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BRIEFING PAPER

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NHS maximum waiting times standards and patient choice policies

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Summary

This briefing describes policies on NHS maximum waiting time standards and patient choice, principally in England, although a brief synopsis of waiting times standards across the UK is provided. The Library also publishes a statistical bulletin, NHS Key Statistics, which provides the latest figures for waiting times.

As set out in the *NHS Constitution*, patients have the right to a maximum 18 week waiting time from referral to consultant-led treatment. Patients also have the right to be seen by a cancer specialist within a maximum of two weeks from GP referral for urgent referrals where cancer is suspected. In September 2015, the Government pledged to introduce a new four week waiting time standard for cancer diagnosis by 2020.

The *NHS Constitution* also provides a series of pledges on maximum waiting times for services such as diagnostic tests, A & E, and treatment for diagnosed cancer.

Many of these expected standards are monitored as a percentage of patients. If the expected percentage of patients is not seen within the standard, the Government can impose financial sanctions if this is set out in a provider's contract. However, although since April 2016 many local NHS teams have not met the standards for A&E and elective care, the Government has not imposed sanctions. Instead it has focussed on improving standards, particularly in A&E departments.

Since 2015, the Government has introduced a number of waiting time standards for talking therapies, treatment for psychosis and children and young people with an eating disorder. The Government is piloting a four-week target for access to specialist children's mental health services in several areas in England.

The Government and NHS England are also working to improve **patient choice** within the NHS, which is a legal right as set out in the *NHS Constitution*.

Patients have a right to choose their provider and consultant-led team when they are referred for their first outpatient appointment with a service led by a consultant. These rights were for the first time extended to mental health services in April 2014. There are some exceptions to this right, including for people detained under the *Mental Health Act 1983*.

To further strengthen patient choice, a legal right to have a personal health budget was introduced for adults receiving NHS Continuing Healthcare and children and young people receiving Continuing Care in October 2014. The *NHS Mandate 2014-15* also set an objective for the NHS to further roll out personal health budgets to anyone who could benefit, by April 2015.

In 2015, the Government made clear its intention to bring greater choice in palliative care. This included personal health budgets, but also introducing new digital solutions, new care coordinator roles, better training and more public campaigns to promote personalisation of end of life care.

In successive Mandates, the Government has expressed the desire to introduce more choice for maternity services, palliative care and people with long-term conditions by 2020. The Government has consulted on giving more groups the **right to have** a personal health budget (including those with learning disabilities and wheelchair users) but has not yet published its response to the feedback.

1. Maximum waiting time policies

The Department of Health states that all patients should receive high-quality care without any unnecessary delay.[1] The NHS Constitution sets out most of the targets related to waiting times. These are either expressed as **rights** and **pledges**.

Rights are legally protected: the source of these rights is part 9 of the *National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012*, as amended.

Pledges are not legal rights; the Department of Health states that "the pledges are not legally binding and cannot be guaranteed for everyone all of the time, because they express an ambition to improve, going above and beyond legal rights.[2]

If stated in a contract, an NHS body which fails to meet an agreed standard may be subject to sanctions.

1.1 Elective (planned) care

The *NHS Constitution* provides that patients have a **right** to certain NHS treatment within maximum waiting times. The maximum waiting time standards are outlined in the handbook to the NHS Constitution:

> You have the right to:
>
> - start your consultant-led treatment within a maximum of 18 weeks from referral for non-urgent conditions; and
> - be seen by a cancer specialist within a maximum of two weeks from GP referral for urgent referrals where cancer is suspected.[3]

The 18 week waiting time target from referral to consultant-led treatment (often known as Referral to Treatment or RTT) was first introduced in June 2004 as part of a series of measures introduced by the Labour Government to reduce hospital waiting. The 18 week measure was originally devised as an ambition to be achieved by 2008, but then remained as an ongoing target.[4]

If it is not possible for treatment to be provided within the current maximum waiting times, the Clinical Commissioning Group (CCG) or NHS England, depending on the type of treatment, must take all reasonable steps to offer an alternative provider, or a range of suitable alternative providers, that would be able to provide treatment more quickly than the provider to which the patient was initially referred.[5] The patient will need to contact either the provider they have been referred to or their local CCG before alternatives can be investigated. The CCG or NHS England must take all reasonable steps to meet their request.

There are certain exceptions to the right to treatment within maximum waiting times:

> In particular, the right to treatment within 18 weeks from referral will cease to apply in circumstances where:
>
> - you choose to wait longer;

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1 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 34
2 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 4
3 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 31
4 Journal of the Royal Society of Medicine, Can the English NHS meet the 18-week waiting list target?, January 2006
5 NHS, The NHS Constitution for England, July 2015, page 6

- delaying the start of your treatment is in your best clinical interests, for example where smoking cessation or weight management is likely to improve the outcome of the treatment;
- it is clinically appropriate for your condition to be actively monitored in secondary care without clinical intervention or diagnostic procedures at that stage;
- you fail to attend appointments which you had chosen from a set of reasonable options; or
- the treatment is no longer necessary.[6]

Certain services are also exempt from maximum waiting time standards. According to the Handbook to the NHS Constitution, these are:

- mental health services that are not consultant-led;
- maternity services; and
- public health services provided or commissioned by local authorities.[7]

Targets have since been introduced for mental health services: see section 1.6 below.

Part 9 of the *National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012* set a target that **at least 92% of patients wait for less than 18 weeks for their treatment**. This has the standard expected of all relevant bodies, although in 2016, this has been slightly relaxed. For more details about recent changes, see section 1.3 below.

Minimum waiting times?

In 2017 and 2018, it has been reported that several clinical commissioning groups have been considering introducing minimum waiting times for non-urgent treatments as a means of reducing expenditure. Primary Care Trusts, the precursors to CCGs, were banned from instigating a minimum wait policy under the Coalition Government but this ban was lifted when CCGs came into being in 2013.[8]

In September 2017, the GP news website Pulse revealed that the NHS Cambridgeshire and Peterborough CCG was bringing in minimum waiting times of approximately 12-18 weeks for "all adults requiring non-urgent treatment." The CCG was subject to a Capped Expenditure Process due to their large budget deficit.[9] The policy was abandoned by the CCG after the move was "widely condemned."[10]

In November that year, NHS Trafford CCG and four CCGs in Lincolnshire were also reportedly considering introducing minimum wait times in order to reduce their costs.[11] By February 2018, NHS South West Lincolnshire CCG had gone ahead with at least some elements of the plans, which may mean an increase in wait times for non-urgent treatment by a month.[12]

The vice president of the Royal College of Surgeons condemned the Lincolnshire CCG's move, believing that it would make meeting the 18 week standard wait time for treatment unlikely. He added,

6 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 33
7 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 33
8 CCGs consider bringing in minimum waiting times, BMJ, 17 November 2017
9 CCG instates minimum 12-week referral waiting times, Pulse, 26 September 2017
10 NHS brings in three month minimum waiting times despite warnings patients will suffer, Telegraph, 18 February 2018
11 CCGs consider bringing in minimum waiting times, BMJ, 17 November 2017
12 NHS brings in three month minimum waiting times despite warnings patients will suffer, Telegraph, 18 February 2018

> This policy is wrong and it is unlikely to save money in the long run. In fact, delaying surgery can cause a patient's condition to deteriorate and reduce the efficacy of an operation – in turn increasing the bill for a patient's social care support.[13]

In response to a parliamentary question in October 2017 on the Department's reaction to such a policy, Phillip Dunne, the Health Minister, said

> Clinical priority is the main determinant of when patients should be treated followed by the chronological order of when they were added to the list. Clinicians should make decisions about patients' treatment and patients should not experience undue delay at any stage of their referral, diagnosis or treatment.[14]

A spokesperson for the Department of Health is also quoted as saying in 2017 that

> Blanket restrictions on treatment are unacceptable. All decisions on treatment should be made by doctors based on a patient's individual clinical needs and ensuring that patients' rights to choice are fully respected.[15]

1.2 Accident and emergency (A&E)

The NHS Constitution **pledges** that there should be "a maximum four-hour wait in A&E from arrival to admission, transfer or discharge."[16] As a pledge, this is not a legal right, but this has been a benchmark for A&E performance for many years.

This commitment was first introduced as a national standard in 2004: 98% of patients were expected to spend no longer in A&E than four hours. This was reduced to 95% in England in 2010.[17]

1.3 Financial sanctions for missed targets

In December 2015, the 18 weeks standard for elective care was breached for the first time since December 2011. The 92% target was met in the following two months but was missed again in March 2016 and in each month up to and including July 2018.[18]

The target of 95% of A&E patients being treated or discharged within four hours has not been met since July 2015.[19]

More information on the waiting times for elective and emergency care can be found in sections one and three of the Library paper, NHS Key Statistics.

NHS leaders have, on the whole, suspended the requirement to meet these targets from April 2016, as explained by the Government in March 2018:

> **Steve Barclay:** Providers of National Health Service-funded healthcare services are expected to meet a range of waiting time standards and other operational standards and quality requirements, in order to deliver the rights and pledges in the NHS Constitution and to achieve other national priorities. These requirements are set out in the NHS Standard Contract, which is used by clinical commissioning groups (CCGs) for all contracts with hospital providers of NHS healthcare services. The Contract sets out the consequences of breaches of the waiting time standards and other requirements. In many cases, this consequence is in the form of a financial sanction.

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13 Royal College of Surgeons, Minimum waiting times are wrong and highlight the need for investment in our NHS, 20 February 2018
14 PQ 107231 [Surgery: Waiting Lists] 18 October 2017
15 CCGs consider bringing in minimum waiting times, BMJ, 17 November 2017
16 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 33
17 National health Executive, The four-hour target: what's the point? December 2016
18 House of Commons Library, NHS Key Statistics, updated 2 October 2018, p.13
19 House of Commons Library, NHS Key Statistics, updated 2 October 2018, p.5

> However, since April 2016, the operation of certain contractual sanctions for reduced performance against waiting time standards, including four hour and 12 hour waits in accident and emergency (A&E) and the Referral to Treatment 18 week incomplete pathways standard has been suspended where a provider is receiving funding from the national Sustainability and Transformation Fund (STF) and meets certain other specified conditions. The overall effect is that, in 2017/18, the Contract sanctions for A&E performance are not being applied to the majority of NHS hospitals – only to a very small minority which refused the offer of funding from the STF and the associated conditions.[20]

Each year, the Government publishes its Mandate to the NHS, which the **NHS Commissioning Board must seek to implement** under Section 13A of the *National Health Service Act 2006.* Recent Government mandates to the NHS have outlined a desire to return to the targets for elective and emergency care by 2020, but in the meantime focussing on improving A&E wait times. For instance, the *Mandate for 2018-19* sets out the following 'deliverables' for the year 2018-19:

- Co-implement the agreed A&E recovery plan with NHS Improvement and deliver aggregate A&E performance in England above 90% in September 2018, with the majority of trusts meeting 95% in March 2019, and aggregate performance in England at 95% within the course of 2019,
- […] With NHS Improvement, meet agreed standards on A&E, ambulances, diagnostics and referral to treatment.[21]

NHS Improvement has reiterated the focus on A&E standards for 2020:

> Objective 8: Consistently meet NHS Constitution standards over the period, with a particular focus on the aggregate A&E standard, while improving quality and efficiency.
>
> We will support providers to achieve NHS Constitution standards, including A&E waiting times, referral to treatment times, diagnostic waiting times, cancer waiting times, ambulance response times and patient choice.
>
> We will focus on the A&E target (95% of patients seen and discharged or admitted within four hours). As well as being an important clinical measure in its own right, this target is a significant indicator of operational performance and patient flow within providers and across local health and care systems. To address A&E performance providers and their local health and care systems will need to take actions to improve patient flows and performance against the range of constitutional standards.[22]

In March 2017, when the suspension of financial sanctions was reaffirmed by NHS leaders, the Chief Executive of NHS England was reported saying that de-prioritising the 92% target allowed the NHS to focus on more 'urgent' targets, including A&E waits, enhancing GP access, and improving treatment of cancer (see section 1.5).[23] In Next steps on the NHS Five Year Forward View (March 2017), the NHS further explained that due to the pressures faced by the NHS, the 'median wait for routine care may move marginally' over the next two years but the rate achieved would still represent a 'strong performance compared both to the NHS' history and comparable other countries.'[24]

1.4 Ambulance response times

The NHS Constitution **pledges** the following:

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20 Written PQ 130061 [Hospitals: Standards] 06 March 2018
21 Department of Health and Social Care, The Government's Mandate to NHS England 2018-19, March 2018
22 NHS Improvement, 2020 Objectives, July 2016
23 Guardian, NHS 'waving white flag' as it axes 18-week waiting time operation target, 31 March 2017
24 NHS, Next steps on the NHS five year forward view, p.47

- all ambulance trusts to respond to 75 per cent of Category A calls within eight minutes and to respond to 95 per cent of Category A calls within 19 minutes of a request being made for a fully equipped ambulance vehicle (car or ambulance) able to transport the patient in a clinically safe manner.[25]

Since then, both the categories of calls and standards for ambulance responses have changed. Most recently, in July 2017, the Government accepted NHS England's proposals for a new ambulance performance framework. All mainland ambulance services adopted this framework in November that year.[26]

There are now four categories of calls:

- Category 1: the most life-threatening emergencies. The expected national standard for an ambulance to arrive is **7 minutes on average**, with 90% of cases to be seen by emergency services in under 15 minutes.
- Category 2: emergency calls. The expected national standard is for an **average 18 minute wait** for an ambulance, with 90% of ambulances arriving in under 40 minutes.
- Category 3: urgent calls, in which an ambulance should arrive within **120 minutes** for at least 90% of patients
- Category 4: less urgent calls in which 90% of patients should be seen by an ambulance within **180 minutes**.[27]

More details on how calls are handled and response times are monitored can be found on NHS England's website.

As explained in section 7 of NHS Key Statistics paper, ambulance trusts have yet to meet the average wait times standards but have achieved, or been close to achieving, the 90th percentile waiting times standards.

1.5 New cancer waiting time standard

The NHS has a number of expected wait-times for cancer treatments, listed below. The target percentage of patients reaching this standard is highlighted in brackets:

- a maximum two week wait from urgent GP referral for suspected cancer to first appointment [93%]
- a maximum one month (31-day) wait from diagnosis to first definitive treatment for all cancers; [96%]
- […] a maximum 31-day wait for subsequent treatment where the treatment is a course of radiotherapy; [94%]
- a maximum 31-day wait for subsequent treatment where the treatment is an anti-cancer drug regimen; [98%]
- a maximum two month (62-day) wait from urgent referral for suspected cancer to first treatment for all cancers; [85%]
- a maximum 62-day wait from referral from an NHS cancer screening service to first definitive treatment for cancer; [90%]
- a maximum 62-day wait for first definitive treatment following a consultant's decision to upgrade the priority of the patient (all cancers); [no operational standard set]

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25 Department of Health, The Handbook to the NHS Constitution, July 2015, p.34
26 PQ 146985 [Ambulance Services: Standards] 31 May 2018
27 See NHS England, New ambulance standards, accessed 9 October 2018 and NHS England, Letter from Professor Sir Bruce Keogh to Jeremy Hunt MP about the Ambulance Response Programme, dated 13 July 2017

- a maximum two-week wait to see a specialist for all patients referred for investigation of breast symptoms, even if cancer is not initially suspected [93%][28]

Only the two-week target is a right set out set out on the NHS Constitution.[29] The rest are **pledges**, and as noted above, these are not legally binding. Indeed, as discussed during a debate on Cancer targets on 1 June 2018, "many CCGs and cancer alliances are not close to achieving many of those targets" and the 62-day standard has only been met once since January 2014.[30] Writing in January 2018, Quality Watch (ran by the Nuffield Trust and the Health Foundation) pointed out that the NHS has persistently missed the 62 day standard, while other targets, such as the 14 and 31 day targets, have been on the whole, achieved: this might be indicative of long diagnostic delays post referral.[31]

Since that comment by Quality Watch, the NHS has also begun to struggle to meet the 14 day standard, which has not been met since April 2018.[32] More details on cancer waiting times can be found in the Library's paper, NHS Key Statistics (chapter 4).

In July 2015, the Independent Cancer Taskforce published a five year strategy for the NHS, to improve cancer outcomes. The Taskforce recommended setting an ambition that by 2020, 95% of patients referred for testing by a GP are definitively diagnosed with cancer, or cancer is excluded, and the result communicated to the patient, within four weeks.[33] This would replace the two-week (14 day) target.

In September 2015, the Government responded to this recommendation and pledged that from 2020, people with suspected cancer will be diagnosed within 28 days of being referred by a GP. The Government also made a commitment that, by 2020, it will spend up to £300 million more on diagnostics every year to help meet the new 28-day target.[34]

In 2016, five sites (NHS trusts in Bournemouth, East Lancashire, Ipswich, Kingston and Leeds) began piloting the 28-day standard across six cancer pathways - gynaecology, urology, head and neck, lung, lower and upper gastrointestinal.[35]

The Independent Cancer Taskforce also recommended the establishment of local Cancer Alliances, which would coordinate relevant services to ensure better joined up working. Cancer Alliances have since been established, and in the Next Steps on the NHS Five Year Forward View, published in March 2017, the Government made a link between future extra funding for cancer alliances and the 62 day waiting time standard:

> We will focus specifically on the **cancer 62-day from referral to treatment standard** ahead of the introduction of the **new standard to give patients a definitive diagnosis within 28 days** by 2020. Performance incentives for achievement of the cancer 62-day waiting standard will be applied to extra funding available to our cancer alliances.[36]

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28 NHS England, The Handbook to the NHS Constitution, July 2015 and National Cancer Registration and Analysis Service website, accessed 15 August 2018
29 Department of Health, The Handbook to the NHS Constitution, July 2015, p.31
30 HC deb 01 May 2018 Volume 640, c.73WH
31 Quality Watch, Cancer waiting times: how has NHS performance changed over time? 23 January 2018
32 House of Commons Library, NHS Key Statistics, updated 2 October 2018, p.14
33 Independent Cancer Taskforce, Achieving World-Class Cancer Outcomes: A Strategy For England 2015-2020, July 2015
34 Department of Health, From 2020, people with suspected cancer will be diagnosed faster, 13 September 2015
35 NHS England, Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020 – Progress Report 2016-17, October 2017, p31
36 NHS, Next Steps on the NHS Five Year Forward View, p.23

Making extra funding to Cancer Alliances subject to conditions regarding the 62-day standard has led to concerns that those which miss the target will lose out on useful funding. When this has been raised in Parliament however, it has been suggested by Ministers that funding might still be available if Cancer Alliances show **plans** to achieve the 62-day standard.[37]

The Government's *Mandate to NHS England 2018-19* reaffirmed that the Government wants to achieve the goals set out by the Independent Cancer Taskforce by 2020: this includes meeting the 62-day cancer waiting times standard in 2018-19.[38] Writing in July 2018, Department for Health and Social Care stated that the Government was 'on track' to deliver on these goals.[39]

1.6 Waiting time standards for mental health services

Parity of esteem and adult mental health services

The NHS has set out that it wants to achieve "parity of esteem" between mental and physical health, in terms of access to services, quality of care and allocation of resources. Since 2010 parity of esteem has increasingly featured in legislation (*Health and Social Care Act 2012*) and in policy. The Government has introduced new waiting time targets for mental health services, as outlined below.

2014: "Achieving better access to mental health services"

In October 2014, NHS England and the Department of Health jointly published Achieving Better Access to Mental Health Services by 2020. This set out a vision to ensure that mental and physical health services were given equal priority in terms of access times and service quality. It set out that from April 2015, patients should access talking therapy treatment within 6 weeks from diagnosis, with a maximum wait of 18 weeks. For patients experiencing a first episode of psychosis, access to early intervention services should be available within two weeks.

The percentage of patients expected to receive treatment within these targets was also set out:

> From 1 April 2015 (to be fully implemented by April 2016), the new waiting time standards will be as follows:
>
> - 75% of people referred for talking therapies for treatment of common mental health problems like depression and anxiety will start their treatment within 6 weeks and 95% will start within 18 weeks
> - at least 50% of people going through their first episode of psychosis will get help within 2 weeks of being referred: the aim is to increase this percentage in future years.[40]

This was supported by an £80 million funding package for 2015-16 from NHS England's budgets, breaking down as:

- £40 million recurrent funding to support delivery of the early intervention in psychosis (EIP) standard;

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37 This was discussed in a debate on the Cancer Strategy (HC deb 22 February 2018, Volume 636, column 431) and later in a debate on Cancer targets (HC deb 1 May 2018 column 77WH)

38 Department of Health and Social Care, The Government's mandate to NHS England for 2018-19, March 2018

39 Written PQ [NHS: Standards] 165678, 23 July 2018

40 Gov.uk, First ever NHS waiting time standards for mental health announced, 8 October 2014

- £10 million to support delivery of the new psychological therapies standards; and
- £30 million to support liaison psychiatry in acute hospitals.[41]

The Department of Health and NHS England said that their ambition was for access and waiting time standards to be implemented for all mental health services over the next five years:

> Access and waiting time standards for treatment in physical health will be complemented by access and waiting time standards for mental health. Starting in some key areas next year, for the next five years the vision is for all mental health services to guarantee people access to timely, evidence-based and effective treatment. In doing so the NHS will not only shorten the time that people go without treatment and support, but also improve outcomes.[42]

For example, the Government said it would like to see 95% of people referred to **IAPT** (Increasing Access to Psychological Therapies programme) to be treated within six weeks of referral, and would like to see rapid access to services within 24 hours for post-partum psychosis, in the perinatal period for women who have a mental health condition.[43]

2016: Five Year Forward View for mental health

The Five Year Forward View for Mental Health was published in February 2016. This was produced by the Mental Health Taskforce which was commissioned by NHS England and chaired by Paul Farmer, Chief Executive of Mind. It made a series of recommendations for improving outcomes in mental health by 2020/21, much of which focussed on building capacity within services, rather than adopting wait times standards, although it recommended that 60% of those with first episode psychosis should receive treatment within 2 weeks by 2020/21.[44]

In July 2016, NHS England published its plans for these recommendations, entitled Implementing the Five Year Forward View For Mental Health. NHS England accepted many of the Taskforce's proposals directed at the organisation, including the 60% standard for first episode psychosis. NHS England also outlined the support it would offer to implement the Five Year Forward Review for Mental Health. This included the development of **'treatment pathways'** which will set out "expectations regarding referral to treatment waiting times, interventions provided and outcomes measured."[45]

In January 2017, the Government accepted all the recommendations of the *Five Year Forward View for Mental Health* report that were directed at central Government, either in full or 'in principle'. In particular, it accepted in principle recommendation 52, that "The Department of Health should carry out a review of existing regulations of the Health and Social Care Act to identify disparities and gaps between provisions relating to physical and mental health services." This included waiting times.[46]

The Government also delineated their achievements so far, including

- Exceeding the target waiting time for early intervention in psychoses: in October 2016 76.6% of people had begun treatment within 2 weeks

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41 PQ HL3514 [on Mental health services], 23 November 2015
42 Department of Health and NHS England, Achieving better access to mental health services by 2020, October 2014, page 11
43 Department of Health and NHS England, Achieving better access to mental health services by 2020, October 2014, page 18
44 NHS England, The Five Year Forward View for Mental Health, p.12
45 NHS England, Implementing the Five Year Forward View For Mental Health, 2016, p.44
46 HM Government, The Government's response to the Five Year Forward View for Mental Health, January 2017, p.21-2

- For those referred to the IAPT, introducing a waiting time standard of 75% patients treated in 6 weeks, and 95% of patients being treated in 18 weeks

The Government said that "the majority of CCGs are meeting the waiting time elements of the standards for IAPT and Early Intervention in Psychosis, but we will go further."[47]

The NHS has continued to meet their waiting time targets for IAPT and Early Intervention in Psychosis. Section two of the Library briefing Mental health statistics for England: prevalence, services and funding outlines waiting time performance for IAPT in England. According to the most recent data, patients wait on average 23 days for their first treatment, although this ranged from 5 to 135 days depending on locality.[48]

As the paper also makes clear, the Early Intervention in Psychosis waiting time standard has also been met since December 2015, although the percentage of those being seen within two weeks has dropped from a peak of 80% in February 2017 to 69% in January 2018. Again, activity across the country varies greatly.[49]

The Government's mandate to NHS England for 2018-19 reiterates the Government's commitment to the implementation of the *Mental Health Five Year Forward View* by 2020. In 2018-19, the Government expects to "embed access and waiting time standards for mental health services for Early Intervention in Psychosis, Improving Access to Psychological Therapies and eating disorders."[50]

Children and young people's mental health services

When asked whether they intend to introduce waiting time standards for child and adolescent mental health services (CAMHS) in 2015, the Government stated:

> The setting of a blanket waiting time target for children and young people's mental health is not feasible due to the wide range of conditions and services this covers, all with very different care pathways. However, we are introducing the first ever waiting time standards for mental health services.
>
> These include an access and waiting time standard for Children and Young People with an Eating Disorder. This states that National Institute of Health and Care Excellence concordant treatment should commence within a maximum of four weeks from first contact with a designated healthcare professional for routine cases and within one week for urgent cases. In cases of emergency, the eating disorder service should be contacted to provide support within 24 hours. The ability of services to meet this standard will be monitored in 2016. From 2017, NHS England will set a minimum proportion of young people referred for assessment or treatment that are expected to receive treatment within the standard's timeframe. Data collected in 2016 will help inform incremental percentage increases, with the aim of 95% of patients being treated within the standard's timescale by 2020.
>
> We have also introduced an access and waiting times standard on Early Intervention in Psychosis announced in *Mental health services: achieving better access by 2020* which came into force in April 2015. Whilst focused on all ages, most individuals experiencing a first episode of psychosis are in the 16-25 age group.
>
> NHS England will be working with partner organisations to lead work on the development of further access and waiting time standards for children's mental health

47 HM Government, The Government's response to the Five Year Forward View for Mental Health, January 2017, pp6 & 22
48 House of Commons Library, Mental health statistics for England: prevalence, services and funding, 25 April 2018, p.20
49 House of Commons Library, Mental health statistics for England: prevalence, services and funding, 25 April 2018, p.25
50 Department of Health and Social Care, Government's mandate to NHS England for 2018-19, March 2018

> as part of the transformation programme on children and young people's mental health.[51]

In Implementing the Five Year Forward View For Mental Health (July 2016) NHS England stated, in regards to children's services, that "In 2016/17, all localities are expected to baseline current performance against the new access and waiting time standard and plan for improvement, in advance of measurement against the standard beginning from 2017/18."[52]

In September that year, NHS England announced that it had "reprioritised spending" to free up an extra £25m to go to CCGs to spend on CAMHS. In order to receive the extra funds, CCGs will need to provide details of how they will reduce average waiting times for CAMHS treatments by March 2017.[53]

In December 2017, the Department of Health and Social Care and the Department for Education jointly published the Green Paper Transforming children and young people's mental health provision. The paper proposes the creation of Mental Health Support Teams, supervised by NHS children and young people's mental health staff, to provide extra capacity for early intervention and ongoing help. Alongside this, the Government noted its intention to "trial a four week waiting time for access to specialist NHS children and young people's mental health services" in pilot areas.[54] Initially this was envisaged to be a four week wait for "**access to assessment** for specialist services."[55] However, the Government response to this consultation, committing to these proposals, stated that from 2018, pilot areas will "seek to start planning for and then providing **access to evidence-based treatment** on average within four weeks". The Government aims to rollout these trials across 20-25% of the country by end of 2022/23.[56]

The Education and Health and Social Care Select Committees published a report in May 2018 - The Government's Green Paper on mental health: failing a generation - which said that the Green Paper does not go far enough and risks leaving children without the care they need. It singled out the timescale of 25% coverage by the end of 2022/3 as particularly unambitious, but also criticises the difficulties there are in identifying mental health problems and meeting the "high threshold" for treatment.[57] As waiting times targets only look at the period following a diagnosis/referral, eligibility thresholds were not addressed by the plans set out in the Green Paper.

The Care Quality Commission's (CQC) report Are we listening? (March 2018) found a number of barriers to treatment, including "excessively restrictive eligibility criteria, confusing referral routes, and gaps in the availability of services." The CQC acknowledge that a lot more will need to be done at a professional and societal level to ensure that issues are tackled when the first symptoms of a problem occur.[58]

The CQC's criticism of eligibility threshold's we raised in the Lords Chamber in March 2018:

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51 PQ 16650 [on Mental health services: Children and young people], 20 November 2015
52 NHS England, Implementing the Five Year Forward View For Mental Health, 2016
53 NHS England, Extra £25m for NHS organisations in England to improve mental health services for children and young people, 27 September 2016
54 DfE and DoH, Transforming Children and Young People's Mental Health Provision: a Green Paper, December 2017
55 HC deb 12 December 2017, Volume 633, column 373
56 DfE and DoH, Government Response to the Consultation on Transforming Children and Young People's Mental Health Provision: a Green Paper and Next Steps, July 2018
57 House of Commons Education and Health and Social Care Committees, The Government's Green Paper on mental health: failing a generation, 9 May 2018
58 Care Quality Commission, Are we listening? March 2018

> **Baroness Thornton (Lab):** […] What emerges from the Care Quality Commission's review of children and young people's mental health is the glaring finding, to which he has not referred, that children are suffering because of high eligibility thresholds. We know that 50% of mental health problems develop before the age of 14, and 75% develop before the age of 18. Does the Minister recognise that imposing high eligibility thresholds means that children and young people are treated only when their condition becomes very serious? Will he look into the referral criteria as a matter of urgency so that children and young people are getting proper treatment at the right time, thereby preventing a crisis that brings greater suffering for those children and their families, and greater expense for the health service?
>
> **Lord O'Shaughnessy:** I thank the noble Baroness for those questions. On the issue of high eligibility thresholds, we are grappling with a need to expand the amount of mental health services that can be provided. Currently, about one in four children with a diagnosable mental health condition accesses NHS services. That is clearly not enough and the intention is to get that figure to one in three by 2021. Again, that is not enough but it would be progress. There is a need to move along the path, dealing first with those in the most acute trouble and then rolling out to those with less acute conditions. I agree with the noble Baroness's point and recognise the issue. However, this cannot achieved overnight, not least because a huge number of new staff are needed to be trained in order to deliver that. We are looking at the issue of referral criteria. I should also point out to her that we have made big steps forward on waiting times and new standards for early intervention in psychosis and eating disorders. We are piloting a waiting time for access to specialist help and hope that that will start to move things along in terms of more children being seen more quickly, which is what we all want.[59]

No comprehensive data on waiting times for CAMHS services is currently collected. In October 2018, the National Audit Office published Improving children and young people's mental health services which noted that the Government believes patient data will be sufficiently improved by April 2019 so that progress can be accurately monitored.[60]

Eating disorders

In March 2015, the Government announced a £150 million investment for eating disorders over the next five years, along with a new waiting time standard for eating disorders to be set from 2016.[61] These standards were set out later that year in commissioning guidance on an *Access and waiting time standard for children and young people with an eating disorder*. The standard is for **NICE recommended treatment to be received within a maximum of 4 weeks** from first contact with a designated healthcare professional for routine cases and **within 1 week for urgent cases**.

In cases of emergency, the eating disorder service should be contacted to provide support **within 24 hours**.

Data collected from 2016 onwards will help inform incremental percentage increases in compliance with the standard, with the aim of 95% of patients being treated within the standard's timescale by 2020.[62]

- From April 2017, progress towards achieving the new access and waiting times for children and young people with eating disorders, so that by 2020 95% of children and young people are seen within one week if urgent and four weeks if routine, will be monitored

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59 HL deb 08 March 2018, Volume 789, Column 1233-4
60 National Audit Office, Improving children and young people's mental health services, October 2018, p.46
61 HC Deb 3 March 2015 c914
62 PQ 16909 [on Mental health services: Children], 20 November 2015

These new waiting times standards for children and young people with an eating disorder came into force in April 2017. The Government hopes that these targets will be met for 95% of patients by 2020.

Data on eating disorder referrals for young people is published on a quarterly basis on NHS England's website, although it is admitted that the "data collection is still experimental." According to this dataset, the percentage of those referred according to the standard has shown improvement since the collection began and in Q1 of 2018-19, 74.7% of urgent cases were referred in a week, and 81.2% of non-urgent cases began their treatments in four weeks.[63] However a survey of 3,158 individuals carried out by Beat (the eating disorder charity) found that some people are still facing significant delays between their first GP visit and treatment. This research found that only 14% of people were referred to treatment within four weeks and that the average wait was 11 weeks; this was partly due to the fact that some GPs did not make an immediate diagnosis and referral. It is worth bearing in mind that, as acknowledged by the authors, this research was an online survey, open to self-selection bias.[64]

1.7 GP appointments

In June 2010 the Coalition Government ended the central performance target for seeing a GP within 48 hours. The Government has said the target did not work, and could make it more difficult for people with complex needs, the vulnerable and frail elderly to get the routine appointments that keep them well and properly supported in the community:

> In response to concerns raised by hon. Members about access to services, GP services need to be available to patients in a convenient place and at a convenient time. Achieving improved access to general practice not only benefits patients, but has the potential to create more efficient ways of working, which benefits GPs, practice staff and patients. The previous Government attempted to improve access to GP services by establishing a 48-hour access target. We know now that that target did not work. From 2007 to 2010, the proportion of patients who were able to get an appointment within 48 hours when they wanted one declined by 6%.
>
> A 48-hour target can make it more difficult for some of the more vulnerable patient groups who GPs look after, particularly people with complex medical co-morbidities, to get the important routine appointments that they need. We should bear in mind that targets can be perverse. That target did not work in its own right, and could make it more difficult for people with complex needs and the vulnerable and frail elderly to get the routine appointments that keep them well and properly supported in the community.[65]

A Parliamentary Question answered in June 2018 confirmed that the Government has no plans to reintroduce a maximum waiting time for GP appointments.[66]

The 2016-17 Government Mandate to NHS England specified that same-day appointments for over 75's should be introduced in general practice. However, the 2017-18 Mandate required NHS England to:

> Work with the Department to agree a programme of work to assess how best to meet the commitment that all over-75s will be able to access a same-day appointment with a GP if they need one.

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63 See Children and Young People with an Eating Disorder Waiting Times, NHS England, accessed 9 August 2018 and Statistical Press Notice: Children and Young People with an Eating Disorder Waiting Times Q1 2018-19, NHE England August 2018.

64 Beat, Delaying for years, denied for months, 2017

65 HC Deb 5 February 2015 c481-482

66 PQ 152734 on General Practitioners: Waiting Lists 15 June 2018

The 2018-19 Mandate included no reference to same-day GP appointments for the over 75s.

There is no official data on GP waiting times so it is not possible to definitively clarify trends over time. It has been reported that waiting times for GP appointments have been on the increase.[67] A BMA survey of GPs conducted in March 2018 found that "59% said waiting times for appointments have either worsened (31%) or significantly worsened (28%), with 33.3% stating they have stayed the same."[68] The latest national report from the GP Patient survey (August 2018) found that 23.8% of patients had to wait over a week for their appointment: of these people, 65.8% "wanted to be seen sooner, either on the same day they contacted the practice (15.8%), on the next day (15.4%), or a few days later (34.6%)."[69]

1.8 Other pledges on waiting times

The other **pledges** in the NHS Constitution are:

- a maximum 31-day wait for subsequent treatment where the treatment is surgery;
- patients waiting for a diagnostic test should have been waiting less than 6 weeks from referral; [there are 15 key diagnostic tests covered in this pledge, including audiology assessments; non-obstetric ultrasounds and cystoscopy[70]]
- a maximum 7 day wait for follow-up after discharge from psychiatric in-patient care for people under adult mental illness specialties on Care Programme Approach.
- all patients who have operations cancelled, on or after the day of admission (including the day of surgery), for non-clinical reasons to be offered another binding date within 28 days, or the patient's treatment to be funded at the time and hospital of the patient's choice; and

  […]
- In addition, local authorities with public health responsibilities should bear in mind that it is best practice for the care of patients and their sexual partners to offer genito-urinary medicine appointments as soon as possible, and that the clinical evidence indicates a maximum of 48 hours.[71]

1.9 Devolved administrations

Health is a devolved area of competence, so waiting times standards differ in Wales, Scotland and Northern Ireland.

Wales

Elective care

67 See for instance Is there a GP appointments crisis? British Heart Foundation, accessed 10 August 2018; Average GP waiting times remain at two weeks despite rescue measures, Pulse, 2 June 2017; More patients waiting longer than a week for GP appointments, Guardian, 6 July 2017
68 BMA, The general practice forward view: two years on, June 2018
69 Ipsos Mori and NHS England, GP Patient Survey, August 2018
70 See NHS England, NHS Diagnostic Waiting Times and Activity Data Monthly Report: March 2014, page 3
71 Department of Health, The handbook to the NHS Constitution for England, July 2015, page 34

In the NHS in Wales, patients should wait no more than 26 weeks from referral to elective/planned treatment. Some services are excluded from the 26 weeks target, including emergency care, mental health services and palliative care.

The target rates are:

- 95 per cent of patients should be seen within 26 weeks.
- No patients should wait longer than 36 weeks for treatment.[72]

However the last time the 95% target was met at a national level was in 2009: since then, the percentage of those waiting over 26 weeks has increased.[73] Between January and July 2018, the 26-week standard was met in 85.6 – 89 % of cases and between 2.9 and 5.5% of patients waited for longer than 36 weeks.[74]

A&E

The Welsh Government aims for 95% of A&E patients to be treated or discharged within four hours, and for no patients to spend longer than 12 hours in A&E. Statistics for Wales looks at performance over time:

- Performance against all targets has steadily been declining over time. Performance is seasonal, with performance closer to target in the summer months.
- Performance against the 4 hour target was lowest in March 2016 (76.5 per cent seen in less than 4 hours), and highest in March 2008 (94.8 per cent seen in less than 4 hours)
- Generally, around 95 per cent of patients were seen and left A&E within 12 hours[75]

Ambulance response times

As of February 2017, Wales adopted a new model for ambulance responses. Of the three categories of calls (red, amber and green) only red has an expected national standard of response: 65% to be seen within 8 minutes. In 2017-18, 74.6 % of red calls in Wales received a response within 8 minutes.[76]

Mental health services

For CAHMS, it is expected that

> 80 per cent of patients should wait no longer than 28 days (4 weeks) from the date the referral is received by the hospital to a first outpatient appointment.

However, as Statistics for Wales highlights,

> Performance for waits for Child and Adolescent Mental Health Services (CAMHS) has not met the target of 80 per cent of patients waiting less than 4 weeks in 2017-18. The performance decreased at the start of the year to a low of 39.4 per cent of patients waiting less than 4 weeks in August 2017, the performance then increased

72 Statistical bulletin: NHS Wales Referral to Treatment Times: 2017–18, Statistics for Wales/Welsh Government, 26 July 2018
73 Wales Audit Office, NHS Waiting Times for Elective Care in Wales, 27 January 2015
74 StatsWales, Percentage of patient pathways waiting to start treatment within target time by month and grouped weeks, last updated 20 September 2018
75 Statistics for Wales/Welsh Government, Time Spent in NHS Wales Accident and Emergency Departments, 2016-17, 5 April 2018
76 Welsh Government/Statistics for Wales, Ambulance services in Wales, 2017-18, 27 June 2018

throughout the year to the highpoint in March 2018 with 68.5 per cent of patients waiting less than 4 weeks.[77]

Adults are also expected to receive mental health treatment within 28 days.

Cancer

Wales also has targets for cancer treatment: 95% of patients with an urgent suspected cancer should start treatment within 62 days and the target is 98% of patients within 31 days for a non-urgent suspected cancer referral.[78]

The 62-day standard has not been met in Wales as a whole since 2008, and has remained below 90% for several years.[79] For instance, between January and July 2018, between 84 and 87% of patients started treatment in 62 days.[80] While the 31-day standard has dropped slightly since 2007, it has remained persistently above 95%.[81] Between January and July 2018, the average wait time for non-urgent referrals averaged at 96.9%.[82]

Waiting time statistics can be found on the Referral to Treatment Times and NHS Cancer Waiting Times pages on the Welsh Government website.

Scotland

The Information Services Division (ISD) publishes data on performance against waiting times standards.

Elective care

The NHS in Scotland has an 18 week maximum waiting time target from referral to elective/planned treatment.[83] The target is to achieve this with 90% of patients. This standard has not been met since June 2014.[84]

Accident and emergency

For A&E, the operating standard is for 95% of patients to wait no longer than 4 hours from arrival to admission, discharge or transfer. In the quarter ending in June 2018, the rate achieved was 92.8%.[85]

Ambulance response times

Like Wales, Scotland has a three-tier system for calls to 999. Before November 2016, the three categories were

- Category A, potentially immediately life threatening
- Category B, serious but not life threatening
- Category C, not serious but may require an ambulance.[86]

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77 Statistical bulletin: NHS Wales Referral to Treatment Times: 2017–18, Statistics for Wales/Welsh Government, 26 July 2018
78 NHS Wales, Rules For Managing Referral To Treatment Waiting Times
79 NHS Wales stands out on improved cancer waiting times, BBC News, 10 May 2018
80 StatsWales, Patients newly diagnosed via the urgent suspected cancer route starting treatment by month, last update 20 September 2018
81 Statistics for Wales/Welsh Government, NHS Wales cancer waiting times: 2016-17, 21 December 2017
82 StatsWales, Patients newly diagnosed not via the urgent suspected cancer route starting treatment by month, last updated 20 September 2018
83 The Scottish Government, 18 weeks RTT [last accessed 16 April 2015]
84 Information Services Division, 18 Weeks Referral to Treatment Quarter End – 31 March 2018, 29 May 2018
85 LDP standard - A&E, Scottish Government website, accessed 16 August 2018
86 Scottish Ambulance Service, Freedom of Information Request, 23 May 2018

75% of category A calls were supposed to be seen by an ambulance in 8 minutes.

A trial began in November 2016 of a new system of categorisation called the New Clinical Response Model, which is attempting to reprioritise ambulance services in a similar way to England. More information can be found in the New Clinical Response Model Q&A, published by the Scottish Ambulance Service. The new categories are:

- Immediately Life Threatening (ILT)
- Ambulance response – not immediately life threatening
- Additional clinical triage required to determine most suitable response[87]

ILT is the only category with a national response standard. Like England, Scotland has now shifted to thinking about average wait times for an ambulance, as well as the 90th centile performance, although the 75% target is still measured.

The average (median) response time for category A and ILT calls have been as follows:

- 2013: 6.46
- 2014: 6.60
- 2015: 7.21
- 2016: 7.44
- 2017: 8.05[88]

The fact that the 2017 average response time is higher may be explained, the Scottish Ambulance Service suggests, by "out of the ordinary levels of demand" in December 2017.[89]

Mental health services

From 2014, it has been the aim that the waiting time for psychological therapies in Scotland would be no longer than 18 weeks: the operating target was set at 90% of patients achieving this turnaround. However in the quarter ending in March 2018, the rate achieved was 78.2%.[90]

Scotland's Auditor-General released a report, Children and young people's mental health, in September 2018 which outlines some of the barriers faced by children who need to access mental health services. The Auditor-General found that,

> Between 2013/14 and 2017/18, the average wait for a first treatment appointment increased from seven to 11 weeks. There is wide variation between NHS boards in the average time that children and young people wait for their first treatment appointment.

Furthermore, in regards to the 18-week standard, the report states the following:

> […] The waiting time standard has not been met nationally since it was introduced in December 2014. In 2013/14, 15 per cent (2,182 children and young people) waited over 18 weeks, compared to 26 per cent (4,012) in 2017/18. There is also significant variation in performance against the standard between NHS boards.[91]

More detail, including comparisons of data across NHS boards, can be found in the report (pages 18-22).

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87 Scottish Ambulance Service, Freedom of Information Request, 23 May 2018
88 Scottish Ambulance Service, Freedom of Information Request, 23 May 2018
89 Scottish Ambulance Service, Freedom of Information Request, 23 May 2018
90 Information Services Division, Psychological Therapies Waiting Times in NHS Scotland Quarter ending 31 March 2018, 5 June 2018
91 Auditor General and the Accounts Commission, Children and young people's mental health, September 2018, pp.18-9

Cancer

The NHS in Scotland has two cancer waiting times standards:

Maximum 31-day wait: Patients starting first treatment within 31 days from decision to treat (95% target).

Maximum 62-day wait: Patients starting treatment within 62 days of receipt of urgent referral with suspicion of cancer (95% target).

The 62-day standard has not been met since 2013, and the 31-day standard has not been met since the quarter ending June 2016.[92]

Northern Ireland

The Department of Health has a website where these hospital waiting times are published.

Elective care

As of March 2018, the 2017/18 Ministerial waiting time target for elective care in Northern Ireland is that 50% of patients should wait no longer than 9 weeks for a first outpatient appointment, with no patient waiting longer than 52 weeks. At the time of the latest statistical release (May 2018), this has so far not been achieved. At 31 March for example, 73.5% of patient were waiting longer than 9 weeks.[93]

A&E

The target for A&E is the following:

> 95% of patients attending any Type 1, 2 or 3 emergency care department are either treated and discharged home, or admitted, within four hours of their arrival in the department; and no patient attending any emergency care department should wait longer than twelve hours.[94]

The NI Executive also hoped that by March 2018, at least 80% of patients would start treatment, following triage, within 2 hours.[95]

In terms of performance, the Information Analysis Directorate has published comparative data:

- 4 hours target: in June 2017 81.2% were seen in four hours and in June 2018, the figure stood at 72.9%.
- 12 hours target: in June 2017, 294 spent over 12 hours in A&E, and in June 2018, that number had increased to 1,358.
- 2 hours target: in June 2017, 84.7% were seen within 2 hours (which met the target) and in June 2018 79.7% were seen in that time (just short of the 80% target).[96]

Ambulance response times

The Northern Ireland Ambulance Service identifies three categories of calls:

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92 Information Services Division, Cancer Waiting Times in NHS Scotland, 26 June 2018
93 Information Analysis Directorate, Northern Ireland Waiting Time Statistics: Outpatient Waiting Times Quarter Ending March 2018, 31 May 2018
94 Information Analysis Directorate, Emergency Care Waiting Time Statistics for Northern Ireland (April – June 2018), 19 July 2018
95 Information Analysis Directorate, Emergency Care Waiting Time Statistics for Northern Ireland (April – June 2018), 19 July 2018
96 Information Analysis Directorate, Emergency Care Waiting Time Statistics for Northern Ireland (April – June 2018), 19 July 2018

> **CATEGORY A –** The most serious calls, where there is, potentially, an immediate threat to life
>
> **CATEGORY B –** Calls which are serious, but not life-threatening
>
> **CATEGORY C –** Calls which are neither serious or life-threatening[97]

The national standard is for 72.5% of category A calls to see an ambulance within 8 minutes, but this target has not been met over the past five years, with progressively less people being seen in the targeted time: between 2013/14 and 2017/18, the percentage has fallen from 67.6% to 45.2%.[98] More information on this and response times for other categories of calls can be found in Hospital Statistics: Emergency Care 2017/18, published by the Information Analysis Directorate.

Cancer

The Ministerial target for cancer waiting times is as follows:

> From April 2017, all urgent breast cancer referrals should be seen within 14 days; at least 98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat; and at least 95% of patients urgently referred with a suspected cancer should begin their first definitive treatment within 62 days.[99]

The 62-day target has not been met since it began, and figures have remained mostly below 70% bar March 2018 in which 75.4% of patients were seen according to this standard. The 98% target has never been met either although since January 2016, the rate has remained above 90%.[100]

Mental health services

Health and Social Care published Working Together: A Pathway for Children and Young People through CAMHS in March 2018. This outlines the expected waiting times for CAHMS after a GP appointment:

- For emergencies, the patient should be seen within 24 hours of referral
- For urgent referrals, an appointment should be made within 5 working Days
- A routine referral should lead to an appointment within 9 weeks.[101]

For adults, the timings are:

- For emergencies: 2 hours
- Urgent referrals: 5 days
- Routine appointments: 9 weeks or 13 weeks for psychological therapies[102]

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97 Northern Ireland Ambulance Service website, Response Categories Explained, accessed 9 October 2018
98 Information Analysis Directorate, Hospital Statistics: Emergency Care 2017/18, p.23
99 Information Analysis Directorate, Northern Ireland Waiting Time Statistics: Cancer Waiting Times (January – March 2018) 28 June 2018
100 Information Analysis Directorate, Northern Ireland Waiting Time Statistics: Cancer Waiting Times (January – March 2018) 28 June 2018
101 Health and Social Care, Working Together: A Pathway for Children and Young People through CAMHS, March 2018, p.4
102 Health and Social Care, Regional Mental Health Care Pathway, October 2014

2. Patient choice policies

The previous Labour Government developed a number of policies to strengthen patient choice within the NHS. Since January 2006, patients requiring a referral to a specialist for elective treatment have been entitled to a choice of at least four NHS hospitals through the NHS e-Referral Service (previously the "Choose and Book" system). From 2007 the Extended Choice Network allowed GPs to refer patients directly to the independent sector.

Since 2008, patients referred to a specialist by their GP have been able to choose treatment from any hospital listed in a national directory, which includes a number of independent sector providers. In 2009 the *NHS Constitution for England* made this a right for NHS patients. The policy was initially named "any willing provider," but was subsequently changed to "any qualified provider" to reflect the requirement that certain service standards must be met and the providers open to regulation by the Care Quality Commission (CQC).

The Coalition Government's *Programme for Government* (May 2010), set an ambition to further embed patient choice and put patients in charge of making decisions about their own care. The *Programme for Government* made specific commitments to patients being able to manage their own health records; introducing the right to register with any GP practice a patient wishes; and having the power to choose any healthcare provider that meets NHS standards, within NHS prices.[103]

2.1 Shared decision making

The *NHS Constitution for England* sets out patient rights to be involved in decisions about their care:

> You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers.[104]

The principle of shared decision making was embedded in the Department of Health's White Paper: Equity and Excellence: Liberating the NHS. The paper stated in line with the principle of "no decision about me without me", shared decision-making should become the norm.

The paper set a series of objectives for the Coalition Government to realise its ambition of putting patients in charge of making decisions about their care:

> We will put patients at the heart of the NHS, through an information revolution and greater choice and control:
>
> a. Shared decision-making will become the norm: no decision about me without me.
>
> b. Patients will have access to the information they want, to make choices about their care. They will have increased control over their own care records.
>
> c. Patients will have choice of any provider, choice of consultant-led team, choice of GP practice and choice of treatment. We will extend choice in maternity through new maternity networks.
>
> d. The Government will enable patients to rate hospitals and clinical departments according to the quality of care they receive, and we will require hospitals to be open about mistakes and always tell patients if something has gone wrong.

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103 HM Government, The Coalition: Our Programme for Government, May 2010
104 NHS, The NHS Constitution for England, March 2013, page 9

> e. The system will focus on personalised care that reflects individuals' health and care needs, supports carers and encourages strong joint arrangements and local partnerships.
>
> f. We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion, HealthWatch England, located in the Care Quality Commission.
>
> g. We will seek to ensure that everyone, whatever their need or background, benefits from these arrangements.[105]

These principles informed the *Health and Social Care Act 2012*.

The paper highlights that the NHS Commissioning Board (now NHS England) will be responsible for championing patient and carer involvement, and the Secretary of State will hold it to account for progress.[106]

The Government's *Mandate to the NHS 2015-16* stated that NHS England's objective is to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment. The *Mandate* outlined the advantages that achieving this objective would bring:

- far more people should have developed the knowledge, skills and confidence to manage their own health, so they can live their lives to the full;
- everyone with long-term conditions, including people with mental health problems, should be offered a personalised care plan that reflects their preferences and agreed decisions;
- patients who could benefit should have the option to hold their own personal health budget as a way to have even more control over their care;
- the five million carers looking after friends and family members should routinely have access to information and advice about the support available – including respite care.[107]

The Government's 2016-17 Mandate to NHS England said that the Government wanted to 'significantly improve' patient choice by 2020, specifying maternity, end-of-life care and for people with long-term conditions as key areas for improvement.[108] The following year, a further two goals were added for 2020:

- With NHS Improvement, improve the percentage of NHS staff who report that patient and service user feedback is used to make informed improvement decisions.
- Ensure that patients, their families and carers are involved, through coproduction, in defining what matters most in the quality of experience of services and assessing and improving the quality of NHS services.

Co-production is explained in this blog by the Head of Experience of Care at NHS England.

Both the 2017-18 and 2018-19 Mandates to NHS England include more specific milestones to be achieved with the 2020 goals in mind.

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105 Department of Health, Equity and excellence: Liberating the NHS, July 2010, page 3
106 Department of Health, Equity and excellence: Liberating the NHS, July 2010, page 13
107 Department of Health, The Mandate: A mandate from the Government to NHS England: April 2015 to March 2016, December 2014, page 11
108 Department of Health, The Government's mandate to NHS England for 2016-17, March 2017

2.2 Choice of provider

The *NHS Constitution* states that "You have the right to make choices about the services commissioned by NHS bodies and to information to support these choices. The options available to you will develop over time and depend on your individual needs."[109]

Patients have the right to choose an organisation to provide NHS care when they are referred for their first outpatient appointment with a service led by a consultant:

> If you need to see a consultant or specialist as an outpatient for a physical or mental health condition, you can choose the organisation that provides your NHS care and treatment anywhere in England for your first outpatient appointment. (An outpatient appointment means you do not need to stay overnight).
>
> You can also choose which consultant-led team or which mental health team led by a named health care professional will be in charge of your NHS care and treatment (employed by the organisation you choose) for your first outpatient appointment.[110]

There are certain exceptions to this right:

> **Persons excluded**
>
> persons detained under the Mental Health Act 1983
>
> serving members of the Armed Forces; and
>
> prisoners (including those on temporary release).
>
> **Services excluded**
>
> where speed of access to diagnosis and treatment is particularly important, e.g.:
>
> emergency attendances/admissions
>
> attendances at a Rapid Access Chest Pain Clinic under the two-week maximum waiting time, and
>
> attendance at cancer services under the two-week maximum waiting time
>
> maternity services
>
> mental health services; and
>
> public health services commissioned by local authorities.[111]

However, greater choice has been available since April 2014 for mental health outpatient services (see section 2.5 below).

If a patient does not feel they have been offered a choice of hospital provider or consultant-led team within a hospital, they should discuss this with their GP. If they are still dissatisfied and feel they have not been offered choices, they could make a complaint to their local CCG.[112]

Transferring to a different hospital

It is possible to request to be referred to a different hospital following an initial outpatient appointment, if the patient is not satisfied with the initial provider. A new referral from the patient's GP must be sought. However, this may delay treatment, as a new 18 week maximum waiting time period will apply.[113]

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[109] Department of Health, The Handbook to the NHS Constitution, 26 March 2013, p50
[110] Department of Health & NHS, 2014/15 Choice Framework, April 2014, page 15
[111] Department of Health, The Handbook to the NHS Constitution, 26 March 2013, p65
[112] NHS Choices, Choosing a hospital [last accessed 4 February 2015]
[113] NHS Choices, Choosing a hospital [last accessed 4 February 2015]

Seeking a second opinion

NHS patients do not have an automatic right to a second or further opinion but doctors should always respect a patient's wish to obtain one and NHS Choices explains that a healthcare professional will rarely refuse to refer a patient for one. NHS Choices explains how patients can seek a second opinion

> If you would like a second opinion after receiving advice from your GP, you can ask them to refer you to another GP.
>
> Alternatively, you may consider asking to see a different GP at your surgery, if you're registered at a surgery with more than one GP, or changing to a different GP surgery.[114]

2.3 GP services

The Coalition Government's Programme for Government included an ambition for patients to have complete choice over their GP practice:

> We will give every patient the right to choose to register with the GP they want, without being restricted by where they live.[115]

There are catchment areas for GP practices, usually referred to as "practice boundaries", although practices do have discretion as to how rigidly they apply these. "Outer boundaries" were introduced in 2012 and were intended to allow registered patients who move outside the practice boundary but within the new outer boundary to remain registered with the same practice. Practices' outer boundaries should be advertised in practice leaflets and on websites and may also be made available on the NHS Choices website.

On 15 November 2013, NHS Employers and the BMA General Practitioners Committee (GPC) announced changes to the General Medical Services (GMS) contract in England for 2014/15. Changes included allowing GP practices to register patients from outside their practice boundaries. Since January 2015, if a GP accepts someone from outside of their practice boundary area, they are no longer obliged to provide home visits: NHS England is responsible for organising home visits during core hours for such patients. More detail can be found in the document, Out of area registration: In hours urgent primary medical care (including home visits) Enhanced Service, published by NHS England.

However, these new arrangements are voluntary for GP practices. If the practice has no capacity for new patients or feels it is not clinically appropriate for an individual to be registered so far away from home, they can then refuse registration.

Further information is available in the Library briefing on General Practice in England, including details of policies to increase the number of surgeries offering evening and weekend appointments. In October 2018, CCGs will be expected to commission extended hours GP services in their areas.[116]

2.4 Personal health budgets

Personal budgets explained

A personal health budget is an agreed sum of money to support a person's identified health and wellbeing needs and provide services which have been planned and agreed by

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114 NHS Choices, How do I get a second opinion? [last accessed 16 April 2015]
115 HM Government, The Coalition: Our Programme for Government, May 2010, page 25
116 NHS England and NHS Improvement, Refreshing NHS Plans for 2018/19, February 2018

an individual, their representative, or, in the case of children, their families or carers, and the local NHS team. Personal health budgets are delivered by CCGs.

NHS England highlights five key advantages to personal health budgets which support patient's having choice, control and flexibility over their care:

> Ideally, individuals or their representatives should:
>
> - Know upfront how much money they have available for healthcare and support.
> - Be enabled to choose the health and wellbeing outcomes they want to achieve, in dialogue with one or more healthcare professionals.
> - Be involved in the design of their care plan.
> - Be able to request a particular model of budget that best suits the amount of choice and control with which they feel comfortable.
> - Be able to spend the money in ways and at times that make sense to them, as agreed in their plan.[117]

There are three ways of delivering and managing a personal health budget. CCGs should make all three options available to allow people to make a choice about the level of control they feel comfortable with:

> People can have a personal health budget in one of the following, or any combination of the three, ways:
>
> 1. A notional budget - where the commissioner (for example the CCG) holds the budget but utilises it to secure services bases on the outcome of discussions with the service user.
> 2. A third party budget - where an organisation independent of the individual and the NHS manages the budget on the individual's behalf and arranges support by purchasing services in line with the agreed care plan.
> 3. A direct payment - where money is transferred to a person or his or her representative or nominee who contracts for the necessary services.[118]

Patients receiving a personal health budget can choose to receive clinical services from any provider, including services that are not currently commissioned by a CCG or NHS England. In such a scenario, NHS guidance suggests that this choice of service does not need to be agreed by an Independent Funding Review Panel but must be approved by the CCG team responsible for approving the patient's personal health budget care plan.[119]

There are some services that direct payments cannot be used for. These include primary medical services provided by GPs; urgent or emergency treatment services; surgical procedures; and NHS charges such as prescription or dental charges.[120]

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[117] NHS England, Guidance on the "right to have" a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care, September 2014
[118] NHS England, Guidance on the "right to have" a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care, September 2014
[119] NHS England, Choice in mental health care, updated February 2018, p.35
[120] For the full list, see NHS England, Guidance on Direct Payments for Healthcare: Understanding the Regulations, March 2014

Roll out of personal health budgets (PHBs)

The national roll-out of PHBs began in November 2012. The results of a series of pilots found that budgets led to an improved quality of life and a reduction in the use of unplanned hospital care.[121]

From April 2014, a legal "right to ask" for a personal health budget was introduced, which was extended, from October 2014, to a legal "**right to have**" a PHB for adults receiving NHS Continuing Healthcare and children receiving Continuing Care.[122] For other patients, CCGs have the discretion to offer PHBs.

The *NHS Mandate 2014-15* set an objective for the NHS to further roll out personal health budgets to anyone who could benefit, by April 2015.[123] Later Mandates have aimed to give between 50,000 and 100,000 people a personal health budget by 2020 (compared to the existing 7,600 budgets estimated in March 2018).[124] For 2018-19, the Government's Mandate to NHS England set out a plan to expand personal health budgets to more groups, "including wheelchair users, those with learning disabilities, and in end-of-life care."[125]

Personal health budgets are also being rolled out or trialled for:

- Learning disabilities
- Mental health
- Personal wheelchair budgets
- End of life care
- Maternity Care

More details can be found on the NHS's website on Personal health budgets.

However these groups do not currently have a 'right to have' a personal health budget. In April 2018, the Department of Health and Social Care opened a consultation on Extending legal rights to have for personal health budgets and integrated personal budgets. In this consultation, the Government identified several groups believed to be suitable for a personal health budget, or an integrated personal budget (see below for more details). The consultation asked for opinions on giving these groups the 'right to have' such a budget. These groups were:

- People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.
- People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services.
- People leaving the Armed Forces, who are eligible for ongoing NHS services.
- People with a learning disability, autism or both, who are eligible for ongoing NHS care.

Section 117 services are explained on the Mind website.

[121] NHS England, Guidance on the "right to have" a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care, September 2014
[122] Department of Health & NHS, 2014/15 Choice Framework, April 2014, page 14
[123] Department of Health, The Mandate, A mandate from the Government to NHS England: April 2014 to March 2015, page 11
[124] Department of Health and Social Care, The Government's mandate to NHS England for 2018-19, March 2018
[125] Department of Health and Social Care, The Government's mandate to NHS England for 2018-19, March 2018

- People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.[126]

The consultation also sought comment on whether any of these groups should also be offered a right to direct payments.

The consultation closed in June 2018. The Government is still analysing the feedback.

The Government has also expressed a desire to integrate health and social care personal budgets and is exploring this via the Integrated Personal Commissioning programme (IPC), jointly led by NHS England and local authorities. An integrated personal budget pools together an individual's health and social care budgets so that care can be better coordinated. The programme is currently being trialled in 19 areas across England: more details can be found on NHS England's website. A formal evaluation of this programme is scheduled to report in Spring 2019,[127] but the Government's *Mandate to the NHS (2018-19)* is committed to the continued expansion of the IPC programme.[128]

2.5 Mental health services

In April 2014, the Government introduced legal rights to patient choice in mental health for this first time. This was in line with the Government's ambition to achieve parity with physical health.[129]

The legal rights cover:

> If you need to see a consultant or specialist as an outpatient for a physical or mental health condition, you can choose the organisation that provides your NHS care and treatment anywhere in England for your first outpatient appointment. (An outpatient appointment means you do not need to stay overnight).
>
> You can also choose which consultant-led team or which mental health team led by a named health care professional will be in charge of your NHS care and treatment (employed by the organisation you choose) for your first outpatient appointment.[130]

In December 2014, NHS England published Guidance on implementing patients' legal rights to choose the provider and team for their mental health care. This is intended to help commissioners, GPs and providers support patients.

There are some exclusions that apply to these legal rights. These are where a patient is:

- already receiving mental health care following an elective referral for the same condition
- referred to a service that is commissioned by a local authority, for example a drug and alcohol service (unless commissioned under a Section 75 Agreement)
- accessing urgent or emergency (that is, crisis) care
- accessing services delivered through a primary care contract
- in high secure psychiatric services
- detained under the Mental Health Act 1983

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126 Department of Health and Social Care, A consultation on extending legal rights to have for personal health budgets and integrated personal budgets, April 2018
127 Written PQ 58418 [Personal Budgets] 11 January 2017
128 Department of Health and Social Care, The Government's mandate to NHS England for 2018-19, March 2018, p.16
129 Department of Health, More choice in mental health, December 2012
130 Department of Health & NHS, 2014/15 Choice Framework, April 2014, page 4

- detained in a secure setting. This includes people in or on temporary release from prisons, courts, secure children's homes, certain secure training centres, immigration removal centres or young offender institutions
- serving as a member of the armed forces (family members in England have the same rights as other residents of England).[131]

2.6 Palliative (end of life) care

As set out on page 9 of the NHS Constitution, patients also have the right to shared decision making in their end of life care.[132]

The Department of Health commissioned a Review of Choice in End of life Care, which was published in 2015.[133] The Government published its response to the review in July 2016. This stated that there should be a clear expectation of the standard of palliative care and what the health and care systems should be doing to ensure personalised and good care. The Government made the following commitment:

> Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:
>
> - have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die;
> - make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families;
> - develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;
> - share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care;
> - involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care;
> - know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.[134]

In order to engender "better, personalised care", the Government stated that it would carry out the following actions:

- NHS England will rollout shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS). The aim is to have these operational in most areas by 2018, and to have 100% coverage by 2020.
- Developing, by 2018, 'digital solutions' that will allow people to "access their own records and add information about their care, including their end of life care preferences."

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131 NHS England, Guidance on implementing patients' legal rights to choose the provider and team for their mental health care, published December 2014 (updated February 2018)
132 NHS, The NHS Constitution for England, July 2015, page 9
133 The Choice in End of Life Care Programme Board, What's important to me: A review of Choice in End of Life Care, February 2015
134 Department of Health, Our Commitment to you for end of life care, July 2016, p.10

- Ensuring that "more people across the country who receive fast track NHS Continuing Healthcare have the option to have more choice and control over the services they receive."
- Developing models for a "care coordinator scheme". The Government believes that this role can help people navigate health services and express their preferences. This will be looked at by the National Council for Palliative Care.
- Testing 'serious illness conversations' in Airedale and Southend. In this model, clinicians are trained to have conversations with seriously ill patients about their priorities.
- Using Faith at the End of Life, published by Public Health England in January 2016, so that spiritual needs and bereavement services are included in an end of life plan. The Care Quality Commission will continue to assess whether healthcare Trusts and community services are delivering on these needs.
- Commissioning "the National Council for Palliative Care to develop an educational film that will provide advice and guidance to help prepare individuals with advanced disease and long term conditions, and those important to them, for their consultations with clinicians."
- NHS England will also "lead a public-facing campaign to promote choice and personalisation in end of life care".

These plans also included a commitment to strengthen patients' rights to individual end of life care in the NHS Constitution by 2020, including the right to have choices recorded in an individual plan of care.[135]

In September 2017, the Department of Health published a progress report on offering the national choice offer by 2020, One Year On. Some progress was identified towards the 'personalisation of care': this included the further rollout of electronic end of life care records, and the implementation of pilot schemes such as the Serious Illness Conversation pilot.

The Department of Health and Social Care mandate to NHS England for 2018/19 announced the following objectives for end of life care:

- Continue to make measurable progress to embed Personal Health Budgets for those with a legal right and expand their use in other groups, including wheelchair users, those with learning disabilities, and in end-of-life care and expand the Integrated Personal Commissioning programme.
- Increase the percentage of people identified as likely to be in their last year of life, so that their End of Life Care can be improved by personalising it according to their needs and preferences.

More information can be found on the website, What is NHS England doing to improve end of life care? Details about Personal health budgets and palliative care can be found on the website Personal health budgets in end of life care.

[135] Department of Health, Our Commitment to you for end of life care, July 2016

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