Contents

Executive summary .................................................................................................................................................. 3
Introduction ......................................................................................................................................................... 6
  The uptake database and methodology .......................................................................................................... 6
  Results: Summary of uptake data .................................................................................................................... 7
Results: Examples of uptake data ....................................................................................................................... 9
  Epilepsy in adults and children and young people ......................................................................................... 9
  Hip fracture .................................................................................................................................................... 12
  Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure ........................................................................................................ 14
  Lung cancer (non-small cell, EGFR-TK mutation positive) ........................................................................... 16
  Non-vitamin K antagonist oral anticoagulants for atrial fibrillation .............................................................. 21
  Quitting smoking in pregnancy and following childbirth .............................................................................. 23
  Specialist neonatal care .................................................................................................................................. 26
  Stroke ............................................................................................................................................................ 28
  The health and wellbeing of looked-after children and young people .......................................................... 31
How NICE is using the uptake data ................................................................................................................... 33
Future plans ......................................................................................................................................................... 34
Executive summary

1. This report gives an overview of how NICE recommendations for effective and cost-effective practice are used in the NHS. It summarises the data recorded in the NICE uptake database by combining information from the database with examples of the uptake of NICE technology appraisals published by the Health and Social Care Information Centre. This is the second annual uptake report and includes data for 24 pieces of ‘active’ guidance published up to March 2015.

2. The uptake database contains published audit data that compares current practice against NICE recommendations. It contains information about the uptake of clinical guidelines and quality standards, with less about public health guidance, technology appraisals and interventional procedures guidance. Every month the Impact team at NICE search national audits and academic journals, sift through references, identify data that maps onto NICE recommendations or quality statements, extract the relevant data and upload this to the uptake database. The uptake database currently holds information on 1339 data points, compared with 614 data points held in January 2015. There is very little uptake data for social care, medical device or diagnostic guidance because these areas are generally under-reported in the published literature.

3. NICE uses uptake data to understand how guidance is currently used in the NHS and to identify areas of variation in care. The data can also inform decisions on updating guidance and to identify areas where uptake is low or under-reported. It is important to understand current practice during scoping and development of NICE guidance as this may affect how recommendations are implemented in practice.

4. This report summarises the uptake of recommendations from 24 pieces of NICE guidance. Guidance is selected based on a review of available data and aims to reflect a wide range of topic areas. Across the 24 pieces of NICE guidance that are included, uptake of NICE recommendations ranged from 38% to 82%. The results suggest that while uptake of NICE guidance has increased over time, further improvements could be achieved. In particular, this report highlights that the provision of transition handover clinics for young people with epilepsy, and
delivery of speech and language therapy in people with stroke are potential areas where uptake of NICE recommendations could be improved.

5. The uptake database continues to be developed in conjunction with other data collecting organisations, such as the Healthcare Quality Improvement Partnership (HQIP) and NHS England. Of the 27 national audits managed by HQIP, 10 have published reports since January 2015. Of the 10 national audits reported this year, 9 have data that maps to NICE recommendations and quality statements and this data has been included in the database. NICE is currently working with HQIP to encourage greater alignment between data collection for national audits and NICE quality standards.

6. NICE encourages organisations to submit audit data directly to the uptake database, and a quality standards service improvement template has been developed to enable organisations to measure their performance across a range of quality standard statements. Collecting more data on the uptake of NICE public health and social care guidance is also welcomed. We are working closely with manufacturers to enable more data to be collected from industry about the uptake of recommended medical devices and diagnostics.
Introduction
7. The Impact team at NICE identifies and extracts data examining the uptake of NICE guidance. This uptake report shares a number of examples from the information we have about how NICE evidence-based guidance is being used. NICE does not have a remit to directly collect data and therefore this report is based on information taken from a wide range of data sources including national and local audits, peer-reviewed publications and other externally produced reports.

8. The uptake of NICE guidance is one way of measuring variation in NHS care. NHS England’s Five Year Forward View (5YFV), published in October 2014, highlighted the need to reduce variations in the quality and safety of NHS care to ensure consistently high standards of care. Addressing variation is a common theme across NHS England’s business plan for 2015-2016. Sharing data on the uptake of evidence-based recommendations will help the NHS identify where it may need to focus to reduce these variations, and to narrow the gap between the best and the worst, whilst raising the quality bar for everyone. At a time when 66% of NHS trusts are forecasting that expenditure will exceed income by the end of 2015/16¹ addressing variation may also help the NHS meet the challenges of rising costs and increasing demand.

9. To help maximise value, NHS England’s Right Care programme examines the distribution of care and relates routinely available data to investment, activity and outcomes to the whole population in need. In addition, working collaboratively with other healthcare organisations, this programme also seeks to underpin the identification of unwarranted variation and the actions needed to tackle it.

The uptake database and methodology
10. Our uptake database, which we have called ‘uptake data’, has been organised to allow users to see the data at individual recommendation or quality statement measure level to help them better understand how our guidance is being used and to see changes in uptake over time. We identify the data for inclusion in uptake data on a monthly basis by reviewing a wide range of sources including

¹ The Kings Fund, Quarterly Monitoring Report 16
peer-reviewed publications and published national audits. We then check the
data to make sure it reflects our guidance and is new and original work. If it
meets these criteria it is entered into the database.

11. The criteria for inclusion are that the publication or audit must:

• contain new and original work (literature reviews are excluded)
• have findings and results that relate to populations resident in England,
  Scotland, Northern Ireland or Wales
• include quantitative data (reported as a compliance measure) and map to
  a specific recommendation or measure published in NICE guidance

12. The guidance and standards used as examples in this report were chosen to
reflect a broad range of topic areas and recommendations, and because each
reported at least 2 data points after publication. The examples have also been
chosen to show areas of low and high uptake.

13. Our first social care guideline was published in 2014 and we have very little
uptake data for it. Three social care guidelines will be published towards the end
of 2015. We will consider how to encourage more audits in social care and intend
to seek the views of people working in this sector on the best way to do this.

14. There is currently little uptake data for NICE-recommended medical devices and
diagnostics. This is partly because routinely collected data in the NHS rarely
includes information about the use of particular technologies. The NHS is working
with industry associations (Association of British Healthcare Industries and British
In Vitro Diagnostics Association) to find ways to collect this data. We are helping
in this by asking companies, whose products have been recommended by us, for
data about their sales.

15. Data from the Innovation Scorecard, have not been included in the uptake
database because the results are not reported as a compliance measure. The
Health and Social Care Information Centre (HSCIC) publishes the Innovation
Scorecard and makes use of data for NICE appraised medicines and medical
technologies currently available from a range of sources, both from the NHS and
the commercial sector. The scorecard was first published in January 2013 and is
updated on a quarterly basis.
Summary of uptake data

16. Table 1 shows how much information we have on NICE guidance and quality standards published before March 2015. We have not included data for interventional procedures guidance because they do not include recommendations for practice. We define uptake data as a single piece of information about the uptake of a recommendation or quality statement measure.

<table>
<thead>
<tr>
<th>Table 1 Uptake data: Number of guidance and standards published before March 2015</th>
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<tbody>
<tr>
<td>Number of published and ‘active’ NICE products by the end of March 2015</td>
</tr>
<tr>
<td>Clinical guidelines</td>
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<tr>
<td>Quality standards</td>
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<tr>
<td>Technology appraisal</td>
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<tr>
<td>Public health guidelines</td>
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<tr>
<td>Medical technologies guidance</td>
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<tr>
<td>Social care guidelines</td>
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<tr>
<td>Medicines practice guidelines</td>
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<tr>
<td>Safe staffing guidelines</td>
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<tr>
<td>Diagnostics guidance</td>
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<tr>
<td>Total</td>
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17. We recognise that not all NICE guidance and quality standards have been implemented fully, and that the data collected to date has been drawn from published sources so does not represent the full picture. Figure 1 shows the number of reported data points broken down by 10% categories. For example, there are 201 data points with reported uptake results between 90% and 100%.

18. Figure 1 is a snapshot of the individual pieces of data held in the uptake database at the end of August 2015. It does not show change for individual pieces of guidance or timescales. For example, results in the lower bands could reflect that audits may be at an early stage of implementing the recommendations.
19. The number of data points held in the database has more than doubled since the last uptake annual board report. Around 95% of the data points relate to clinical guidelines and quality standards, with a fairly even split between the two. Much of this new data has come from national audits and reports. There is usually a break between the point of data collection and publication, leading to a delay in data availability.

**Results: examples of uptake data**

**Epilepsy in adults and children and young people**

20. Epilepsy is one of the commonest serious neurological disorders seen in primary care\(^2\). There are currently around 320,000 adults and 34,000 children and young people with epilepsy who are receiving anti-epileptic drugs\(^3\). Studies carried out

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\(^3\) NICE (2013) *Diagnosis and management of the epilepsies in adults, children and young people: commissioning guide*. Figures based on primary care data from IMS Disease Analyser.
in various settings have estimated that up to 30% of people are incorrectly diagnosed with epilepsy\textsuperscript{4}.

21. The need for continuity of care during transition from paediatric to adult services is particularly important for young people. Good management during this period is vital for developing and maintaining self-esteem and confidence. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood\textsuperscript{5,6}.

22. The NICE guideline on \textit{the epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care}, published in January 2012, recommends that during adolescence a named clinician should take responsibility for the ongoing management of the young person with epilepsy and ensure smooth transition of care to adult services.

23. NICE quality standards for \textit{the epilepsies in adults} and \textit{the epilepsies in children and young people} published in February 2013 and prioritise 9 areas from relevant guidance. Both quality standards state that young people with epilepsy should have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services. The \textit{Epilepsy12 national audit} reports on healthcare for children and young people with suspected epileptic seizures. This includes data on the proportion of units that provide an epilepsy handover clinic (a clinic where young people ‘leave the paediatric service and join an adult service’ which comprises both adult and paediatric health professionals).

\textsuperscript{5} NICE (2013) \textit{The epilepsies in adults quality standard}
\textsuperscript{6} NICE (2013) \textit{The epilepsies in children and young people quality standard}
24. The chart shows an 8 percentage point increase in the proportion of units providing an epilepsy handover clinic, from 30% in 2011 to 38% in 2014. Unfortunately, data is not available before 2010 or after 2014. Similar results were found in the Epilepsy Action report A Critical Time for Epilepsy in England, published in January 2013. It reported that 35% of acute trusts offered transition clinics for young people moving from paediatric to adult services.

25. Epilepsy misdiagnosis is a costly problem, estimated at around £268 million a year\(^7\). Providing transition clinics where diagnosis is reviewed may help the NHS to reduce misdiagnosis rates and the associated costs.

26. In 2007 an All Party Parliamentary Group\(^8\) report established that 70% of people with epilepsy could be seizure-free with optimal treatment and that the case for improving epilepsy services was overwhelming. They received evidence that transition services were not routine for people with epilepsy and, 8 years on, our

\(^7\) The Joint Epilepsy Council of the UK and Ireland. Epilepsy prevalence, incidence and other statistics. 2011

\(^8\) All Party Parliamentary Group on Epilepsy. The human and economic cost of epilepsy in England. 2007
uptake data suggests that this is still the case. Evidence from other studies, for
different conditions, has shown that patient outcomes can be improved by
providing transition services\textsuperscript{9}.

27. This area of epilepsy care warrants further quality improvement; therefore this
data will inform the quality standards annual review process in summer 2016.
The NICE guideline on \textit{transition from children's to adult's services} is also in
development and due to be published in February 2016. Improving the availability
of transition clinics will provide better integrated services, having a significant
impact on both the costs to the NHS as a whole and the individual management
of epilepsy.

\textbf{Hip fracture}

28. There were around 65,500 emergency hospital admissions for hip fracture in
adults\textsuperscript{10} in England in 2013/14\textsuperscript{11}, higher than the 61,772 reported in 2010/11\textsuperscript{12}.
Hip fracture risk increases with age, and with an ageing population the total direct
cost to the NHS is expected to rise. The total direct costs of all fragility fractures
are forecast to rise, reaching £2.2 billion by 2020, with most of these costs
relating to hip fracture care\textsuperscript{13}. The choice of procedure to treat hip fracture will
need to take account of comorbid conditions, which may affect subsequent
recovery and rehabilitation.

29. Traditional types of uncemented hemiarthroplasty are associated with a poorer
functional outcome and increased risk of mortality compared with cemented
implants. The use of cement reduces postoperative pain and aids recovery\textsuperscript{14}. The
NICE \textit{hip fracture} guideline, published in June 2011, recommends cemented
implants in patients undergoing surgery with arthroplasty.

30. The NICE quality standard on \textit{hip fracture}, published in March 2012, prioritised
12 areas from relevant guidance, including a statement that people with
discharged intracapsular fracture receive cemented arthroplasty, with the offer of

\textsuperscript{9} R Cowley, I Wolfe, K Lock, M McKee. \textit{Improving the transition between paediatric and adult
healthcare: a systematic review}. Archives of Disease in Childhood 2011.
\textsuperscript{10} Aged 18 years and over
\textsuperscript{11} Hospital Episode Statistics for financial year 2013-2014
\textsuperscript{12} Hospital Episode Statistics for financial year 2010-2011
\textsuperscript{13} Quality Watch (2013) \textit{Focus on hip fracture}
\textsuperscript{14} Royal College of Physicians (2014) \textit{National Hip Fracture Database extended report 2014}
total hip replacement if clinically eligible. The process measure is the proportion of people with displaced intracapsular fracture who have cemented arthroplasty\(^{15}\).

31. The **National Hip Fracture Database** reports annually on all eligible hospitals in England, Wales and Northern Ireland. It describes care and outcomes for people admitted with a hip fracture, and is the largest database of its kind in the world. It reported on the proportion of people with displaced intracapsular fracture who had cemented arthroplasty between 2010 and 2014.

**Figure 3 NICE quality standard on hip fracture, statement 7 (intracapsular fracture)**

32. Figure 3 shows a 19.3% increase in the proportion of people who had a displaced intracapsular fracture with cemented arthroplasty between 2010 (63%) and 2014 (82.3%).

33. The NICE hip fracture guideline **costing report** estimated that a cemented arthroplasty saves £63.68 per procedure compared with the uncemented version.

\(^{15}\) An audit standard of less than 100% should be expected for this process measure, to allow for cases where the practitioner considers it not in the best interests of the person to have surgery.
This could equate to an annual cost saving of £690,000 for the NHS. Although cemented arthroplasty is currently being used for 82% of appropriate hip fractures as shown above, there is room for further improvement to allow better functional outcomes for patients and generate potential cost savings for the NHS.

**Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure**

34. Arrhythmia is a term used to describe conditions where the heart contracts irregularly, or at a faster or slower pace than normal. Arrhythmias that arise from ventricles (ventricular arrhythmias) can occur unexpectedly and can cause sudden death when insufficient blood is pumped by the heart. Ventricular arrhythmias most commonly occur in people with underlying heart disease. Approximately 75% to 80% of the 70,000 sudden cardiac deaths in England and Wales in 2010 could be attributed to ventricular arrhythmias.

35. Heart failure is a chronic condition predominately affecting people over 50 years old. It is estimated that there are about 900,000 people in the UK who have definite or probable heart failure. About two-fifths of people with heart failure will have left ventricular systolic dysfunction, a proportion of whom will be suitable for implantation of a cardiac rhythm management device. People with heart failure are at risk from sudden cardiac death; this is the most common cause of death in people with mild to moderate heart failure.

36. The NICE technology appraisal guidance on implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (review of TA95 and TA120) was published in June 2014. Implantable cardioverter defibrillators (ICD) are recommended as an option for people who have had a serious ventricular arrhythmia, who have an inherited heart condition linked to a high risk of sudden death, or who have had surgery to repair

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16 NICE Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (review of TA95 and TA120)
19 NICE Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (review of TA95 and TA120)
congenital heart disease. For certain people with heart failure caused by left ventricular systolic dysfunction, ICDs, cardiac resynchronisation therapy with defibrillator (CRT-D) or with pacing (CRT-P) are recommended as treatment options.


38. The National Audit of Cardiac Rhythm Management Devices collects data on the implant rate for new implantable cardioverter defibrillators and the total cardiac resynchronisation therapy implant rate (including both new and replacement CRT-D and CRT-P).

Figure 4 Implant rate for new implantable cardioverter defibrillators and cardiac resynchronisation therapy, per million population

![Figure 4](image)

39. The national audit shows an increase in implant rates for implantable cardioverter defibrillators and cardiac resynchronisation therapy in England between 2003 and 2013. The increase is more significant for cardiac resynchronisation therapy.
40. The national audit also compares implant rates with the Western European average. The cardiac resynchronisation therapy implant rate for England in 2013 was above the average (151 per million population compared with 119 per million population). This is mainly due to a higher than average implant rate of CRT-P devices. For implantable cardioverter defibrillators, the implant rate was below the average (72 per million population compared with 141 per million population). The results of the 2013/14 audit suggest that the 2014 NICE guideline is simpler and more closely aligned with international guidance, and it is hoped that future implant rates will continue to move closer to the Western European average.

41. Cardiac rhythm management devices have been shown to be an effective use of NHS resources in improving quality of life and survival for people with ventricular arrhythmias and heart failure. The national audit shows that more people are having implantable cardioverter defibrillators and cardiac resynchronisation therapy implants. Progress appears good but this is against a background of an ageing population and an increase in heart disease and heart failure. In particular, further improvements could be made in respect of ICDs and CRT-D devices.

Lung cancer (non-small cell, EGFR-TK mutation positive)

42. Lung cancer is the second most common cancer in adults, with 36,653 cases registered in England in 2013. Non-small cell lung cancer (NSCLC) accounts for 85% to 90% of all lung cancers. Nationally it is estimated that one-third of people with NSCLC have chemotherapy, and of those it is expected that 16.6% will have EGFR-TK mutation-positive tumours. This equates to an estimated treatment population of 1200 people each year. The 2014 National Lung Cancer Audit showed that the number of patients with histologically confirmed NSCLC tumours which are not further subtyped has fallen from 15.8% to 12.9%.

43. Treatment options differ depending on a person’s EGFR status as either positive or negative. Mutated EGFRs show an increased rate of uncontrolled tumour

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21. Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (review of TA95 and TA120)
growth, which can speed up the cancer’s progression. People with mutation-positive tumours may gain more benefit from targeted therapies compared with standard chemotherapy. Although lung cancer is one of the more common cancers, survival is generally low (median survival 232 days)\textsuperscript{24}. This trend is similar for NSCLC, with median survival of 293 days\textsuperscript{25} and 100 days\textsuperscript{25} for stage 3 and 4 NSCLC respectively.

44. NICE recommends 3 biological therapies for NSCLC:

- NICE technology appraisal guidance on \textit{afatinib for the treatment of epidermal growth factor receptor mutation-positive locally advanced or metastatic non-small cell lung cancer} (2014) recommends afatinib as an option for people with locally advanced or metastatic NSCLC if they test positive for EGFR-TK mutation, have not previously had an EGFR-TK inhibitor and the manufacturer provides the drug at the fixed price agreed under the patient access scheme.

- NICE technology appraisal guidance on \textit{erlotinib for the first line treatment of locally advanced or metastatic EGFR-TK mutation-positive non-small cell lung cancer} (2012) recommends erlotinib as a first-line treatment option for people with locally advanced or metastatic NSCLC if they test positive for EGFR-TK mutation and the manufacturer provides the drug at the fixed price agreed under the patient access scheme.

- NICE technology appraisal guidance on \textit{erlotinib for the treatment of non-small cell lung cancer} (2008) recommends erlotinib as a second-line treatment option for people with NSCLC.

- NICE technology appraisal guidance on \textit{gefitinib for the first-line treatment of locally advanced or metastatic non-small cell lung cancer} (2010) recommends gefitinib as a first-line treatment option for people with locally advanced or metastatic NSCLC if they test positive for EGFR-TK mutation and the manufacturer provides the drug at the fixed price agreed under the patient access scheme.

\textsuperscript{24} Public Health England (2015) \textit{National Cancer Intelligence Network Rare and less common cancers. Incidence and Mortality in England 2010 to 2013}

\textsuperscript{25} Health and Social Care Information Centre (2014) \textit{National Lung Cancer Audit Report 2014}
45. During 2013, biological therapy treatment services for lung cancer patients in England and Wales were available on-site in 90% of trusts and off-site in 10% of trusts\textsuperscript{26}.

46. Uptake data for these medicines has been taken from the Innovation Scorecard (May 2015), which used primary and secondary care prescribing data from the PACT system and the Hospital Pharmacy Audit Index (HPAI) database from April 2010 to September 2014.

47. The data in figure 5 shows the number of defined daily doses (DDDs) per quarter for afatinib, erlotinib and gefitinib. (DDD is the assumed average maintenance dose per day for a drug used for its main indication in adults.) It is important to note that erlotinib is also indicated for treatment of metastatic pancreatic cancer and it is not possible to establish proportional usage by indication.

\textsuperscript{26} Health and Social Care Information Centre (2014) National Lung Cancer Audit Report 2014
Figure 5 Defined daily doses of afatinib, erlotinib and gefitinib in primary and secondary care (April 2010 to September 2014)

48. Figure 5 shows that the volume of all medicines prescribed increased from 77,965 DDDs in quarter 1 of 2010/11 to 103,632 DDDs in quarter 2 of 2014/15. This potentially equates to an additional 281 patients receiving treatment with these medicines over that period. These results suggest that more people are receiving treatment for NSCLC. In particular, there was a steady increase in prescribing for gefitinib following publication of NICE technology appraisal guidance on gefitinib for the first-line treatment of locally advanced or metastatic non-small cell lung cancer in 2010. During the same time period, prescribing for erlotinib was decreasing. Afatinib prescribing shows a small increase following publication of the related technology appraisal guidance in 2014, but more data is needed to explore this in the future.
Figure 6 Observed prescribing as a proportion of expected prescribing of afatinib, erlotinib and gefitinib in primary and secondary care (April 2010 to September 2014)

49. Figure 6 shows that following publication of NICE technology appraisal guidance on gefitinib for the first-line treatment of locally advanced or metastatic non-small cell lung cancer in 2010, the observed use of treatments for NSCLC has become closer to predicted use. For the financial year 2013/14, the observed volume of these medicines was 5% higher than expected, with 397,645 daily doses (expected) and 418,847 daily doses (observed)\textsuperscript{23}. However, given that erlotinib is also used for the treatment of metastatic pancreatic cancer, it is likely that observed use is close to predicted use.

50. In summary, there has been a general increase in the volume of all 3 medicines prescribed for the treatment of NSCLC in England in 2014/15. These upward trends appear to follow publication of the associated NICE technology appraisals, which have provided more treatment options for people with NSCLC. Prescribing trends for the individual drugs for NSCLC vary over time but may reflect
increased patient choice. Earlier treatment may have a beneficial impact on survival\textsuperscript{25}, and so the increasing trends in prescribing data are encouraging. However, it is important to note that erlotinib has licensed indications that have not been appraised by NICE.

**Non-vitamin K antagonist oral anticoagulants for atrial fibrillation**

51. Atrial fibrillation is the most common cardiac arrhythmia that affects about 1.6% of the population in England. The number of people in England with a diagnosis of atrial fibrillation has increased steadily from 823,000 in March 2012 to 883,938 in March 2014\textsuperscript{27}. Atrial fibrillation is a major cause of ischaemic stroke, with the risk of stroke being five times higher than in a person with a normal heart rhythm\textsuperscript{28}. Anticoagulation reduces the risk of stroke for people with atrial fibrillation. The Department of Health estimates that 7000 strokes could be avoided and 2100 lives saved each year in England if everyone with atrial fibrillation was appropriately managed\textsuperscript{29}.

52. The vitamin K antagonist warfarin is the main oral anticoagulant used in the UK, but a number of newer medicines are now available for stroke prevention in atrial fibrillation. Non-vitamin K antagonist oral anticoagulants (NOACs) do not need the same level of routine coagulation monitoring as warfarin. In 2012 and 2013, NICE positively appraised apixaban, dabigatran etexilate and rivaroxaban\textsuperscript{30} for use in the prevention of stroke in people with non-valvular atrial fibrillation.

53. NICE updated its clinical guideline on atrial fibrillation in June 2014. This stated that anticoagulation for atrial fibrillation may be with apixaban, dabigatran etexilate, rivaroxaban or a vitamin K antagonist. The clinical guideline also recommended that aspirin monotherapy should not be offered solely for stroke prevention to people with atrial fibrillation.

\textsuperscript{27}Health and Social Care Information Centre (2014) *Quality and Outcomes Framework (QOF) - 2013-14*.  
\textsuperscript{29}Department of Health (2013) *Cardiovascular Disease Outcomes Strategy: Improving outcomes for people with or at risk of cardiovascular disease*
54. The NICE Implementation Collaborative published a consensus statement alongside the guideline which addressed some of the barriers to prescribing NOACs.

55. NICE published a quality standard on atrial fibrillation: treatment and management in June 2015. The quality standard prioritised the following areas for quality improvement: offering anticoagulation to reduce stroke risk; not using aspirin as monotherapy for stroke prevention; discussing options for anticoagulation (including vitamin K antagonists and NOACs); and reassessing anticoagulation for adults taking a vitamin K antagonist who have poor anticoagulation control.

56. Uptake data for the NOACs was taken from the October 2015 Innovation Scorecard, and provides primary care prescribing data from April 2011 to March 2015. This data shows the volume of medicine prescribed and dispensed in the community, measured in DDDs. Figure 7 includes use of these medicines for the prevention of stroke in atrial fibrillation and also for other licensed indications.

Figure 7 Defined daily doses of apixaban, dabigatran etexilate and rivaroxaban in primary care (April 2011 to March 2015)
57. Figure 7 shows an increase in the prescribing of these medicines following publication of the respective technology appraisals. Since quarter 4 of 2011/12 (when NICE technology appraisal guidance on dabigatran etexilate for the prevention of stroke and systemic embolism in atrial fibrillation was published) to quarter 4 of 2014/15, the volume of medicine prescribed increased from 0.1 million to 20.3 million DDDs. This potentially equates to an additional 220,771 patients taking NOACs over this period. It is not known when these additional patients were diagnosed with atrial fibrillation or whether they were previously anticoagulated. In addition, these medicines may have been used for other licenced indications.

58. In primary care, over the same period of time, prescribing of warfarin increased from 35.8 million DDDs in quarter 4 of 2011/12 to 40.1 million DDDs in quarter 4 of 2014/15.

59. NOACs do not require the same level of routine coagulation monitoring as warfarin and so they represent an attractive option for some people with atrial fibrillation. They are potential lifesavers for some people with atrial fibrillation, particularly those who find it difficult to control their blood clotting with vitamin K antagonists or those who are intolerant to them. NOACs also represent an option for people newly diagnosed with atrial fibrillation and for those currently taking aspirin for stroke prevention. Given the important role of NOACs in preventing stroke in people with atrial fibrillation, there will be significant health benefits from the observed improved uptake of these medicines.

**Quitting smoking in pregnancy and following childbirth**

60. Smoking during pregnancy can cause serious pregnancy-related health problems. These include complications during labour and an increased risk of miscarriage, premature birth, still birth, low birthweight and sudden unexpected
death in infancy\textsuperscript{31}. Smoking during pregnancy increases the risk of infant mortality by an estimated 40\%\textsuperscript{32}.

61. The NICE public health guideline on \textit{quitting smoking in pregnancy and following childbirth} was published in June 2010. The guideline includes a recommendation to assist midwives in identifying pregnant women who smoke and referring them to NHS Stop Smoking Services. It recommends: assessing exposure to tobacco smoke through discussion and use of a carbon monoxide test; explaining the health benefits of stopping smoking for the woman and her baby and advising her to stop; referring all women who smoke to NHS Stop Smoking Services; checking if the referral was taken up; re-referring where appropriate; and at each stage recording smoking status, CO level, whether a referral is accepted or declined and any feedback given.

62. During guideline development, \textit{fieldwork} was carried out to evaluate how relevant and useful NICE’s recommendations were for practitioners and how feasible it would be to put them into practice. During the workshops and focus groups midwives raised concerns about the impact of the guidance on their time and workload. However, it was established that most areas already made use of a referral system in relation to offering smoking cessation advice.

63. Publication of the guideline was followed, in September 2012, by a NICE quality standard on \textit{antenatal care}. The quality standard prioritised 12 areas from relevant guidelines and includes a statement that pregnant women who smoke are referred to an evidence-based stop smoking service at the booking appointment. Smoking rates in pregnancy are an outcome measure for this statement.

64. The HSCIC \textit{Statistics on NHS Stop Smoking Services in England} provide data on the number of pregnant women setting a quit date through NHS Stop Smoking Services.

\textsuperscript{31} The Royal College of Physicians (1992) \textit{Smoking and the young: A report of a working party of the Royal College of Physicians}. Royal College of Physicians of London.

65. Figure 8 shows that the number of pregnant women setting a quit date through NHS Stop Smoking Services peaked in 2011/12 but has since fallen, from 26,080 in 2011/12 to 18,887 in 2014/15.

66. Data for the quality statement outcome measure can be found in the HSCIC Statistics on Women’s Smoking Status at Time of Delivery, England. The data shows a small year-on-year reduction in the proportion of women smoking at time of delivery from 14% in 2009/10 to 11.4% in 2014/15. This is close to the national ambition of 11% or less women smoking at the time of delivery, outlined in the tobacco control plan for England. At the same time there has been a year-on-year reduction in the actual number of women smoking at time of delivery from 91,328 in 2009/10 to 70,879 in 2014/15.

67. Additional data in respect of the quality standard will be available from the new Maternity Service Data Set, which includes smoking status as recorded at the initial booking appointment. Data submission started on 1 June 2015.

68. Since publication of the NICE guideline on quitting smoking in pregnancy and following childbirth there has been a year-on-year reduction in the proportion of
women smoking at time of delivery. However, the reduction is small and an initial peak in the actual number of pregnant women setting a quit date through NHS Stop Smoking Services has been followed by falling numbers. Given the poor maternal and infant outcomes associated with smoking in pregnancy, this remains a priority area.

Specialist neonatal care

69. Babies born prematurely, sick or with low birthweight need specialised care in their first hours, days and often months. In 2013, 80,000 babies received care in neonatal units in England and Wales. Breastfeeding affects the incidence of certain childhood diseases, including gastroenteritis, otitis media and necrotising enterocolitis (a serious inflammatory condition of the gut) in pre-term babies.

70. The Department of Health produced a toolkit for high quality neonatal services in 2009, recommending that neonatal services should provide dedicated support for breastfeeding and the expression of milk, and the provision of breast pumps for every mother who needs them.

71. The NICE quality standard on specialist neonatal care, published in October 2010, prioritises 9 areas from relevant guidance and includes a statement that: mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk. The quality statement outcome measure is the proportion of babies born at less than 33 weeks of gestation having specialist neonatal care who are breastfed when discharged from hospital. The Department of Health toolkit is a source document for the quality standard.

72. The National Neonatal Audit Programme (NNAP) considers care processes and outcomes of babies admitted to neonatal units in England and Wales. The audit provides data on the proportion of babies born at less than 33 weeks gestation who are discharged home and having breast milk.

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33 National Neonatal Audit Programme
73. Figure 9 shows an increase following publication of the NICE quality standard from 44% in 2010 to 59% in 2013.

74. The Picker Institute survey of parents’ experiences of neonatal care reported on a number of processes relating to the proportion of babies receiving breastmilk on discharge. The 2014 survey found that different proportions of parents received support from neonatal staff to express breast milk (78%), were provided with breastfeeding expressing equipment (83%), were given privacy for expressing milk (77%) and were offered support from neonatal staff for breastfeeding (75%). The results were similar to those from the 2011 survey.

75. Preventing disease and saving resources: the potential contribution of increasing breastfeeding rates in the UK referred to the cost of treating necrotising enterocolitis in infants in neonatal units. It estimated that if the rate of any breastfeeding/breastmilk feeding at discharge increased from 35% (reported in 2006) to 50% there would be a cost saving of £2.3 million per year. The data from the NNAP suggests that this saving is already being achieved. It also estimated
that increasing the rate from 50% to 75% would result in additional savings of £3.8 million per year, and that a further £3.8 million per year would be saved by increasing the rate to 100%. Rates of 100% at discharge have been achieved in some European and US neonatal units.

76. The NNAP data shows an increase in the number of premature babies discharged home receiving breast milk between 2010 and 2013. Parents report high levels of support from staff with privacy and equipment for expressing and breastfeeding. This has remained stable between 2011 and 2014, although it is not known how many women decide to not breastfeed. The increase in babies discharged home receiving breastmilk can be expected to reduce the incidence of a number of childhood diseases, including necrotising enterocolitis, generating further cost saving for the NHS.

**Stroke**

77. More than 966,000 people living in England have had a stroke\(^{35}\), including around 300,000 who live with moderate to severe disability as a result. Stroke is one of the top 3 causes of death and costs the NHS over £3 billion annually\(^{36}\). Many people have a high burden of impairment, activity limitation and participation restriction after stroke, and much of the post-stroke care relies on rehabilitation services. Stroke rehabilitation delivered by a multi-disciplinary team including physiotherapists, occupational therapists and speech and language therapists plays a key role in care.

78. In addition to the clear benefits of stroke rehabilitation for people after stroke, there are also potential cost savings for the NHS. The Department of Health *Impact Assessment: National Stroke Strategy* report (2007) estimated that full implementation of community-based rehabilitation would cost £11.4 million, leading to £38.2 million in savings and a net saving of £26.8 million or £53,025 per 100,000 population. It is likely that both the costs and savings estimated in the report have increased over time.


\(^{36}\) National Audit Office (2010) *Progress in improving stroke care*
79. The NICE quality standard on stroke published in June 2010 prioritises 10 areas from relevant guidance, including ongoing rehabilitation. The quality standard includes a statement that: patients with stroke are offered a minimum of 45 minutes of each active therapy that is required, for a minimum of 5 days a week, at a level that enables the patient to meet their rehabilitation goals for as long as they are continuing to benefit from the therapy, and are able to tolerate it\(^{37}\).

80. The NICE guideline on stroke rehabilitation published in June 2013 recommends initially offering at least 45 minutes of each relevant stroke rehabilitation therapy for a minimum of 5 days per week to people who have the ability to participate, and where functional goals can be achieved.

81. Uptake data for the quality standard is available from the Sentinel Stroke National Audit Programme (SSNAP). The audit measures the quality of care people living with stroke receive throughout the whole care pathway up to 6 months after admission. This includes data on the percentage of the required minutes of physiotherapy, occupational therapy and speech and language therapy which were delivered. The data reported is an indirect means of measuring the uptake of NICE stroke quality standard 2 statement 7, and is shown in figure 10.

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\(^{37}\) The source guidance for this statement was the Royal College of Physicians National clinical guideline for stroke, published in 2008.
82. Figure 10 shows an increase in the percentage of necessary minutes of therapy which were delivered following the publication of the NICE guideline on stroke rehabilitation in June 2013. There has been an increase from 24% in 2013 to 74% in 2015 for occupational therapy, from 19% to 69% for physiotherapy, and from 8% to 38% for speech and language therapy.

83. Speech and language therapy can help people after stroke if they have communication or swallowing problems. It is estimated that one-third of people will have some level of communication difficulty after stroke and at least 40% will initially experience some difficulty swallowing, although many recover their swallow quickly\(^{38}\). Difficulties with communication can make it harder for people to get help and information, affect their social relationships, limit their independence and reduce their self-confidence. Problems with swallowing can put people at risk of infection or spoil their enjoyment of food.

\(^{38}\) Stroke Association (2012) *Speech and language therapy after stroke*
84. The data shows that following publication of the NICE guideline on stroke rehabilitation and the NICE stroke quality standard, progress has been made in the intensity of rehabilitation therapy delivered after stroke. This improvement has been lower for speech and language therapy and may reflect fewer speech and language therapy staff working in the NHS compared with other members of the stroke rehabilitation team. There is strong evidence that rehabilitation improves outcomes for people after stroke and demonstrates that further improvement could be made in this priority area for quality improvement.

The health and wellbeing of looked-after children and young people

85. Every year around 10,000 16- to 18-year olds leave foster or residential care in England. Children and young people in care must leave local authority care by their 18th birthday, although local authorities must support care leavers until they are 21 years of age. On leaving care, some young people return home to their families, but many start to live independent lives.  

86. In 2014 the Department for Education introduced Staying Put, which offers care leavers the opportunity of staying with their former foster carers until they are 21-years old. The aim is to ensure that young people can remain with their former foster carers until they are prepared for adulthood, experience a transition akin to their peers, avoid social exclusion and be more likely to avert a subsequent housing and tenancy breakdown.

87. The NICE public health guideline on looked after children and young people, published in October 2010, includes a recommendation on preparation for the transition to adulthood and moving to independent living.

88. The guideline was followed, in April 2013, by a NICE quality standard on the health and wellbeing of looked-after children and young people. The quality standard includes a statement that care-leavers ‘move to independence at their own pace’. The focus is on young people having a pathway plan that prepares them for leaving care and equips them with the skills they need to live independently. The statement’s outcome measures are: feedback from care leavers that they felt supported to move to live independently at their own pace;

39 National Audit Office (2015) Care leavers’ transition to adulthood Department for Education
care leaver satisfaction with their accommodation, and the accommodation status of young people leaving care.

89. The Children’s Care Monitor survey reported children’s views on the state of social care in England up to 2013. The Children’s Commissioner for England subsequently took over responsibility for the survey and amended the questionnaire.

**Figure 11 NICE quality standard on looked-after children and young people, statement 8 (support to move to independence)**

90. The Children’s Care Monitor survey showed a small increase in the number of care-leavers who reported having a pathway plan in place. In addition, there were increases in the number of care leavers who rated the support they were getting and their accommodation as good or very good.

91. The Children’s Commissioner for England Children in Care and Care Leavers survey published in July 2015 reported that 54% of care-leavers stated that they had left care at the right time. Where care-leavers felt that they had not left at the right time the main reasons were feeling settled in their placement and being forced to leave before they were ready.
92. The Department for Education publishes national statistics on children looked after in England, including adoption. In the financial year 2013/14, 77.6% of former care-leavers aged 19 to 21 years were in accommodation classed as suitable (5.7% in accommodation classed as unsuitable and 16.8% no information). Some types of accommodation were judged by the local authority as suitable when this would not be expected by the Department of Education, and work is being done to assess and improve the quality of the data for future publications.

93. The National Audit Office report Care Leavers' Transition to Adulthood was published in July 2015 and concluded that the system for supporting young people leaving care was not working effectively. In respect of accommodation, it referred to the Staying Put policy as a positive step but noted that it was too early to assess its impact.

94. The Children's Care Monitor survey showed a small improvement in outcomes in respect of care-leavers moving to independence at their own pace between 2010 and 2013. However, data from the other reports described now indicates that further improvements could be made in this area.

**How NICE is using the uptake data**

95. We have many examples where uptake data shows change over time, which helps us to better understand the factors that may influence uptake. Some of the examples included show occasions when uptake has reached a high level. It seems likely that rapid change has been influenced not only by our guidance but also by incentives in the NHS such as best practice tariffs and CQUIN payments.

96. The prescribing data, taken from the Innovation Scorecard, demonstrates uptake in the NHS after we have recommended the use of a medicine in a technology appraisal. The NHS is legally obliged to fund and resource medicines and treatments recommended by NICE’s technology appraisals within 3 months (unless otherwise specified) of the date of publication. The prescribing data allows us to observe pace and scale of uptake and to consider what might be influencing this. The Department of Health and the Office for Life Sciences are currently undertaking a review into plans to give NHS patients quicker access to
innovative medicines and medical technologies. The use of uptake data to optimise the adoption and diffusion of innovations in the NHS is included in the Accelerated Access Review.

97. The Innovation Scorecard includes estimates of how many people might be prescribed a particular medicine, and based on this an expected volume of medicine is calculated. It can be difficult to estimate how many patients are likely to benefit from each treatment. When more than 1 treatment option is available for patients and clinicians to choose from, there may be a number of influences on the decision-making process including patient experience, how the medicine is administered, how frequently it needs to be taken, any monitoring requirements and a clinician’s familiarity with individual products. As part of our work to support the development of the Innovation Scorecard we are further developing and improving the ways in which we calculate estimates.

98. One of the most important uses of our uptake data is at the point when we are reviewing guidance or quality standards. In the last 12 months there have been 4 occasions when the use of uptake data has led to a recommendation to update quality standards. These were the quality standards for venous thromboembolism prevention, chronic kidney disease, end-of-life care for adults and lung cancer.

Future plans
99. This report has presented an overview of the information that we have about how our evidence-based guidance and quality standards are being used. The selected examples reflect the different types of guidance, the diversity of the information available and the different levels of uptake. It has provided examples of the areas that continue to be priorities for the NHS and social care.

100. Having access to data is an essential part of delivering service improvement and measuring changes in outcomes for people who use services. We intend to continue to publish and expand our uptake data to support both commissioners and providers of the prevention, care and treatments we recommend.

101. By assembling this data in one place we aim to provide an opportunity for organisations to compare their own uptake of our guidance or quality standards with others. This may help organisations identify warranted and unwarranted
variation. The resource will become more useful over time as its content increases.

102. We want to encourage organisations to send their audit data related to our guidance and quality standards directly to us for inclusion in the uptake data. We are aware that many thousands of audits are conducted across the NHS and increasingly in social care every year, representing a potentially rich source of uptake data that will be of interest to those using our guidance. We have developed a quality standards improvement template to enable organisations to measure their performance across a range of quality standard statements. This will facilitate the measurement of uptake as the NHS moves to new models of care as part of delivering the Five Year Forward View. We expect that a tailored approach to assessment will encourage more organisations to review their progress against self-selected quality statements and that this will encourage them to submit this data to our uptake database.

103. We know that when the data we identify and include in our uptake data closely matches our recommendations it becomes more meaningful to organisations that are monitoring their use of our guidance. For this reason we intend to continue our discussions with the Healthcare Quality Improvement Partnership, and other teams that develop the datasets for national audits, to align with and to influence the metrics used in national audits.

104. We know that the Care Quality Commission (CQC) is increasingly using NICE guidance to help assess whether organisations are compliant with CQC standards. We are aiming to develop our uptake data into a resource that can be used by organisations to compare their own rate of implementation of NICE guidance. We do not believe that our uptake data should be used by CQC inspectors because of the diversity of the data sources, the small sample sizes of local audits, and the fact that most data is at a national level lends itself only to general comparison.

105. We now meet each company whose medical device or diagnostic products we recommended for use 1 month after guidance is published and then about 6 months later. During these meetings a detailed discussion is held about how best
to measure uptake. At the same time we are talking with the HSCIC to identify how data that is routinely collected in the NHS can help to evidence uptake.

106. We hope that you have found this report informative and interesting. We would be very pleased to receive ideas and suggestions about how our uptake data can be improved and expanded. Feedback from people working in the NHS, public health, social care and other health settings as well as the wider public is welcomed. Please send your ideas to uptake@nice.org.uk.