighbourhood income quintile, residence, immigrant status, living in long-term care and number of health care encounters 12-36 months before diagnosis, continuity of care index



Table 11 – Strategies in mental healthcare and their impact on waiting time intervals

	Setting	Design	Type (mechanism)	Description	Impact on waiting time
Cass 2020²³²	USA Hospital Ohio Paediatric neuropsychology	Interrupted time series n=5606	Complex intervention (mixed)	Quality improvement project with 3 PDSA cycles: increase scheduling call volume and standardize process, add intake model of care, additional providers, increase consultations	From referral to intake/first appointment Mean difference - 94d (67%) (SD reduction 39d)
Donovan 2020²³³	UK Region Bedford and Luton 4 Memory assessment services	Before after study n= unknown	Complex intervention (mixed)	Quality improvement project with PDSA cycles: standardized referral criteria, editable letters, dedicated time for scoring, flexibility supervision, not waiting for written report for gathering information from memory assessment service	From first visit to report finalized Mean difference – 28.8d (43%)
Gullhav 2022²³⁴	Norway Hospital Trondheim CAMHS	Interrupted time series n=unknown	Administrative efficiency (supply)	New scheduling policy developed by mixed methods: reserved time for new patients intake, an operational booking rule specifying how to use the reserved time for intake, computer simulation tool	From referral to intake/first appointment Mean difference at least -25d (38%), p<0.01
Kovach 2021²³⁵	USA Centre Texas Substance abuse	Interrupted time series n=unknown	Complex intervention (mixed)	Lean methods improving process: appointment reminders, admission process info online, transferring tasks to non-clinical staff	From referral to treatment Mean difference -5d (36%), p=0.00
Kreutzberg 2020²³⁶	UK England Psychosis	Controlled before after n=9327	Rapid access clinic and max waiting time (mixed)	Waiting time targets mental healthcare 14 days: Early intervention psychosis (EIP) services compared to care from standard community mental health service	From referral to treatment Median difference +0.083d (SE 0.253), coarsened exact matching, not significant Median difference +0.049d (SE 0.245) propensity score matching, not significant (there is a reduction before compared to after, but both in intervention and control)
Omrani 2022²³⁷	UK Service London Learning disability	Interrupted time series n=52	Complex intervention (mixed)	Quality improvement project with PDSA cycles: eligibility screening checklist and assessment, training staff, template letter, referral from, workshops GP	From referral to assessment completion Median difference -208d (77%) Mean difference -220d (74%)



	Setting	Design	Type (mechanism)	Description	Impact on waiting time
Roughan 2019²³⁸	UK Hospital London CAMHS ADHD	Before after study n=unknown	Complex intervention (mixed)	Quality improvement project with PDSA cycles for ADHD pathway: referral form, standardized screening tool before booking and all info collected before booking assessment, school observation only if complex, MDT decision making and care coordination by one clinician, allocation and booking assessment (flexibility, feedback appointments), report template, letters to stipulate importance of attendance	From referral to completion of assessment Mean difference -69d (79%)
Stafford 2020²³⁹	UK London 5 CAMHS services	Interrupted time series n= unknown	Complex intervention (mixed)	Quality improvement project with PDSA cycles combined with collaborative learning system change order of process steps, SNAP instead of longer Conners, standardization, split MDT meeting in smaller groups, diary system to book MDT in advance, daily discussions for new referrals, develop contingency plans, extend specialist's time, standardized template, ...	From referral to first appointment Mean difference Reduction -2d (3%)

ADHD attention deficit hyperactivity disorder, CAMHS children and adolescent mental health service, EIP early intervention psychosis, MDT multidisciplinary team, PDSA plan-do-study-act, SE standard error.



3. APPENDIX III – EXPERIENCES FROM CANADA (CA)

3.1. Health system at a glance

3.1.1. Health care organisation

As a federation, Canada has two levels of government that share the power to make laws and govern: the federal level and the 13 provincial and territorial governments. In the area of health, Canada's health care system, Medicare, is based on five pillars under the Canada Health Act (1984): it must be universal, publicly administered, portable across provinces, accessible to the population, and have comprehensive coverage.²⁴⁰ **Each of the country's 13 provinces and territories operates as a single-payer; each of them has its own health insurance plan and benefits, with different approaches to service delivery**, allowing each province and territory to focus on the needs of its population. Canada's provincial and territorial governments are responsible for the financing, organization and delivery of health services and the oversight of providers. The federal government co-finances provincial and territorial health plans on a per-capita basis, administers a range of services for certain populations, and oversees certain functions through federal governmental agencies (e.g. drug safety, emergency preparedness and response).²⁴¹

The health system is predominantly publicly funded through provincial and territorial government revenues (taxes). In 2023-24, the Canada Health Transfer (the federal programme that funds health care in the provinces and territories) provided funding of CAD 49,421 million.²⁴² Total health spending is estimated to reach CAD 344 billion in 2023, or CAD 8740 per Canadian. In 2023, health expenditure accounted for 12.1% of Canada's GDP.²⁴³

Medicare coverage is automatic, meaning that 100% of the Canadian citizens and permanent residents receive medically necessary hospital and physician services at no cost at the point of care. There is no cost-sharing for publicly insured doctors, diagnostic or hospital services. Supplementary service or non-Medicare services such as outpatient prescribed drugs, vision or dental care are largely privately funded (out-of-pocket payments or employer-based or private insurance; 69% of Canadians have private supplementary insurance). In 2021, expenditure covered by government or compulsory health insurance reached 72.9%.²⁴⁴

Depending on their status, doctors are paid on a fee-for-service basis (in primary and specialty care), and they are not allowed to charge more than a negotiated fee or they may submit their claims for service directly to the provincial or territorial health insurance plan for payment or they may be salaried or remunerated through an alternative payment system (e.g. pay-for-performance, capitation). Fees are negotiated between the provinces or territories and the professional associations. Most specialist care is provided in hospitals (inpatient or outpatient). GPs largely act as gatekeepers, but patients can choose to go directly to a specialist and they are not required to be registered in a primary care setting, and many provinces pay lower fees to specialists for non-referred consultations.²⁴¹

3.1.2. Healthcare resources in 2020

In 2021, the GPs and practicing specialists' density was 1.3 and 1.5 per 1 000 population respectively, and the density of practicing nurses was 10.3 nurses per 1 000 population^a. Other healthcare practitioners were 0.7 licensed dentists, 1.0 practising pharmacists, and 0.7 practising physiotherapists per 1 000 population. Canada has 550 general hospitals (i.e. 14.5 hospitals per million population), and the density of hospital beds was 2.6 beds per 1 000 population in 2021.²⁴⁵ There were 14.6 CT scanners, 10.1 MRI scanners, 1.5 PET scanners, 15.3 Gamma cameras, and 2.9 radiation therapy machines per million population in hospitals and the ambulatory sector (2019).²⁴⁶ In 2021, there were about 17.5 mammography units per million population.²⁴⁷

^a No data available for midwives, in OECD Stat.



3.1.3. Health status

In the years 2015 to 2021, the life expectancy at birth was around 82y, with 81.9y in 2017 and 2018, 82.3y in 2019, 81.7y in 2020 and 81.6y in 2021. Avoidable mortality from preventable and treatable causes has fallen steadily over the past decade to 171 per 100 000 population in 2019.²⁴⁶

3.2. Waiting times

3.2.1. Organisational framework

Legal framework

In the 2004 Ten-Year Plan to Strengthen Health Care, Canada's Premiers (federal, provincial, and territorial) agreed to strengthen health care, including **providing timely access to care when needed**. This includes better managing of waiting times and reducing waiting times when they are longer than medically acceptable. The 13 Premiers have committed to achieving meaningful reductions in **waiting times in five priority clinical areas**: cancer care, cardiac care, diagnostic imaging, joint replacement, and sight restoration. They agreed to collect information on waiting times and make it available to Canadian citizens, and to establish **benchmarks and comparable indicators for public reporting on waiting times**. All provinces and territories made a public commitment to establish a patient wait time guarantee in at least one of the five priority areas. The 2007 Wait Time Guarantee Program consists of a defined timeframe and access to alternative options for care, if the timeframe is exceeded.^{248, 249, 250, 251}

To support the reduction of waiting times, the Government of Canada (through the 2004 First Minister's Meeting) established a CAD 5.5 billion Wait Times Reduction Fund for provinces and territories to address the priorities in their respective systems and make the system more sustainable for the future (training and hiring more health professionals, reducing backlogs of patients needing care, building capacity for regional centres of

excellence, expanding ambulatory, and community care programs and developing and implementing tools to better manage waiting times).²⁴⁹

Implementation of the waiting times assessment and agreement on the definitions

Since 2004, the Canadian Institute for Health Information (CIHI) and the provinces have been working together to develop public waiting time indicators and have agreed on their definition.²⁵² 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 improve health across Canada by consolidating health data. Agreement on the definition of waiting times, procedures to report on, standards and benchmarks^b has been reached by **consensus among the provinces and territories**, with CIHI coordinating the discussions (with the discussions including policy-makers or technical representatives from each province or territory). There are **no penalties** for the provinces or territories that do not send data to CIHI. Sending the data to CIHI is based on a long-term collaboration that benefits all partners (Personal communication).

Establishment of waiting lists

The 2004 Ten-Year Plan to Strengthen Health Care provides for the measurement of waiting times for provinces and territories, but it does not require provinces and territories to implement waiting lists in the five selected clinical priority areas. It is up to each province and territory to decide whether or not to implement waiting lists, and waiting lists can be established by a practice, a hospital or a region, on its own initiative. For example, the province of Quebec has implemented a mechanism to monitor the evolution of waiting lists for some elective surgeries, including monitoring the achievement of the strategic commitments for each hospital and the province (Personal communication).

^b Except for hip fracture repair, where the 48-hour benchmark is taken from the literature.



3.2.2. Purpose of waiting times data collection

The main goal of waiting time monitoring is to improve access to health care in Canada.²⁵⁰

3.2.3. Application areas of waiting times assessment

The collection of waiting time data covers the following areas²⁵¹:

- 5 priority procedures (for which benchmarks have been set)
 - Hip replacement
 - Knee replacement
 - Cataract surgery
 - Hip fracture repair
 - Radiation therapy
- 2 diagnostic imaging procedures
 - MRI scan
 - CT scan
- 5 cancer surgeries
 - Breast
 - Bladder
 - Colorectal
 - Lung
 - Prostate
- Coronary artery bypass graft (CABG)

Procedures include all priority levels for patients aged 18 years or older, excluding emergencies. Days when the patient is unavailable are not counted as waiting times.

The provinces, territories and CIHI use the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada (ICD-10-CA) and the Canadian Classification of Health Interventions (CCI) to define procedures for which a waiting time is recorded. However provinces don't necessarily use these standards in the systems that they use to collect the data.

Table 12 shows the definition, benchmarks, and population for each procedure. The data collection does not include emergency procedures (with the exception of emergency hip fracture repair).

In 2017, federal, provincial and territorial governments endorsed *A Common Statement of Principles on Shared Health Priorities*, and CIHI has been working with the provinces and territories to meet a commitment from Health Ministers to monitor and report on progress in improving access to **home and community care and to mental health and addictions services**.²⁵³

As part of this commitment related to the Shared Health Priorities, waiting times for Community Mental Health Counselling and for Home Care Services were selected.²⁵⁴ Two indicators have been developed: waiting times for community mental health counselling, and waiting times for home care (e.g. personal support or clinical care such as nurses) and reported for the first time in 2021.²⁵⁵

The coverage and submission of data was low at the beginning, but CIHI has put a lot of effort to improve them. For example the population coverage for home care waiting time has increased to over 90% (Personal communication).

The **Community mental health counselling indicator** aims to measure “the median number of calendar days that client waited for ongoing counselling services from the date that the initial referral was received to the date of the first scheduled counselling session. The first scheduled counselling session refers to the first appointment offered and accepted by the client, regardless of whether they attended the appointment. This indicator includes only publicly funded services that are scheduled/booked in advance. For the purpose of this indicator, publicly funded means services that are provided, coordinated or overseen by the government. This may include cases where a co-payment is required. This indicator provides an indication of whether Canadians are getting timely access to community



mental health counselling". It includes patients of all ages and all priority levels, and all forms of real-time mental health counselling (e.g. in person, phone, videoconferencing, online) are considered, regardless of the source of referral (e.g. walk-in, family physician, emergency department, crisis services, etc).²⁵⁶

The waiting times for **home care services** "measures the median number of calendar days clients waited, from the date that the initial referral was received to the date when the first home care service was received. It includes only services that are provided, coordinated or primarily funded by the government. This may include cases where a co-payment is required. This indicator provides an indication of whether Canadians are getting timely access to home care", which consists of both home health services and home support. Home support means assistance provided to clients to enable them to live at home, which includes homemaking (such as house cleaning, dishwashing, laundry and meal preparation etc.) and personal care (such as eating, bathing, dressing and toileting etc.). Home health is defined as services provided by home health care professionals (such as nurses, physiotherapists, occupational therapists, and clinical nutritionists etc). It includes patients of all ages and all priority levels.²⁵⁷

In addition to these priority clinical areas and community care, provinces and territories may decide on their own to report waiting times for other procedures or treatments.

Some measures of waiting times are collected by the Commonwealth Fund among samples of health professionals through surveys, to measure waiting times for general and specialist care (Personal communication).

3.2.4. Definition of waiting times

Start date and finish date for waiting times measurement

Priority clinical areas

The Comparable Indicators of Access Sub-Committee (CIASC) developed a pan-Canadian definition for waiting time measurement in 2005. This definition, which has been adopted by the federal, provincial and territorial ministries, defines the start and end points for waiting time measurement as follows:

- Start date of waiting times measurement: "Waiting for a health service begins with the booking of a service, which is when the patient and the appropriate physician agree to a service, and the patient is ready to receive it."
- End date for waiting times measurement: "Waiting for a service ends when the patient receives the service or the initial service in a series of treatments or services."

Community Mental Health Counselling

The waiting time 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 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 attended the appointment.²⁵⁶

Home Care Services

The waiting time starts on the date the initial referral is received by the coordinating organisation (or at the date of discharge if the patient is in hospital when the referral is received) and it ends on the date the first service is received (i.e. the first home care event). This care event should not be for the sole purpose of carrying out an assessment, arranging a service visit or checking in with the client.²⁵⁷

3.2.5. Waiting times data collection methods

The method of collecting waiting times is intended to reflect the capacity of the system in a province or territory to provide a healthcare procedure.²⁵¹

In terms of waiting times, CIHI calculates the waiting times for hip fracture repair using the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS). For all other recorded procedures, CIHI collects aggregated waiting time results submitted directly by provincial ministries and agencies (it is up to each province and territory to organise its own data collection system); 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).²⁵¹



In waiting times for community mental health counselling and for home care services, data come from the provincial and territorial data collection systems. Values for Canada are calculated using a weighted average of the median wait times submitted by jurisdictions, and weights are calculated using the volumes of referrals submitted by jurisdictions.^{256, 257}

The provinces, territories and CIHI work together to ensure the **quality of the data and accurate analyses of waiting times**. Methods are standardised across provinces and territories to provide comparable data.

However, the system is not designed at a national level: each province or territory has its own way of collecting and reporting retrospective waiting times (e.g. from dedicated waiting time systems or booking systems). The provinces and territories do all the waiting time calculations and send the aggregated figures to CIHI (median, P90, percentage meeting benchmarks and volume – volume is used as a quality check. CIHI also organises regular meetings with representatives of the provinces and territories to discuss the best practices and share experiences on waiting time data collection (Personal communication).

Time frame

Waiting times in the priority clinical areas are recorded retrospectively: the patients' cohort includes all procedures that were performed between April 1 and September 30, each year. Waiting times are determined by recording the booking date and procedure date for these procedures. **The use of this 6-month period is intended to improve timeliness and is considered to be representative of the whole year and contributes to the high quality of the CIHI waiting time reporting.** The reporting of waiting times is based on the place of the procedure, and not on the place of residence. Exceptionally, to investigate the impact of the COVID-19 pandemic, an additional data period was collected for specific analysis (from October 2019-March 2020 to October 2022-March 2023). Although the interactive tool on the CIHI website (see 3.2.7) only include the data from April to September each year, the additional data was included in the released data tables (Personal communication).

Waiting times for community mental health counselling and home care services are reported over a 1-year period (fiscal year).²⁵⁵ Data only include cases where the waiting time ended (i.e., the first scheduled/booked appointment falls or the first home care event occurred) within the reporting fiscal year.^{256, 257}

3.2.6. *Waiting times data analysis*

Used parameters

CIHI's waiting time reporting includes the following metrics (for priority clinical areas)²⁵¹:

- Median: half of all patients waited this many days (or hours) before receiving care
- 90th percentile: 1 out of 10 patients waited this many days (or hours) or more before receiving care
- Number of procedures performed (during the 6-month period)
- The proportion of patients who received their procedure within the benchmark timeframe (where applicable) (number of patients treated within the timeframe divided by the total number of procedures performed)

In their own reporting, some provinces also present the mean, 95th percentile, number of patients waiting, distribution of patients waiting for a procedure.

Waiting times for community mental health counselling and for home care services provides the number of days that^{256, 257}:



- half of the patients waited for their first scheduled appointment for counselling services, and half were still waiting, and
- that half of the patients waited for their first home care service and half were still waiting, respectively^c.

The 50th, 90th percentile and referral volume were reported by age and gender.

3.2.7. *Waiting times data publication*

Information to be provided to the citizens

Each province has made waiting time information available on a dedicated public website, to provide useful information for patients, their families and health care providers^d. Waiting times are available by geographic area and procedure in an interactive manner. There is no single way to report waiting times, but most of the provinces have implemented a user-friendly website to search for waiting times by selecting a specific procedure, area or hospital. Reporting may vary between provinces, while some provinces monitor other procedures (e.g. neurosurgery) and allow comparisons between regions within the province or territory.²⁵¹

The CIHI website provides an online reporting tool for the priority clinical areas, as an overview and by province. It also shows trends over time (percentage of patients meeting the benchmarks, P50 P90 and procedure volume).²⁵⁸

Waiting times for community mental health counselling and for home care services are also available online (interactive maps, open data).^{256, 257}

CIHI publishes also several reports on waiting times.²⁵⁹

^c P25 and P90 for community mental health counselling waiting times are collected but not reported; P90 for home care services waiting times is collected to show a fuller distribution of waiting time, but is not used for public reporting.

3.2.8. *Strategic commitments for waiting times*

Benchmarks

For each priority clinical area (except for imaging, cancer surgery and CABG), a timeframe has been established that is considered medically acceptable (see Table 12). The waiting time benchmarks were developed through provincial, territorial and federal collaboration: discussions took place between clinicians and researchers in expert panels. Processes varied by priority area. Benchmark for hip and knee surgery came 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 (Personal communication).

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. Waiting times (along with other indicators) are used by the provinces to monitor the health system performance, so they also have an interest in transmitting their data on waiting times (Personal communication).

3.2.9. *Points of evaluation*

3.2.9.1. *Comparability between provinces and territories*

Even though the provinces and territories have agreed on definitions of waiting times, comparability between them is not perfect (they send data that best fits the definitions). This is because each province or territory has its own way of collecting and reporting retrospective waiting times and sends aggregated data (median, P90, percentage of patients meeting the benchmark, volume); there's no pan-Canadian integrated waiting time data system. Each province maintains record-level waiting times data and reports aggregate data to CIHI. The fact that the services may be organised

^d The territories (Yukon, Northwest Territories and Nunavut) do not have wait time website.



differently can also have an impact on waiting times (Personal communication).

3.2.9.2. *Data quality checks and limitation in the interpretation*

CIHI carries out data quality checks, based on the volume of procedures reported by the provinces. They check this against the hospital data and the number of surgeries performed in that area that were reported to CIHI's administrative databases (Personal communication).

As a limitation, some surgeries are outsourced to private clinics (e.g. cataracts), which are not included in the provincial data collection (Personal communication).

Comparing waiting times for coronary artery bypass graft (CABG) surgery also remains a challenge.

The benchmark time frames for CABG were established based on the urgency level of a patient's condition; however, there is no consensus across provinces on how physicians should prioritize patients needing CABG surgery.²⁶⁰

Waiting times for community mental health counselling and for home care services should be interpreted with caution due to the known differences in definitions (data come from independent provincial and territorial systems). There is a commitment among jurisdictions to work towards harmonising definitions and improving the comparability of results. Several factors are reported as potentially influencing the results, such as^{256, 257}:

- Variation in data coverage across Canada, primarily due to data missing by geography or service type (e.g., wait time data for publicly funded services that are contracted to third-party organizations is missing for a number of jurisdictions)
- Differences in the organization, funding and availability of services and care providers
- Differences across jurisdictions in which clients qualify to receive publicly funded counselling services

- The number of people requiring community mental health counselling services
- Urgency of the client's condition
- Client choice

3.2.9.3. *Barriers to the data collection system*

Given that each province and territory is responsible for organizing and providing care, collecting comparable wait time data requires the commitment of all jurisdictions. CIHI has a good pan-Canadian coverage of hospital administrative data and continues to improve the coverage of the community-based data.

Some improvements in the health care system can have an impact on data collection, but can take a long time to be implemented, such as digitalized records with both clinical and administrative data (Personal communication).

Since no benchmark has been set for cancer care, if waiting times for cancer surgeries increases (as they did during the COVID pandemic, for example, when waiting times increased by 2 to 4 days), it is hard to conclude whether these few days have a significant impact on patient outcomes or not (Personal communication).

3.2.9.4. *Positive elements of the waiting time measurement and lessons learned*

One of the key lessons learned from the Canadian system is that it is not necessary to actually hold the data to be able to report on waiting times, as long as there is an agreement on the definitions (in this case, from the provinces and territories). If further analysis is required, the provinces and territories can disaggregate the dataset as requested by CIHI (Personal communication).



Some elements of the waiting times measurement system are positive:

- It has provided a segment over time, that has been used by the provinces to have 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).
- The use of ICD-10 codes and consensus definitions have contributed to the quality of the data.
- The meetings with the provinces and territories to share and discuss practices have enabled learning from each other.
- Establishing comparable waiting time measurement took time, but it's positive that all stakeholders have been actively involved in the project (Personal communication).

3.2.9.5. *Evolution with time*

According to CIHI, waiting times increased during the pandemic, which was associated with a reduction in the volume of surgeries performed. With the recovery efforts by federal, provincial, and territorial governments and health systems, it was first observed that the P90 started to go down, and then the P50 was also positively affected, but later. This has confirmed that the indicators chosen to monitor waiting times really captured what was happening in the health system.

To alleviate the backlogs, some provinces made plans to send patients of out province. Its impact on wait times will need to be monitored.

However, the most recent data (2022) shows that *while the monthly number of scheduled surgeries is nearing pre-pandemic levels, this is insufficient to clear the backlog and improve wait times.*²⁶¹

Another area to monitor is the use of private clinics to deliver publicly funded services as a strategy to alleviate the backlog of care. CIHI continues to work with provincial stakeholders to monitor collection of data from these private clinics and the impact on waiting times (Personal communication).


Table 12 – Data collection information for the priority clinical areas eligible to waiting time data collection

Definition	Benchmark	Population	Decisions/rationale
Hip replacement			
The number of days a patient waited, between the date when the patient and the appropriate physician agreed to a total hip replacement surgery and the patient was ready to receive it, and the date the patient received a planned total hip replacement surgery (as of 2010)	Within 26 weeks (182 days)	Includes - those aged 18 and older - all total hip replacements (primary and revision); bilateral joint replacements count as a single wait - all priority levels Excludes - emergency cases - elective partial hip replacements - days when the patient was unavailable	- The exclusion of bilateral hip replacements and inclusion of patients younger than age 18 and out-of-province patients are not considered material to the waiting times. These are not reported as exceptions^e for provinces that are unable to include/exclude these cases. - Provinces continue to work toward removing “patient unavailable” days from reported waiting times. This will continue to be an area of variation that CIHI will note.
Knee replacement			
The number of days a patient waited, between the date when the patient and the appropriate physician agreed to a total knee replacement surgery and the patient was ready to receive it, and the date the patient received a planned total knee replacement surgery (as of 2010)	Within 26 weeks (182 days)	Includes - those aged 18 and older - all total knee joint replacements (primary and revision); bilateral joint replacements count as a single wait - all priority levels Excludes - emergency cases - days when the patient was unavailable	- The exclusion of bilateral knee replacements and inclusion of patients younger than age 18 and out-of-province patients are not considered material to the waiting times. These are not reported as exceptions for provinces that are unable to include/exclude these cases. - Provinces continue to work toward removing “patient unavailable” days from reported waiting times. This will continue to be an area of variation that CIHI will note.
Hip fracture repair (inpatient)			
The number of hours a patient waited, from the time of first inpatient admission with a hip fracture (index admission) to the time the patient received hip fracture repair surgery(as of 2017)	Within 48 hours	- Includes those age 18 and older Excludes - scheduled procedures (urgent admissions only) - records with invalid admission, discharge, or procedure time^f	

^e An "exception" is when a province submits data that doesn't meet the agreed definition. In most cases, CIHI reports exceptions publicly through its waiting time tool (<https://www.cihi.ca/en/explore-wait-times-for-priority-procedures-across-canada#additional-resources>), but in some cases CIHI does not publish exceptions because it is judged that it won't have an impact on waiting times (Personal communication).

^f It's actually -12 to 24 hours because the ED time and acute care time may overlap (Personal communication).



Definition	Benchmark	Population	Decisions/rationale
Hip fracture repair (emergency and inpatient)			
The number of hours a patient waited, from the time the patient was first registered in an emergency department (ED) to the time the patient received hip fracture repair surgery (as of 2017)	Within 48 hours	- Includes those age 18 and older - Excludes records with invalid admission, discharge or procedure time	- The methodology begins with inpatient episodes for hip fracture repair (see before) and is linked to prior emergency department (ED) visits. - The ED visit is considered related to the inpatient hip fracture episode if the length of time between leaving the ED and admission to acute care is between 12 and 24 hours. - If more than one ED visit is linked to a single inpatient hip fracture episode, then the ED visit with the earliest entry date/time is selected to identify the start of the waiting time.
Cataract surgery			
The number of days a patient waited, between the date when the patient and the appropriate physician agreed to cataract surgery and the patient was ready to receive it, and the date the patient received a planned cataract surgery (as of 2010)	Within 16 weeks (112 days)	Includes - those aged 18 and older - first eye only; bilateral cataract removal counts as a single wait - all priority levels Excludes - emergency cases - days when the patient was unavailable	- CIHI will note the cases that have been included in which a procedure has been performed on the second eye. - There is no universal definition of high-risk cataract surgery procedures across provinces; hence, they are not consistent across jurisdictions. CIHI will note where high-risk patients are included. - Including out-of-province patients is not material to the reported waiting times for cataract surgery. These are not reported as exceptions for provinces that are unable to remove these cases from their data. - Provinces continue to work toward removing “patient unavailable” days from reported waiting times. This will continue to be an area of variation that CIHI notes. The rationale for including the first eye only: About 40% of all cataract surgery procedures involve the second eye. Second-eye surgery is often performed after a medically determined interval. Since these patients can be thought of as continuing under treatment rather than waiting for surgical availability, the inclusion of second-eye surgery could distort the cataract waiting times results.
Coronary artery bypass graft (CABG) surgery			



Definition	Benchmark	Population	Decisions/rationale
The number of days a patient waited, between the date when the patient and the appropriate physician agreed to a coronary artery bypass graft (CABG) and the patient was ready to receive it, and the date the patient received a planned CABG (as of 2011)	Currently not reported*	Includes - those aged 18 and older - isolated CABG only - all priority levels Excludes - emergency cases - days when the patient was unavailable	- Including out-of-province patients and those younger than age 18 is not material to the reported waiting times for bypass surgery. Inclusion of these patients will not be reported as an exception. - Provinces continue to work toward removing “patient unavailable” days from reported waiting times. This will continue to be an area of variation that CIHI notes. - Due to variations in the way clinical urgency is defined across Canada, CIHI is currently unable to report on CABG benchmarks.
Radiation therapy			
The number of days a patient waited, between the date the patient was ready to treat and the date of the first radiation therapy treatment (as of 2011)	Within 4 weeks (28 days) of the patient being ready to treat	Includes - those aged 18 and older - all referrals to start or initiate radiation treatment - all priority levels and all cancer types rolled up - oncology planning time Excludes days when the patient was unavailable	- Emergency patients are included; the exclusion of these patients will not be reported as an exception. - All referrals to start or initiate treatment may include patients who have had previous radiation treatment for the same or other cancers, patients who have metastases from previous cancer, and/or palliative patients. - Provinces that include radiation treatments other than external beam will be noted in the exceptions.
CT and MRI scans			
The number of days a patient waited, between the date the order/requisition was received and the date the patient received the scan (as of 2010)	(no benchmark set)	Includes - those age 18 and older - diagnostic scans (may be inpatient or outpatient) - all priority levels Excludes - emergency cases - routine follow-up scans - mammography screening and prenatal screening	- The inclusion of emergency patients is not considered material to the reported waiting times. These are not reported as exceptions for provinces that are unable to exclude these cases. - Routine follow-up scans are material to reported waiting times as they comprise between 10% and 15% of all cases, and are typically scheduled at regular intervals. For those provinces that are unable to remove follow-ups, CIHI will note this as an exception.

**Cancer surgery**

The number of days a patient waited, between the date when the patient and the appropriate physician agreed to a cancer surgery and the patient was ready to receive it, and the date the patient received a planned cancer surgery (as of 2014)

(no benchmark set)

Includes

- all surgeries for proven and suspected cancers
- all surgeries for palliative patients
- all cancer surgery for new and recurrent/metastatic cancers

Excludes

- days when the patient was unavailable
- patients who received a biopsy as the sole procedure
- patients on neoadjuvant therapy
- emergency cases

- Suspected cases are included because a pathology report may not be completed before surgery and data collection limitations do not allow for accurate collection of pathology results.
- Surgical treatment for palliative patients and recurrent cancers is included because it competes for operating room time, the same as treatment for newly diagnosed cancer patients.
- Provinces unable to exclude biopsies as a sole procedure will be noted in the exceptions.

Population and decisions/rationale also defined for each of each of the 5 cancer surgeries.

CIHI: Canadian Institute for Health Information

***Benchmark CABG:**

Despite agreement on waiting time benchmarks, there is not yet consistency in how urgency levels are applied across the country. Prior to 2012, to address the differences in urgency levels among provinces, CIHI's waiting time reports presented the proportion of patients receiving CABG surgery within the longest time frame only.

In 2012, it was decided that assessing the percentage of patients receiving care within the longest benchmark does not truly reflect the experiences of patients who have different requirements for treatment — particularly for the group of patients in need of the most urgent care. As a result, reporting on CABG waiting time benchmarks was discontinued, with the goal of resuming reporting when provincial urgency levels are better aligned.



4. APPENDIX IV – EXPERIENCES FROM SPAIN (ES)

4.1. Health system at a glance

4.1.1. Healthcare organisation

The Spanish national health system (Sistema Nacional de la Salud – SNS) is based on principles of **universality** (99.1 % of the population is covered), **free access with GP acting as a gatekeeper**, equity, and financial fairness.²⁶² The majority of the health expenditure (71,1%) is covered by taxes.²⁶² In 2022, Spain spends 10.4% of its GDP on health care.²⁴⁴ The out-of-pocket payments reached 21.8% of health expenditure in 2019 consisting mainly of co-payments for medicine, medical devices in the ambulant sector, and dental care.²⁶² In 2021, the percentage of expenditure covered by government or compulsory health insurance reached 71.6% and 15% of the population had a private duplicate⁹ health insurance.²⁴⁴

Spain has a decentralized health system with national coordination and is divided into 17 autonomous regions (comunidades autonomas – CCAA) and 2 autonomous cities, Ceuta and Melilla, situated in North Africa. The Ministry of Health, Social Policy and Equality is responsible for national planning and regulation, while the regional health authorities are in charge of regional operational planning, resource allocation, purchasing, and service delivery. Actions from regional and national health authorities are coordinated by the SNS Interterritorial Council.²⁶² The healthcare of the two autonomous cities is managed by the INGS (Instituto Nacional de Gestion Sanitaria) at the national level.

4.1.2. Healthcare resources

In 2021, the GP density was 0.94 practicing GPs per 1 000 population. The density of specialists was higher with 2.78 practicing specialists per 1 000 population.²⁴⁴ Practicing nurses' density was 6.4 nurses per 1 000 population while the density of midwives licensed to practice was 28.2 per 1 000 live births (data 2020).²⁴⁶ The healthcare workforce also included 0.8 dentists licensed to practice, 1.3 practicing pharmacists, and 1.3 practicing physiotherapists per 1 000 population.²⁴⁶

There were 12.0 general hospitals per million population.²⁴⁶ Overall, the density of hospital beds was 3.0 beds per 1 000 population in 2021.²⁴⁴

Imaging infrastructures in hospitals and ambulatory sectors encompassed per million population: 20.0 CT scanners, 18.2 MRI scanners, 1.9 PET scanners, 6.8 Gamma cameras, and 16.6 mammography units. For both sectors, 5.4 radiation therapy machines per million population were available.²⁴⁶

In the report "Health at a glance" in 2023, the OECD emphasises that there is uneven local densities in the healthcare resources distribution in Spain.²⁴⁴

4.1.3. Health status

In 2020, the life expectancy at birth fell to 82.4y, due to the COVID-19 pandemic. In 2021, the life expectancy increased again (83.3), but it did not yet reach the level observed before COVID (84.0y in 2019).²⁴⁶

Avoidable mortality can be used to assess the effectiveness of a health system. In Spain, avoidable mortality for preventable and treatable causes (standardized rate) was 169 per 100 000 population in 2020, higher than before the COVID period (144 per 100 000 population in 2019).²⁴⁶

⁹ Either a larger choice of providers or a faster access to health care services



4.2. Waiting times

4.2.1. Legal framework

More than 20 years ago, the Ombudsman (Defensor Del Pueblo^h) received many complaints about waiting in health. Its efforts to obtain objective information on the magnitude of the problem were hampered by the varied data, obtained with varied criteria and definitions sent by the Autonomous Communities. So he looked for primary information on his own using the secret shopper method i.e. asking his staff to make an appointment for outpatient consultation in different hospitals and services of several Autonomous Communities.²⁶³ It was much criticised (as a not valid method!) but out of these vicissitudes came the very interesting Ombudsman's report of 2003²⁶³ and the current official information systems.²⁶⁴

Currently, two Royal Decrees (RD) address the waiting times: one on the information system, the other which establishes the framework criteria to guarantee a maximum time of access to the National Health System.²⁶⁵

The Royal Decree 605/2003 of 23 May 2003²⁶⁶ aims the implementation of **an information system on waiting lists for outpatient consultations, diagnostic/therapeutic tests and surgical interventions** provided by the centres and services of the National Health System. The information system is established within the National Health System Interterritorial Council. As the regions have to provide homogeneous data to the Interterritorial Council, the law defines the criteria, how to compute them, and the minimum data set that must be provided. **Emergency healthcare** (urgent consultations, tests and surgical interventions), organs transplants (for which realization will depend on the availability of organs), health care provided in disaster situations and health care not included in the portfolio of services of the National Health System are excluded from application of this Royal Decree. The purpose of this RD is to achieve a homogeneous treatment of the

information for the system as a whole, guaranteeing transparency and uniformity in the information provided to citizens.

The RD 605/2003 also defines the indicators for an **adequate prioritisation** of patients on the National Health System waiting list for non urgent outpatient consultations, diagnostic/therapeutic tests and elective surgical interventions. However in practice it is not used as such. It depends on each Autonomous Community to justify the need for more resources or agreements with private providers (Personal communication).

The Royal Decree 1039/2011 of 29 August 2011²⁶⁷ defines a couple of **maximum waiting times** in order to guarantee users of the National Health System a maximum time of access to health benefits (see Table 15). There are exclusions specifically mentioned for the RD application as emergency health care, organ and tissue transplants, health care provided in disaster situations, interventions that may require a waiting period to meet the conditions suitable for their implementation, such as those related to assisted human reproduction techniques and health care not included in the portfolio of services of the National Health System regulated by Royal Decree 1030/2006, of 15 September.

4.2.2. Purpose of waiting times data collection

The purpose of the waiting times data collection is defined by the Royal Decree 605/2003, 23 May on harmonisation of waiting times data collection.²⁶⁶ The aim is, on the one hand, to **publish information on access delays** for health care provided in the national health system and on the other hand, to provide **information to citizens registered on a waiting list**.

^h The Ombudsman is the High Commissioner of the Spanish Parliament responsible for defending the fundamental rights and public freedoms of citizens by supervising the activity of the Spanish public administrations. (<https://www.defensordelpueblo.es>)



4.2.3. Application areas of waiting times assessment

The assessment of waiting times currently covers two areas:

- **Waiting lists and waiting times for outpatient consultations i.e.**

ambulatory consultations with a specialist (ACS)

The data are reported by medical specialty (10 main specialties i.e., gynaecology, ophthalmology, traumatology, dermatology, otolaryngology, neurology, general surgery, urology, digestive and cardiologyⁱ) and by region. All specialists and departments of the public network are concerned.

- **Waiting lists and waiting times for elective surgery:**

The data are reported by department (14 surgical specialties: ophthalmology, dermatology...), by procedure (15 interventions: cataract, inguinal hernia...), and by region (see Section 4.2.7).

Contrary to the purpose mentioned in the RD 605/2003, diagnostic/therapeutic tests are not collected.

4.2.4. Definition of waiting times

Waiting lists and waiting times for ACS

The start of the waiting times is defined in the RD 1039/2011 as the moment of the indication of care by the physician (i.e. the referral date mentioned on the prescribing doctor's request), which corresponds to the date of entry in the waiting registry.²⁶⁷ The end of the waiting times is linked to the departure from the list (for several reasons explained in this chapter below).

Patients are classified as followed:

- Patients in structural waiting i.e. patients waiting for a specialised consultation or whose waiting is due to the organisation and resource availability.
- Patients in non-structural waiting i.e. patients whose waiting is due to :

- the patients' wishes (personal reasons, work issues, or willingness to freely chose their doctor) ;
- appointment fixed to a specific date asked by the prescribing doctor.

Waiting lists and waiting times for elective surgery

The waiting times for surgery start with the indication for surgery which is made by the specialist physician. 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).^{269, 270} This issue is discussed in the Section 4.2.9. The end of the waiting times is linked to the departure from the list.

Patients are classified according to the type of waiting:

- Patients in structural waiting i.e. patients available for the surgery whose waiting is due to organisation of care and human resource availability.
- Patients waiting after refusing surgery in an alternative centre i.e. the waiting is motivated by the citizen's free choice.
- Temporarily unprogrammable patients: a patient waiting for surgery whose planning is not possible due to the following reasons:
 - Clinical reasons that contraindicate or make the procedure temporarily inadvisable;
 - Postponement of the intervention for personal or professional reasons.

The **maximum access time** is the time period, expressed in calendar days, which does not may be exceeded to attend outpatient clinics or intervene surgically to a user of the National Health System.²⁶⁷

The **waiting lists** are not associated to individualised specialists, but to hospital departments (any doctor in the department would eventually do the visit or surgical intervention). Some consultations and interventions are in

ⁱ In 2021, these 10 specialties account for 62% of patients waiting.²⁶⁸



fact performed by private hospitals under agreement instead of by the surgeons in the public hospital (Personal communication).

4.2.5. *Waiting times data collection methods*

The health information system on waiting lists (Sistema de Información de Listas de Espera or SISLE) is based on the Patients Register which gathers standardized information from regions about patients on the waiting list for ACS and surgical interventions. The data collection is in real time. When an indication of a medical consultation or surgery is filled up in a patient's medical record, that patient is included automatically in the list. A patient can be in several lists at the same time if she/he has several health problems (Personal communication).

Waiting times data collection for ACS

Each patient waiting for a first consultation with a specialist in the ambulatory sector must be entered on the Patients Register by the regional administration of health (Autonomous Communities, department of health). The first consultation is defined as a consultation where a patient is to be seen for the first time by a specialist in a specific speciality related to a new health problem.²⁶⁶

The minimum data set for ACS is defined in the RD 605/2003²⁶⁶ as:

- Date of entry: Date of registration of the request (The number of entries correspond to the number of requests).
- Petitioner (applicant for the visit) in:
 - Primary care (date of the referral)
 - Specialist care
 - Hospitals/reference areas
 - Other authorised bodies
- Speciality/subspeciality/diagnostic test/therapy requested.
- Type of service requested:
 - First consultation.
 - First diagnostic/therapeutic test.
- Priority of the patient, according to the definitions given in Law (Royal Decree 605/2003 - Annex III) and updated by SNS Interterritorial Council.
- Circumstances of the registration request: Appointment on the first available date.
- Date of registration requested:
- It will coincide with the date of entry into the registry, except in cases where there is a date expressly indicated as appropriate by the requesting doctor, in which case it will be this date.
- Appointment date assigned:
- The date the patient is scheduled for an appointment.
- Reason for leaving the register (types of conclusion of the episode):
 - Consultation/diagnostic/therapeutic test carried out in the centre itself.
 - Consultation/diagnostic/therapeutic test carried out in another centre.
 - Other reasons for leaving.
- Departure date: Date of the patient's visit or date of departure for other reasons.



Waiting times data collection for elective surgery

There is a similar process for patient waiting for a surgical intervention that includes all patients with a non-urgent prescription of a surgical diagnostic or therapeutic procedure, established by a surgical specialist, once his diagnostic studies have been completed, accepted by the patient, and for which the hospital plans to use an operating room.

The minimum data set for elective surgery is defined in the RD 605/2003²⁶⁶ as :

- Date of entry of the patient in the register.
- Surgical department prescribing inclusion in the surgical waiting list.
- Priority of the patient, according to the definitions given in given in Law (Royal Decree 605/2003 - Annex III and updated by SNS Interterritorial Council.).
- Inclusion diagnosis: coding according to the International Classification of Diseases in force in the National Health System.
- Intended surgical procedure: coding according to the International Classification of Diseases in force in the National Health System.
- Patient's situation (type of waiting):
 - Patient in "structural" waiting period.
 - Patient waiting after rejection of an alternative centre.
 - Patient temporarily not programmable.
- Reason for leaving the register (type of conclusion of the episode):
 - Due to intervention:
 - Scheduled at the centre itself.
 - Urgent at the centre itself.

- In another alternative centre.
 - For other reasons.
- Departure date: Date of the patient's surgical intervention or date of departure for other reasons.

Waiting lists for surgery are managed by the specialists who make decisions about whether and when adding a patient to the waiting list. Patients are added to the waiting lists based on prioritization criteria such as disease severity, disease progression or limitation of daily life activities.^{271, 272} Non-explicit prioritization criteria are used, decided by each physician and hospital (Personal communication).

4.2.6. *Waiting times data analysis*

Waiting list and waiting times for ACS

Seven indicators were described in the RD 605/2003 for ambulatory consultations.²⁶⁶ However some of them are currently not available (indicators 1, 5 and 7 as defined below).

Indicators are computed at two specific moments called reference dates (i.e. 30 June and 31 December). A study period refers to the 6-month period between from 1 January to 30 June, and 1 July to 31 December.

1. Number of patients waiting for an ACS = total number of patients in the waiting list who are structurally waiting for an ACS on a given reference date.
2. Average waiting time for waiting patients = average of waiting time in days that all patients on structural waiting had to wait for an ACS on the first date available. The waiting time of each patient is the difference, in calendar days, between the date of the request registration and the **reference date** (30/06 or 31/12)^j.

^j It is important to notice that the average waiting times is not the calculated from the difference between the date of entry into the register/or request and

the date of the visit but well between the date of entry into the register and the date reference date (30/06 or 31/12)



3.
$$\frac{\sum \text{end date of study period} - \text{date of entry in the register}}{\text{Number of patients in the register}}$$
4. Distribution of patients by waiting time = number of patients structurally waiting, included in each of the following waiting categories: ≤ 30 days, 31-60 days, 61-90 days, and > 90 days
5. Number of entries on the waiting list : according to the ACS asked, the number of entries on the waiting list is calculated as the ratio of the number of new cases entered into the registry during a study period per 1 000 population (children 0-14 years for paediatrics, women for gynaecology, total population for the other specialties).
6. Number of exits from the waiting list: there are two indicators to assess the number of exits from the waiting list. The first indicator is the number of patients removed from the waiting list after the first visit during a study period. The second indicator is the number of patients removed from the waiting list for any reason during a study period.
7. Average waiting time to get an ACS = average length of time, expressed in calendar days, that patients on the waiting list waited to obtain a ACS, i.e. the difference between the date of the request registration on the waiting list and the **date of the visit**.
8. Prospective average delay = time, expressed in calendar days, that it would take to absorb the total number of patients on the waiting list during a study period at the work rate observed over the previous 12 months.

Waiting list and waiting times for surgery

Seven indicators are also described in the RD 605/2003 for surgery²⁶⁶:

1. Number of patient waiting for an elective surgery = total number of patients waiting for a surgery on a given reference date by waiting categories.
2. Average waiting time for waiting patients = average of waiting time for a surgery for, on one hand, patients on structural wait and on the other hand, for patients who refuse surgery at an alternative centre. The

waiting time of each patient is the difference, in calendar days, between the date of the request registration and the reference date.

3. Distribution of patients by waiting time = number of patients by waiting categories, included in each of the following waiting categories: ≤ 90 days, 91-180 days, 181-365 days, and > 365 days.
4. Number of entries on the waiting list for an elective surgery = number of entries on the waiting list is calculated as the ratio of the number of new cases entered into the waiting list during a study period per 1 000 population.
5. Number of exits from the waiting list for an elective surgery : there are two indicators to assess the number of exits from the waiting list. The first indicator is the number of patients removed from the waiting list after surgery during a study period. The second indicator is the number of patients removed from the waiting list for any reason during a study period.
6. Average waiting time to get an elective surgery = average length of time, expressed in calendar days, that all patients on the waiting list waited for surgery, i.e. the difference between the the date of the request registration on the waiting list and the date of surgery.
7. Prospective average delay = time, expressed in calendar days, that it would take to absorb the total number of patients on the waiting list for elective surgery during a study period at the work rate observed over the previous 12 months.

Level of priority for inclusion on the waiting list.

There are two levels of priority for ACS: level 1 - preferential request within 15 days and level 2 - ordinary request and three levels for surgery: level 1 - surgery cannot be delayed for more than 30 days, level 2 - surgery cannot be delayed for more than 90 days, level 3 - surgery can be delayed because the pathology does not cause significant after-effects. However, there are no standardised criteria for priority setting (Personal communication).



4.2.7. *Waiting times data publication*

For each patient in the register, the Autonomous Communities send the data to the National Healthcare System Interterritorial Council. This is done two times per year, some weeks after the reference date (31/06 or 31/12). Based on this information, the Ministry of Health, Social Policy and Equality publishes information on waiting times twice a year.²⁷³

The published waiting times and waiting list indicators do not encompass all indicators proposed in the Royal Decree 605/2003.

It is the case for example of the average waiting time to get an ACS (indicator 6), the number of exits from the registry in the last 12 months (indicator 5), the prospective average delay (indicator 7) and the total pending patients/daily average of total exits from the registry in the last 12 months.

Waiting lists and waiting times for ACS

- Number of pending patients per 1 000 inhabitants by specialties (see Table 13) in the reference date (see indicator 1);
- Percentage of WT > 60 days by specialties (see indicator 3);
- Average structural waiting times for the first consultation in days by specialties (see indicator 2).

Table 13 presents the 3 indicators for the 10 specialties as gathered in December 2022. Data are also available by region but not reported here.

The average waiting time for the first consultation was 95 days, with a longer time to wait in dermatology, neurology and traumatology (see Table 13).

On June 30, 2021, 6.2 % of Spanish people were waiting for a first consultation and the average waiting time was two and a half months (75 days).²⁶⁸

**Table 13 – State of the waiting list for an ambulatory consultation in Spain at the national level (31/12/2022)²⁷³**

Specialties	Num. of pending patients per 1 000 population	% with a date assigned to more than 60 days	Average waiting times for a first consultation (days)
Total	85.43	55.7	95
Gynaecology	3.65	48.8	69
Ophthalmology	10.28	62.0	91
Traumatology	10.64	60.2	102
Dermatology	8.20	69.7	110
ENT	5.32	50.8	72
Neurology	4.06	59.3	113
General surgery and digestive system	2.93	39.7	64
Urology	3.28	51.4	88
Digestive system	3.27	55.6	94
Cardiology	2.18	44.7	86

There are also notable differences between Autonomous Communities as mentioned in the Section 4.2.9. Point of evaluation.

Waiting lists and waiting times for elective surgery

There are two distributions: one for 14 surgical specialties and another for 15 surgical procedures both with the same 6 indicators.

- Total number of patients in structural waiting for surgery (among 14 specialties or 15 surgical procedures) in the reference date (see indicator 1);
- Difference with the previous year (e.g. in December 2022, difference with December 2021) by specialties or procedures;

- Number of pending patients per 1 000 inhabitants by specialties or procedures (see indicator 1);
- Percentage of WT > 6 months by specialties or procedures (see indicator 3);
- Average waiting times in days by specialties or procedures (see indicator 2);
- Difference of this average with the previous year.

Table 14 presents the three last indicators from the list above for the 15 elective surgical interventions in December 2022. Data are also available for the 14 surgical specialties and by region but not reported here.



Table 14 – Waiting times for elective surgery in Spain (31/12/2022)²⁷³ LISTAS PUBLICACION dic 2022.pdf (sanidad.gob.es)

Selected interventions	Num. of pending patients per 1 000 population	Percentage of patients waiting for more than 6 months (%)	Average waiting times (days)
Cataract	2.73	5.0	73
Inguinal / crural hernia	0.85	16.1	101
Hip prosthesis	0.32	21.7	122
Arthroscopy	0.37	25.8	128
Varicose veins	0.34	18.4	110
Cholecystectomy	0.42	19.4	113
Hallux valgus	0.28	27.2	133
Adeno-tonsillectomy	0.28	15.6	100
Benign prostate hypertrophy	0.24	24.6	128
Pilonidal cyst	0.12	18.1	106
Carpal tunnel	0.30	13.2	88
Knee prosthesis	0.66	29.4	141
Cardiac valve surgery	0.04	9.0	80
Coronary bypass	0.44	4.5	57
Hysterectomy	0.16	21.1	117

Each region publishes also information on waiting times every 6 months according to their organisational structures. However, the information published on each official web pages is heterogeneous.²⁷⁰ For example, in some CCAA as Valencia, citizen can access personalised information about the foreseen waiting times in his care process for surgical interventions but it is not generalized.²⁷⁴

4.2.8. Targets for waiting times

The Royal Decree 1039/2011 of 29 August 2011²⁶⁷ defines a couple of **maximum waiting times for surgical interventions, imposed/suggested by 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 affected and the Council of Consumers and Users.

In the appendix to the RD, a couple of maximum waiting times were presented (Table 15). It was foreseen that these maximum limits would be used as references by the CCAA health services and would offer the user an alternative considered most appropriate if the effective provision of care could not be achieved within the maximum timeframe (maximum waiting times guaranteed).



This guarantee, however, may be suspended or ineffective for personal reasons of the user.

The Table 15 presents the maximum waiting times for surgical interventions as mentioned in the annex of the Royal Decree 1039/2011.²⁶⁷

Table 15 – Maximum waiting times guarantee for surgical interventions as mentioned in the annex of the Royal Decree 1039/2011.²⁶⁷

Selected interventions	Maximum waiting times (calendar days)
Cataract	180
Hip prosthesis	180
Knee prosthesis	180
Valvular heart surgery	180
Coronary heart surgery	180

According to the Royal Decree 1039/2011, the maximum waiting times would be subject to monitoring through the information system regulated in the RD 605/2003, of May 23 and should be periodically reviewed to be adapted, with prior agreement of the Interterritorial Council of the National Health System, to the health reality of each moment, to the socioeconomic situation and the needs of users of the National Health System. It was also foreseen in the RD 1039/2011 the possibility to define maximum access times for first ACS and for diagnostic or therapeutic tests, applying the same criteria indicated for surgical interventions, with prior agreement of the Interterritorial Council.²⁶⁷

A revision of this list was performed in 2015 in Catalonia with elimination of few interventions and addition of others. The revised list is presented in the

Table 16 below. The Catalan Health Service can transfer patients to other hospitals in its network to ensure that the maximum waiting times guarantee are satisfied. Transfer patients to a hospital of another region is very difficult (Personal communication). Patients can also decide to go to the private sector at their own expense (out-of pocket or private health insurances) to be faster operated.²⁷²



Table 16 – Maximum waiting times guarantee for surgical interventions as revised in 2015.²⁷²

Selected interventions	Maximum waiting times (calendar days)
Cataract	180
Hip prosthesis	180
Knee prosthesis	180
Major cardiac surgeries	90
Surgical procedures for cancer of bladder and prostate	60
Remaining cancer	45

For the remaining elective surgeries, there is no guarantee but 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 such as the impact of the illness to the quality of life, risks associated to waiting, and clinical effectiveness. The priority is defined by health professionals.²⁷²

4.2.9. Points of evaluation

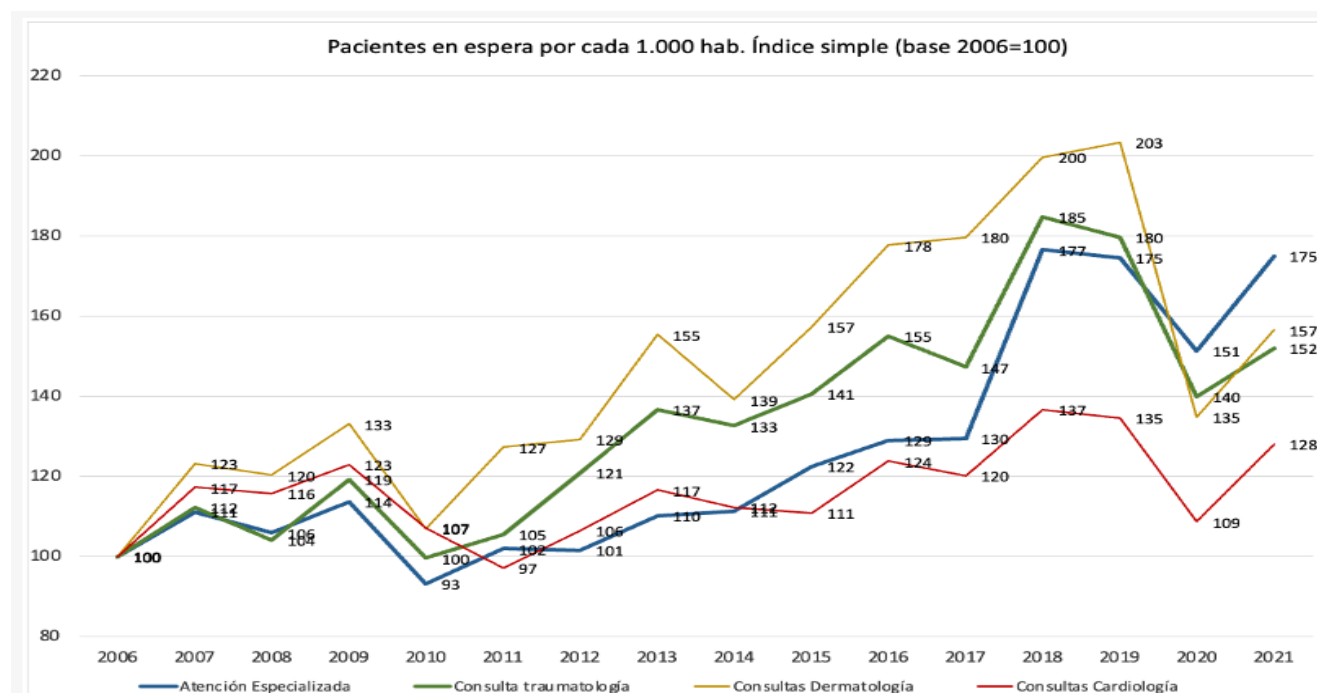
Several issues were raised by the Spanish experts regarding waiting times and the waiting lists in their country. We identified the trends of increasing waiting times and waiting lists for both ACS and surgical interventions, persistent regional differences, heterogeneity of data between CCAA, possible underestimation due to the way waiting times are measured, questions about the accuracy of the data, the lack of useful information for citizen, the potential perverse effect of the system and the risk of inequity. Some solutions proposed by Spanish experts are presented at the end of this chapter.

4.2.9.1. Increase over time

Waiting lists and waiting times for ACS

Between 2006 and 2021, the temporal evolution showed a worsening both in the proportion of patients waiting a first consultation with a specialist and in the duration of the waiting times.

The Figure 1 presents an index based on 100 in 2006, to compare the temporal evolution of patients waiting for the total of specialised care consultations and for three selected specialties: traumatology, dermatology and cardiology. For all consultations, in 2021 there are 75% more patients waiting per 1 000 inhabitants than in 2006. Cardiology has only increased by 28% while dermatology and traumatology exceed 50% increase in the period. The problem of invisible COVID-19 patients is obvious, because in 2020 the index falls abruptly, which in this case is not good news.²⁶⁸

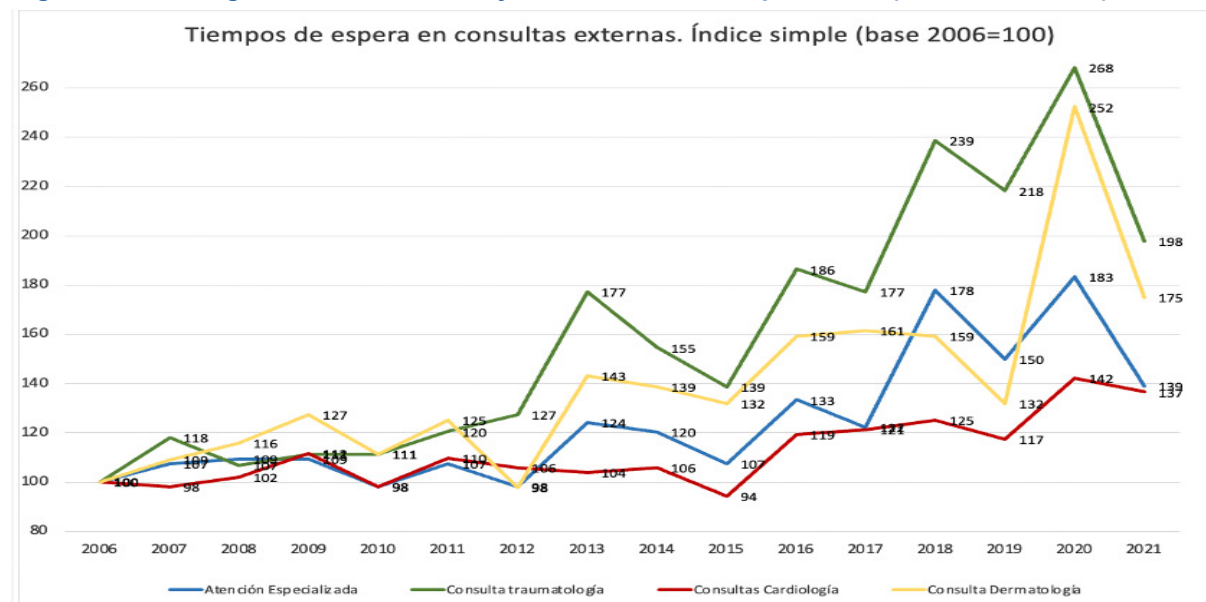
**Figure 1 – Proportion of patients waiting for a first ambulatory consultation with specialist (base 2006=100)**

Source: López-Valcárcel B.G.^{268,k}

Regarding the duration of the waiting times, between 2006 and 2021, average waiting times to access the specialist have worsened more than the volume of patients (see Figure 2). In 2021, it is almost double that of 2006. The neglect of non-COVID patients during the pandemic is reflected in the abrupt worsening of the times of those who were waiting in 2020. As of June

30, 2021, if you live in Catalonia you have to wait 234 days to be seen by a urologist (25 days in the Basque Country), in Extremadura 158 days to go to the traumatologist (in the Basque Country, 27), in Castilla La Mancha, you will wait 149 days for the dermatologist (in the Basque Country, 19).²⁶⁸

^k <https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/las-listas-de-espera-sanitarias-en-espana-y-ii-las-consultas-a-especialistas>

**Figure 2 – Waiting times for ambulatory consultation with specialists (base 2006 = 100)**

Source: López-Valcárcel B.G.^{268,1}

According to a more recent study, comparing data between 2019 and 2022, the worsening is clear. In 2019, the situation was already very poor in five registered specialties where more than 40% of patients waiting at least 61 days but in 2022, more than 50% of patients were concerned by this delay.²⁷⁵ The deterioration of the situation has been much more pronounced in ACS than in surgery (see below).

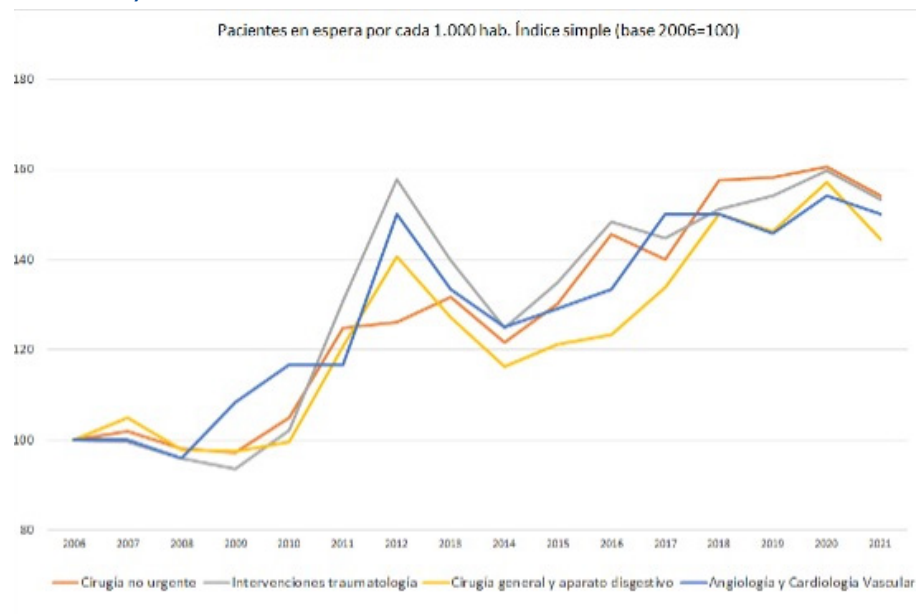
Waiting lists and waiting times for elective surgery

The Figure 3 shows the trend of the variable "waiting patients per 1 000 inhabitants" for the total number of interventions (elective surgery) and for three specific types selected (traumatology; general surgery and digestive system; angiology and vascular cardiology), based on 2006. The picture is clear: the number of patients waiting for an elective surgery has increased significantly in these five years. This is not due to the emergence of SARS-CoV-2: in 2019 the rate of waiting patients per 1 000 inhabitants had increased by 58 % compared to 2006, increasing slightly in 2020 and decreasing in 2021, but only slightly compared to 2019.

¹ <https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/las-listas-de-espera-sanitarias-en-espana-y-ii-las-consultas-a-especialistas>



Figure 3 – Proportion of patients waiting for an elective surgery (base 2006=100)

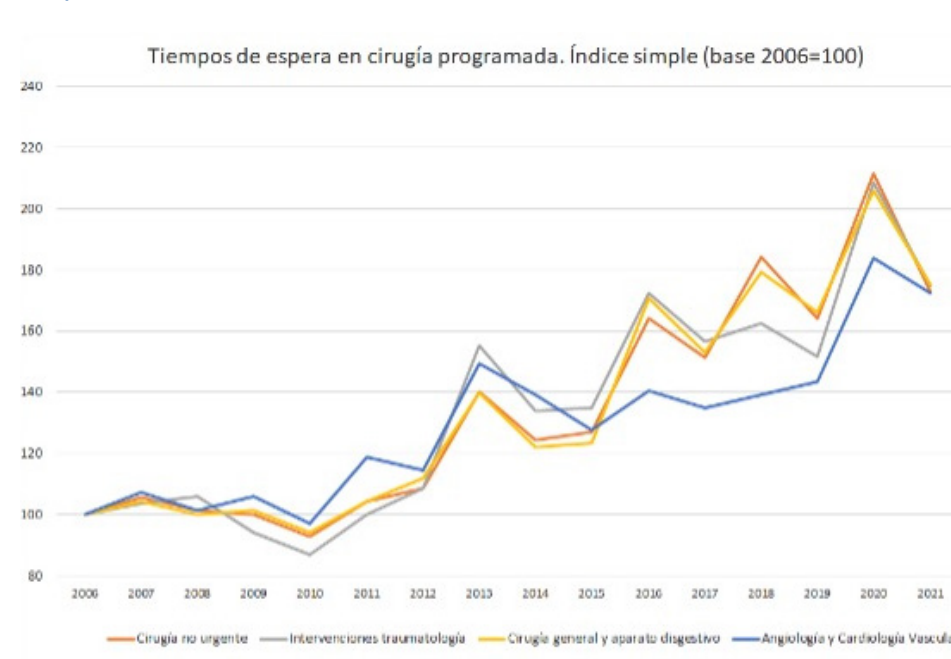


Source: López-Valcárcel B.G.^{269,m}

Regarding the duration of the waiting times, an increasing trend is noticed both for the total of scheduled surgical interventions and for the three additional series selected (Figure 4). The increases are even greater than for the proportion of patients as presented above (Figure 3). Both figures show that the effects of Covid on waiting times are more acute than on the number of waiting patients.²⁶⁹

^m <https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/las-listas-de-espera-hospitalarias-en-espana>

Figure 4 – Duration of waiting times for elective surgery (base 2006 = 100)



Source: López-Valcárcel B.G.^{269,n}

A more recent study shows that although some surgical specialties have increased average waiting times (cardiac surgery, angiology and vascular surgery, urology, maxillofacial and neurosurgery) between 2019 and 2022, others reduced them (dermatology, thoracic, paediatric and plastic surgery).²⁷⁵ In 2022, the "best" is general surgery, which fails to comply with the maximum guaranteed times in "only" 33.9% of patients.²⁷⁵

ⁿ <https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/las-listas-de-espera-hospitalarias-en-espana>



The number of CCAA failing to comply with the maximum guaranteed times also increases: in 2019 there were two CCAA with more than 20% of non-compliance with deadlines, in 2022, there were five.²⁷⁵

In conclusion, the number of patients on waiting lists and the duration of waiting times in the Spanish public health environment show a growing and worrying trend in recent years that the arrival of SARS-CoV-2 has only accentuated. The SNS appears to be at one of the most critical moments since its creation.²⁶⁸

4.2.9.2. *Differences of WT between Autonomous Communities*

There are notable differences between CCAA both for ACS and for surgical interventions.

In 2019 for example, 1.5% of citizens were waiting for a specialised consultation in the Basque Country versus 8.6% (5.7 times more) in Andalusia. This ratio tripled in 2022 with 0.6% of citizens waiting for a first specialist consultation in Murcia versus 11.04% in Andalusia i.e. 17.5 times higher.²⁷⁵ The differences suggest that other factors, on the supply and demand side, not necessarily related to COVID-19, have also influenced the delay time and size of the lists.²⁷⁵

The duration of the waiting times for ACS differed also, for example 24 days in the Basque Country versus 121 days (5.04 times more) in Catalonia.²⁶⁸

For surgery, as for the ACS, there is a high variability between Autonomous Communities in the proportion of patients waiting, establishing a range between 4 (Melilla) or 7.1 patients per 1 000 inhabitants (Community of Madrid) and 22.8 in Catalonia.²⁶⁹

Regarding the duration of the waiting times, the regional differences are also considerable, highlighting negatively the CCAA of Catalonia, the Canary Islands and Castilla La Mancha, among those with the highest average values (with respectively 166, 159 and 140 days of waiting surgical interventions). In the case of some of the selected interventions, such as traumatology, the average waiting days exceed even 200 days in some CCAA.²⁶⁹

4.2.9.3. *Accuracy of the data*

In Spain, the publication of WL data was introduced in 2002 by an Ombudsman mandate, which reported that data were sparse, broken and sometimes not very truthful.²⁶³

Several years have gone by since then with major improvements to create waiting list information systems and clear regulations on how to count people waiting and waiting times. However, there is no independent control of the data quality and the limitations and lack of rigor of such data persists (Personal communication).

Some problems are currently clearly identified by Spanish experts: a measurement not reflecting reality, an imperfect identification of patients waiting for care and possible data failure.

Longer waiting times in the reality

In Spain, the waiting times data do not encompass the whole pathway of the patients from the need since the WT starts at the moment of the indication of care by the physician (i.e. the referral date mentioned on the prescribing doctor's request). However, before the first specialist consultation, time can be long and even longer before the decision for surgical intervention (since there are the initial "primary care" contact, the first consultation with specialist, the waiting time for diagnosis tests, etc.) Therefore, the times of the complete process are longer in reality than those presented in the official published waiting times. There is a risk of underestimation.

In 2014, Abasolo et al.²⁷⁰ studied the difference between the waiting times as gathered in the Patients Registry (i.e. indication for surgery and its performance) and the total waiting times for three selected surgical interventions. They used the average total waiting times (including all outpatients visits and diagnostic tests prior to surgery) for carpal tunnel release, cholecystectomy and inguinal/femoral hernia repair. They found total waiting times of 355, 331 and 137 days, respectively versus 68, 83 and 73 days, respectively within the official data.²⁷⁰ This means that the total waiting times were, respectively, five, four and two times higher than those officially published.²⁷⁰



The underestimation risk does not concern only surgery but also consultation with specialists. Another source of information provides information on waiting time according to the citizens perspective. The [Centro de Investigaciones Sociológicas](#) (CIS) Health Barometer is an annual study based on interviews. According to the data for the year 2022, the average waiting times declared for the first consultation with a specialist (referred from the general practitioner) is 131.6 days, i.e. 65% higher than the average waiting times for the 10 basic specialties published by the health information system on waiting lists (Sistema de Información de Listas de Espera – SISLE) in June 2022.²⁷⁵

Another interesting feature of the Barometer is that it differentiates between consulting the general practitioner (GP) and consulting the specialist doctor. In 2022, the average time to get an appointment with the GP was 7.81 days (while it was 3 days in 2019 because of a substantial increase in the percentage of people who go to the GP).²⁷⁵ This waiting time should be considered in the problematic which it is currently not the case.

Imperfect identification of patients waiting

Another problem with the waiting time assessment is that the lists are not accurate. For example, when patients are referred to the private sector, they are removed from the list at the time of referral, not when the service is provided (even if there are still waiting for care); if they reject the referral, the counter is restarted (such as they have not waited before).

Furthermore, not all patients waiting for care are in the register of waiting times. There are "exceptions" (e.g. the footnotes of the tables of the official statistics) and lack of information on certain care as mental care. In the opposite, some patients are still in the lists although they are not waiting (e.g. patients who have undergone emergency surgery but still registered in the list for elective ones).

Data trustworthiness

In the last decade, three ruptures in the series of waiting list data for surgical interventions were observed, due to the exit or entry from the Community of Madrid and the revision of the calculation methods that were being applied (the case of Catalonia and Andalusia).²⁶⁹ These breaks do not exactly help to banish the idea that there are problems with the accuracy of waiting list statistics and a risk of manipulation of the data is not excluded as suggested by the article from Pinilla et al.^{268, 269, 276}

This study used the Newcomb-Benford's Law (NBL)^o, a mathematical model to test the validity of the data on waiting times in Spain (from December 2003 to December 2015) and in Finland (from December 2007 to December 2012). Findings showed a suspicion of trustworthiness of the Spanish data and not Finland one.²⁷⁶ *"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".*²⁷⁶

Finally, there is also an issue with the data from Autonomous Communities. Each CCAA has responsibilities in health planning, information systems and service delivery. Although the collecting method has been established, it appears that some CCAA do not follow it or even do not always provide information on waiting lists (WL) to the Spanish Ministry of Health central authority. As a consequence, the available information can be considered as a proxy to the challenge posed by WLs, but not state of the art or definitive.²⁶⁴

^o 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.²⁷⁶



4.2.9.5. *Lack of useful information for citizens*

What interests the patient is to know in real time how many days or weeks he/she will still have to wait. The number of patients in front of him/her in the queue, his position, is of less interest to him/her. 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.²⁷⁵ 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.

Moreover, as mentioned in the section 4.2.9.3, there is no possible comparison between regions since the data available on the CCAA websites are not homogeneous despite the standardization of definitions and the regulation of public disclosure of information.^{264, 270}

In conclusion, the public information available, with some exceptions, is 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.²⁶⁴

4.2.9.6. *Potential perverse effect of the system*

In Spain, in some places and cases when a waiting list is too large, physicians are eventually hired to do extra work and are paid by activity performed. 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 attend to 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 continue feeding the source of additional income.²⁶⁸

4.2.9.7. *Fairness not really guaranteed*

In Spain, free (and almost) universal coverage is the aim of the health insurance systems. Unlike in countries with voluntary insurance, there are no price rationing mechanisms and patients are treated according to their need (although the lists usually follow the implicit “first served” rule^P) and not according to their ability to pay.

However, this does not mean that equity is perfectly respected. One study based on administrative data 2015-2019 from Catalonia²⁷² showed that people with medium-high socioeconomic status (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.^{264, 272} This issues has been already mentioned in another Spanish study from Abasolo et al in 2014 who find that individuals with lower education and income levels waited significantly more time than their counterparts for specialists care.²⁷⁷

Inequity can be explained by several factors: 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.

They may also live in areas where hospitals have higher capacity and shorter waiting times and have the option to search treatment in another public or private hospital while waiting. The probability of voluntarily exiting the waiting list is indeed larger for patients with higher SES than lower.²⁷²

Furthermore, the same study found that patients with higher SES have a lower probability of having a surgery canceled for medical reasons. This may be due to the fact that lower SES is link to worse health, and delays (by sickness) along the patient pathway.²⁷²

^P Also named FIFO “First In, First Out” rule



More globally, the worsening of waiting times in the public network appears to lead to an increase in private insurance which is far from the aim of the Spanish Healthcare system.²⁶⁸

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, employment level and income) in access to ACS but shows also a modest SES gradient (on basis of the employment status) in primary care.²⁷⁸

4.2.9.8. *Proposed solutions*

Spanish experts published some propositions for improving the waiting times and waiting lists problematic: improvement of the data (e.g. by considering the whole pathway in the waiting times calculation for surgery²⁷⁰, improvement of the published information (e.g. more individualized, with waiting time by type of intervention and hospital²⁶⁴ and changes in the prioritization of patients in waiting list²⁷⁰). This last point is out-of-scope of this project.

5. APPENDIX V – EXPERIENCES FROM FINLAND (FI)

5.1. Health system at a glance

5.1.1. *Healthcare organisation*

The Finnish public system is tax-funded and provides universal care. According to the National Health Insurance (operated by the Social Security Institution, Kela), every permanent resident of Finland has access to reimbursement of the costs of prescription drugs and medical treatment provided by health care providers.²⁷⁹ Maternity and child health clinic visits, nurse consultation, laboratory and X-ray examinations (except if done privately), and emergency care in the public healthcare system are totally free of charge.²⁸⁰ Visits to general practitioners are not free of charge. The fee can be charged to those over 18 years of age. The one-time payment is currently a maximum of 23 euros for primary health care (Personal communication).

Access to private health care is conditional on the payment of user fees. Private insurances cover solely private health care. Occupational health care is only available to those in employment and covers care specified by the employer.²⁸¹ In 2021, 23% of residents in Finland have private supplementary insurance.²⁴⁷

Primary health care is provided in municipal health centres and the service consists of diagnosis and treatment of diseases, promotion of health and well-being, and prevention of diseases.²⁷⁹ To a lesser extent, primary care may be provided by private or occupational health systems. As part of a non-urgent care pathway, patients must contact the local health centre or its predetermined nurse-doctor team, either by telephone or by visiting the centre. A health professional (usually a nurse) will first assess the patient's needs and direct him/her to the appropriate care provider. In addition, a strong gatekeeping system for access to specialist services is managed by the general practitioner (GP).²⁸¹ Specialised health care is performed in hospitals. Specialised healthcare in Finland plays a role as a service provider and can give the patient/client a service voucher to the private party that arranges the care (Personal communication). In addition, access to



health care could be organised through occupational health care and the public health sector could buy services from a private health care provider.²⁷⁹

The organisation of health care in Finland is characterised by a highly decentralised administration, multiple sources of funding, and multiple delivery channels. Health care is regulated at both national and local levels.²⁸¹ A structural social and health care reform adopted by Parliament in June 2021 is currently being implemented into practice.²⁸² Since the January 1st 2023, all municipal provision of health care⁹ was transferred to newly found welfare service counties which are now responsible for organizing the public health and social care. There are 21 wellbeing services counties, formed from several municipalities and mainly based on the division into regions. The wellbeing services counties are self-governing. Their funding is based on central government funding, and they do not, so far, have the right to levy taxes. Differences in the service needs of the counties are taken into account when determining funding. The duties of the wellbeing services counties include primary and specialised healthcare, social welfare, student welfare, mental health, prehospital emergency medical services, services for children, young people, families, people of working-age, persons with disabilities and rescue services.²⁸²

The reform aims to improve the availability and quality of health and social services in Finland. After the reform, the public sector is the main health and social service provider while the private sector is additional service provider.²⁷⁹

The NHI (National Health Insurance – Kela) is financed by the government (42%), employees' income tax (36%), and employers' contributions (21% - only for occupational health services).²⁸¹ In 2022, seventy-nine per cent of health care expenditures were covered by public funds equivalent to 10% of GDP.²⁴⁷ In 2019, total health expenditures were distributed as follows: outpatient care (39%), inpatient care (24%), long-term care (17%), pharmaceutical and medical devices (15%), and prevention (4%).²⁸³

5.1.2. Healthcare resources

Finland is characterised by a very uneven distribution of health professionals across the country leading to uneven local professional densities. In 2020, the density of specialists was 2.2 per 1 000 inhabitants.²⁴⁷ The density of GPs is lower, at 1.4 per 1 000 inhabitants.²⁴⁷ In the same year, the density of practising midwives is 49.6 per 1 000 live births. The health workforce also included 13.6 practising nurses, 0.7 dentists licensed to practice, 1.0 practising pharmacists, and 1.6 practising physiotherapists per 1 000 inhabitants.²⁴⁶

There were 45.0 hospitals per million inhabitants. Of these hospitals, 66% were public hospitals. There are private hospitals for specific targeted care such as orthopaedic surgery, cardiology or cancer care.²⁸¹ All private hospitals have been established since 2013.²⁸¹ The overall density of hospital beds was 2.8 beds per 1 000 inhabitants in 2021.²⁴⁷

In 2020, imaging infrastructure in hospitals and the ambulatory sector per million inhabitants included: 17.0 CT scanners, 30.6 MRI scanners, 2.9 PET scanners, and 30.9 mammography units. In 2021, there were also 7.0 gamma cameras. There were 10.3 radiation units available per million inhabitants.

5.1.3. Health status

Life expectancy in Finland has risen over the past two decades.²⁸³ The Finnish population has gained two years of life expectancy since 2010 reaching 82y in 2021. In contrast to other countries, the COVID-19 pandemic did not affected life expectancy.²⁴⁶

Avoidable mortality from preventable and treatable causes (standardised rate) was 181 by 100 000 population in 2019²⁴⁶ and 186/100 000 in 2020.²⁴⁷

⁹ Except in Uusimaa region where Helsinki (the Capital of Finland) retains responsibility for organising social welfare, primary health care and rescue service and HUS (Helsinki University Hospital) provides all specialised care for the whole region



5.2. Waiting times

5.2.1. Legal framework

Data on waiting lists was published for the first time in Finland in 1993. Three years later, the Finnish government recognised by law patients' rights to know waiting times and the possibility of complaining in the event of not being satisfied with them. Specific maximum times for accessing healthcare interventions in primary and secondary care were also established in 1996.²⁷⁶

In 2005, a **National Health Care Guarantee** was introduced into law by the government setting **new maximum waiting times** for primary care and hospital services including dental care.²⁸⁴ In case of non-respect of these maximum, the Regional State Administrative Agency were able to give orders to improve the situation and added a threat of a penalty fine.²⁷⁹

In 2008, a research about Health Care Guarantee fulfillment in Finland was carry out by the Ministry of Social Affairs and Health. The research showed several issues such as that only approximately 7 % of patients got an appointment to a doctor in a regulated time in primary care in 2007 and that not every healthcare center published their waiting times even though there was a **regulation that obligated them** to do so.²⁷⁹

This legislation was refined and was incorporated into the **Health Care Act of the 30th of December 2010** (amended in 2013).²⁸⁵ This Health Care Act sets the **maximum waiting times for the primary care (including dental care)** needs assessment, **specialised care services, and mental health services for children and young people < 23y^r**. The waiting time to elective specialist care services also covers elective surgery.^{285, 279} A recent reform in healthcare proposes stricter waiting times in primary care for 2023 and 2024 (see 5.2.8.).²⁷⁹

The Finnish Health Care Act (1326/2010) requires that public service providers publish waiting times for non-urgent care on their websites. There is an obligation to inform patients on waiting lists, the reason for the delay and its expected duration.²⁸⁴ Waiting times should be signalled every fourth month by functional units and since recently every month from primary

health care (Personal communication).

The National Supervisory Authority for Welfare and Health (Valvira) and Regional State Administrative Agencies (AVI) are responsible for supervising the wellbeing services counties to ensure that waiting times for primary care and non-urgent medical care do not exceed the regulated limit.²⁷⁹

In the event that a local authority or the joint municipal authority for a hospital district is unable to provide the care within the maximum periods of time specified, the provision of the treatment shall be outsourced to another service provider (Health Act 2010).

The data subjects and their representatives have no right of access to the data entered into the Register of Primary Health Care Visits and the Care Register for Health Care, because the data are used solely for research and statistical purposes under section 27(1)(3) of the Personal Data Act (523/1999).²⁸⁶

5.2.2. Purpose of waiting times data collection

The data on waiting time is mainly collected for monitoring the **access to care** for research and decision-making purposes (including care organisation) but also for **patient information** (e.g. to facilitate the patients' choice of treatment place for non-urgent care). It allows to detect the exceeding of the maximum waiting times defined by law.

^r 1326/2010 English - Translations of Finnish acts and decrees - FINLEX ®



5.2.3. Application areas of waiting times assessment

Three areas of care are considered for the WT assessment:

- Waiting times for **primary care**²⁸⁷, including dental care.²⁸⁸
- Waiting times for specialised care²⁸⁹: Specialised care is classified using a 2 digits code based on the speciality. If there are subspecialties within a particular discipline, a third digit is used (e.g. Internal medicine (code 10): Allergology (code 10A), Endocrinology (code 10E), Internal geriatric (code 10F), Gastroenterology (code 10G), Haematology (code 10H), Infectious diseases (code 10I), Cardiology (code 10K), Nephrology (code 10M), and Rheumatology (code 10R)).
- Waiting times for mental health care for people aged under 23 years: Several categories of pathologies are considered such as:
 - Major brain syndromes,
 - Drug and substance abuse-related organic brain syndromes and behavioural disorders
 - Schizophrenia, schizotypal disorder, and delusional disorder
 - Mood disorders [affective disorders]
 - Neurotic, stress-related, and somatoform disorders,
 - Behavioural syndromes related to physiological disorders and physical factors
 - Adult personality and behavioural disorders
 - Intellectual disability
 - Mental development disorders
 - Behavioural and emotional disorders usually beginning in childhood or adolescence
 - Unspecified mental disorder
 - Other diagnostic categories

Mental health of persons under 23 years of age is collected in a separate cube, regardless of whether they are treated on the side of children, young people or adults. Patients under 23 years of age have stricter access to treatment than adults (Personal communication).

5.2.4. Definition of waiting times

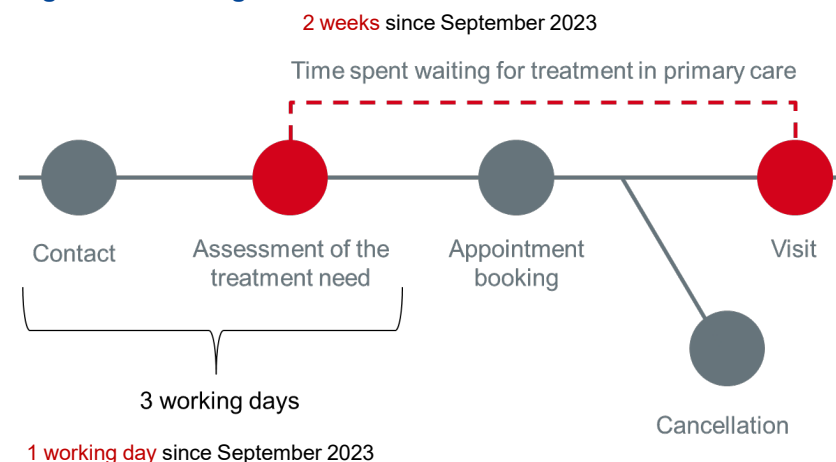
The definition of waiting times depends on the type of care provided. A distinction is made between primary care, specialised care, and mental health care for people under 23 years of age.

Waiting times in primary care

As shown in Figure 5, several waiting times can be assessed in primary care:

- Waiting time to perform assessment of the treatment need (most often by the nurse)
- Waiting time to book the appointment with the GP
- Waiting time for starting the treatment in primary care after the assessment of the treatment need

Figure 5 – Waiting times in primary care under the Health Care Act²⁹⁰



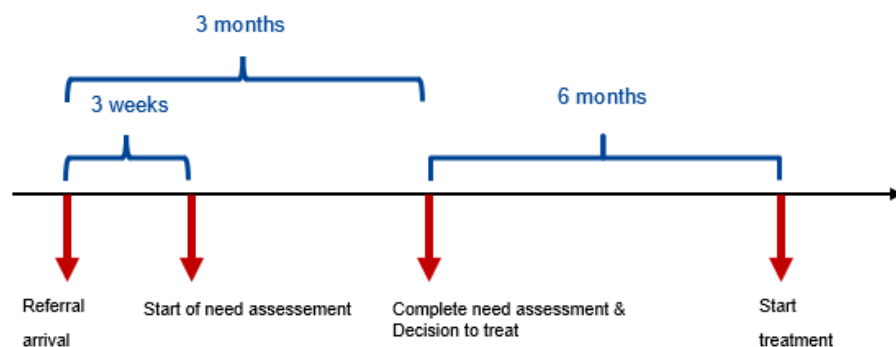


Maximum waiting times in specialised care

As shown in Figure 6, three waiting times are proposed²⁸⁹:

- Waiting time to start the care need assessment
- Waiting time to complete the assessment of the need for treatment
- Waiting time for starting the treatment i.e. interval between the decision to treat and the start of treatment

Figure 6 – Waiting times in specialised health care under the Health Care Act²⁸⁹

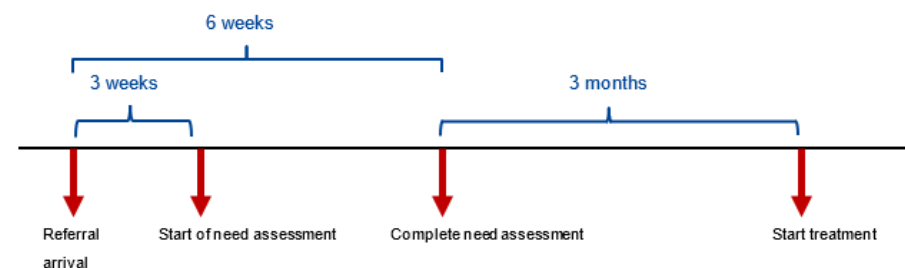


Waiting times in mental health care for people younger than 23y

As shown in Figure 7, three waiting times are calculated:

- Waiting time to start the care need assessment
- Waiting time to complete the assessment of the need for treatment
- Waiting time for starting the treatment

Figure 7 – Waiting times for mental health services for children and adolescents under the Health Care Act²⁸⁹





5.2.5. *Waiting times data collection methods*

Waiting times in primary care

Data are collected through an automatic daily extraction from the information system on patients owned by service providers and gathered into the Register of Primary Health Care visits called "Avohilmo". This registry is the primary care part of the Health Care Reporting System (Hilmo), a national data collection and reporting system for social protection and health care. The Register of Primary Health Care Visits started with data collected from pilot municipalities in 2008–2009. At the national level, the data collection on primary health care in the public sector was started in 2011, covering all health centres in Finland.²⁸⁶

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 time, the degree of urgency, and the reason for the visit which is reported by the nurse according to a specific and standardised classification and by the doctor using the ICD-10 classification of diagnoses.²⁸⁷

For the waiting time to appointment with GP, the third next available appointment time is used in some places, but it is not a legal practice (Personal communication). The third next available appointment is preferred to the first available appointment in primary care or dental care as random cancellations in these cases do not have as much effect as on first available appointments.²⁸⁸

Waiting times for specialised care and mental health care for people aged under 23 years.

The specialised care part of Hilmo is "The Care Register for Health Care". The data are available since 2007 and are extracted from the system of social and care treatment notification. Specialised medical care units collect data from their own patient information systems themselves (Personal communication). Each hospital district or specialised unit must send the data to the national Ministry of Health by the 15th of the following month and data describe the situation observed on the last day of the month. Data are sent

as a separate file and these files are uploaded to Hilmo. The transmission of information is based on the law.

Each type of waiting times is recorded according to the classification of specialisation (as described in the 1.2.3.). The reason for waiting is also 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. In addition, the on-call service category describes the case of patients admitted to the hospital with an urgent need without a pre-arranged appointment, either with or without a referral. There is also a separate category for waiting times that do not fit into the other categories.

Data collected on mental health include gender, place of care (inpatient, outpatient, or both), age, and type of care.

5.2.6. *Waiting times data analysis*

Currently, the data is at the level of the aggregate, but personal data collection in access to care is foreseen. The transition to personal data collection will take place in stages, possibly already next year (Personal communication).

We present below some indicators used in primary and specialised care.

Waiting times in primary care

Data is available for the last 5 years and can be extracted from a 'cube' (an interactive platform). The 'cube' provides a couple of possibilities for reporting the waiting times:

- Number of patients who had waited their non-urgent visits according to different categories (e.g., for 0-7 days / 8-14 days / 15-30 days / 31-90 days / or over 90 days)
- Percentage (%) of how all non-urgent visits distributed between several categories according to the WT areas (e.g., : 0-7 days / 8-14 days / 15-30 days / 31-90 days)

The data can be viewed either monthly or annually by the following indicators: by visit, percentage of access to care, and percentage of all non-urgent medical visits. The data are extracted from actual non-urgent individual medical visits, both in-office and telemedicine, preceded by a



contact and an assessment of the need for treatment. The data can also be viewed by the profession (doctors versus nurses) and by the type of service (outpatient care, student health care).²⁸⁷,

Waiting times for specialised care and mental health care for people aged under 23 years

These data are also available on 'cubes' (interactive platform). The following data are available:

- Type of somatic care by region/province
- Number of annual procedures
- Number of procedures by type of care providers
- Type of psychiatric care by type of care providers and type of psychiatric care by region
- Type of psychiatric care for children and adolescents by type of care providers and by region
- Prevalence of post-traumatic stress disorders in the population born abroad between 2016-2020
- Admission by hospitals or health care unit presented by discipline such as internal medicine, anesthesiology, surgery (general, visceral, orthopaedics and traumatology, cardiac and thoracic, vascular, urology, paediatric, plastic, neurosurgery), gynaecology and obstetrics, paediatrics, ophthalmology, ENT, phoniatics^s, stomatology, dermatology and venereology, oncology, psychiatry, pedopsychiatry, neurology, paediatric neurology, pneumology, intensive care, other; and
- Admission to treatment by waiting time category
 - Number of persons waiting for 1-90 days / 91-180 days / more than 180 days
 - Number of persons waiting for more than 90 days
 - Percentage of persons waiting for more than 90 days
 - Median number of waiting day

- Number of persons waiting between 1-90 days for an assessment of the need for treatment
- Number of persons waiting more than 90 days for an assessment of the need for treatment
- Percentage of persons waiting more than 90 days for an assessment of the need for treatment
- Median number of waiting days for assessment of the need for treatment
- Number of referrals processed in primary care within 3 days / within 4 to 21 days / in more than 21 days
- Percentage of referrals processed in more than 21 days
- Median number of days to process referrals
- Median number of days for referrals processed
- Number of persons waiting more than 180 days for treatment

Waiting times for elective surgery

There are specific analysis of waiting time for elective surgery. For example, there are data for persons who have waited over 180 days (care guarantee) for selected surgery/interventions.²⁹¹

5.2.7. *Waiting times data publication*

The Finnish Health Care Act (1326/2010) required that **public service providers publish** waiting times for non-urgent care on their websites. There is an obligation to inform patients on waiting lists, the reason for the delay and its expected duration.²⁸⁴

Currently, access to primary and specialised healthcare is published once a month on the website of the Finnish Institute for Health and Welfare (Personal communication). In addition, the regions report access to treatment on their own pages. This is the same information (Personal communication).

^s Phoniatics is a subspecialty under ear-nose and throat disorders, but requires further specialisation in Finland



As recommended in the Health Care Act 2010, the information is not only available on the Internet but also in other sources to ensure universal access to information.²⁸⁵

The national Ministry of Health publishes (in Finnish) twice a year a report on access to primary and dental care at national and provincial levels and 3 times a year for specialised care.

5.2.8. *Targets for waiting times*

The maximum of waiting times depend on the type of care provided and followed the distinction between primary care, specialised care, and mental health care for people under 23 years of age. There were fixed according to the work of the expert group (Personal communication).

For primary care, the maximum waiting time ruled by the law concerns the difference between the first contact with the health centre and the assessment of care needs by an health care professional (most often a nurse) (see Figure 5). The primary care needs assessment must be carried out without delay during weekday office hours by a health centre or other health care unit. If the assessment of the need for treatment cannot be carried out immediately, the law defined a maximum waiting period of 3 working days. This has just been changed in 1 day from September 2023 onwards due to the health and social services reform in primary care. After the assessment, the patient should have access to treatment in primary care within two weeks (it was three months until September 2023), and in oral care within four months.²⁷⁹ From November 2024 onwards, the patient should have access to treatment within one week and in oral care within three months.²⁷⁹

In **oral health care**, the first examination or treatment event must be organized within four months at the latest (within three months from November 1, 2024). If the first treatment event is for someone other than a dentist, the necessary follow-up visit to the dentist must be arranged within four weeks of the first visit or within three months of the first contact and assessment of the need for treatment. If a need for primary care specialist dental care or examination is identified, access must be arranged within three months (Personal communication).

For **other primary care outpatient care**, as of September 1, 2023, treatment by a licensed healthcare professional must be obtained within 14 days of the assessment of the need for treatment regarding treatment involving illness, injury, worsening of a long-term illness, new symptoms, or decreased ability to function. The treatment guarantee applies to both physical and mental health problems. 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.

Some treatment events are subject to a maximum period of three months, if an individual deadline is not specified in the treatment or rehabilitation plan (Personal communication).

For non-urgent specialised care service, the law mentions a maximum of 3 weeks for assessing the need for care based on the referral (from a general practitioner or a dentist). If further examinations (imaging/labs/specialist consultation) are needed, they have to be done within three months when the hospital received the referral, after which there is a maximum of 6 months to begin the necessary treatments (see Figure 6).²⁸⁹

The limits are similar for **non-urgent surgery** with a first evaluation in three weeks after reception of the patient referral. In situations where the assessment of the need for treatment requires consultation with a specialist or special imaging or laboratory tests, the assessment and any required tests shall be carried out within three months after reception of the patient referral. Any treatment and provision of advice deemed necessary on medical or dental grounds or on the basis of health science in connection with the assessment of the need for treatment shall be provided and begin within a reasonable period of time, taking into consideration the urgency of the case, and in any case within six months of the need for treatment having been ascertained. As regards diagnosed illnesses or symptoms that are best treated in a health centre, patients shall be referred to the appropriate health centre and the health centre issued with any necessary instructions for providing the treatment required.²⁸⁵ In case of surgery is required, the limit is three months from the time of the assessment, but it can be extended to six months for non-urgent treatments.



In the mental health sector for people under the age of 23, the maximum legal waiting time is 3 weeks for an assessment in the hospital or other specialised medical care unit after the reception of the referral, or 6 weeks if imaging or laboratory tests or consultation with a specialist are needed to carry out the assessment (see Figure 7).²⁷⁹ Any treatment of an individual of less than 23 years of age deemed necessary on the basis of the assessment of the need for treatment shall begin within three months of the need for treatment having been ascertained, taking into consideration the urgency of the case, unless otherwise required on medical, therapeutic, or other comparable grounds.²⁸⁵ Thus, the third domain of child and youth mental health is stricter than the respective care guarantees for adult (the general ones for PHC and specialised care).

The **implementation of the WT guarantee policy** is supervised by the National Supervisory Authority for Welfare and Health (Valvira) and Regional State Administrative Agency (AVI). When the patient or a next of kin finds that the rights to be seen in the WT guarantee have been violated, the person can file a written objection to the manager in charge of the health care center 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).

Both AVI and Valvira, based on their own findings or a person's complaint, can set an order to the health care 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 health care unit.²⁷⁹

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 and are placed on the waiting list of the specialist care unit of a purchaser such as a district hospital, or a health centre unit.²⁸⁹ Sometimes the treatment might even be purchased from abroad.²⁷⁹ 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.

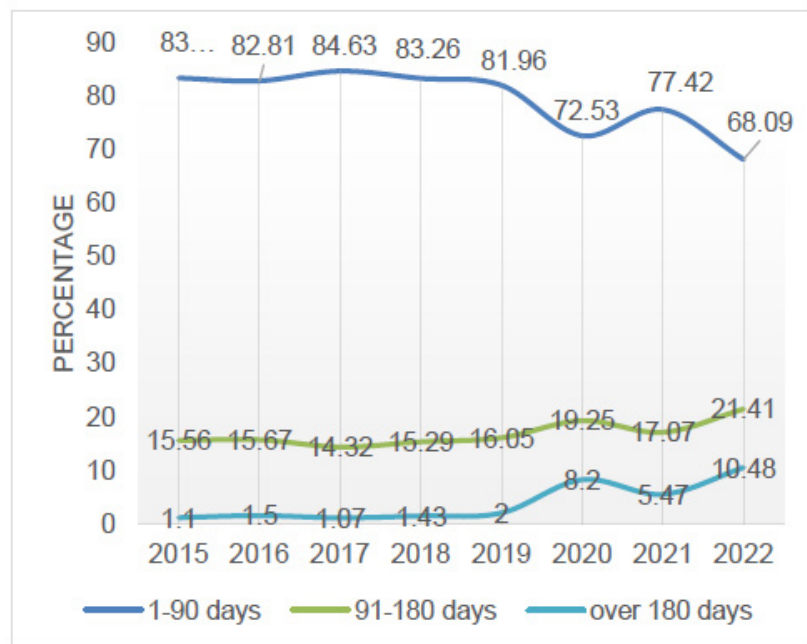
5.2.9. Points of evaluation

5.2.9.1. Change over time

After the National Health Care Guarantee from 2005, a significant reduction in waiting times was observed in Finland 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).²⁷⁹ It appears that the penalty fine given by the Regional State Administrative Agency had a positive impact 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.²⁷⁹

Furthermore, there is, between the year 2010s until 2019, a persistent record of exceeding one percent of patients that had longer than 6 months waiting times threshold (which exceeds the Health Care Act's (1326/2010)), especially more notably in specialised care.²⁷⁹ A study published in 2014 concluded ineffectiveness of policies such as health care guarantee, presenting the decline in patient satisfaction and accessibility during the year 1988 to 2011.²⁷⁹

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).²⁷⁹ The COVID-19 pandemic changed the trend with an increase of people waiting over 180 days until 10% in 2022 and consequently the shares of shorter waiting times decreased²⁷⁹ (see Figure 8).

**Figure 8 – Specialised medical care waiting times in Finland: 2015-2022**

Source: Haiko H. *Health care guarantee in Finland - Implementation and impacts on waiting times*: Metropolia University of Applied Sciences; 2023²⁷⁹

5.2.9.2. Current crucial issue

According to the OECD, unmet medical needs is particularly linked to waiting times in Finland with more than 4% of the population cited waiting times as a barrier for access to care.^{247,279}

Since the COVID-19 pandemic, Finland decided to provide more financial support to reduce the backlog in treatment and rehabilitation services. In 2023, EUR 110 million of the EU's Recovery and Resilience Plan would be allocated for this purpose, followed by additional funding of EUR 90 million in 2024 and EUR 30 million in 2025.²⁹²

5.2.9.3. Quality of data

The Finnish Institute for Health and Welfare does not carry out a proper quality check. 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 suppliers themselves are usually asked to correct any errors or deficiencies detected in their data. The rules and procedures regarding data checks and automatic correction are described in the Hilmo manual published annually.²⁸⁶

In primary care, there are quality reports (laaturaportit) about the quality of data.²⁹³

In **specialised care**, sometimes there may be technical challenges in sending information. Hilmo can detect large discrepancies in the data, for example in comparison with previous months, and ask the regions to check the data. The future transition from aggregated data to personal data collection that will take place possibly next year should allow for a more detailed quality check (Personal communication).

It appears that the quality of the national monitoring of waiting times has improved during the past decade in Finland.²⁷⁶

One recent study, used mathematical model (the Newcomb-Benford's Law (NBL))^t, to test the validity of the data on waiting times in specialised care in Spain (from December 2003 to December 2015) and in Finland (from December 2007 to December 2012). Findings showed a suspicion of trustworthiness of the Spanish data but not Finland one.²⁷⁶

^t 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



5.2.9.4. Negative effects of waiting times targets

The health care guarantee appears to be based on a sincere will to help the patients effectively and allow them to have timely access for care. However, there is negative side of the health care guarantee. Some examples are that the WT guarantee might **not be tolerable for all patients** nor **based on any evidence-based information of appropriate waiting time**; providing equal and economically sustainable service to all nationally might be **difficult if the density of the population is spread unevenly**; the question of the level of **responsibility** if the health care guarantee is not fulfilled is not clear: is it a governmental problem, a problem in the specific health care organization, or should the health care experts be able to treat more patients?²⁷⁹

5.2.9.5. Proposed solutions

The Finnish Federation for Social Affairs and Health (SOSTE) proposes several solutions to address the challenges of long waiting times and healthcare access in Finland. Are quoted investing in **recruitment and training of healthcare professionals**, implementing digital healthcare services and telemedicine to improve efficiency, prioritizing **preventive measures** to address the root causes of health problems, **involving patients** in decision-making processes (and considering patients' needs and preferences), providing **access to information** and support, and **enhancing collaboration between different sectors of the healthcare system** to provide comprehensive care, including collaboration among the health care and social service providers.²⁷⁹

6. APPENDIX VI – EXPERIENCES FROM THE NETHERLANDS (NL)

6.1. Health system at a glance

6.1.1. Healthcare organisation

The Dutch health system has a social insurance background with dominant roles for sickness funds (not-for-profit), independent providers, and a modest role for the government. From 1941 social health insurance was reserved for 2/3 of the population with lower incomes, whereas the population with higher incomes depended on private health insurance. Social insurance was extended to long-term care, elderly care, and mental health service in the later 1960s. With the health reform in 2006 (HIA Health Insurance Act), regulated competition and a **unified compulsory insurance system for all citizens** was introduced. Health insurers are obliged to accept all applicants at a community-rated premium plus an income-dependent premium that is redistributed amongst insurers on a risk-adjusted base. Health insurers and providers negotiate on price and quality of care. Special characteristics of the Dutch healthcare system are **GPs in a gatekeeping position and independent community-based midwives responsible for low-risk deliveries**.²⁹⁴

The Netherlands spent 11.3% of its GDP on health in 2021²⁹⁵ and 10.2% in 2022²⁴⁴. The majority of health expenditure (71%) is covered by compulsory health insurance contributions from citizens combined with 13% from taxes.²⁴⁴ The basic insurance package includes GP care, maternity care, hospital care, home nursing care, pharmaceutical care, and mental health care. The **first €385 must be paid out of pocket, except for GP consultations, maternity care, home nursing care, and care for children under the age of 18**. Glasses, dental care, and other care, not covered by the basic package, can be insured via voluntary health insurance.²⁹⁴

The Ministry of Health, welfare, and sport develops policies and measures to promote health and well-being and to safeguard access to a high-quality system. The responsibilities are increasingly shared with **local authorities**. In contrast, the operational role of the government in the delivery of services is very limited. The Dutch Health care authority (Nederlandse Zorgautoriteit



NZa) is an independent (but funded by the Ministry of Health) supervisor of the core principles of the Health Insurance Act and of the three healthcare markets (the health insurance market, the healthcare purchasing market, and the healthcare provision market). They also have the capability to impose tariff and performance regulations.²⁹⁴

Traditionally, Dutch medical specialists work independently within the hospital organization for both inpatient and outpatient care. Mostly they are formally self-employed and work in partnerships per specialty that are contracted to one of the hospitals. Between 2008 and 2015 independent medical specialists were paid through the DBC (Diagnosis Treatment Combination) system by a normative hourly tariff. Since 2015 medical specialists have to negotiate their remuneration with the hospital they are working in. **Bundled payments (financing the whole treatment instead of the separate care givers)** have resulted in more integration between medical specialists and hospitals. Gradually more medical specialists are salaried. They also participate more in independent treatment centres (Zelfstandige Behandel Centra, ZBCs), which are clinics for elective services providing care included in the basic insurance package.²⁹⁴

6.1.2. Healthcare resources

In 2021, the GP density was 0.9 GPs per 1 000 population. The density of specialists was higher with 2.0 practicing specialists per 1 000 population. Practicing nurses' density was 11.4 nurses per 1 000 population while the density of practicing midwives was 25.3 per 1 000 live births. The healthcare workforce also included 0.6 dentists licensed to practice, 0.2 practicing pharmacists, and 1.97 practicing physiotherapists per 1 000 population.²⁴⁶

The Netherlands is characterised by a completely private hospital landscape. There are no publicly owned hospitals in the Netherlands. The hospital density is 4.3 general hospitals per million population in 2021. The density of hospital beds was 2.1 beds per 1 000 population.

Imaging infrastructures in hospitals and ambulatory sectors encompassed per million population: 14.7 CT scanners, 13.4 MRI scanners, 4.8 PET scanners and 6.9 Gamma cameras.²⁴⁶

6.1.3. Health status

Due to the COVID-19 pandemic, the life expectancy at birth fell from 82.2 in 2019 to 81.4y in 2020. The life expectancy remained stable at 81.5 in 2021.²⁴⁶

In the Netherlands, avoidable mortality for preventable and treatable causes (standardized rate) was 161 per 100 000 population in 2020, higher than before the COVID period (149 per 100 000 population in 2019).²⁴⁶

6.2. Waiting times

6.2.1. Legal framework

In 1999, care for the elderly faced long waiting lists. A number of elderly people's organisations sued the state in the court, claiming that the state was failing in its duty of care. The court agreed. However, it found that it was not the state that had a duty of care but the health insurers. This ruling was a crucial point in reforming the insurance system towards a system with regulated competition (managed competition) in 2006.²⁹⁶

In 2009, the Dutch Healthcare authority established an obligation for hospitals and independent treatment centres to publish their waiting times per (sub)specialty for consultation, diagnostics and treatment on their website. It was published in the regulation CI/NR-100.084 "Regulation on **mandatory publication** of waiting times for somatic care" and aimed to make data on waiting times for elective medical-specialist care available for people in an ambiguous, transparent and comparable way.²⁹⁷ Mental health was excluded from this regulation, but separate regulations were issued end 2009 (GG/NR-100.106) for secondary ambulatory mental health care²⁹⁸ and in 2016 (NR/CU-557) for primary and in-hospital mental health care.²⁹⁹ The publication of waiting times for subspecialties was optional, although they could serve as a proxy for the waiting time of a specialty. In this case the subspecialty with the lowest waiting time (thus the most favourable indicator) was selected.



In 2018, the Dutch Healthcare authority published a 'national regulation concerning waiting times and waiting time mediation in medical specialised care'.³⁰⁰ This regulation has the similar aim than the CI/NR-100.084 (transparent information) but adds an **obligations for healthcare providers to inform patients of the possibility of waiting time mediation when the Treek norms are exceeded** (see Section 6.2.8.). This was followed in 2021 by a 'regulation on delivery of waiting times' for medical specialised care.³⁰¹ This regulation aims to provide centralised waiting times data for elective medical-specialist care, per (sub)specialty, in an unambiguous and accessible manner for both patients and health insurers. From 2021, the information on waiting times needs to be delivered through a portal to the Dutch Healthcare authority (NZa) and not (only) published on the institution's website. The **mandatory** periodic submission of waiting times by institutions falling within the scope of this regulation is therefore **centralized**.³⁰¹ The regulation elaborates on **which obligations institutions must comply with and which methodology they must use to calculate waiting times**. The information is provided by hospitals and independent treatment clinics every 2 weeks (prior to 2021 this was monthly). Submitting waiting times can be enforced and failure to submit waiting times can result in a fine. In practice this has hardly ever necessary (Personal communication).

There are no established priority criteria on waiting lists in the Netherlands.

6.2.2. Purpose of waiting times data collection

The purpose of waiting time data collection is defined by the regulation on delivery of waiting times for medical specialised care. This regulation aims at **providing insight** in an unambiguous way and accessible for both patients and health insurers.³⁰¹ Patients are informed in a transparent way to make the best possible choice for them. Healthcare providers can use the data as a quality instrument to review the opinion of patients about things that are going well and what can be improved (zorgkaartnederland.nl). Health insurers use the data for healthcare mediation and the Dutch Healthcare Authority uses the data for monitoring accessibility of healthcare. The data can also be used by journalists and for scientific research (Personal communication).

6.2.3. Application areas of waiting times assessment

Three types of waiting times are collected:³⁰²

- **Waiting times for a specialist consultation:** this can be a physical or digital, telephonically, or written contact between patient and specialist on/through or from the outpatient clinic. The data are reported by institution and by (sub)specialty (e.g. paediatrics, dermatology, internal medicine/endocrinology, ...). Waiting times are currently registered for 53 (sub) specialties (see section 6.2.10.1).
- **Waiting times for diagnostics:**
The data are reported by institution, currently for a list of 15 diagnostic procedures (see section 6.2.10.2).
- **Waiting times for treatment:**
The data are reported by institution, currently for a list of 47 treatments (see section 6.2.10.3).

The included items in each category are chosen in **agreement with the different stakeholders**: hospitals and independent treatment centres, patient organisation and health insurers. It are either items with long waiting times or of specific interest to the patients. The list of items is **yearly revised** (Personal communication).

The methodology used for building the system encompasses:

- Working groups with stakeholders: discussion on different options to collect waiting times;
- Decisions made by the Nederlandse Zorgautoriteit based on discussions;
- Feedback from stakeholders on decisions made;
- Pilot with 2 options in institutions involved in working groups and analysis of data;
- Evaluation of the system with working group and umbrella organisations: data analysis and interviews with users;



6.2.4. Definition of waiting times

The definition of waiting time depends on the type of care provided. A distinction is made between outpatient clinic appointments/diagnostic tests and treatment.

Outpatient clinic appointments and diagnostic tests WT

The waiting time for an outpatient clinic appointment or diagnostic test is 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 possibility in the digital booking system, to prevent coincidences influencing a realistic waiting time, for example unexpected cancellation of an appointment.³⁰¹

Treatment WT

The waiting time for treatment is calculated as follows (since 2021): First the mathematical waiting time of all booked appointments for treatment for the 2 months following the date of registration in the digital booking system is calculated. The mathematical waiting time is the number of calendar days between order date (mostly the same date of booking the appointment, but if need for appointment was detected earlier, the latter is used as order date) and appointment date. Next, the median of the total number of observations of appointments for treatment is determined in calendar days.³⁰¹ Prior to 2016 'the third possible appointment' was also used to define and calculate treatment waiting time.²⁹⁷ Between 2016 and 2021, retrospective WT was calculated (i.e. the median of all treatment waiting times (between order date and execution date) in the past 3 months).^{300, 303} It was transitory. Since 2021, the recording is again more prospective.

6.2.5. Waiting times data collection methods

The Dutch Healthcare authority (NZa) collects centrally waiting times for a **selected number of consultations, diagnostics, and treatments in medical specialised care**.³⁰¹

Each institution (hospital or independent treatment centre) has to submit every two weeks for each location an overview with waiting times for outpatient clinic visit, diagnostics and treatment to the Dutch Healthcare authority through the **portal 'Zorgbeeldportaal'**, by application programming interface (API) or Excel file. The executive board of the

institution is responsible (Personal communication). This obligation does not include urgent appointments for outpatient clinic visits, diagnostics and treatment or for repeated outpatient clinic appointments. Waiting times do not have to be provided when based on less than 5 observations. Registered waiting times are prospectively collected to come close to real time and to pick up changes quickly for outpatient clinic appointment and diagnostic tests. Until the 2021 regulation, the published waiting times could be either 'prospective' waiting times or '3-monthly averages', as long as this was specified.^{297, 300, 301, 303} There is a system with automatic reminders and (semi-)automatic quality checks. Delivering data can be legally reinforced in theory and not delivering data can result in a fine. HCPs are contacted in case of structural problems or illogical waiting times to find solutions before additional measures were taken (Personal communication).

6.2.6. Waiting times data analysis

Information system on WT for outpatient clinic appointments and diagnostic tests

On zorgkaartnederland.nl you can find per (sub)speciality consultation or diagnostics, the shortest and national average of the median WT in days. For all individual hospitals and independent treatment centres the most recent median waiting time evaluation is provided.³⁰¹

Information system on the WT for therapeutic interventions

On zorgkaartnederland.nl you can find per (sub)speciality treatment the shortest waiting time and national average of the median WT in days. For all individual hospitals and independent treatment centres the most recent median waiting time evaluation is provided.³⁰¹ From 2016 waiting times are expressed in number of calendar days (before in weeks).^{297, 300, 301, 303}

6.2.7. Waiting times data publication

Information to be provided to the citizens

Waiting times for consultation (outpatient clinic visit), diagnostics and treatment in medical specialised care are available for every citizen on www.zorgkaartnederland.nl. Shortest and median waiting times are indicated for each (sub)speciality, diagnostic test or treatment and waiting



times can be compared between all hospitals and independent treatment centres.³⁰⁰ Data is also available in other formats (Excel, API) to anyone who asks the NZA for it.

6.2.8. Targets for waiting times

Treek norms (Treeknormen)

The maximum acceptable waiting times were agreed upon by healthcare providers and health insurers during a consensus meeting in 2000 on Estate 'Den Treek'. The so-called 'treeknorm' for a consultation and diagnostics in medical specialised care is four weeks and for treatment is seven weeks.^{301, 304} The Treek norms have no clear underpinning and no distinction is made between specialties, but they are widely accepted (by public, government and patient advocacy groups).

They serve as **benchmark** for evaluation of waiting times and as informal guideline for doctors. There is no maximum waiting time guarantee. There was a court decision in 1999 stating that patients have an enforceable right to timely health care, but the maximum waiting time guarantee had to be established by case law (and there was no link with Treek norms).²⁸⁴ A maximum waiting time guarantee for hospital care, considered in 2001, was not introduced because it would increase bureaucracy and administrative burden and because it would be costly to operationalise.

The health system reform in 2006 implies contracts between hospitals and insurers. It is the responsibility of the health insurer to ensure a timeliness standard (within the limits of the 'treeknorm') for the patient.^{301, 305}

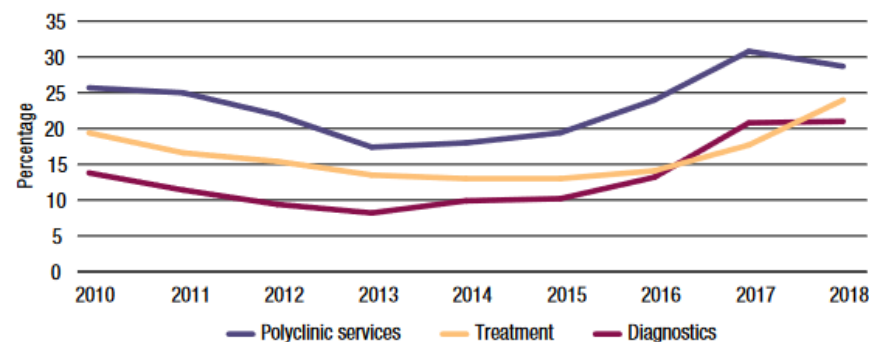
When patients consider their waiting time to be too long, they can ask their health insurer for 'waiting list mediation' to be helped more quickly in another hospital or ZBC.³⁰⁰ This works as follows: patients can contact their health insurer by phone or email, who will then investigate the willingness of the patient to travel and check in alternative hospitals or freestanding clinics, 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.²⁸⁴

6.2.9. Points of evaluation

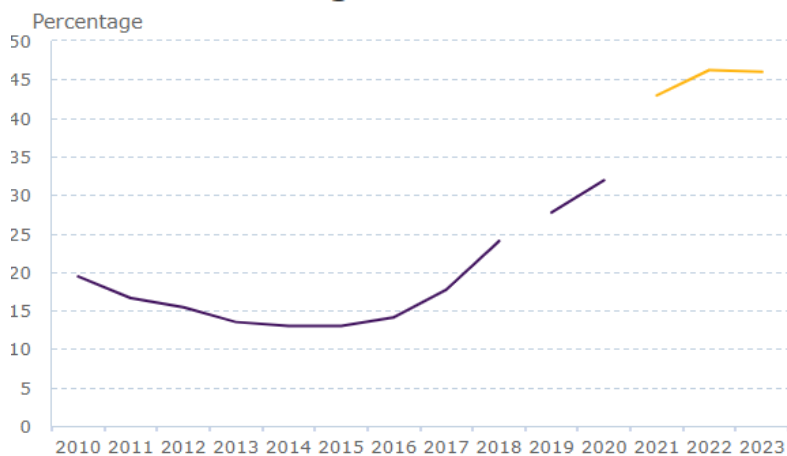
6.2.9.1. Evolution over time

Between 2013 and 2017, an increase in waiting times was noticed in The Netherlands as shown in the percentage of hospital department exceeding the WT standards (Figure 9).³⁰⁵ The evolution of percentage of WT for treatment, consultation and diagnostic procedures above WT standard (Treeknorm) can be found in Figure 10, Figure 11 and **Error! Reference source not found..** (www.staatvenz.nl)

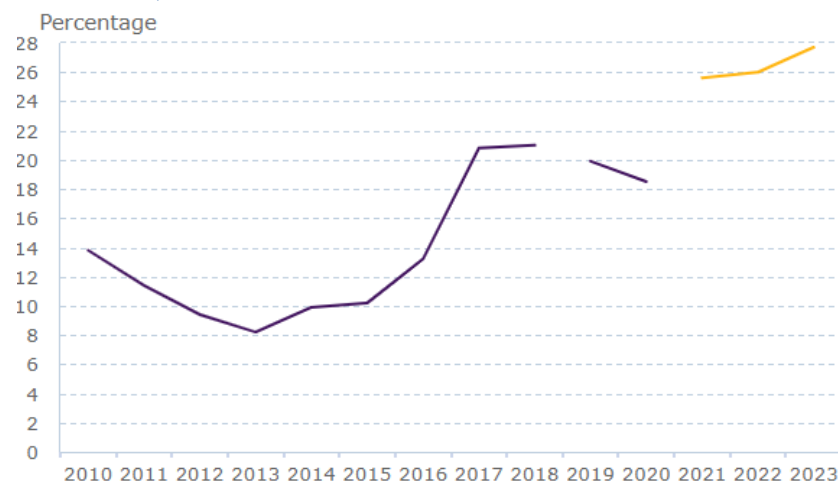
Figure 9 – Percentage of hospital departments above WT norms, 2010-2018



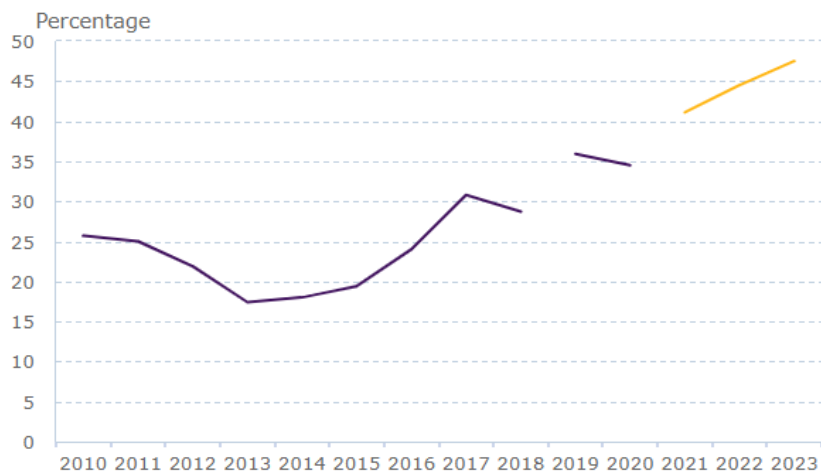
Source: OECD/World Health Organization, 2019.

**Figure 10 – Percentage WT for treatment above Treeknorm, 2010-23**

Source: <https://www.staatvenz.nl/kerncijfers/wachttijd-diagnostiek-medisch-specialistische-zorg-overschrijding-treeknorm-en-gemiddelde-wachttijd>

Figure 12 – Percentage of WT for diagnostic procedures above Treeknorm, 2010-2023

Source: <https://www.staatvenz.nl/kerncijfers/wachttijd-behandeling-medisch-specialistische-zorg-overschrijding-treeknorm-en-gemiddelde-wachttijd>

Figure 11 – Percentage of WT for consultation above Treeknorm, 2010-23

Source: <https://www.staatvenz.nl/wachttijd-poliklinisch-consult-medisch-specialistische-zorg-overschrijding-treeknorm-en-gemiddelde>



These increases are linked to several factors such as the rising demand for health care and the shortage of healthcare professionals.

In 2023, the waiting lists are so long that the duty of care is considered as under pressure (such as in 1999 according to Mierau 2023). The indirect competition strategy^u used since many years appears unable to prevent the rise of waiting lists in healthcare. Furthermore, for regulated competition to be possible, the sum of potential production capacity must exceed demand but whereas in 1999 it was still possible to attract more health care providers to make up the shortages, those people are not there now.²⁹⁶

6.2.9.2. Limitations in the data interpretation

A downside of the system is that the data **do not reflect the real waiting time**. This means that the actual waiting time of a patient can be different from the published waiting time depending on the complexity of his problem or holiday/absence of a physician.

6.2.9.3. Risk of manipulation of the data

There is a risk for institutions manipulating data (falsely low waiting times) to attract patients. And HCPs could also manipulate data for receiving more or less patients.²⁹⁶

6.2.9.4. Technical limits and administrative burden

The small institutions have more **difficulties with automatization** because they don't have the capacity in their ICT system (e.g., no link between

electronic patient record and the booking system). Institutions need **time to adjust** their ICT system. Other barriers include heterogeneity (different types of institutions with different ICT systems) and administrative burden.

6.2.9.5. Facilitators of the WT assessment

Different facilitators were identified for building a system of waiting times measurement (Personal communication). Most of them are related to the technical aspects for gathering the data:

- **Uniformity (some) of the ICT system**; there are only a few large ICT providers in the Netherlands which allows an harmonisation of the data collection;
- **Minimal effort** to collect the data (e.g., with automated system built by large ICT providers in large hospitals but also by only asking necessary information and nothing more);
- **Flexibility: Different ways to collect the data**: automated or with Excel or manual (depending on the institution with more or less advanced ICT system);
- **Simple and safe** way to provide data through a portal.

Financial rewards for providing data are forbidden; positive, motivating aspects of waiting time registration are the possibility to attract patients by lower waiting times. Umbrella organisations can help to motivate institutions for providing their data by explaining why data collection is important.

^u Providers are forced to make an attractive offer because health insurers will otherwise buy the care elsewhere. Competition is thus not directly between healthcare providers for patients, but indirectly, and regulated, through healthcare insurers.²⁹⁶



6.2.10. Tables for the application areas of WT assessment

6.2.10.1. Consultations

Specialty	Subspecialty
Paediatrics	Paediatrics – General
Paediatrics	Paediatrics – Internal medicine
Paediatrics	Paediatrics – Cardiology
Paediatrics	Paediatrics – Orthopedics
Paediatrics)	Paediatrics – Neurology
Dermatology	Dermatology – general
Dermatology	Dermatology – Oncology (suspicious spot)
ENT	ENT – General
ENT	ENT – Deafness and hearing loss
Gastro-enterology and hepatology	Gastro-enterology and hepatology – General
Neurology	Neurology -General
Neurology	Neurology – Hernia neck
Neurology	Neurology – Hernia back
Reumatology	Reumatology – General
Surgery	Surgery – General
Surgery	Surgery – Hernia inguinalis/hernia femoralis
Surgery	Surgery – Proctology
Surgery	Surgery -Breast
Surgery	Surgery – Vascular surgery
Neurosurgery	Neurosurgery – General
Neurosurgery	Neurosurgery – Hernia neck
Neurosurgery	Neurosurgery – hernia back
Orthopedics	Orthopedics -General
Orthopedics	Orthopedics – Back problems
Orthopedics	Orthopedics – Knee problems



Specialty	Subspecialty
Orthopedics	Orthopedics – Shoulder problems
Orthopedics	Orthopedics – Foot or ankle problems
Orthopedics	Orthopedics – Hip problems
Anesthesiology	Anesthesiology/pain relief
Plastic surgery	Plastic surgery – General
Plastic surgery	Plastic surgery – oncology
Internal medicine	Internal medicine – General
Internal medicine)	Internal medicine – Endocrinology
Internal medicine	Internal medicine – Immunology
Internal medicine	Internal medicine – Oncology
Internal medicine	Internal medicine – Nefrology
Internal medicine	Internal medicine – Allergology
Ophthalmology	Ophthalmology – General
Ophthalmology	Ophthalmology – Cataract
Cardiology	Cardiology – General
Geriatrics	Clinical geriatrics
Gynaecology	Gynaecology – General
Gynaecology	Gynaecology – Infertility
Gynaecology	Gynaecology – Female incontinence
Maxillofacial surgery	Maxillofacial surgery
Pneumology	Pneumology – General
Psychiatry	Psychiatry
Revalidation	Revalidation
Urology	Urology – General
Sports medicine	Sports medicine
	Sleep centres
	Transgender care

*6.2.10.2.Diagnostics*

Specialty	Diagnostic test
Gastro-enterology and hepatology	Colonoscopy
Gastro-enterology and hepatology	Gastrosocopy
Radiology	CT
Radiology	MRI brain
Radiology	MRI hip(s)/lower extremity/(ies)
Radiology	MRI neck
Radiology	MRI back
Radiology	MRI shoulder(s)/upper extremity/(ies)
Radiology	Mammography
Radiology	Ultrasound
Radiology	X-ray
Radiology	Bone densitometry DEXA
ENT/Pneumology/Neurology	Sleep apnoea diagnostics investigation / screening
ENT/Pneumology/Neurology	Sleep study / Polysomnography



6.2.10.3. Treatments

Specialty	Treatment
Surgery	Surgical treatment of hernia umbilicalis in adults
Surgery	Benign proctological surgical treatment
Surgery	Surgical treatment of hernia inguinalis/ hernia femoralis
Surgery	Removal of the gallbladder
Surgery	Bariatric surgery, gastric volume reduction
Surgery	Surgical removal of oesophagus
Surgery/plastic surgery/orthopedics	Initial surgical treatment carpal tunnel syndrome
Maxillofacial surgery	Extraction of tooth/teeth
Maxillofacial surgery	Apex resection(s)
Ophthalmology	Eyelid surgery
Ophthalmology	Initial cataract surgery
Orthopedics/Neurosurgery	Surgical treatment hernia nuclei pulposi/canal stenosis
Orthopedics/Neurosurgery	spondylodesis surgery on the spine other than for treatment of nuclei pulposi hernia/canal stenosis
Neurosurgery	Neurolysis peripheral nerve, including carpal tunnel syndrome
Orthopedics	Initial total hip replacement
Orthopedics	Diagnostic and/or therapeutic keyhole surgery knee
Orthopedics	Initial total knee replacement
Orthopedics / Surgery	Surgical treatment of meniscus and/or knee ligaments (no fresh injury, excluding arthroscopic treatment)
Plastic surgery	Triggerfinger release



Plastic surgery	Surgical treatment of Dupuytren's contracture
Plastic surgery	Surgical breast reconstruction
Rehabilitation medicine	Cardiac rehabilitation
Rehabilitation medicine	Rehabilitation after stroke
Rehabilitation medicine	Pulmonary rehabilitation
Urology	Lithotripsy kidney stones
Urology	Percutaneous kidney stone removal
Urology	Surgical treatment for enlarged prostate
Urology	Surgical treatment urinary incontinence and/or bladder prolapse in man
Urology	Surgical treatment for prostate carcinoma
Urology/ Surgery	Male sterilization as an independent operation
Urology/ Surgery	Circumcision as an independent operation
Cardiology	Ablation
Cardiopulmonal surgery	Bypass surgery as an independent operation
Cardiology	Heart catheterisation
Cardiology	Angioplasty
Gynaecology	IUI
Gynaecology	IVF/ICSI
Gynaecology	Isolated uterine removal
Gynaecology	Surgical treatment urinary incontinence and/or prolapse in woman
Gynaecology	Female sterilization as an independent operation



Surgery	(Vascular) surgical treatment varicose veins
Dermatology / Surgery	Treatment varicose veins (endovascular procedure)
Dermatology	Mohs surgery
ENT	Tonsillectomy and/or adenotomy
ENT	Primary surgical treatment of anomalies of nasal septum
ENT	Placing middle ear tubes

Are there any consequences if the waiting times are not submitted?

If a healthcare provider structurally refrains from submitting the waiting times, we contact them to discuss any problems. As much as possible, we put our effort in resolving problems in consultation with healthcare providers,

before we proceed to additional measures. Ultimately, there can be consequences. For more information we refer you to the Informatiekaart Informatiekaart Toezichtmaatregelen en instrumenten. We only have this information available in Dutch



7. APPENDIX VII – EXPERIENCES FROM SWEDEN (SE)

7.1. Health system at a glance

7.1.1. Healthcare organisation

The Swedish health care system is based on three principles: the principle of dignity, which gives access to the health care system regardless of a person's status in the community; the principle of need and solidarity, which ensures that priority is given to those who are most in need of health and medical care; and the principle of cost-effectiveness, which means choosing health care interventions that offer the best health outcomes and quality of life at the lowest cost.³⁰⁶ The principles are ranked and the cost-effectiveness principle is subordinate to the other principles (Personal communication).

Swedish health care is largely **publicly funded**, with the same financing model and low equivalent patient fees for public and private care providers.^{307, 308}

In Sweden, the care is organised at three levels: the national, regional (county councils), and local levels (municipality). The Swedish healthcare system is characterised by a high degree of **decentralisation**. The **national level** is responsible for the overall healthcare policy i.e. regulation and supervision of the health system. The **regions** are responsible for managing the largest part of health and medical care by working to promote health, prevent, investigate and treat illnesses and injuries. There is also collaboration in the form of six healthcare regions, where they agree on price lists and where special specialties should be located. All healthcare regions have at least one regional hospital. ([Division of responsibilities, medical care | SKR](#)) The 21 **regions** are responsible for financing, purchasing, and providing health services in primary care, secondary care including hospitals. Environmental hygiene, care for the elderly and people with

disabilities, rehabilitation services, long-term psychiatric care, home care, and nursing homes are the responsibility of the 290 local municipalities.³⁰⁶

GPs mainly provide care in team-based facilities which usually include 4 to 6 GPs but may also include nurses, midwives, physiotherapists, psychologists, or gynaecologists. In 2023, there were 1 100 public and private primary care units.³⁰⁶ Patients must be registered with a primary care practice accredited by the local council.^v Since the health care reform “Freedom of choice” in 2009, people are free to choose provider of care they want. GPs do not have a formal gatekeeping role in most regions; patients are often free to contact specialists in outpatient care, but there are also different referral rules. They have a free choice of care and can be transferred (by the county council) to other regions if the waiting time exceeds the legal guarantee of care in their own region.³⁰⁹ Specialised clinics in Sweden are single-specialty, for example urology, psychiatry, paediatrics, ophthalmology and otorhinolaryngology.³⁰⁷ Hospitals are organised in regional networks and are mainly publicly owned. Since the 1990s, there has been a shift from hospital inpatient care to outpatient care at hospitals and primary care settings.³⁰⁶

The sources of funding for health care are mainly based on taxes at national level (employers' payroll taxes) and at local level (income taxes).³⁰⁶ In 2022, Sweden spent 10.7% of its GDP on health care. In 2021, expenditure covered by government or compulsory health insurance reached 85.9%. and A part of the population in Sweden have private health insurance that is covered by their employer or bought independently from their private insurance company. These private health insurances are completely separated from the rest of the health care system that is publicly funded. The presence of a private health insurance does not affect access to or treatment in the public health care sector (Personal communication) According to the OECD, 7% of the population had duplicate (Time/choice) private health insurance.²⁴⁴

^v But people who are not registered with a certain practice are not denied.



7.1.2. Healthcare resources

Sweden is characterised by a low density of GPs^w, with 0.61 GPs per 1 000 inhabitants in 2020.²⁴⁴ To address the low supply of GPs, Sweden has organised nurse consultations with advanced practice nurses and specialist nurses some of whom can prescribe some medicines.³¹⁰ The density of specialists is more than three times higher with a density of 2.21 per 1 000 inhabitants in 2020.²⁴⁴

In the same year, the density of practising midwives was 68.9 per 1 000 live births. The health workforce also included 10.7 practising nurses, 0.8 practising dentists, 0.8 practising pharmacists, and 1.3 practising physiotherapists per 1 000 inhabitants.²⁴⁷

Currently, in 2023, there are 7 university hospitals with the most advanced technical equipment. There are also around 70 public hospitals and 6 private hospitals.³¹⁰

The number of hospital beds was 2.0/1000 inhabitant in 2021.²⁴⁵

According to OECD provisional data, there are 23 computed tomography (CT) scanners, 17.5 magnetic resonance imaging (MRI) units, 12.3 mammography machines and 5.8 radiography equipment per 10⁶ inhabitants in 2022.²⁴⁵

7.1.3. Health status

Life expectancy at birth in Sweden is one of the highest in Europe reaching 83.1 in 2021.²⁴⁷ In 2020, there was a temporary decrease of 0.8 years due to the COVID-19 pandemic but with a quick return one year later to its pre-pandemic level.³¹¹

The most recent data on avoidable mortality from preventable and treatable causes (standardised rate) dates from 2018 and are evaluated at 150 per 100 000 population.^{244,247}

7.2. Waiting times

7.2.1. Legal framework

Since the 1990s, Sweden has implemented various forms of guaranteed waiting times to improve access to care for the population.

The current form of guarantee was developed in 2005 and has been incorporated into the Health and Medical Services Act in 2010.³⁰⁶ The waiting time guarantee was originally based on the '0-7-90-90' rule, although changed to a '0-3-90-90' rule since 1st January 2019. This WT guarantee rule stipulates that contact with primary care should be offered the same day of the request, a medical assessment should be performed within three days after the contact with primary care, when relevant a visit the specialised care should be scheduled after the (self-) referral and treatment should be planned within 90 days after the decision to treat (see Figure 13).

There is an obligation for data reporting as mentioned in the Health and Medical care Act, chapter 9 (2017:30)³¹² and for maximum WT as defined in the "Health and healthcare regulation" (2017:80), chapter 6.³¹³

The Health Care Ordinance Chapter 6 §3 states that the regions (county councils) are obliged to report on waiting times by submitting information on waiting times to the "National waiting time database" maintained by The Swedish Association of Local Authorities and Regions (SALAR). SALAR is an employers' organisation that represents and advocates local government in Sweden. According to a regulation (2019:1118), SALAR is tasked with providing the national waiting time database that must exist according to the Health and Medical Care Act (Chapter 9 §3). Thus, SALAR are currently responsible for the organisation and collection of data concerning waiting times from the regions.

There is a national investment for supporting WT care guarantee within the performance-based compensation implemented in Sweden in 2009-2014 and re-introduced in 2019. In this model, regions (county councils) can receive additional funds if they met different targets in WT in specialised and

^w GP are graduated after a minimum of 5-year training



primary care. The regions would improve their results compared to the previous year.³¹⁴

There are performance requirements also for improving waiting time statistics. The regions would submit one regional action plan, including comprehensive regional objectives for waiting times and care queues, as well as a description of how the region worked and strategically intended to work on improving accessibility. In addition, the regions would continue to work on developing the reporting of waiting time statistics (according to the appropriate guidelines and procedures and following the regulations that can be found in the health care regulation).³¹⁴

There is an obligation to inform patients about the waiting time guarantee and the options available in accordance with the Patient Act (2014:821)³¹⁵ and the Health and Medical Care Act (2017:30)³¹². Furthermore, patients have the right to receive personalized information, i.e., the information must be adapted to the recipient's age, maturity, experience, linguistic background, and other individual conditions.³⁰⁸

7.2.2. Purpose of waiting times data collection

The purpose of measuring waiting times is multiple:³⁰⁶

- To guide the choice of healthcare provider (empowering the patient)
- To improve accessibility by guiding patients in their choice of where to seek elective care
- To follow up on the care guarantee and ensure equal access to elective care across the country.

7.2.3. Application areas of waiting times assessment

In Sweden, assessment of waiting time is available in four areas:

- **Waiting times for primary care:** two WT are assessed (first contact and first assessment)
- **Waiting times for specialised care:** care provided by health care providers specialised in areas other than general. This covers WT for assessment and WT for treatment or intervention. Type of specialities

can be the following: allergology, general internal medicine, general surgery, general psychiatry, paediatric and adolescent medicine, paediatric and adolescent psychiatry, oncology, endocrinology, geriatrics, hand surgery, haematology, dermatology, infectious diseases, cardiology, gynaecology, pneumology, gastroenterology, neurosurgery, nephrology, orthopaedics, plastic surgery, rehabilitation medicine, rheumatology, specialised pain management, dentistry, urology, ophthalmology, otolaryngology. **Waiting times for child and adolescent psychiatry are specifically addressed** (see Section 7.2.8.).

- **Waiting times in emergency department** (out-of-scope of this study)
- **Other WT in specific regions such as waiting times for imaging, functional medicine and clinical neurophysiology³¹⁶ or Cancer WT.**

7.2.4. Definition of waiting times

Waiting times for first contact with primary care (i.e. the 0 day between the patient call and the first contact with the primary care service).

Waiting times for assessment by a primary care provider (i.e. GP, specialist nurse or advanced practice nurse). This WT starts with the date of first contact and ends the date of medical assessment by a primary care provider. This encompasses the total number of completed visits, but also the distribution between different types of visits, such as (consultation, remote visits, home visits, telephone/letter contact).

Waiting times for specialist assessment covers the difference between the date of medical assessment by a primary care provider and the date of assessment by a specialist.

Waiting times for specialised treatment or intervention covers the difference between the date when the decision is made that the treatment or intervention should be done and the date of treatment or intervention.

Waiting times for imaging, functional medicine and clinical neurophysiology. This is not regulated by law but collected by some regions.



7.2.5. *Waiting times data collection methods*

As mentioned in the Health and Medical Care Act, chapter 9 (2017:30), the regions must report data on waiting times to a national database. (Law (2019:973)) The National Board of Health and Welfare may issue further regulations on the regions' reporting obligation. Ordinance (2019:1118). However, there are no sanctions if database is not completed (Personal communication). It's rather an incentive for the regions to provide care according to the guaranteed waiting time limits since they will receive a payment depending on to what degree they provide care within the guaranteed waiting time limits (Personal communication).

The **National waiting time database** was started around 2008, in order to be able to follow up and reimburse the performance program (P4P) 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. that allows for more analyses. But still, the core of the database is that it is built around the law (Personal communication).

The National waiting time database is based on data extracted automatically from electronic records, aggregated and transferred to region through an online platform.³⁰⁷ The process starts with healthcare professionals planning the care and documenting in the patient's medical record (the healthcare provider's healthcare information system). A data transfer takes place from the healthcare information system to the region's data warehouse. Some data items are still reported manually (e.g. care not linked to maximum waiting time such as when patients actively choose to wait longer).

After that, the data is processed by the region for onward transfer to the national waiting time database. Each month, all 21 regions send their WT data in primary and specialised care to the national database maintained by the Swedish Association of Local Authorities and Regions (SALAR). For specialised care, waiting time data is assessed in public hospitals. Private hospital or specialised clinics recognised by the region report data on waiting time only if right conditions to report the requested data are met (Personal communication).

Data is retrospective (the regions report the previous month's data) and the database contains large amounts of information about appointments and waiting times in healthcare. Every year, around 20 million contacts are reported in primary health care and the same number in specialised care. The regions own the data and are data controllers. The SALAR provides the database and is a personal data processor, on behalf of the regions. The database does not contain any information about individuals that can be identified, but there is information that is classified as personal data according to GDPR, such as gender and age. All data items in the national waiting time database is anonymised.

In the Accessibility Agreement between the Government and the SALAR, funds have been allocated to test, quality assure and develop the database to create the conditions for the development and improvement of the accessibility of health and medical care. On the basis of these agreements, the regions decide which data they will report to the national WT database.³¹⁷

The regions are responsible for quality and should make sure it is correct by verifying their data in Qlikview before its published. However there is no system to check if it is the reality (Personal communication).

There is another reporting system used in Stockholm for specialised care and named the supply service database. This prospective database includes clinics' self-reported estimations of short-term future waiting times for elective surgery.³⁰⁷ The purpose of this database is to give a picture of where there is free capacity or where waiting times are shorter (e.g., a median four-week waiting time for cholecystectomy). It was used to refer patients to care units with the shorter waiting time.³⁰⁷ This is a way to measure waiting times indirectly, but perhaps more importantly it may be a way for patients (or care givers) to decide where they can have their care with decent waiting times. This information can be found on the skr.se website.³⁰⁹ Furthermore, there is a current initiative going on at the national level where the Swedish eHealth Agency is mandated (by the government) to see if it is possible to set up a national system where all regions will be able to see free capacity in other parts of the country (Personal communication).



The Swedish Association of Local Authorities and Regions collects also waiting time data through the National Health Care Barometer Survey and the National Patient Surveys.³⁰⁶

7.2.6. *Waiting times data analysis*

In the national waiting time database maintained by the SALAR, samples and calculations are made by tool called Qlikview.³¹⁸

Waiting times for primary care

Under the National Care Guarantee, every caller should contact the health centre for same-day advice and/or an appointment (the so-called 'rule 0'). The 'rule 0' indicator is the proportion of patients who were able to make telephone or physical contact with the health centre on the same day of the initial call. The indicator for assessing the 'zero delay' rule (or direct access to the health system for consultation) is the proportion of patients who are contacted on the same day after making a request to a primary care practice by telephone, digital channels or physical visit.

This indicator is available for the country as a whole, for a region, for a type of practice (private versus public), for a specific year or period (autumn / spring). In autumn 2022, 83% of the people have been able to contacted by telephone or to access primary care for a visit within 0 days.³¹⁹

A person who contacts primary care with a new or worsening health problem is entitled to a medical assessment within 3 days. The assessment must be carried out by a primary care provider (see above). The indicator is the proportion of patients getting an assessment within 3 days. This indicator is available at the national level, but also by region, type of practice (private/public), gender, type of care provider, and type of contact, for a given year or month. The following care providers are considered for this indicator: occupational therapist, audiologist, midwife, dietician, physiotherapist, chiropractor, speech therapist, doctor, optician, psychologist, nurse. The considered types of contact are consultation, home

consultation, remote visit, telephone or mail contact. By February 2023, 86% of people have received a medical assessment by a primary care provider within 3 days.

Waiting times for specialised care

Waiting times for specialised care are analysed according to two groups of patients^{x,320}

- Those who have received the activity they were waiting for such as an appointment for a first consultation, a surgery/a healthcare intervention or an investigation (procedure completed). The waiting time is calculated from the time the caregiver makes the decision to perform an activity to the time the patient receives an activity.
- Those still waiting for an appointment for a first consultation, a surgery/a healthcare intervention or an investigation (procedure still on hold or pending WT). The pending waiting time is calculated from the time the care provider decides to carry out a procedure or an intervention until the time of recording, i.e. the last day of each month.

These are two different ways to look at the waiting times which complement each other. Both are important (Personal communication).

For the two patient groups, indicators such as the percentage and number of contacts within 30, 60, 90 days, mean and median waiting time (in days) are reported. Another last indicator is the ability to manage patients from other health care providers.

These indicators are reported by age group, gender, region, hospital/clinics, type of practice (private/public), place of care (outpatient/hospital), type of professional, type of contact, and type of care for a given year or month.

The professionals considered in the data analysis^y are for example: occupational therapist, audiologist, midwife, dietician, physiotherapist,

^x On vantetider.se, there are also a third types of waiting times: the current waiting time – an estimate of how long the patient's waiting time will be. The waiting time is based on an estimate of each reporting unit. The device reports manually on a monthly basis.

^y A patient can meet certain professionals, e.g. a dietician, in both primary and specialised care.



chiropractor, speech therapist, doctor, optician, orthoptist, psychologist, nurse, assistant nurse.

The considered types of contact are consultation in an outpatient clinic, home visit, remote visit, and telephone or mail contact.

Waiting times for child and adolescent psychiatry³²¹

Waiting times in child and adolescent psychiatry are assessed for made and pending first contacts.

For each group of contacts, the percentage of patients receiving or waiting for a first visit, assessment or treatment within 30 days is reported by region, gender, hospital or type of visit (visit, remote visit, home visit, telephone or postal contact) for a given year or month.

Average waiting time between telephone access and medical assessment or between telephone access and first-line assessment for children and young people with mental health problems are available by health centre, by region or at the national level.³²²

Waiting times in emergency department³²³

Emergency care is defined as care requiring immediate attention from health and medical services. A national target is that the patient is assessed within one hour and stays in the emergency department for a maximum of four hours.

Three indicators are available and collected monthly:

- Percentage of patients arriving and being discharged from emergency departments within four hours
- Percentage of patients assessed within 1 hour
- Percentage of patients with a ED stay of maximum 4 hours

These indicators are reported by age group, gender, region, type of practice (private/public), place of care (outpatient/hospital), type of professional, type of contact, and type of care for a given year or month.

Indicators are available by day of week, time of day (morning, afternoon, evening and night), region, hospital/clinic, sector (private/public), age group, gender and specialty.

A large number of missing data is observed.

Waiting times for imaging, functional medicine and clinical neurophysiology³¹⁶

Median waiting times, the proportion of patients waiting 30 days or less, 60 days or less or 90 days or less are reported for computerised tomography (CT), magnetic resonance imaging (MRI), carotid ultrasound and heart ultrasound, PET CT, myocardial scintigraphy, stress ECG, exercise ECG, Holter ECG, spirometry, EEG, and electromyography (EMG).

These indicators are available by region and gender for a given year or month.

7.2.7. Waiting times data publication

Every month, statistics (on primary and specialised care) are displayed on the SALAR website vantetider.se. The national waiting time database and the website vantetider.se make it possible for decision-makers and those working in healthcare to constantly monitor how many people are waiting for different types of care and how many care visits are carried out.³¹⁷

The regions and the healthcare providers that report to the national waiting time database have the opportunity to access the analysis tool QlikView. In the analysis tool, users can analyze their waiting time statistics in more depth than is possible on vantetider.se.³¹⁷

The data is usually provided as the amount and percentage that have received care and for those still waiting (Personal communication).

Available statistics are:

- Patients' waiting times for a range of procedures in primary health care and specialised care, broken down by gender and age groups.
- A compiled overview of the availability of different specialties.



- The waiting time at different healthcare providers in a particular specialty.
- Free capacity that shows whether it is possible for regions to receive patients from other healthcare providers.
- The actual waiting time for the patient (mean and median).
- Summary of completed visits/measures within the framework of the care guarantee.
- Which professional category received the visit.
- The form in which the visit took place (traditional appointment, home visit, telephone contact or through a digital visit).³¹⁷

Waiting times in healthcare is primarily aimed at decision-makers and practitioners in health care but is open to everyone.³¹⁷ Patients and other stakeholders can also have access to report extraction on WT in the SRK web site.³⁰⁷

Data from the **supply service database** (used only in Stockholm) is presented through an online platform for care providers and administrative management.³⁰⁷

There is no annual report on WT in Sweden. The government sometimes gave a public agency, such as the Swedish Agency for Health and Care Services Analysis and the National Board of Health and Welfare, a specific task to produce a national report (including statistics but also analyses). This was done per year between 2010-2017. However, this is no more the case maybe because these reports were quite similar every year – long waiting times and nothing got better. The website is the main place for the statistics, as much quicker and with more up to date results (Personal communication).

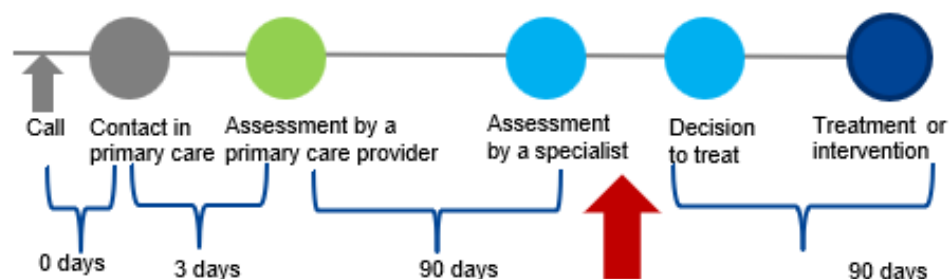
Some [National Quality Registries](#) contain information about specific waiting times measured in certain regions (such as for cancer).

7.2.8. Targets for waiting times

As mentioned in the legal framework, the waiting time guarantee was based in Sweden on the '0-7-90-90' rule. However, since 1 January 2019, 7 was changed to 3 and the "content of 3" was changed from physician appointment to medical assessment by physician or other authorized personnel. According to the Chapter 9 Section 1 of the Health Care Act (2017:30)³¹², the individual must have:

8. Contact (phone call or visit) with primary care on the same day that the individual seeks contact with primary care (guarantee of availability). This rule provides for direct access to the health system with a phone contact, or visit (zero delay).
9. Medical assessment by a GP or other health care provider within primary care within three days of the individual seeking contact with primary care, if the care provider has assessed that the individual needs a medical assessment and such cannot be done when the individual first seeks contact (assessment guarantee within primary care),
10. Assessment by a specialist within 90 days (visit guarantee within the specialised care) with two possible starting point³⁰⁸ : from referral or from the day when the person self takes contact with specialist clinic in cases when possible (so called self-referral).
11. Planned care within 90 days from when the care provider has decided that the individual should receive the care in question (treatment guarantee). Ordinance (2018:1129).

The WT guarantee in specialised care does not include all parts of the care chain: time between the assessment by a specialist and the decision-to-treat which encompasses investigations, controls, re-visits, follow-ups are not included (Personal communication). This is shown by the red arrow in the Figure 13

**Figure 13 – Waiting time targets in primary and specialised care**

Exceptions from maximum target can be made on medical grounds known as medically motivated waiting (e.g., when a complicating co-morbidity temporarily prohibits a planned elective treatment) or when patients actively choose to wait longer (e.g., if the patient declines a booking or a certain professional) or if the patient chooses to change care provider for the same health problem.³⁰⁸ In these cases, the waiting time episode is assigned a label known as an exception code. This means that there is no time limit in, or monitoring of, the waiting time.³⁰⁷

Regional health care providers can have local policies for even shorter waiting times.^{307,308} In the Stockholm Region for example, there is a target of maximum waiting time of 30 days (instead of 90) for appointments (measured from decision to refer to a specialist to the first appointment), and 90 days for treatments in specialist care (measured from the decision to treat to the actual treatment).^{307,308}

Furthermore, the waiting time guarantee defined by the law has been extended over time. For example, there is also information about WT for imaging, functional medicine and clinical neurophysiology or waiting times specifically for cancer.³²⁴

As mentioned in the Health care Act, chapter 9 (2017:30)³¹², § 2, if the region does not fulfill the guarantee according to § 1 3 or 4, the region must ensure that the patient receives care from another care provider at no extra cost to the patient. Law (2019:973).

It varies between regions how they work to help patients to find another provider if the waiting time is too long. In Stockholm for example, activities in specialised care that cannot maintain the time limits of the waiting time guarantee are reported to the specialist clinic's contract administrator through a computerized system.³⁰⁸ A specific regional support function, (e.g. Region Stockholm's Care Guarantee Office), helps patients change care providers when long waiting times occurred.³⁰⁸

There are no national sanctions for health care providers, hospitals or clinics when the waiting time guarantee is not met. It is up to each region to decide if they want to define sanction. Some of them such as Stockholm had it but now if this still exists it is rare (Personal communication). 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 (Personal communication)

Patients who want avoid any waiting list can also access a private provider and pay for treatment out of pocket or through a voluntary health insurance plan (but few people have one) (Personal communication).



7.2.9. Points of evaluation

7.2.9.1. Heterogeneity between regions, clinics and professionals

The 21 regions 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, and they are not interconnected. Sweden is working to create a national digital infrastructure but this is not decided yet. In principle, decision on what must be collected must be taken on a national level (all regions together), and then all regions have to figure out how to do that in their own systems. This means that there may be difficulties to find the same starting points, etc. – because it depends on what the system allows.

Furthermore, great variance in waiting times data is observed between clinics for the same medical service and between professionals at the same clinics.³⁰⁷ There are also some local policies providing by regional health care providers for even shorter waiting times than the national legal ones which leads to variation between Swedish regions.

7.2.9.2. Low validity and usefulness of registry

One survey among administrative management (n = 11) and care professionals (n = 17) interviewed between October 2017 and January 2018 shows several challenges regarding the WT assessment in the region of Stockholm.³⁰⁷ The validity and usefulness of the regional system is generally perceived as low by the respondents who mentioned slow and insufficient feedback on results, lower value of the findings since they are presented as numbers and percentages of patients not receiving care within the WT guarantee instead of mean values for waiting times (more useful in production planning and auditing^z), insufficient granularity of the medical conditions and exception codes...³⁰⁷ For example, two units had developed an additional manual system to collect WT data in parallel with the registry because the last one was considered as too slow and insufficient to

understand the WT situation. There are also structural barriers to validity (technical errors, procedural errors or errors in data caused by role divisions between actors and self-perceived/explicit job descriptions) and cognitive barriers to validity (misinterpretations of guidelines in terms of how to enter data^{aa}, situations not covered by guidelines or conscious sidestepping of guidelines such as using medically unnecessary revisit as starting date). All these concerns are important because as shown by Ebbevi et al. in the

Figure 14, “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”.³⁰⁷

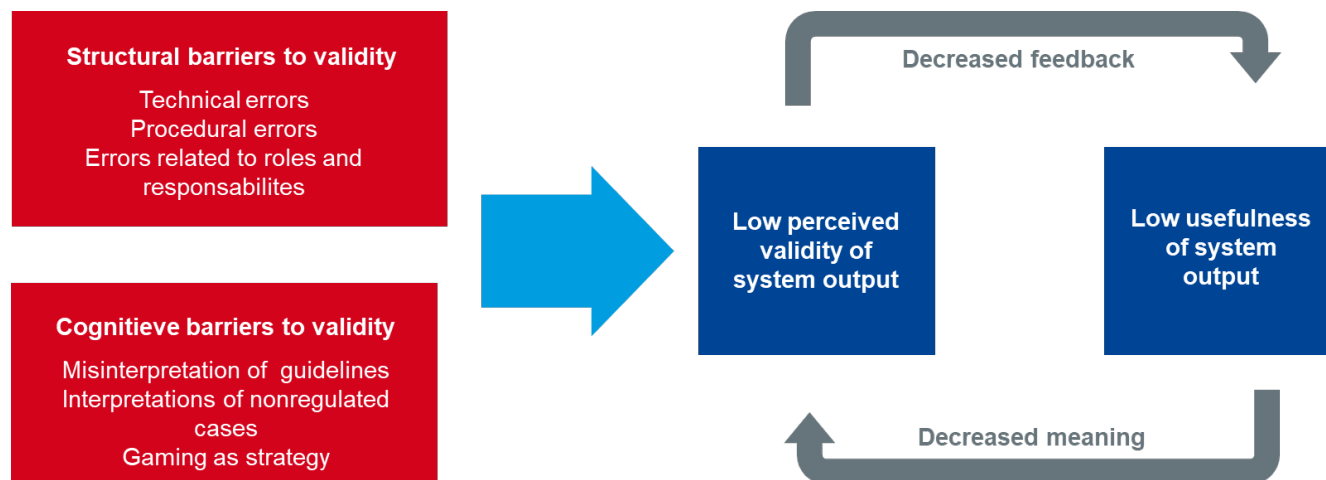
^z Currently, median and mean waiting times are also published.

^{aa} With sometimes different starting date in treatments used in the same unit (referral date or medical pre-examination instead of the decision date)



Figure 14 – Interrelation of the themes according to Ebbevi et al.³⁰⁷

Subtheme self-reinforcing validity and usefulness is represented as decreased feedback & measuring.



Source: Ebbevi et al.³⁰⁷ Challenges to ensuring valid and useful waiting time monitoring - a qualitative study in Swedish specialist care. *BMC Health Serv Res.* 2021;21(1):1024.

Quality problems in the data are known and were pointed at that many times and many years in Sweden. At macro levels, it is quite acceptable but at a more micro level, e.g. a single clinic, the errors impact can be more problematic (Personal communication).

Some problems are in the IT-systems but as more and more information can be extracted automatically, there is improvement with time (Personal communication).

Other problems are related to the fact that people does not fill in and send in correct information. The set-up is that each region is responsible for their own information; they should make sure information is correct before it comes to the national database at SALAR. SALAR does not do any quality check but leaves that to the regions (which perhaps don't do that all the times). In general, some more quality check would be needed. However, it may be important to know that Stockholm is different from other regions

because they have a clear buyer-provider-model. It means that the central region gives a lot of responsibility to the providers and governs a lot through contracts. It varies, but other regions have more direct control and are also smaller, which may possibly make this thing easier in other places than Stockholm (Personal communication).

7.2.9.3. Inconsistent patient' information on WT guarantee

Since several years, there is a concern in Sweden 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.³⁰⁸ Soft-law regulations and care contracts seem insufficient, and economic mechanisms undermine



care providers' willingness to inform patients^{bb}. There is also a lack of established routine to assist care providers in informing patients.³⁰⁸

7.2.9.4. *Potential inequity*

Even if it is against local law, it is not uncommon for health care providers to make some patients responsible for finding a new provider or arranging a new referral if the waiting time exceeds the guarantee. Finding appropriate information is not easy, even through a digital platform that displays waiting times, and this process is seen as a risk of exacerbating inequalities in health care.³⁰⁸ Furthermore, if the system does not display all relevant health care quality indicators, it may not help patients achieve good health, but only short waiting times. Patients with low health literacy will still need guidance from the health professional in interpreting the health care quality indicators displayed. In such situations, the general practitioner may be best placed to inform patients at the time of referral.³⁰⁸

^{bb} 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 incomes.³⁰⁸

8. APPENDIX VIII – EXPERIENCES FROM THE UNITED KINGDOM (UK)

8.1. Health system at a glance

8.1.1. *Healthcare organisation*

The 1946 Act required the Secretary of State for Health in the United Kingdom to provide a **comprehensive, free health service** to replace voluntary insurance and out-of-pocket payments. (Hit 2022 total) Since the late 1990s, the organisation and delivery of health services has been a devolved matter, with the devolved governments in Wales, Northern Ireland and Scotland organising and funding their own health and care services. Health policy in England has remained the responsibility of the UK Government and UK Parliament. As a result, there are four National Health Services (NHS): NHS England, NHS Scotland, NHS Wales and Health and Social Care in Northern Ireland. While each government is responsible for health legislation, each NHS has the day-to-day responsibilities such as managing the budget, overseeing and allocating funding to the bodies that manage and pay for care delivery at the local level. All four nations share the same principle of providing health services free at the point of use.³²⁵ A key feature of the NHS is that **access is based on clinical need rather than ability to pay**.³²⁶ In England and Northern Ireland, NHS-owned hospitals are called trusts.³²⁵

In recent years, total health spending in the UK has increased, both as a percentage of GDP and as public spending on health per capita. In 2022, health spending was 11.3% of GDP.²⁴⁴ Another figure is that about £1 in every £5 of government spending goes on health. The majority of health funding comes from public sources of revenue raised through general taxation; the three largest taxes are income tax, national insurance contributions and VAT. The proportion of public funding for health is about



80% and private health spending accounts for about 20% (private insurance and out-of-pocket payments).³²⁶

The NHS is universal (100% coverage) in the four nations: all UK residents have access to (mostly) free public health care. The services provided by the NHS include preventive care (screening, immunisation), inpatient and outpatient hospital care and medicines, primary care, maternity care, mental health care, palliative care, etc.³²⁷ Co-payments exist for some goods or services provided by the NHS (e.g. outpatient medicines in England) and direct payments for services not covered by the NHS/private treatment. There is no general cap on cost-sharing, but some prepaid certificates can be bought for unlimited use and some groups of patients are exempt from payment. In 2019, out-of-pocket expenditure by households accounted for 17% of total expenditure in the UK.³²⁶ In 2021, 11% of the UK population had voluntary private insurance, which accounted for 2% of total health expenditure.²⁴⁴ This private insurance allows for quicker access to care and better amenities, for example for elective inpatient procedures.

Primary care is mainly provided by GPs: they act as gatekeepers and people can register with a local practice of their choice as their first point of contact. GPs work under the General Medical Services contracts. These contracts are negotiated between the NHS and doctors' representatives (the British Medical Association), and are for practices rather than individual providers. GPs are paid predominantly through risk-adjusted capitation for essential services, but also through some fee-for-service activities (mostly based on a pay-for-performance model).

Outpatient specialist care is provided by referral from a GP. Most outpatient specialist care is provided in hospitals³²⁷, at nationally set rates; many NHS clinics have satellite clinics to provide care closer to patients. Doctors are salaried and paid with top-up payments to incentivise performance.³²⁷

Most hospitals are public. In England, they are paid based on the activity (upon tariffs set at national level); blended payments are gradually being introduced (the system is currently being reformed to introduce a combination of blended payments, consisting of a fixed budget and pay-for-performance). In Scotland, Wales and Northern Ireland, block contracts

(payment made to a provider to deliver a specific, usually broadly defined service) are the main payment system.³²⁶

Private hospitals (for-profit and not-for-profit) provide a range of services, some of which are the same as to those provided by the NHS (although some services are provided only by the NHS, such as emergency care^{cc}); for some elective care, these hospitals may also provide care to NHS patients under contractual arrangements. Private hospitals are free to charge patients without regulation and they receive no public funding.³²⁷

8.1.2. Healthcare

In 2021, the density of general practitioners and practising specialists was 0.8 and 2.4 per 1 000 population, respectively, and the density of practising nurses was 6.9 nurses per 1 000 population. Other health professionals were 0.5 licensed dentists (2019), 0.9 practising pharmacists (2019), 0.5 practising physiotherapists (2018) per 1 000 population, and 52.3 midwives licensed to practice per 1000 live births.²⁴⁷ The United Kingdom has around 1996 public hospitals, including 802 general hospitals (i.e. 11.9 hospitals per million inhabitants), and the density of somatic beds was 2.1 beds per 1 000 inhabitants in 2021.²⁴⁷ In the same year, there were 10.0 CT scanners, 8.6 MRI scanners, 0.5 PET scanners, and 4.7 gamma cameras (data not available for radiation therapy machines) per million inhabitants in hospitals. In 2021, there were about 11.2 mammography units per million inhabitants.²⁴⁷

8.1.3. Health status

In the years 2011-2019, the life expectancy at birth increased from 81 to 81.4y. In 2020, with the COVID crisis, the life expectancy at birth fell to 80.4y, lower than in 2010. Data for 2021 and 2022 are not yet available, so it is not possible to verify the evolution of life expectancy.²⁴⁷ Between 2010 and 2019, the avoidable mortality from preventable and treatable causes decreases steadily (221-194 deaths per 100 000 inhabitants), but in 2021 it

^{cc} Except some private walk-in urgent care centres (Private Urgent Care Centres in London <https://www.hcahealthcare.co.uk/our-services/urgent-care>)



rises again to a level similar to that of 2010 (222 deaths per 100 000 inhabitants).²⁴⁷

8.2. Waiting times in the NHS England

8.2.1. Legal framework

Under the NHS Constitution for England published in March 2012 (last updated 17 August 2023), patients have the right to access certain NHS-commissioned services **within maximum waiting times (standards)**.³²⁸ If this is not possible, the NHS has a duty to provide **appropriate alternatives**.³²⁹ These waiting times are described in the Handbook to the NHS Constitution.³³⁰ A guidance published in October 2022 focuses on the referral to treatment (RTT) data,³³¹ which is used to monitor NHS WT performance against the standards set out in the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012. This guidance aims to provide a framework for the NHS to work within to make clinically sound decisions locally about applying them, in consultation between clinicians, providers, commissioners and patients.³³¹ Monthly RTT WT data has been published since March 2007.³³²

The Department of Health and Social Care introduced voluntary collection of Allied Health professional referral to treatment period waiting time information from April 2010, and mandatory collection from April 2011.³³³

During several years, providers failing to deliver on a national performance target received financial penalties. However, due to the financial challenges faced by many NHS Trusts, fines were gradually withdrawn for certain standards. In 2015/16, to incentivise providers to meet waiting time standards, trusts were required to submit monthly performance trajectories against a number of maximum waiting time standards (see Section 8.2.8.) in order to receive funding from the new 'Sustainability and transformation Fund' (Trusts that chose not to access the Sustainability and transformation

Fund would face the usual contractual penalties). Various changes have been made to the penalty rules and to the definitions of standards .

In mental health, the first waiting time target was defined in 2015 for early intervention in psychosis with different aims: a WT less than 14 days for 50% in 2016 and 60% in 2020-21.²³⁶

8.2.2. Purpose of waiting times data collection

Waiting times are measured in a standardised way **to ensure that access to care is the same for everyone in England**. When patients are referred for a physical or mental health condition, they have the legal right to receive care (e.g. start non-urgent consultant-led treatment, or to be seen by a specialist for suspected cancer) within a certain maximum waiting time (see section 8.2.8.).³³⁴

8.2.3. Application areas of waiting times assessment

The assessment of waiting times covers several areas in England:

- **Referral to treatment (RTT) waiting times for consultant-led elective care permitted by an English NHS commissioner:** This includes outpatient, day and admitted operations, as well as patients waiting for diagnostics or decisions, as long as their care is consultant-led. This concerns not only acute trusts but also specialist trusts, mental health trusts, any other providers of consultant-led services for NHS patients in England, and providers of interface services^{dd}. Data are reported by consultant specialties (18 categories).³³⁵
- **RTT WT for allied health care professionals** covers the RTT data for art therapists, music therapists and drama therapists (arts Therapists), chiropodists/podiatrists, dieticians, occupational therapists, orthoptists, physiotherapists, prosthetists and orthotists, radiographers (diagnostic and therapeutic), speech and language therapists.³³³

^{dd} Any intermediary levels of clinical triage, assessment and treatment between traditional primary and secondary care.



- **Cancer waiting times (CWT):** This assessment measures NHS performance against the national NHS Constitution Standards for cancer diagnosis and treatment, as well as a number of other metrics.³³⁶
- **Diagnostic tests WT:** There is an assessment of waiting times for **15 key diagnostic tests** or procedures (Imaging: MRI, CT, non-obstetric ultrasound, barium enema, dual-energy X-ray absorptiometry (DEXA) scan; Physiological measurements: audiological assessment, echocardiography, electrophysiology, neurophysiology - peripheral neurophysiology, respiratory physiology - sleep studies, urodynamics - pressures & flows; Endoscopy: gastroscopy, colonoscopy, flexible sigmoidoscopy, cystoscopy.³³⁷
- **Urgent and emergency WT:** Since 2004, there is an assessment of the target of less than four hours from arrival to departure, admission or transfer (which should be reached for 95% of attendances in A&E). There is also an ambulance WT.

There is no automatic assessment of the waiting time within the primary care in England although some measurements exist.³³⁸

Among the different English application areas of WT assessment, the urgent and emergency waiting times are out of scope for the KCE study and no more detailed in the following chapters on England description.

8.2.4. Definition of waiting times

Referral to treatment waiting times

The way RTT waiting times are measured is set nationally and applied locally; the waiting times apply to services commissioned by the NHS in England and to patients under its responsibility.^{331, 335}

Planned procedures or operations that are due to take place in a specific time, such as a repeat colonoscopy, or repeated therapeutic procedures, such as radiotherapy are outside the scope of RTT measurement.³³⁵

A waiting time clock starts when a referral is noticed to a provider by any care professional or service permitted by an English NHS commissioner to make such referrals. For NHS e-Referral Service (formerly Choose and Book) referrals, this will be the date that the patient converts their UBRN

(Unique Booking Reference Number); for referrals that are not made via the NHS e-Referral Service, the clock starts on the date that the referral is received by the provider organisation.

The referral can concern:

- a consultant-led service, regardless of setting, with the intention that the patient will be assessed and, if appropriate, treated before responsibility is transferred back to the referring health professional or general practitioner;
- an interface or referral management or assessment service, which may result in an onward referral to a consultant-led service before responsibility is transferred back to the referring health professional or general practitioner.

As patients will perceive their wait as starting from the time that the consultant told them they were going to refer, there should not be a significant delay between the date the decision to refer was made (and communicated to the patient) and the date that the referral is received in the receiving provider.³³⁵

A waiting time can also start when the patient books their first appointment online (and once the referral is ratified by a care professional permitted to do so).

Where a patient has more than one referral for unrelated clinical reasons, each referral will have its own patient pathway.³³⁵

The waiting time ends in the following situations:³³⁵

- the clinician decides that no treatment (or only an active monitoring) is necessary and communicates this decision to the patient (and subsequently their GP and/or other referring practitioner),
- the patient decides not to have treatment (or do not attend the first appointment),



- at the start of the treatment provided by a consultant-led or an interface service (e.g. admission to hospital for elective treatment or surgery, fitting of a medical device, adding the patient to a transplant list).

In the meantime (between the start and the end of the waiting time measure), the patients may undergo some tests, scans or other procedures to monitor their condition and check that the treatment is appropriate, or they may receive therapy or medicine to manage their symptoms (e.g. painkillers). If a patient reschedules an appointment after missing the first one, the waiting time measure is cancelled (restarted from zero).³³⁴

Cancer waiting times

There are three measurements (related to WT standards) and therefore three definitions of waiting times for cancer in England.

There is a **Faster Diagnosis Standard** (FDS) applied to patients referred with suspected cancer or breast symptoms from general medical practitioner, general dental practitioner, optometrist and any other referral source as agreed locally by commissioners and providers (including cancer screening programme (breast, bowel, cervical), advanced nurse practitioner (ANP), Accident & Emergency department (A&E)).³³⁶

The Faster Diagnosis Standard start point is the receipt of the referral by the provider who will first see the patient. Receipt of referral is day zero.³³⁶

The 28-days FDS pathway^{ff} ends only at the point of communication with the patient, whether that is to inform them of a diagnosis of cancer, a ruling out, or if they are going to have treatment before a clinical diagnosis of cancer can be made. There are other exceptional ends of the FDP or no applicability of the FDS such as patients death before the communication of diagnostic, patients refusing all appointments, patients opting for private diagnostics...³³⁶

There is also a **pathway of 62 days** who starts as the 28-day FDS pathway and ends with the first definitive treatment of cancer. A first definitive treatment (FDTs) is defined as the start of the treatment aimed at removing

or eradicating the cancer completely or at reducing tumour bulk. A list of the enabling treatments that can be classed as FDTs is available.³³⁶

Another **standard of 31 days starts with the decision to treat** (DTT) date, i.e. the date that a consultation between the patient and the clinician took place and a Planned Cancer Treatment was agreed (consent form signed) and ends with the first definitive treatment. This standard takes into account that in some cancers it is common for the diagnosis to take place after first treatment. For example, in testicular cancer, orchidectomy is counted as the first definitive treatment, although a definitive diagnosis will not be obtained until after this operation has taken place. The DTT can be changed if the patients decide they do not want the treatment originally agreed.³³⁶

Diagnostic tests waiting times

The diagnostic tests waiting times starts from the time of referral. Referrals may be from a variety of sources including GPs. Data reported are for those patients who have been referred for a test, but whose test had not taken place by the end of the reporting period. One of the main measurements covered is the number and proportion of patients waiting six weeks or more for a diagnostic test, from time of referral.³³⁷

8.2.5. Waiting times data collection methods

Referral to treatment waiting times

Every organisation providing NHS services is required to complete monthly a provider return to NHS Digital's online data collection tool and to report the RTT waiting times via a dedicated portal (the Strategic Data Collection Service (SDCS) portal, which is a secure data collection system); then data are checked and signed off by each trust and reviewed by their relevant commissioners. The data is compiled through the Secondary Uses Service (SUS), which provides anonymous patient-based data for healthcare planning, performance improvement. The data is held by NHS England and NHS Improvement.³³⁵

^{ee} Even if the treatment is started the day after admission (or later).

^{ff} The Two Week Wait Standards no longer applies to providers for patients seen on or after the 1st October 2023.



There are 18 treatment functions based on consultant specialties, plus one category "Other".³³⁵ The national data collection looks at RTT waiting times in weeks, split by treatment function. Data should be allocated to the following time bands: 0-1 weeks (0-7 days), >1-2 weeks, >2-3 weeks, then for all weekly time bands through to >103-104 weeks, >104 weeks.

In exceptional circumstances, where a trust has no confidence in the accuracy of its RTT data, it may be appropriate to suspend reporting but this decision must be taken by the board with a plan to resolve the problem.³³⁵

The data from clinical outcome sheets is transferred into the local IT system, generally by data clerks/administrators.³³⁵

Cancer waiting times

As for RTT, the cancer waiting times are collected on a monthly basis through the Cancer Waiting Time (CWT) database hosted by NHS Digital. Entries are also sent to a dedicated portal, before being published on the NHS England website.³³⁹

Diagnostic tests waiting times

The UK Statistics Authority has designated statistics on diagnostic tests, as National Statistics, in accordance with the Statistics and Registration Service Act 2007. NHS England compiles diagnostic waiting time and activity data through a central return.³³⁷

8.2.6. Waiting times data analysis

The median (50th percentile) is the preferred measure of the average waiting time as it is less susceptible to extreme values than the mean. The 92nd percentile waiting time is also used for incomplete pathways (see Section 8.2.8.) as it corresponds with the 92% operational standard. This is the time that 92% of patients had been waiting less than (and 8% of patients had been waiting more than). It should be noted that median and 92nd percentile waiting times are calculated from aggregate data, rather than patient-level data, and therefore are only estimates of the position on average waits. There are used for the RTT.³⁴⁰

8.2.7. Waiting times data publication

NHS England is responsible for publishing waiting times on its website (accessible to everyone), and databases on waiting times are openly available online.³³² 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 the waiting times by hospital (and compare) (<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.³³⁵

Referral to treatment waiting times

The RTT WT data is published monthly (according to a pre-announced timetable, roughly 6 weeks after the end of the reference month) and covers a number of measures, both for commissioners and providers:^{340, 341}

- Admitted completed pathways, sometimes referred to as inpatient waiting times. They include the complete time waited from referral until start of inpatient treatment for patients whose RTT started during the month and ended during the month with an inpatient or day case admission.
- Non-admitted completed pathways, sometimes referred to as outpatient waiting times. They include the time waited for patients whose RTT waiting time clock started during the month and stopped during the month for reasons other than an inpatient or day case admission such as a patient declining treatment.
- Incomplete pathways (waiting times for patients waiting to start treatment at the end of the month). These patients will be at various stages of their pathway, for example, waiting for diagnostics, an appointment with a consultant, or for admission for a procedure. The volume of incomplete RTT pathways is sometimes referred as the size of the RTT waiting list. Since 2015, the incomplete pathway standard became the sole measure of patients' constitutional right to start treatment within 18 weeks.³⁴⁰ There is a subgroup of incomplete



pathways for patients with a decision to admit for treatment^{gg} (waiting times for patients whose RTT clock is still running at the end of the reporting month for whom a decision to admit to a hospital bed for treatment has been made).

- New RTT period for all patients (the waiting time starts during the month even if the pathway stops within the reporting month).

Each pathway relates to an individual referral rather than an individual patient. Patients waiting for multiple treatments may be included in the figures more than once.³⁴⁰

The data is used to monitor NHS waiting time performance against the standards set out in the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012/Amended 2015.^{331, 342}

NHS providers and commissioners need to use this information to ensure 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.³³⁵

Full CSV data files are also available.³⁴¹

Cancer waiting times

Cancer waiting time statistics are presented on a monthly and quarterly basis, broken down both by provider (where the patients are first seen following an urgent referral for suspected cancer or breast symptoms or where treatment takes place) and by the local NHS organisation that commissions the patient care.³⁴³ The results present the percentage of patients for different waiting times (diagnosis or treatment), kind of cancers and subsequent treatment.

^{gg} The difference between the values submitted for this data item and for total incomplete pathways equates to the number of incomplete pathways without a decision to admit for treatment. This will include patients where first contact has not yet been made, patients waiting for first definitive treatment as an outpatient and patients where a decision to admit for a diagnostic procedure has been made

Diagnostic tests waiting times

These data are published monthly and report on the 15 key diagnostic tests (see Section 8.2.3). The results are presented in an online report, using a 6-week cut (=number of patients waiting six weeks or more for a diagnostic test at the end of the month from referral); the median of waiting times and the 13+ week waits are also shown as well as the total activity (number of diagnostic tests performed during the month).^{342, 337}

8.2.8. Waiting times standards

There are several waiting times standards in England which are regularly reviewed and adapted. Commissioners are responsible for enforcing waiting time standards through contracts with service providers, mostly NHS Trusts. Financial sanctions were defined initially but have been gradually removed from the Standard Contract for waiting time standards, including the 18-week RTT and cancer standards.³²⁹

In 2019, a Clinically-led Review of NHS Access Standards occurred.³⁴⁴

Referral to treatment waiting times

Since 2015, the RTT standards encompass both physical and mental health care. The right for maximum waiting times applies to NHS-commissioned services in England and does not include local authority-commissioned public health services, maternity services, or non-consultant-led mental health services.³³⁴

Patients can ask to be seen or treated by a different provider if the maximum waiting time for treatment is exceeded: the Clinical commissioning group^{hh} (CCG) or NHS England, which commissions and funds the treatment, must take all reasonable steps to offer a suitable alternative provider(s) that would be able to see or treat the patient more quickly. It is the responsibility of the

^{hh} CCGs are group of GPs practices that are responsible for commissioning most health and care services for patients. https://www.datadictionary.nhs.uk/nhs_business_definitions/clinical_commissioning_group.html



patient to contact either the provider or their local CCG before alternatives can be investigated.³²⁹

The following RTT WT standards are currently available in England:

- The maximum of 18 weeks from referral to consultant-led treatment (incomplete pathway) for 92% of patientsⁱⁱ; this WT standard was reviewed in 2019; two options were proposed: i) the amendment of the maximum number of weeks and the percentage threshold, ii) the introduction of an average waiting time target for incomplete pathways (rather than an upper most length of time).³²⁹
- A zero tolerance of any referral to treatment waits of more than 52 weeks (introduced by the NHS in 2013/14 and related to a fine for providers and commissioners to each pay £2,500 per patient that exceeds a 52-week waiting time from referral to treatment in 2019; this fine was suspended).³²⁹

There is no target for the allied health professional RTT.³³³

In mental health care, there are also WT standards:

- 2 weeks for access to early intervention care for people experiencing a first episode of psychosis (for 60% of the patients in 2020/2021).^{329,345}
- 4 weeks to receive NICE-approved treatment with a designated healthcare professional for 95% of children and young people with an eating disorder (and 1 week for urgent cases);³²⁹
- 6 weeks between referral and first treatment for IAPT (Increasing Access to NHS Psychological (Talking) Therapies) for 75% of patients, and 18 weeks for 95% of patients. This standards apply to adults only.³²⁹

Since 2019, it is also proposed to reduce the length of time patients in a **mental health crisis** have to wait for treatment³⁴⁶: access within one hour of referral to liaison psychiatry services and children and young people's equivalent in A&E departments; expert assessment within hours for

emergency referrals; and within 24 hours for urgent referrals in community mental health crisis services) and to introduce a four-week waiting time for children and young people who need specialist, and for adult community mental health services.

For **cancer waiting times**, new standards are applied since the 1st October 2023 (instead of 2 weeks to see a specialist for urgent cancer referrals, for 93% of patients):^{329,343}

- 28 days from the receipt of GP urgent referral for suspected cancer, receipt of urgent referral from a cancer screening programme (breast, bowel, cervical), and receipt of urgent referral of any patient with breast symptoms (where cancer not suspected), to the date the patient is informed of a diagnosis or ruling out of cancer in 75% of patients;³³⁶
- One month (31 days) from decision to treat/earliest clinically appropriate date to first definitive treatment of cancer in 96% of patients;³³⁶
- Two months (62 days) from receipt of an urgent GP (or other referrer) referral for urgent suspected cancer or breast symptomatic referral, or urgent screening referral or consultant upgrade to first definitive treatment of cancer in 85% of patients.³³⁶

For diagnostic tests WT, the NHS Constitution gives patients the legal right to treatment within 18 weeks of referral (18-week RTT) and as part of this, pledges:

- Six weeks for a diagnostic tests (for the 15 diagnostic tests or procedures selected). The NHS Standard Contract 2022/23 states that there is a standard threshold of 1% for this pledge. NHS England's planning guidance for 2023/24 requests that a threshold of at least 5% should be met by March 2025.³³⁷

ⁱⁱ This standard does not apply if patients choose to wait longer, if it is in the patient's interest to wait longer (e.g. to stop smoking), or if the patient needs to be actively monitored in secondary care.



8.3. Waiting times in the NHS Scotland

8.3.1. Legal framework

As specified in the “Patient Rights (Scotland) Act 2011”, Scotland gives to everyone the right to receive healthcare that considers their needs, considers what would most benefit their health and wellbeing and encourages them to take part in decisions about their health and wellbeing, with information and support to do so. It also gives patients a right to give feedback and make comments, and raise concerns or complaints about the care they have received.³⁴⁷

The Patient Rights (Scotland) Act 2011 established a 12 week Treatment Time Guarantee (TTG) written into legislation for eligible patients who are due to receive planned inpatient or day case treatment from 1 October 2012: it states that eligible patients must start to receive that treatment within 12 weeks (84 days) of the treatment being agreed. This guarantee is based on completed waits where a patient is removed from the list after being admitted for treatment. To support the above guarantee, from 31 March 2010 no patient should wait longer than 12 weeks for a new outpatient appointment at a consultant-led clinic. This includes referrals from all sources.

The Scottish Government’s NHS Scotland Waiting Times Guidance was updated in November 2023, which replacing the 2012 publication, to provide guidance for Health Boards to assist them in the delivery of the national waiting times standards and make sure that patients who are waiting for their appointments are managed fairly and consistently across NHS Scotland. The provision of relevant data by the health board of receipt of referral is mandatory.³⁴⁸

The “Patients Rights (Treatment Time Guarantee) (Scotland) (No.2) Directions 2022” provides information on how to monitor and record the waiting times in Scotland. Communication issues with patients are also presented in the text.^{349;347}

Because waiting times persists to be long in health care, in October 2018 the Cabinet Secretary for Health and Sport launched the £850 million for the Waiting Times Improvement Plan.³⁵⁰ The Plan focused on reducing the length of waiting times for key areas of healthcare and set out several

actions such as supporting health boards with additional funding to increase their elective activity, developing a network of regional elective and diagnostic centres, increasing capacity at the Golden Jubilee National Hospital, investing £4 million to increase domestic and international recruitment across specialties with the highest vacancy rates.³⁵¹

8.3.2. Purpose of waiting times data collection

The purpose of measuring waiting times is to “**help to sustain a better quality of life for patients and help achieve the objective of a Healthier Scotland. Reduced waiting times leads to a better outcome for patients**”. The NHS Scotland uses waiting times to help reduce patient anxiety, and also to improve patient quality of life, their clinical outcomes and the timeliness of treatment.³⁵²

8.3.3. Application areas of waiting times assessment

In Scotland, the assessment of WT covers:

- **Referral to treatment (RTT)** waiting times: The “18 Weeks” RTT is a whole journey waiting time standard from initial referral to the start of treatment. The RTT performance is dependent on the diagnostic tests, new outpatient appointments and, inpatient and day case treatment (see below).³⁵³
- **New outpatients appointments WT** (i.e. when a GP or other type of professional refers for the first time a patient to an outpatient clinic to get a more specialist opinion on the patient’s condition). Outpatient statistics only cover clinics led by a medical consultant. They do not cover clinics led by other professionals, including nurse-led clinics. However, there is specific dataset covering the first outpatient appointment at Allied Health Professional (AHP) led Musculoskeletal (MSK) services. The AHP MSK data collection covers Physiotherapy, Occupational Therapy, Chiropody/Podiatry and Orthotics services. The current statistics are severely constrained by the availability of quality assured data from several NHS Boards which means that there is no overview of data at a Scotland level at this moment.³⁵⁴



- **Diagnostic tests and investigations WT:** This encompasses 8 key diagnostics tests covered by national waiting time standard (upper endoscopy, lower endoscopy (excluding colonoscopy), colonoscopy, cystoscopy, CT scan, MRI scan, barium studies and non-obstetric ultrasound and 6 diagnostic tests which are not covered.³⁵⁵
- **General Acute Inpatient and Day Case WT:** This dataset covers all residents in Scotland that receive care in hospital and general acute specialties (including for example hip, knee or cataract removal surgery). This dataset is used for the Treatment Time Guarantee.
- **Mental Health waiting times:** This concerns **Inpatient and Day Case** which covers every adults admitted to psychiatric hospitals in Scotland (non-residents of Scotland as well as residents)³⁵⁶ and **Child and Adolescent Mental Health Services (CAMHS) waiting times for people from birth to 18 years old.**³⁵⁷
- **Cancer waiting times:** The database covers all newly diagnosed primary cancers (among the 10 major cancer types such as breast, lung, head and neck) in all Scottish residents aged over 16 years at the time of diagnosis.³⁵⁸
- **Accident and Emergency (A&E) waiting times:** The Scottish Government has set a target that 95% of people attending A&E should be seen, admitted, discharged or transferred within 4 hours (but not reached since the current pressures on services).³⁵⁹
- **Drug and Alcohol Treatment :** This dataset reports on waiting times for people accessing specialist drug and alcohol treatment services. In 2011, the Scottish Government set a Standard that 90% of people referred for help with problematic drug or alcohol use will wait no longer than three weeks for specialist treatment that supports their recover.³⁶⁰
- **In vitro fertilization (IVF):** This dataset concerns the WT from referral to a screening appointment for in vitro fertilisation (IVF) treatment by the NHS in Scotland. The statistics available in this release continue to be constrained by the availability of quality assured data. The standard is for 90% of eligible patients to be screened at an IVF Centre within 52 weeks of receipt of a referral from a secondary care/acute consultant.³⁶¹

There is a local delivery plan (LDP) standard regarding the access to GPs but this measure is monitored through the results of the national healthcare experience survey, which directly measures patients' experience of getting access to primary medical services.³⁶² As this patient experience is already measured in Belgium by the HIS, this indicator is not further developed.

Furthermore, either because they are out of scope of the KCE study or to specific to Scotland, it was decided not to detail the Accident and Emergency, Drug and Alcohol Treatment, and IVF waiting times in the following chapters on Scotland description.

8.3.4. Definition of waiting times

The waiting times is referred to as a waiting time clock with start and stop but there are also adjustments (periods not count in the WT calculation or clock pause) for several reasons such as patient with reasonable notice given to the Health Board that they cannot attend an appointment or when they refuse a reasonable offer.³⁶³

Definitions of several concepts such as reasonable offer (2 dates minimum for appointment, proposition seven days before the first appointment...), non-attendance, patient unavailability for treatment (medical or patient reasons), etc. are available in the NHS Scotland Waiting Times Guidance November 2023.³⁴⁸

The different definitions of each indicator are presented below. Most of them start when the referral is received.

Referral to treatment waiting times

In Scotland, the 18 Weeks RTT standard applies to the entire patient journey from the initial referral to the start of treatment; it is defined as the time it takes for patients to receive treatment after being referred to hospital.³⁴⁸ This depends on the nature and the complexity of the patient's condition, and how easily the condition can be diagnosed. The kind of treatment can also affect the WT.

The RTT clock starts on the date when the referral is received by hospital and stops on the date when the treatment starts.³⁴⁸

For patients that self-refer, the WT clock starts on the date that the patient self-refers.



Achieving the standard depends on waiting times for diagnostic tests, new outpatient appointments, inpatient and day case treatment. The 18 Weeks RTT performance is based on adjusted waits for consultant led treatments and fully measurable completed patient journeys. This is not legally binding, although NHS Boards are expected to ensure 90% of referrals meet this standard (Personal communication).

New outpatient appointments WT

For new outpatient appointments, the clock starts on the date the referral is received (or the date the patient self-refer) and stops on the date of the new outpatient appointment.³⁴⁸

Diagnostic tests and investigations WT

For the 8 key diagnostic tests and investigations, the clock starts when the request for the test is received within the department and stops when the verified report has been received or made available.³⁴⁸

General acute inpatient and day case WT

Under the legal Treatment Time Guarantee, the clock starts on the date the clinician and patient agree on the treatment (which will be the date when the decision is made by the clinician to put the patient on waiting list) and stops on the date the patient starts to receive the agreed treatment (in case of hospital admission, this can be the day before surgery).³⁴⁸

The treatment agreement is made in an outpatient appointment in the majority of patients, often after reception of the results of diagnostic tests and sometimes after additional time for patient reflection.³⁴⁸

Mental health waiting times

There are the times between the referral to psychotherapies and the first treatment and the times between the referral to the Child and Adolescent Mental Health Waiting Services (CAMHS) and the first treatment.^{356, 357}

Cancer waiting times

Two WT are measured: one starts with the decision made to treat the cancer and stops with the first treatment; the other is extended, starting with receipt of referral for suspected cancer (including referrals from national cancer screening programmes) and stopping with the first treatment.³⁶⁴

8.3.5. Waiting times data collection methods

Aggregated data are collected using a standard template, submitted monthly by each NHS Board (except for the General/Acute and Inpatient Day Case collecting patient-level data). To improve data quality, the standard template is completed, checked and signed off by an authorised NHS Board colleague and then submitted to Public Health Scotland (PHS).

The dataset for cancer WT contains 21 fields, the majority of which are mandatory.³⁶⁴ Data is collected by cancer trackers and administrative staff (including medical secretaries) across NHS Scotland, and are based on locally available information drawn from sources such as patient administrative systems, laboratory systems, and medical records across the country; which are then recorded onto the NHS Boards' Tracking systems. Once submitted to PHS, the data are entered into a dedicated database (e.g. the PHS Referral to Treatment database). The data can be extracted from this database to produce the reports for the Boards (the Boards check the content for accuracy) and to produce the reports that are shared with the Scottish Government.

The frequency of data collection is on a monthly basis (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). The open data is available on the Scottish Health and Social Care Open Data platform. Detailed information on each WT dataset can be found here: for **RTT**³⁵³, **New outpatients appointment WT**³⁶⁵, **General Acute Inpatient and Day Case database**³⁶⁶, **Diagnostic tests waiting times**³⁶⁷, **Mental Health Inpatient and Day Case dataset**³⁵⁶,



CAMH Services waiting times³⁵⁷, Cancer WT³⁵⁸ and Allied Health Professional-musculoskeletal waiting times.^{354jj}

The Patient Rights (Treatment Time Guarantee) (Scotland) (No.2) Directions 2022³⁴⁹ and the updated guidance (2023)³⁴⁸ defined the data to be recorded by the responsible Health Board in relation to each **treatment time guarantee** such as the date on which the patient agrees to proceed with the agreed treatment; the date on which the patient starts to receive the agreed treatment; any period of time when the patient is unavailable for treatment for a known period (and the reason for that unavailability) or when the treatment time guarantee is suspended, etc.

8.3.6. Waiting times data analysis

Not all application areas presents additional analysis. For example, the data of the RTT WT is sent to PHS at an aggregate level which hampers to calculate the average, shortest or longest patient journey times. PHS only holds data on the number of patient journeys that are less than 18 weeks, over 18 weeks, over 26 weeks for key specialties, and unknown waits.

Median and percentiles are available for others such as new outpatient attendances or inpatient or day case admissions (with median and 90th percentile wait in days for both). The median is used because an average (mean) can be skewed incorrectly by a small number of very long waits that are recorded in error in the national data.³⁶³

For cancer waiting times, median wait and 95th percentile in days are presented against two standards (see Section 8.3.8.).³⁶⁸

Regarding the assessment of NHS hospitals' performance, two statistics are considered of interest by the PHS of Scotland:³⁶³

- **Ongoing waits**, i.e. the **number of open waits** at the end of a month or quarter where patients have been referred to the hospital and are on one or more list waiting to be seen at a new outpatient appointment or admitted for treatment as an inpatient or day case. According to the PHS: *"These statistics measured at a census point show the length of*

time that patients on a waiting list have been waiting at the month end. This is the most useful measure for NHS managers who may need to take prospective action to make sure patient waits do not exceed the national maximum waiting time standard set by the Scottish Government."

- **Attendance/admissions**, i.e. **the waits that have been completed** due to a patient having attended a new outpatient appointment or having been admitted for inpatient or day case treatment respectively, and the patient has subsequently been removed from the list. These statistics show a complete picture of waiting time experienced by patients. It is a good retrospective measure of how well the NHS is performing against the target or standard and is easier to understand.

8.3.7. Waiting times data publication

The majority of waiting times measured in Scotland are published on a quarterly based on the Public Health Scotland website (<https://publichealthscotland.scot/publications/>). There are also statistics for outpatient and inpatient waiting time by NHS on the NHS Inform website (<https://www.nhsinform.scot/waiting-times>). A range of information is available: graphs (showing trends over time), raw aggregate data and open access databases.

The website of Public Health Scotland presents also many specific publications on waiting times such waiting times for patients with chronic pain seen at a consultant-led outpatient clinic³⁶⁹ or findings from review of adherence to national waiting times guidance³⁷⁰.

Communications with patients is particularly highlighted in the Scottish legal documents on waiting times.³⁴⁹ The Charter of Patient rights and responsibilities (revised June 2022) explains the patient rights (to ask questions, to receive clear information, in a format or language that meets needs, etc.) including the use of communication support.³⁷¹ The Scottish Government's NHS Scotland Waiting Times Guidance provides guidelines

jj <https://publichealthscotland.scot/publications/allied-health-professionals-musculoskeletal-waiting-times-in-nhsscotland/allied-health-professionals-musculoskeletal-waiting-times-in-nhsscotland-quarter-ending-30-june-2023/>



for patients information and communication content with patients when the TTG is breached.³⁴⁸

8.3.8. *Targets for waiting times*

The Scottish Patient Rights Act 2011 guaranteed a 12-week (84 days) legal **Treatment Time Guarantee^{kk} for inpatient and day case treatment**, meaning that once a diagnosis has been made and treatment has been agreed, each health board must ensure that patients receive inpatient and day case treatment within 12 weeks. If treatment has not started within this time, the health board responsible for the patient should arrange the treatment, including outside the board's area.³⁴⁷

A small number of specialist treatments provided as an inpatient or day case are not covered by the TTG such as fertility treatment, obstetrics services, organ, tissue or cell transplantation.³⁵⁹

In very exceptional circumstances, the TTG can be suspended by Scottish Ministers for a period of up to 30 days.

Beside the 12-week TTG, several other standards are determined by the Scottish Government

- 6 weeks for the 8 key **diagnostic tests and investigations**³⁴⁸;
- 12 weeks for **new medical outpatient appointments** in 95% of patients³⁴⁸;
- 18 weeks for the **RTT** (completed pathway) in 90% of patients³⁴⁸;
- 4 weeks for **new outpatient appointment with allied health professionals-musculoskeletal waiting times** in 90% of patients³⁵⁴.

For cancer waiting times, the "Better Cancer Care - an action plan" was launched on 27 October 2008 (only for the adults newly diagnosed with a

primary cancer of one of the 10 major cancers, such as breast, lung, head and neck).³⁵⁸ Two standards are currently used:

- 31 days from decision to treat until first cancer treatment, no matter how patients were referred,
- 62 days from receipt of referral for suspected cancers until first treatment. This applied to any patients urgently referred with a suspicion of cancer by their primary care clinician (for example GP) or dentist; any screened-positive patients who are referred through a national cancer screening programme (breast, colorectal or cervical) and any direct referral to hospital where the signs and symptoms are consistent with the cancer diagnosed as per the Scottish Referral Guidelines (for example self-referral to A&E)
- The 5% tolerance level (i.e. 95% rather than 100%) is applied to these standards because for some patients it may not be clinically appropriate to start treatment within the standard time.³⁵⁸
Waiting times may be adjusted for some medical reasons (e.g. infection).

For mental health, the Scottish Government standard states that 90% of people should start their treatment within 18 weeks of referral to psychological therapies; the 12 week Treatment Time Guarantee (TTG) does not apply to psychiatry. Two standards are defined:

- 18 weeks between referral and treatment in 90% of people referred to Child and Adolescent Mental Health Services (CAMHS)
- 18 weeks between referral and treatment in 90% of people referred for psychological therapies

For GPs, the LDP Standard offers 48-hour access or advance booking to an appropriate member of the GP team for at least 90% of patients.³⁶²

^{kk} The TTG was defined when the Patient Rights Act 2011 was passed by the Scottish Parliament on 24 February 2011 and became an Act on 31 March 2011. Scottish Ministers agreed regulations to the Treatment Time Guarantee in 2012.



8.4. Waiting times in the NHS Wales

8.4.1. Legal framework

The Welsh Government has set targets about healthcare, including waiting times in the NHS Wales Delivery Framework.³⁷²

In Wales, there is a **right to be seen in the healthcare system within a certain maximum delay** (depending on the care required). Health Boards are responsible for meeting these targets and if the patient cannot be seen within this maximum waiting time, the local health board can investigate the reason for the delay and may offer an alternative.³⁷³

In 2005, the Welsh Assembly Government published the “Designed for life: Creating world class, health and social care for Wales”, following the announcement by the First Minister and the Minister for Health and Social Care to transform the system, including tackling long waiting times.³⁷⁴

In 2012, the Welsh Government introduced waiting times for assessment and treatment by local primary mental health support services.³⁷³

In April 2022, a plan to end long waiting times and transform planned care was published by the Welsh Health Minister to decrease the backlog of appointment and treatment during the pandemic. The plan aims to ensure no one will be waiting more than a year for treatment in most specialties by Spring 2025. The plan will be supported by an extra £60m – £15m a year over the next four years – for Health Boards.³⁷⁵

8.4.2. Purpose of waiting times data collection

NHS Wales is committed **to ensuring that patients are seen as quickly as possible according to their clinical needs**.³⁷³

8.4.3. Application areas of waiting times assessment

In Wales, the waiting times measurement covers similar areas than England and Scotland but with specificities:

- **Referral to Treatment (RTT)** waiting time is defined as the “total time from referral by a GP or other medical practitioner for hospital treatment in the NHS and includes time spent waiting for outpatient appointments,

diagnostic tests, therapy services and inpatient or day-case admissions”.^{373, 376}; It is recorded since 2009 and is considered as the main source of information on Welsh NHS waiting times. Some specialties are not covered by RTT covering (see below). Many specialties are encompassed such as cardiology, gastroenterology, dermatology, ENT, general medicine, gynaecology, ophthalmology, paediatrics, all kind of surgery... but also allied health profession services, anaesthetics, audiological medicine, dental medicine, orthodontics or pain management.

- **Inpatient and outpatient WT for non-RTT specialties** concerns **mental illness, forensic psychiatry, learning disability, old age psychiatry, psychotherapy, orthodontics, paediatric dentistry, restorative dentistry and palliative medicine**.³⁷⁷ The WT assessment for access to local primary **mental health** support services was included in the records in 2012.
- **Diagnostic and therapy services WT: Diagnostic services** include: cardiology diagnostic, endoscopy, imaging, neurophysiology, physiological measurement, radiology (consultant referral or GP referral) and **therapy services** include: arts therapies, audiology – adult hearing aids, dietetics, occupational therapy, physiotherapy, podiatry and speech language.³⁷⁸
- **Cancer waiting times:** The dataset only includes patients newly diagnosed with cancer, who have started definitive treatment during the month and the quarter.³⁷⁹ Two types of measure are proposed: open and closed pathway for suspected cancer (see below in the Section 8.4.4)
- **Eye care WT for outpatients:** In the context of the introduction of the eye care framework in 2019, this dataset gathers monthly data on patients waiting for an outpatient ophthalmology appointment and outpatient ophthalmology appointments attended.^{380, 381}
- **Emergency department WT** (e.g. number of attendances, performance against 4, 8 or 12-hour waiting time targets).³⁸² This area is out of scope for the KCE study and therefore, not detailed in the following chapter.

Data on waiting times in primary care is not recorded by the system in Wales.



8.4.4. Definition of waiting times

Referral to Treatment (RTT) waiting times

As for Scotland, the RTT clock in Wales starts when the referral letter sent by a health professional (e.g. GP, dentist, optician or other clinician) is received by the hospital. It ends when the treatment starts or is no longer needed (e.g. admission to the hospital for a surgery or treatment, starting medication outside of the hospital, beginning fitting of medical device, being monitored to see if treatment is needed, receiving advice from hospital staff to self-management).^{373,383}

If the patient is not available, this time is not included in the waiting time calculation, for example if the patient is on holiday.³⁷³

Mental health waiting times

Since 2012, waiting times for assessment and treatment by local primary mental health support services is assessed. There are two measures: the WT between the receipt of referral and the mental assessment and the WT between the assessment and the start of treatment.³⁷³

Diagnostic and therapy services WT in hospital

The waiting time is calculated from the date the referral request was received until the date on which the diagnostic test for which the patient has been referred is carried out; or the hearing aid is fitted; or the patient commences the first treatment following an assessment or examination.³⁸⁴

Cancer waiting times

Both for the closed and open pathway, the Cancer WT starts at the point of cancer suspicion (e.g. when a GP makes a referral). A closed pathway means that the waiting time has ended with the start of the treatment, confirmation of no cancer, decision not to treat or death and is measured from the point of suspicion for patients who have started their first treatment during the month. An open pathway means that the waiting time is still ongoing. The unit of measurement is the pathway (not the individual patient), which means that patients with more than one open pathway may be included.³⁷⁹

Eye care WT for outpatients

There are three categorizations of risk: risk of irreversible harm or significant patient adverse outcome if target date is missed; risk of reversible harm or adverse outcome if target date is missed; no risk of significant harm or adverse outcome.³⁸¹

The WT data focuses on the total number of new and follow-up ophthalmology patient pathways that have been assessed as being at risk of irreversible harm or significant adverse outcome that are waiting for an outpatient appointment. The purpose of the measure is to ensure that all individuals who are referred for ophthalmology will have a maximum waiting time which is based on a clinical assessment of their condition and well-being, and that all ophthalmology patients who require regular ongoing review or treatment are seen within clinically indicated intervals, also based on their condition and well-being, which should be reviewed at each appointment.

8.4.5. Waiting times data collection methods

Each Local Health Board (LHB) in Wales reports waiting times for NHS-funded services on a dedicated platform. There is a semi-automated process which allows the Health Statistics and Analysis Unit to produce statistics, with highlights and commentary produced separately and information on StatsWales produced automatically.^{384,383}

Data is aggregated and collected monthly. The NHS Wales Informatics Service (or the Digital Health and Care Wales for cancer WT or The Delivery & Performance Division for Eye care WT) validates the data as it is uploaded onto their database.^{384,385}

Any abnormalities 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.³⁸¹

Guidance is provided on how to measure and report the relevant data (see Section 8.6.4).



8.4.6. *Waiting times analysis*

Number or percentage of patient pathways but also median waiting time can be found in the Welsh statistics (e.g. patient pathways waiting to start treatment by month, grouped weeks and stage of pathway; percentage of patient pathways waiting to start treatment within target time by month and grouped weeks; median WT for referral to treatment (weeks), by local health board or by treatment function³⁷⁶, median WT for diagnostic and therapy services by local health board and by service³⁷⁸ or measure if the appointment date respects their target date or is 25% beyond their target date for eye care.³⁸¹

8.4.7. *Waiting times data publication*

The StatsWales website (<https://statswales.gov.wales/>) presents monthly waiting time data for each application area and provides a data dictionary and an analysis of the data quality. Open access databases are also available.

A more detailed statistical bulletin is published annually.³⁸⁴

Digital Health and Care Wales (<https://dhcw.nhs.wales/>) also publishes on the suspected cancer pathways and secondary care, and provides access to interactive dashboards (with information such as the number of hospital admissions, inpatient activity, day case activity, outpatient activity); the dashboard allows selection of, for example, a particular year, health board (provider) or treatment specialty (medical, psychiatry, radiology, surgery).

8.4.8. *Targets for waiting times*

Several targets are defined in Wales. If the patient has already waited longer than the standards or think the WT will be longer, they should contact the WT department in the hospital they have been referred to or the health board. The local health board that commissions the treatment can investigate and may be able to offer suitable alternative hospitals or community clinics that may be able to see or treat the patient more quickly.³⁷³

Three kinds of service are excluded from the maximum WT: maternity services, palliative care and some fertility services.³⁷³

The maximum WT do not apply in some circumstances such as if the patients choose to wait longer, if it is in the best interest of the patients to delay the start of the treatment (e.g. for stopping smoking or losing weight), if it is clinically appropriate to be actively monitored in secondary care without diagnostic procedure or treatment, if there is failed attendance from a set of reasonable options or if the treatment is no longer necessary.³⁷³

The targets for **RTT** are to ensure:

- 26 weeks between referral and treatment in 95% of referred patients,
- 36 weeks between referral and treatment for patients whose condition is too complex to be treated within 26 weeks (or who choose to wait).

For **mental health**

- 28 days to be seen for people referred for a mental health assessment,
- 28-day post-assessment target to ensure that people have timely access to treatment following the outcome of the assessment.

urgent referrals within 48 hours, routine referrals within 28 days for children and young people.³⁷³

We found no maximum WT for **diagnostic and therapeutic services**.

For **cancer** waiting time, there is one target :

- 62 days from point of suspicion and start of definitive treatment in 75% of patients referred for suspected cancer.³⁷³

For **eye care**, maximum waiting time standards are clinically determined in line with national condition specific guidance. Any patient missing their target date for an outpatient appointment will be seen in priority sequence across all conditions (results measure if the appointment date respects their target date or is 25% beyond their target date)³⁸¹



8.5. Waiting times in Northern Ireland

8.5.1. Legal framework

In Northern Ireland, a specific plan has been published (2017 Elective Care Plan - Transformation and Reform of Elective Care Services); this is an action and transformation plan for the health service that does not specifically address waiting times, but rather a broad transformation of the health services. In addition, the 'New decade, new approach deal' mentions that the Executive will introduce a new action plan on waiting times in 2020. The impact of these measures has yet to be assessed.³⁸⁶ (https://assets.publishing.service.gov.uk/media/5e178b56ed915d3b06f2b795/2020-01-08_a_new_decade_a_new_approach.pdf)

The Department of Health produces independent statistics on hospital WT and activity, designated as National Statistics and governed by the Statistics and Registration Service Act 2007 and the Code of Practice for Statistics. This statistical practice is regulated by the Office for Statistics Regulation (OSR) Office for Statistics Regulation (<https://www.statisticsauthority.gov.uk/>). The Statistics & Registration Service Act 2007 established the Statistics Board in the UK (which also covers Northern Ireland). In the exercise of its functions, the Statistics Board is to have the objective of promoting and safeguarding the production and publication of official statistics that serve the public interest (Personal communication).

The Northern Ireland Health Minister has set some targets for WT, but there are no penalties or fines for Health and Social Care Trusts that fail to meet these targets (Personal communication).

8.5.2. Purpose of waiting times data collection

The primary aim is to **provide the public, the Department of Health and Trusts with information** on Health and Social Care (HSC) performance, particularly on timely access to care. This data also informs health service policy makers.. In addition, the information is used in response to a significantly high volume of Parliamentary / Assembly questions and ad-hoc queries each year.³⁸⁷

8.5.3. Application areas of waiting times assessment

As in the other countries of the UK, several types of waiting times are collected:

- **Outpatient appointment waiting times:** this concerns Health Service patients who are waiting for a first outpatient appointment with a consultant-led service in an HSC Trust ("ongoing waits" are measured, not "completed waits"). List of specialties includes cardiology, ophthalmology, gynaecology, paediatrics, gastroenterology, ENT, urology, dermatology, general medicine, surgery (general, T&O, oral, paediatrics, plastic)...³⁸⁸
- **Diagnostic waiting times** relate to all tests with a diagnostic element. Diagnosis services are grouped into 3 categories – Imaging tests, Physiological Measurement tests and Day Case Endoscopies. There are two measures: i) waiting times for diagnostic services and ii) diagnostic reporting turnaround time.³⁸⁹
- **Inpatient waiting times:** this focuses on patients waiting to be admitted as an inpatient or day case following a "decision to admit" by their consultant.³⁹⁰ There is a list of specialties with waiting list numbers, including cardiology, ophthalmology, gynaecology, paediatrics, gastroenterology, ENT, Urology, dermatology, general medicine, surgery (general, T&O, oral, paediatric, plastic), pain management, specialists GPs carrying out inpatient treatment...
- **Cancer waiting times:** the dataset covers three kinds of waiting time: i) urgent GP referral to first definitive treatment, ii) decision to treat to first definitive treatment and iii) urgent referral for breast cancer to appointment with a breast cancer specialist.³⁹¹
- **Emergency waiting times:** It monitors the length of time patients spend in A&E departments in Northern Ireland.³⁹² This area is out of scope for the KCE study and therefore, not detailed in the following chapters.

There is no waiting time measure for primary care in Northern Ireland.



8.5.4. Definition of waiting times

Outpatient waiting times

This indicator is derived to show the “number of Health Service patients attending a first consultant-led outpatient appointment”. This WT starts when the GPs referral request is received; the end is the time of the data collection. In this case, the measure concerns **ongoing and not completed WT** ongoing waits.³⁸⁸

Diagnostic waiting times

Two measures relate to the diagnostic services, which are defined as services that involve an examination, test or procedure to detect a disease or condition and that allow a medical diagnosis to be made.³⁸⁹

- Waiting time for a diagnostic service (“diagnostic waiting time”) starts on the date on which the referral is received by the health care provider; assessment concerns ongoing waits. The WT is adjusted for example if patient cannot attend. There are exclusion such as purely therapeutic procedures, emergency procedure in patients admitted to a hospital bed, planned procedure or procedures part of screening programmes. Since a number of the diagnostic services, particularly endoscopies, are managed as an admission, they will be included in both the inpatient and day case waiting time and diagnostic waiting time figures.
- 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. Diagnostic reporting turnaround times are collected for both urgent and routine diagnostic tests. Diagnostic reporting turnaround times relate only to a selected subset of imaging (MRI, CT, non-obstetric US, Barium studies, DEXA Scan, radio-nuclide imaging, plain film X-ray) and Physiological Measurement tests (Pure tone audiometry, echocardiography, perfusion studies, peripheral neurophysiology, sleep studies and urodynamics pressures and flows). Day case endoscopies are reported on the day of the test and as such are not included.

Inpatient and Day case waiting times

The inpatient and day case waiting times start the date the clinician decided to admit the patient; WT assessment concerns ongoing waits.

Some adjustments are possible: for example, for patients who cannot attend or miss their appointment, the WT starts on the date they informed the HSC Trust that they could not attend or the date of the missed appointment; in case of the patients are suspended for medical or social reasons, but re-instated after, the period of suspension is excluded from the waiting time.³⁹⁰

Definition of inpatient and day case admissions is clearly presented: Inpatient admissions are patients admitted electively with the expectation that they will remain in hospital for at least one night. Day case admissions are patients admitted electively with the expectation that although they may require supervised recovery, they do not require the use of a hospital bed overnight and will return home as scheduled the same day.

Patients can be waiting for more than one inpatient or day case admission.

There are some exclusions to the inpatient and day case admission such as emergency cases, planned admission, maternity specialties (except where the intention is to terminate the pregnancy), regular day and night patients.

Cancer waiting times

Three measures assess waiting times for patients accessing cancer services within the HSC Trusts:³⁹¹

- Urgent referral for breast cancer: The measure starts on the date an initial breast cancer referral is first received by the HSC Trust and stops the date that the patient attends their first outpatient appointment with a breast cancer specialist.
- Urgent GP referral to first definitive treatment: the start date is the date the first urgent GP referral for suspected cancer was received by the HSC Trust and the end date is the date the patient received their first definitive treatment for cancer at a HSC Trust.³⁹¹ Referrals from sources other than a GP, routine referrals and patients who have not been given an ICD-10 diagnosis are excluded.³⁹³



- Decision to treat to first definitive treatment: The measure starts on the date the patient and the clinician agree on the planned treatment and ends on the date the patient receives their first definitive treatment for cancer at a HSC Trust. Patients that have not been given an ICD-10 diagnosis are excluded.

For each cancer waiting time, the patient may be temporarily removed from the waiting list, for medical or social reasons, such as: the patients have another commitment (holiday), the patients need to consider the proposed treatment, the patients are unavailable for treatment due to another medical condition.

8.5.5. *Waiting times data collection methods*

Data collection is based on a methodology developed by the Hospital Information Branch (HIB) and follows the UK Code of Practice for Statistics.^{II} HSC Trusts are given a set period of time to submit the information to HIB. HIB is responsible for data collection, quality assurance, analysis and publication.

Statistical information is collected routinely from a variety of electronic patient level administrative systems and pre-defined EXCEL survey return templates.

Following submission, HIB perform 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. Background quality reports are published by The Department of Health and Northern Ireland Statistics and Research Agency (NISRA).³⁹⁴⁻³⁹⁷

Technical notes and Guidance are available to support the submission of data^{387, 393, 398, 399} (see Section 8.6.4. Data quality);

For cancer, another source of data is used (the Cancer Patient Pathway System (CaPPS)) which collects information on cancer treatment services within HSC Trusts in Northern Ireland.

8.5.6. *Waiting times data analysis*

Most indicators are reported as number of patients waiting and length of time at the end of the quarter surveyed ("current waiters"). There are differences with completed waits as the "current waiters" relates to how long patients have been waiting for a (diagnostic service or treatment), not the length of time they waited before being seen, also known as completed waits.³⁸⁷

The median and the 95th percentile are also used in Northern Ireland. *The median waiting time (i.e. middle value when all patients are ordered by length of time waiting) is preferred over the mean because waiting times tend to be skewed by longer waits and therefore more patients are waiting for less time than the mean.*

The 95th percentile waiting time is the length of time that 95% of patients have been waiting equal to or less than, i.e. one in twenty patients have been waiting longer than this time. The 95th 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.

For cancer, the Trust at which a patient receives treatment is not necessarily the Trust to which the patient was referred, or the nearest HSC Trust to the patient's residence, as, in the case of numerous cancer services, treatments are provided at specialist centres such as the regional cancer centre for Northern Ireland in the Belfast HSC Trust. Users should therefore be cautious in how they use these data.

Trend analyses are used to monitor annual variations and emerging trends.

8.5.7. *Waiting times data publication*

Waiting times are published on a quarterly basis. To be transparent for the patients, the different waiting times can be found on the Internet in the National Statistics (Northern Ireland Statistics and Research Agency NISRA) website^{mm}. Each type of waiting time (outpatient, inpatient, diagnostic, cancer, A&E) is presented on a separate web page fully accessible to everyone.

^{II} <https://code.statisticsauthority.gov.uk/>

^{mm} <https://www.nisra.gov.uk/>



Results are broken down by HSC Trust and specialty or tumour site. The evolution of patients waiting for care over time, as well as the median and P95 are presented. Where a target has been set, it is also shown on the graph. There is a strict timetable for publication.

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.

Most of the data is also published in CSV format in order to aid secondary analysis. For outpatient and cancer waiting times, the Data Portal allows users to filter results, plot interactive charts and read data via API queries and to download data in CSV, XLSX, JSON-stat and PX formats. It can be accessed at the following link: <https://data.nisra.gov.uk/product/HWTS>

The publications are also accessible through the UK National Statistics Publication Hub at: <http://www.statistics.gov.uk/hub/index.html>

Patients in Northern Ireland can use a new online system to check how long they are to wait for outpatient hospital appointments across the different clinical specialties in each HSC trust area. [My Waiting Times NI | Department of Health \(health-ni.gov.uk\)](http://health-ni.gov.uk) The website is called “My Waiting Times NI”. The webpage will be expanded over time to also provide the latest waiting time information for procedures, treatment and diagnostics. My Waiting Times NI is available via the [HSC NI website](http://health-ni.gov.uk).

8.5.8. Targets for waiting times

Several waiting times targets are defined in Northern Ireland and allow reporting on the performance of the HSC trusts.

First consultant-led outpatient waiting times

- 9 weeks for a first outpatient appointment in 50% of patients.
- No patient (0%) should wait longer than 52 weeks.

Diagnostic waiting times

- 9 weeks for a diagnostic test in 75% of patients; since March 2023, the targets are monitored, though are mostly not achieved.
- No patient (0%) should wait longer than 26 weeks.
- Two days for all urgent diagnostic tests; since March 2023, the targets are monitored, though are mostly not achieved).

Inpatient waiting times

- 13 weeks for inpatient/day case treatment in 55% of patients.
- No patient (0%) should wait longer than 52 weeks.

Cancer waiting times

- 31 days between the decision to treat and the first definitive treatment in at least 98% of patients diagnosed with cancer.
- 62 days RTT between the referral and the start of the first definitive treatment in at least 95% of patients urgently referred by a GP with a suspected cancer.
- All urgent breast cancer referrals should be seen within 14 days.



8.6. Points of evaluation

Several issues are raised by authors analysing waiting time data: difficulty of comparing the four UK countries, trends in increasing waiting times and waiting lists over time, heterogeneity between regions within a country, questions about the accuracy of the data, risk of misinterpretation and potential perverse effect of the system on equity.

8.6.1. UK countries comparability

As shown in the previous chapters, each country in the UK has its own organisation and standards regarding waiting time. This hampers perfect comparisons between countries. For example, there are differences in how the time period for RTT is calculated and in the length of targets.

Northern Ireland highlights this issue on its websiteⁿⁿ, mentioning that “*users should be aware that hospital waiting times in other administrations are not always measured in a comparable manner to those in Northern Ireland.*”³⁹⁴

The Office for National Statistics is working with partners across the UK statistical system **to make it easier to understand the comparability of health data for England, Wales, Scotland and Northern Ireland, whilst respecting the devolved nature of these statistics**. This is expected to be published in 2024.⁴⁰⁰

There is also a ‘UK Comparative Waiting Times Group’ where statisticians from all four home nations have been collaborating: this group works to produce **technical guidance on several waiting time measures** (RTT, diagnostics, cancer, inpatients, outpatients...).⁴⁰¹

Regarding the waiting time targets, there are some similarities, such as the 18 weeks for RTT in England and Scotland for 92% and 90% of the population respectively, or the cancer waiting times for the first definitive treatment within 62 days of referral, but with different standards in England (target for 85%), Scotland and Northern Ireland (95%), and Wales (for 75%). Another difference is the 26 weeks for RTT in 95% of population in Wales

(which is longer than the 18 weeks in the 3 other countries). For some authors, “*the variation in waiting times is reflected in the targets each country has set itself for elective care: by necessity, the worse the waiting times, the less ambitious the target.*”⁴⁰²

8.6.2. Evolution over time

Trends over time are an interesting indicator, particularly for assessing the impact of policy decisions on waiting times. As in other European countries, there has been a continuous increase in the number of patients waiting for care and of the median times on waiting lists for several waiting times in the UK. Many factors play a role in these results and it is not the aim of this study to detail them. The COVID-19 pandemic has dramatically worsened the situation, leading governments to take additional measures.

In England, it was decided in autumn 2021 that the NHS England would receive £5.9 billion of additional funding to tackle the backlogs by increasing the diagnostic capacity and supporting innovative use of digital technology. The aim was to clear the backlogs but also to “provide around 30% more elective activity by 2024-25 than before the pandemic”.⁴⁰³ In the longer term, the ambition is to eliminate waits of more than 18 months to start cancer treatment by April 2023 and waits of more than one year by March 2025.²⁹²

In Scotland, new national targets have been defined to address the impact of the pandemic on long WT for planned care. For example, there were the targets to treat patients waiting longer than two years for outpatient appointments in most specialties by the end of August 2022 or one year for outpatients appointments in most specialties by the end of March 2023.⁴⁰⁴

In Wales, the Welsh Government published in April 2022 a programme to modernise planned care and reduce waiting lists, with national targets of no patient waiting longer than a year for their first outpatient appointment by the end of 2022 or eliminate the number of people waiting longer than two years in most specialties by March 2023.^{405,406}

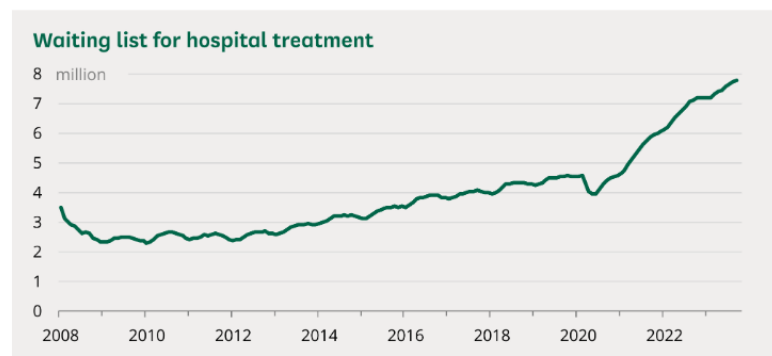
Below we present some illustrative figures as published on the UK countries websites. There are also data available for Scotland³⁶³ and Wales⁴⁰⁷.

ⁿⁿ <https://www.health-ni.gov.uk>



In England, an increase in the number of people on the waiting list for hospital treatment is noticed since 2012⁴⁰⁸ as presented in Figure 15.

Figure 15 – Evolution over time of the number of patients on the waiting lists for hospital treatment in England

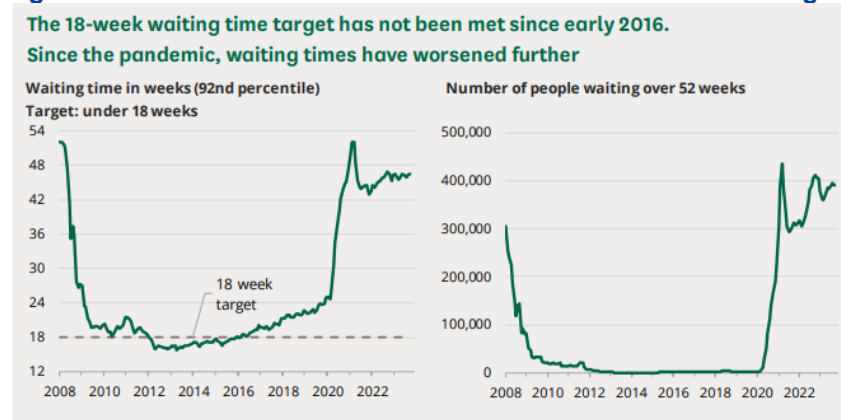


The waiting list for hospital treatment rose to a record of nearly 7.8 million in September 2023. The 18-week treatment target has not been met since 2016.

Source: [NHS key statistics: England - House of Commons Library \(parliament.uk\)](https://www.parliament.uk/library/publications/publication/2023-09-14/nhs-key-statistics-england)⁴⁰⁸

The RTT for consultant-led appointment exceed the targets of 18-weeks since several years in England as shown in the Figure 16.

Figure 16 – Evolution over time of the consultant-led RTT in England



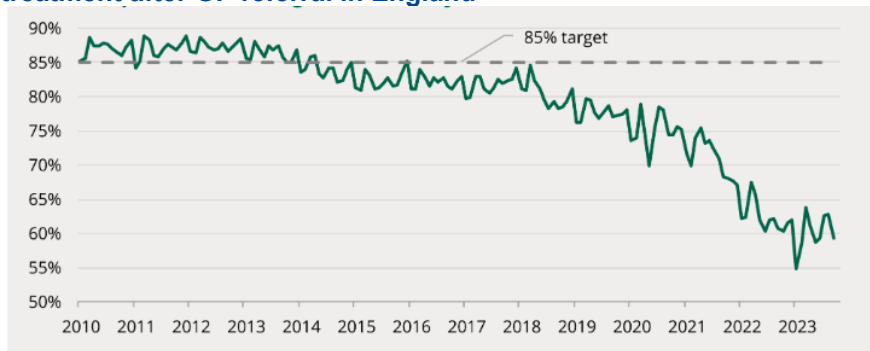
Source: NHS England, [Consultant-Led Referral to Treatment](https://www.nhs.uk/consultant-led-referral-to-treatment/), RTT overview timeseries

Source: [NHS key statistics: England - House of Commons Library \(parliament.uk\)](https://www.parliament.uk/library/publications/publication/2023-09-14/nhs-key-statistics-england)⁴⁰⁸



The waiting times for cancer treatment show also a problematic trend, with more and more patients not meeting the maximum WT of 62 days from the GP referral as reported in the Figure 17.

Figure 17 – Percentage of patients waiting under 62 days for cancer treatment after GP referral in England



The 62-day waiting time standard for cancer treatment (measured from urgent GP referral) has not been met in recent years. Performance declined between 2013 and 2018. Since the pandemic it has fallen further. In September 2023, 59.3% of patients waited under 62 days for treatment after an urgent GP referral, compared with an target of 85%.

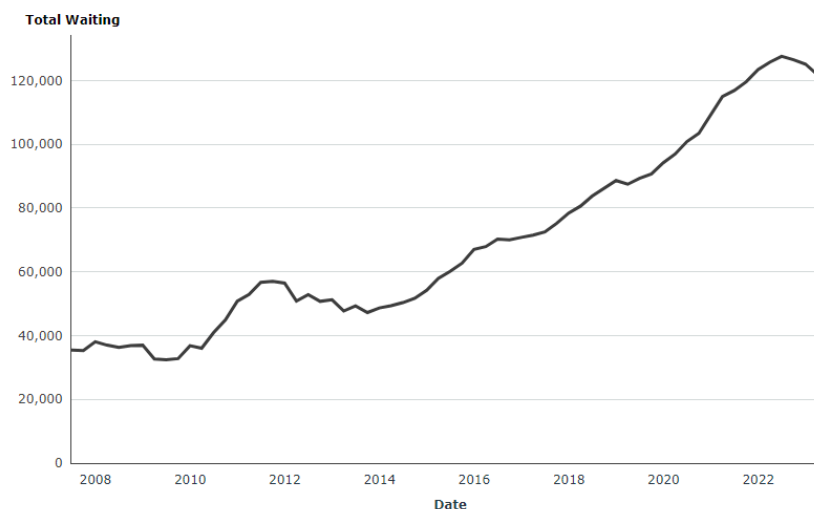
Source: [NHS key statistics: England - House of Commons Library \(parliament.uk\)](#)⁴⁰⁸

Some interesting interactive figures are also available for England in the British Medical Association.⁴⁰⁹

In Northern Ireland, several figures present the evolution of waiting times over time.³⁹⁰ For example, the number of patients waiting for an inpatient or day case admission shows a steady increase from 47,223 on 30 September 2013 to 127,541 on 30 June 2022. It has since decreased to 119,095 on 30 June 2023 as shown in the Figure 18.

Figure 18 – Patients waiting for an Inpatient or Day Case Admission in Northern Ireland

30 June 2007 to 30 June 2023



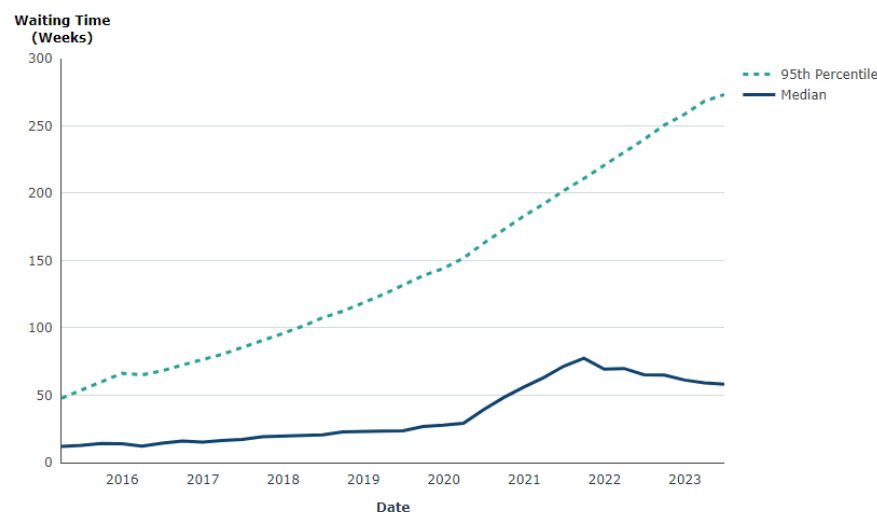
Source: [Northern Ireland Inpatient and Day Case Waiting Time Statistics \(nisra.gov.uk\)](#)³⁹⁰



The median and 95th percentile for inpatient and day case waiting times also show an increase over time as presented in the Figure 19.

Figure 19 – Median and 95th percentile Inpatients and Day case WT in Northern Ireland

31 March 2015 to 30 June 2023



Source: [Northern Ireland Inpatient and Day Case Waiting Time Statistics \(nisra.gov.uk\)](https://www.nisra.gov.uk/nisra/inpatient-and-day-case-waiting-time-statistics)³⁹⁰

8.6.3. Variation between regions within each UK country

The thresholds and the respect of standards do not only differ between the four UK countries but they can also vary substantially within each country. For example, in England, detailed information and regional comparisons of Increasing Access to Psychological Therapies (IAPT) waiting times for first treatment show huge differences across the country, from lows of 4 days in one region (Basildon and Brentwood) to highs of 61 days in another (Manchester).³²⁹

Furthermore, making comparisons across one country can be difficult because of small numbers. In Scotland for example, there can be substantial differences in cancer waiting times percentages from quarter to quarter in the Island NHS Boards, which may represent the pathway of one or two patients.³⁵⁸

8.6.4. Data quality

Data quality is a shared concern of the four UK countries and the National Statistics Status means that official statistics comply with all aspects of the Code of Practice for Official Statistics and meet the highest standards of trustworthiness, quality and public value. National Statistics status can be withdrawn at any time if the highest standards are not being maintained, and reinstated when standards are restored. Further information on the Code of Practice for National Statistics is available at: <https://www.statisticsauthority.gov.uk/monitoring-and-assessment/code-of-practice/>

In England, to ensure that Trusts have robust data collection systems and processes in place, NHS England and NHS Improvement:

- require all Trust annual governance statements from April 2015 to include an explicit statement on how the Trust will assure the quality, accuracy and risks of waiting time data, and;
- mandate regular assurance of waiting time data through internal audits, external audits or quality reports as part of their respective accountability frameworks for trusts and foundation trusts from April 2015.³³⁵

NHS England and NHS Improvement consider all requests for revisions to published data in line with the NHS England Analytical Services revisions policy.⁴¹⁰ Data revisions are normally published every six months (usually in January and July), alongside the latest release of new monthly data.³³⁵



In Scotland, PHS, in partnership with the Boards, look for unusual changes or patterns in the data (for example in RTT) that may indicate a data quality issue. Any potential anomalies are raised/discussed with the individual Board in order to verify the accuracy of the data or to correct any problems. PHS records any data quality issues and include them in the data quality section of the publication tables where appropriate. For example, a significant data quality issue was identified in 2020 in datasets submitted by six NHS Health Boards due to a problem in a software update.³⁶³

In Wales, the statistics website describes, if any, the quality issues for each indicator. Thematic quality reports are also published.^{381, 384}

In Northern Ireland, validation checks are conducted by both HSC Trust providers and statisticians in the Department of Health, with changes made to the data as required, to help improve the accuracy and reliability. Irregularities, potential duplicate records, incorrect dates, cases reallocated to another HSC Trust are outlined and require amendment and explanation by the HSC Trust.^{394, 395}

In each country, **guidance** with the requirements for data collection and quality assurance checklists is available. For example in England for consultant-led treatment³³⁵ and for cancer waiting times^{339, 336}, in Scotland, for cancer waiting times⁴¹¹, in Northern Ireland, for outpatient waiting times³⁹⁸ or diagnostic waiting times³⁸⁷

8.6.5. Limitations in the interpretation of waiting times

Waiting time data should be interpreted with caution for several reasons. As it is not possible to be exhaustive in this matter, some examples are given below, as mentioned in the different UK national websites.

Missing data

The global country-level WT percentage may change if a large trust, which has previously had extreme values, fails to submit data.³⁴⁰

False representation of the reality

The clock pause is an issue highlighted by some authors as it allows the calculation of waiting time to exclude certain periods of time and therefore gives a false representation of the real time the patient has waited.⁴¹² The aim of recording is to measure waiting times that are due to the provider (not the patient deciding to put on hold the wait, for example because they have a plan or go on holiday) but it is not so simple in practice (Personal communication).

It is not the single source of error in interpreting the results.

In Northern Ireland, the risk of users misinterpreting waiting time data as the average time patients wait within each specialty is identified and documentation is provided to clarify that data refer to the length of time patients were waiting at a specific point in time. Patients included in this data may have only recently been added to the waiting list. Therefore, the reported waiting times may not correlate with the total expected wait for any given specialty.³⁸⁷

In Scotland, the WT measures for new outpatient appointments and inpatients of day case do not report on how long patients actually waited until they received care. Patients removed from the waiting list between the census dates in February 2019 and March 2019 will only be in February data. However, the additional length of wait can be between 1 and 31 days in this instance.³⁶³

Relevance

Relevance (i.e. the extent to which the statistical product meets user needs in both coverage and content) is an important concern for data providers. This is explicitly mentioned in Northern Ireland, where Hospital Information Branch (HIB) ensures the relevance of outpatient WT to users by including: openly welcoming feedback from known users upon issuing each quarter's publication, providing contact details publicly so that other users can easily get in touch, and undertaking national statistics consultations where necessary.³⁹⁸



Seasonality

It is important to take into account the season when making quarter-on-quarter comparisons, as measures of waiting time performance are subject to seasonality. For example, bad weather in winter can change the balance between elective and emergency care. Similarly, the number of patients starting treatment is influenced by the number of working days in the quarter.³⁴⁰

8.6.6. Equity or not

An important equity issue is the way in which patients are prioritised on the waiting lists. According to a report published in November 2023, *“there are structural, economic and social factors that can lead to inequalities on elective waiting lists”*, with people living in the most deprived parts of England being 2.1 times more likely to wait more than a year for elective treatment than people living in the most affluent areas. Explanations given are: difficulties in attending appointments, difficulties in navigating the NHS, different health status and rate of disease progression (*“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”*)...⁴¹³

As mentioned on the NHS England website: *“For the many individuals who are subject to long waiting times or who seek care not routinely available on the NHS, the alternative is to seek care in the private health care sector, either through out-of-pocket payments or supplementary private medical insurance (see Section 3.5, Voluntary health insurance). NHS England (2021e). Consultant-led referral to treatment waiting times data 2020–21”*.⁴¹⁴

Purchasing private capacity is not new, but the pandemic has required unprecedented block-booking arrangements. As the British Medical Association (BMA) highlighted, asking the support from the private sector was even one of the measures taken by the governments to reduce pressure on hospitals and decrease waiting lists.⁴⁰⁹ And it shows that the number of patients buying private hospital care in England has increased since the pandemic.⁴¹⁵

However, this option is not available to every UK citizen and raises the question of equity in relation to waiting times.



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