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Rt. Hon. Jeremy Hunt MP
Secretary of State for Health
Department of Health
Richmond House
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LONDON
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7 February 2014

Dear Secretary of State

PATIENT OUTCOME STATISTICS IN ENGLAND

The UK Statistics Authority has today published its Monitoring Review on Patient Outcomes in England, a copy of which I enclose. This review of those patient outcome statistics that are currently recognised as official statistics was undertaken following recommendations made by Mr Robert Francis QC arising from his public inquiry into the role of the commissioning, supervisory and regulatory bodies in the monitoring of Mid Staffordshire NHS Foundation Trust.

The central point from the review is that users of these statistics we contacted tended to share the view expressed by Robert Francis in his report, that the statistics are not sufficiently accessible for use by the public. The presentation of the statistics often appears designed for performance management purposes and suited to expert users. Less-expert users – whether in the NHS or members of the public – require further interpretation, guidance and summary by analysts to aid their use and understanding of the statistics. These comments echo those gathered during the Statistics Authority's review of the Accessibility of Health Statistics and suggest that a fundamental change in attitude and culture within the bodies producing such health statistics is still needed.

The Statistics Authority considers that key official statistics relating to patient outcomes should, where appropriate, be designated as National Statistics, and that the bodies that produce these should be invited to put forward particular official statistics for assessment against the Code of Practice for Official Statistics. This has benefits for producers, decision makers and the public: producers, as the process of assessment helps to improve the quality of the statistics and related commentary; decision makers, recognising that good quality statistics lie at the heart of good decision making; and the public, as public trust in statistics is enhanced.

We found that the sources for almost all of the indicators in *The NHS Outcomes Framework* come from official statistics, however, a number of these indicators are new; the statistics used to measure them are in development and regarded as experimental. Almost all of the indicators have a public profile and can attract significant media reporting and other public attention. We judged that these statistics are of national importance and on this basis are seen as priorities for the Statistics Authority to assess compliance with the *Code of Practice*.

These findings lead us to our principal recommendations which are:

Recommendation 1 (paragraph 30). The following sets of statistics should be put forward for assessment against the *Code of Practice*:

- *NHS Outcomes Framework; quarterly update*
- *Summary Hospital-level Mortality Indicator (SHMI)*
- *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England*
- *NHS Safety Thermometer: Patient Harms and Harm Free Care*
- *Friends and Family Test (FFT)*
- *Patient Experience Survey statistics*
- *National Reporting and Learning System Quarterly Data Workbook*

The Statistics Authority will pursue these recommendations bilaterally with the Health and Social Care Information Centre (HSCIC), NHS England and the Care Quality Commission, as appropriate.

Recommendation 2 (paragraph 32). The Statistics Authority sees a vital need for HSCIC and NHS England to disseminate consistent patient outcome statistics from all publicly-funded healthcare providers (whether NHS or independent sector) and, in the interim, to state clearly whether the current statistics do so.

Recommendation 3 (paragraph 45). The Statistics Authority recommends that HSCIC and NHS England engage closely with expert users such as in third sector organisations with a view to improving the clarity and accessibility of current patient outcome statistics for less-expert users.

Recommendation 4 (paragraph 45). The Statistics Authority recommends that HSCIC provide more straightforward guidance about hospital mortality statistics directed towards less-expert users.

Recommendation 5 (paragraph 50). The Statistics Authority recommends that: HSCIC, NHS England, and CQC further research and publish the views of a wide range of users about their needs in respect of: (a) ensuring that the presentation of relevant statistics is accessible, clear and at a level of detail that supports their further use; and (b) extending the range of patient outcome statistics to address currently unmet needs.

Recommendation 6 (paragraph 51). The Statistics Authority considers that the results from the review of the FFT would be significantly enhanced if NHS England gathered the views of a wide range of users and published its findings.

The Statistics Authority is currently embarking on a new programme of work relating to the use of administrative data in the production of official statistics. We will look at how these data are currently being quality assured and audited by producers of statistics, and ways in which the statistical audit arrangements can be improved to enhance public confidence in the derived statistics. We will also look at the issues that arise when official statistics become the basis of performance targets at an individual or organisational level. As many of the data underpinning patient outcomes statistics are derived from administrative sources, this programme of work is highly relevant.

The Statistics Authority stands ready to offer further assistance in the future. I will ask the National Statistician (who oversees the Good Practice Team whose role is to identify and promote good

practice and to drive improvements) to explore with the Head of Profession for NHS England how these recommendations might be taken forward in an appropriate timescale.

Although the findings and recommendations of the report focus on patient outcome statistics in England, their implications may be expected to influence the reporting of outcomes for patients in the devolved administrations. For this reason, I am copying this letter to the Chief Executives of the Health and Social Care Information Centre, NHS England and the Care Quality Commission. I am also copying this letter to Bernard Jenkin MP, Chair of the House of Commons Public Administration Select Committee and to Rt. Hon. Stephen Dorrell MP, Chair of the House of Commons Health Committee, and to Jil Matheson, the National Statistician. I am copying this letter and the report for information to the relevant Ministers in the Devolved Administrations as well as to Robert Francis QC.

Yours sincerely

Sir Andrew Dilnot CBE

UK Statistics Authority

Monitoring Review

Monitoring Review 1/14
February 2014

Official Statistics on Patient Outcomes in England

Introduction

1. Following publication of the *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*[1] (Chaired by Robert Francis QC – and referred to hereafter as the *Francis Inquiry Report*) in February 2013, the UK Statistics Authority undertook[2] to conduct an independent review of patient outcome statistics[3] in England that are currently recognised as official statistics (and therefore within the Authority's statutory remit). This review, conducted by the Authority's Monitoring and Assessment Team, focuses on:

   - statistics used in *The NHS Outcomes Framework*[4], which sets out the outcomes and corresponding indicators used to assess improvements in health outcomes
   - the principal hospital mortality statistics being used by the NHS in England

   This review considers the extent to which these statistics could be made more readily useable by the public. This review focuses on patient outcome statistics in England as the Francis Inquiry recommendations were principally directed to the Department of Health (DH) and NHS England. It may be expected, however, that the implications of the Francis Inquiry may influence the reporting of outcomes for patients in the devolved administrations, and this is picked up in paragraphs 54 to 57.

2. The *Francis Inquiry Report* recommended that the Statistics Authority review whether there were any patient outcome statistics that DH or the Health and Social Care Information Centre (HSCIC) do not currently regard as being official statistics, but which the Authority would recommend in future be treated as official statistics and so be produced in accordance with the *Code of Practice for Official Statistics*[5]. This review examines the current status of the patient outcome statistics included in *The NHS Outcomes Framework* and identifies some sets of statistics which the Authority recommends be recognised as official statistics and be assessed against the *Code of Practice* with a view to designation as National Statistics[6].

3. The central point from the review is that users of these statistics we contacted tended to share the view expressed by Robert Francis in his report, that the statistics are not sufficiently accessible for use by the public. The presentation of the statistics often appears designed for performance management purposes and suited to expert users. Less-expert users – whether in the NHS or members of the public – require further interpretation, guidance and summary

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[1] http://www.midstaffspublicinquiry.com/report
[2] http://www.statisticsauthority.gov.uk/reports---correspondence/correspondence/letter-from-andrew-dilnot-to-bernard-jenkin-mp-13032013.pdf
[3] For the purposes of this review, we define 'patient outcomes' as the direct result of a treatment or intervention by health professionals to try to improve a patient's health and wellbeing; for example, patients' experiences of GP services, deaths among people aged under 75 from cardiovascular disease, and healthcare associated infections. The measurement of these experiences or events can be objective, recorded by administrative systems, or subjective and reported by patients in surveys
[4] https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014
[5] http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html
[6] References to assessment hereafter can be taken to mean assessment against the *Code of Practice*

by analysts to aid their use and understanding of the statistics. These comments echo those gathered during the Statistics Authority's review of the Accessibility of Health Statistics and suggest that a fundamental change in attitude and culture within the bodies producing such health statistics is still needed. In particular, the recognition that supporting the beneficial use of official statistics outside the NHS, whether by Parliament, business, the voluntary sector or by patients and their families, is just as important as supporting the use within the NHS and within government. The Statistics Authority will continue to work with the statistics producers to bring about that change in attitude.

4. The Statistics Authority is currently embarking on a new programme of work relating to the use of administrative data in the production of official statistics. We will look at how these data are currently being quality assured and audited by producers of statistics, and ways in which the statistical audit arrangements can be improved to enhance public confidence in the derived statistics. We will also look at the issues that arise when official statistics become the basis of performance targets at an individual or organisational level. As much of the data underpinning patient outcomes statistics are derived from administrative sources, this programme of work is highly relevant.

5. The next section summarises the main uses of these statistics, our findings and the main recommendations. It is followed by a review of the extent to which patient outcome statistics are treated as official statistics; an evaluation of the accessibility and statistical presentation, and a summary of feedback from users about improving the patient outcome statistics.

Contents

Summary of findings and conclusions

6. Central government uses the statistics in the formulation and monitoring of health policies. Healthcare regulators (such as the Care Quality Commission (CQC)) use them to support the benchmarking of performance and to inform investigative work. Academics and researchers and the health and commercial sectors use them to identify and explore variations in health outcomes over time. Parliament, media, and third sector organisations, including charities and lobby groups, use them to answer queries, monitor and draw conclusions about the performance of healthcare providers and the performance of the Government more generally. Increasingly patients, their relatives and carers use the statistics to help make choices about treatments and healthcare providers (paragraphs 35 to 37).

7. Due to the variety of user needs and the differences in their expertise, it is important that the statistics are presented in ways that are accessible and understandable by a broad audience. The *Francis Inquiry Report* expressed concern that official statistics about patient outcomes may not be readily useable by the public. Those users we contacted during this review tended to share that view, telling us that the statistics were not sufficiently accessible for use by the public.

8. We reviewed a selection of patient outcome and hospital mortality statistics and found that their accessibility and presentation appear more suited to NHS and government users. The presentation often appeared designed for performance management purposes and suited to expert users. Less-expert users – whether in the NHS or members of the public – require further interpretation, guidance and summary by analysts to aid their use and understanding of the statistics (paragraphs 39 to 45).

9. We found that *The NHS Outcomes Framework* sources almost all of its indicators from official statistics[7] (Annex 3 lists the statistical sources for all measures used in the 2013/14 *NHS Outcomes Framework*). However, a number of these indicators are new; the statistics used to measure them are in development and regarded as experimental. The *Code of Practice for Official Statistics* describes experimental statistics as '*new statistics undergoing evaluation. They are published in order to involve users and stakeholders in their development and as a means to build in quality at an early stage*'. The Statistics Authority has published guidance on the assessment and designation of experimental statistics[8]. While *The NHS Outcomes Framework* presents some of the statistics in development, not all are yet ready to be reported. HSCIC's *Summary Hospital-level Mortality Indicator (SHMI)*[9] are still experimental official statistics and other hospital mortality indicators in use, such as Dr Foster's Hospital Standardised Mortality Ratios[10] (HSMR), are not official statistics. Almost all of the indicators have a public profile and can attract significant media reporting[11,12] and other public attention.

10. The Statistics Authority takes account of questions of risk and materiality[13] in judging whether bodies that produce official statistics should be invited to put forward particular official statistics for assessment against the *Code of Practice*. Under the *Statistics and Registration Service Act*

[7] Official statistics publications are produced to a high professional standard and comply with the *Code of Practice for Official Statistics*. The *Code of Practice* is produced and monitored by the UK Statistics Authority which is independent of Government
[8] http://www.statisticsauthority.gov.uk/news/assessment-and-designation-of-experimental-statistics.html
[9] http://www.hscic.gov.uk/SHMI
[10] http://www.drfosterhealth.co.uk/features/what-are-hospital-standard-mortality-ratios.aspx
[11] http://uknewsnow.blogspot.com/2013/07/30-jul-2013-1549.html
[12] http://www.independent.co.uk/life-style/health-and-families/health-news/sir-bruce-keoghs-report-the-14-nhs-trusts-and-their-failings-8711708.html
[13] See Annex A of http://www.statisticsauthority.gov.uk/assessment/assessment/guidance-about-assessment/re-assessment-statement.doc

2007, the Authority may propose such assessment but requires the agreement of the producer body before proceeding. Annex 2 lists criteria that the Authority takes in to account before making such a proposal. This review focuses on statistics (about patient outcomes) that have not yet been assessed against the *Code of Practice* and do not have the National Statistics designation. Drawing on the criteria in Annex 2, **the Statistics Authority recommends the following sets of statistics be put forward for assessment against the *Code of Practice*** (Recommendation 1, paragraph 32)**:**

- ***NHS Outcomes Framework*; *quarterly update***[14]
- ***Summary Hospital-level Mortality Indicator (SHMI)***[15]
- ***Provisional Monthly Patient Reported Outcome Measures (PROMs) in England***[16]
- ***NHS Safety Thermometer: Patient Harms and Harm Free Care***[17]
- ***Friends and Family Test***[18] **(FFT)**
- **Patient Experience Survey statistics**[19]
- ***National Reporting and Learning System Quarterly Data Workbook*** [20]

Assessment has benefits for producers, decision makers and the public: producers, as the process of assessment helps to improve the quality of the statistics and related commentary; decision makers, recognising that good quality statistics lie at the heart of good decision making; and the public, as public trust in statistics is enhanced. The Statistics Authority will pursue these recommendations bilaterally with HSCIC, NHS England and CQC, as appropriate (paragraphs 18 to 31).

11. The Statistics Authority's Monitoring Review *The accessibility of official statistics on health*[21] noted that we see a need for high quality statistical data from independent sector providers of healthcare, produced to NHS standards where they relate to NHS patients. Supporting information currently provided alongside patient outcome statistics does not always make sufficiently clear whether the reported outcomes relate to all publicly-funded health care provided by NHS and independent sector providers. The range of patient outcome information on the NHS Choices website differs depending upon whether the provider is an NHS organisation or independent. **The Authority sees a vital need for HSCIC and NHS England to disseminate consistent patient outcome statistics from <u>all</u> publicly-funded healthcare providers (whether NHS or independent sector) and, in the interim, to state clearly whether the current statistics do so** (Recommendation 2, paragraph 34).

12. Third sector organisations, such as Cancer Research UK[22], Arthritis Research UK[23] and BirthChoiceUK[24], provide valuable support to the public by republishing many of the official

[14] http://www.hscic.gov.uk/nhsof
[15] http://www.hscic.gov.uk/SHMI
[16] http://www.hscic.gov.uk/proms
[17] http://www.hscic.gov.uk/thermometer
[18] http://www.england.nhs.uk/statistics/category/statistics/fft/
[19] http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys
[20] http://www.nrls.npsa.nhs.uk/resources/collections/quarterly-data-summaries/?entryid45=135153
[21] http://www.statisticsauthority.gov.uk/assessment/monitoring/monitoring-reviews/monitoring-review-7-2012-accessibility-of-official-statistics-on-health.pdf
[22] http://www.cancerresearchuk.org/cancer-info/cancerstats/
[23] http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics.aspx

patient outcome statistics in their own reports and websites, alongside information about the associated health conditions. Third sector organisations told us that they want easier access to patient outcomes information relevant to their work, with statistics provided in formats that are accessible to their client groups etc. These third sector organisations often quote official statistics in their own publications, sometimes explaining their relevance and meaning more effectively than in official statistics reports. The Statistics Authority's Monitoring Review *The accessibility of official statistics on health* called for the introduction of an easily understood framework of concepts, categories and terminology. **The Statistics Authority recommends that HSCIC and NHS England engage closely with expert users such as in third sector organisations with a view to improving the clarity and accessibility of current patient outcome statistics for less-expert users** (Recommendation 3, paragraph 46).

13. In the light of our research (paragraphs 22 to 24) we conclude that the presentation of the hospital mortality indices, SHMI[25] and HSMR[26], is not well suited to the needs of less-expert users – who, while less expert than NHS professionals, are nonetheless, in aggregate, a very important audience for the statistical data. **The Statistics Authority recommends that HSCIC provide more straightforward guidance about hospital mortality statistics directed towards less-expert users** (Recommendation 4, paragraph 47).

14. Users identified several aspects of patient outcomes where they required more, or more detailed, information than is currently published. Examples where it was suggested that further information would enhance the public value of the statistics include: specific health conditions such as cancers; on patient characteristics such as ethnicity and disability; about the outcomes themselves, such as providing more types of patient-reported outcomes (PROMs)[27], and surgery outcomes at greater levels of disaggregation, for example, by speciality or surgical teams. **The Statistics Authority recommends that**: **HSCIC, NHS England, and CQC further research and publish the views of a wide range of users about their needs in respect of: (a) ensuring that the presentation of relevant statistics is accessible, clear and at a level of detail that supports their further use; and (b) extending the range of patient outcome statistics to address currently unmet needs** (Recommendation 5, paragraph 52).

15. Some commentators on healthcare matters expressed concerns about the conceptual basis underpinning the new Friends and Family Test FFT. The FFT programme board has commissioned a review into the test. **The Statistics Authority considers that the results from the review of the FFT would be significantly enhanced if NHS England gathered the views of a wide range of users and published its findings** (Recommendation 6, paragraph 53).

[24] http://www.birthchoiceuk.com/Frame.htm
[25] http://www.hscic.gov.uk/SHMI
[26] http://www.drfosterhealth.co.uk/features/what-are-hospital-standard-mortality-ratios.aspx
[27] At present four types of elective interventions are reported – for more information see paragraph 25

Part 1:

The review of official patient outcome and hospital mortality statistics in relation to the *Code of Practice for Official Statistics*

16. Part 1 of this Monitoring Review examines the extent to which statistics used to measure patient outcomes within *The NHS Outcomes Framework*, as well as hospital mortality statistics (which are not in *The NHS Outcomes Framework*), are treated as official statistics and so produced with reference to the *Code of Practice*. As the Francis Inquiry had hospitals as its focus, this review has not examined the Government's other health frameworks for public health or adult social care, except where some of the indicators are shared with *The NHS Outcomes Framework*[28].

17. We have examined the statistics presented in *The NHS Outcomes Framework*, the sources used by HSCIC to calculate these statistics; and also statistics on hospital mortality, using the aspects of materiality referred to in paragraph 10 and detailed in Annex 2. The statistics set out below satisfy almost all of the aspects of materiality, and it is on this basis that they are seen as priorities for the Statistics Authority to assess compliance with the *Code of Practice*.

The NHS Outcomes Framework, Quarterly Update

18. *The NHS Outcomes Framework* was first published in 2011 and, since 1 April 2013, forms part of the way in which the Secretary of State for Health holds NHS England to account for commissioning healthcare for English patients. It sets out 15 overarching healthcare indicators and 52 improvement areas[29] arranged in five domains, aiming to improve by:

    1. Preventing people from dying prematurely
    2. Enhancing quality of life for people with long-term conditions
    3. Ensuring that people have a positive experience of care
    4. Helping people to recover from episodes of ill health or following injury
    5. Treating and caring for people in a safe environment and protecting them from avoidable harm

    HSCIC collates and releases the statistics in *the NHS Outcomes Framework* through its indicator portal[30].

19. The public was consulted about the establishment of *The NHS Outcomes Framework* before it was published[31] and patient groups were asked for their views about specific indicators. DH reviews the scope of indicators included in the *The NHS Outcomes Framework* and these are updated from time to time. It has established an Outcomes Framework Technical Advisory Group[32] to provide advice on the development of *The NHS Outcomes Framework*. Data are supplied to HSCIC by a range of providers, from government departments to academic research centres. Using these data, HSCIC produces indicators for *The NHS Outcomes Framework* that it considers to be official statistics.

20. HSCIC also publishes *The NHS Outcomes Framework; quarterly update* about the performance of the NHS against the indicators. This includes only those indicators which have

[28] Shared indicators are detailed in Annex 3
[29] For ease of reference we have used the term 'indicators' to refer to both indicators and improvement areas in this report
[30] http://www.hscic.gov.uk/indicatorportal
[31] http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117583
[32] https://www.gov.uk/government/policy-advisory-groups/outcomes-framework-technical-advisory-group

been revised or updated. In accordance with Principle 8 of the *Code of Practice*, DH and NHS England work with HSCIC to ensure that the statistical presentation of the update is meaningful to users. HSCIC is redeveloping the indicator portal to improve dissemination of the data and is currently consulting with users about these developments. It is aiming to enhance the data visualisation, extend the explanation about the statistics, and provide further information about the limitations of the statistics.

21. DH and NHS England are keen that *The NHS Outcomes Framework; quarterly update* is put forward for assessment. DH told us that it is guided by the HSCIC Statistical Head of Profession's view about the timing of the assessment.

Hospital Mortality Statistics

22. Healthcare providers use a variety of mortality indicators developed over time to suit particular needs. These include: HSCIC's Summary Hospital-level Mortality Indicator (SHMI); Dr Foster's Hospital Standardised Mortality Ratios (HSMR); and the Risk Adjusted Mortality Index (RAMI). This has given rise to confusion about the measures and relative status (for example whether the statistics used are official statistics or are produced by academic or commercial bodies) for the different variants used. Arising from a recommendation made by the Francis Inquiry, the methodologies used were examined by a working group established by DH[33]. This group recommended, among other things, better ways to assist hospitals to use such statistics to examine particular areas of patient care. The *Francis Inquiry Report* made it clear that the hospital mortality statistics should be available from 'unimpeachable, independent and reliable sources'[34]. In November 2010, DH announced that it was commissioning HSCIC to produce the *SHMI*. Since 2011, HSCIC has published the *SHMI* as experimental official statistics. These are important patient outcome statistics but are not used to inform *The NHS Outcomes Framework*. DH is developing a new indicator called 'hospital deaths associated with hospitalisation'[35].The Berwick review into patient safety[36] recommended that, until a better metric is developed, the NHS should use mortality rate indicators like the HMSR, or suitable alternatives, as one of its ways to detect potentially severe performance defects that are worth further investigation.

23. There are differences in the coverage of deaths between the SHMI and HSMR (which takes into account around 80 per cent of hospital deaths), as well as differences in the definitions used. Considerable debate has taken place within the clinical and hospital management community about the use of such indicators, particularly around their use as a measure of quality of care without clear explanation of their limitations. Since the publication of the *Francis Inquiry Report*, there has been comment in the media stemming from an apparent misunderstanding of the nature of these indicators, often referring to them as measuring 'excess' or 'avoidable' deaths[37]. Sir Bruce Keogh (NHS Medical Director), in his report focusing on 14 NHS trusts[38], described as 'outliers' in terms of hospital mortality, based on either their HSMR or on their SHMI scores, stated: 'It is clinically meaningless and academically reckless to use such statistical measures to quantify actual numbers of avoidable deaths'.

[33] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_121328.pdf
[34] See paragraph 59 of the *Francis Inquiry Report* – http://www.midstaffspublicinquiry.com/report
[35] http://www.hscic.gov.uk/article/2021/Website-Search?productid=12623&q=SHMI+&sort=Relevance&size=10&page=1&area=both#top
[36] https://www.gov.uk/government/publications/berwick-review-into-patient-safety
[37] http://fullfact.org/factchecks/excess_nhs_hospital_deaths_13000_keogh_review_mortality-29053
[38] http://www.nhs.uk/nhsengland/bruce-keogh-review/Pages/Overview.aspx

24. A number of hospitals report their standardised or risk-adjusted hospital mortality using non-official statistics, such as HSMR and the Risk Adjusted Mortality Index[39] (RAMI), rather than SHMI results in their Trust quality accounts[40]. HSCIC told us that it is engaging with healthcare providers concerning advice on how to interpret SHMI statistics. Professor David Spiegelhalter[41] has drawn attention to the fact that the two indices often produce different results. HSCIC told us that it wishes to make SHMI statistics available in a more detailed form, such as, by diagnosis type, care areas, and weekday versus weekend treatment. It also confirmed to us that, in the first instance, it would be requesting assessment of the overall SHMI statistics early in 2014 with a view to designation as National Statistics. HSCIC may subsequently also release additional, more detailed, SHMI statistics as experimental statistics.

Patient Reported Outcome Measures Statistics

25. *PROMs*[42] have been collected in the form of a survey since April 2009. HSCIC publishes patient outcome statistics, derived from PROMs survey data, for four elective interventions – hip replacement, knee replacement, treatment of groin hernia and treatment for varicose veins. There have so far been three annual releases. The PROMS dataset provides information for indicator 3.1 (see Annex C) in the NHS Outcomes Framework. HSCIC regards PROMs as experimental official statistics and intends to request the Statistics Authority to assess these statistics in 2014. Ongoing development to the statistics will include adjustment of the case mix method[43], as well as improvement to the presentation, before HSCIC is satisfied that PROMs statistics are ready for assessment.

Friends and Family Test (FFT)

26. In July 2013, NHS England published the first statistics from FFT[44] on its website alongside other health related statistics. In the FFT, more than 400,000 hospital in-patients and A&E patients are asked whether they would recommend their hospital to family and friends, with answers ranging on a five-point scale from 'very unlikely' to 'very likely'. The proportion of negative respondents is subtracted from the number of 'very likely' positive responses to give each A&E unit and ward an overall score which can be either positive, negative or neutral. The statistics are published at a national level as experimental statistics. They are further disseminated through NHS Choices at ward, accident and emergency department, hospital and NHS trust levels. FFT is an indicator within *The NHS Outcomes Framework* domain 4 'ensuring that people have a positive experience of care', although the *The NHS Outcomes Framework* has yet to be populated with these statistics.

27. DH told us that the FFT Programme Board has commissioned a review of these statistics as they require further development and will involve users and stakeholders in improving them. High profile media reporting[45, 46, 47] and other public attention have accompanied publication of the statistics.

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[39] www.chks.co.uk/userfiles/files/Differences_RAMI_AND_SHMI.pdf
[40] http://www.nhs.uk/aboutNHSChoices/professionals/healthandcareprofessionals/quality-accounts/Pages/quality-accounts-2011-2012.aspx
[41] http://www.bmj.com/content/347/bmj.f4893
[42] See footnote 16
[43] All indicators should, as far as possible, be adjusted for risk factors and other characteristics of patients – for example age, gender beyond the control of healthcare systems. Not making these adjustments could lead to unfair comparisons when it comes to assessing performance relative to other organisations
[44] http://www.england.nhs.uk/statistics/statistical-work-areas/friends-and-family-test/friends-and-family-test-data/
[45] http://www.theguardian.com/healthcare-network/2013/sep/05/patients-views-feedback-questionnaire
[46] http://www.hsj.co.uk/news/satisfaction-survey-damages-staff-morale-and-alarms-patients/5062673.article
[47] http://www.bbc.co.uk/news/health-23489102

Patient Experience Statistics

28. *The NHS Outcomes Framework* includes indicators within domain 4, 'ensuring that people have a positive experience of care', where the statistics are derived from patient experience surveys. NHS England commissions CQC to run patient experience surveys covering outpatient care[48], inpatient care[49], A&E care[50], maternity services care[51] and care received by community mental health services[52]. CQC publishes the statistics from these surveys as official statistics. Additionally, NHS England publishes results from the GP Patient Survey[53], which is conducted by Ipsos MORI. DH published headline patient experience statistics, as part of its monitoring of indicators in *Overall Patient Experience Scores*[54]. The responsibility for this statistical release moved to NHS England from April 2013. The Statistics Authority has assessed the statistics in *Overall Patient Experience Scores*, publishing its report[55] in February 2011, and confirmed their designation as National Statistics in October 2011.

29. CQC told us that it seeks to make its patient experience statistics about NHS trusts more understandable by the public. It has produced, since 2007, a summary of changes in performance, using designations such as 'better than' or 'worse than' or 'about the same as' the majority of other NHS trusts. The CQC surveys team is considering improvements to the way the survey scores are shared, especially with less-expert users.

Patient Safety Statistics

30. Since March 2013, *The NHS Outcomes Framework* has included indicators relating to patient safety, such as reported patient safety incidents. The importance of transparent and timely non-personal data on quality and safety has recently been underscored in the recommendations arising from the Berwick review into patient safety [56]. The review emphasised that such data should be 'shared in a timely fashion with all parties that want it, including, in accessible form, with the public'. Before the publication of *The NHS Outcomes Framework*, the National Patient Safety Agency[57] reported these statistics using data from the National Reporting and Learning System (NRLS). NHS England took over responsibility for this service in June 2012. It publishes the Patient Safety Incident Report as official statistics sourced from NRLS every six months. Aggregated data returns are collected from individual providers on a quarterly basis. The statistics are published in data tables giving the numbers of reported incidents, the care setting of the incidents (including a breakdown for England and for Wales) and the degrees of harm to patients. There is no commentary accompanying these statistics, although supporting information is provided on the scope, methods, and data quality. NHS England told us that NRLS is currently being reviewed and that this review is likely to impact on the future collection and reporting of patient safety data.

31. HSCIC has published *NHS Safety Thermometer: Patient Harms and Harm Free Care*[58] as experimental statistics, on a monthly basis, since May 2013. The report presents statistics on four patient harms:

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[48] http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/outpatient-survey-2011
[49] http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2012
[50] http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/accident-and-emergency-2012
[51] http://www.nhssurveys.org/surveys/483
[52] http://www.nhssurveys.org/surveys/612
[53] http://www.gp-patient.co.uk/
[54] https://www.gov.uk/government/organisations/department-of-health/series/patient-experience-statistics
[55] http://statisticsauthority.gov.uk/assessment/assessment/assessment-reports/confirmation-of-designation-letters/letter-of-confirmation-as-national-statistics---assessment-report-91.pdf
[56] See footnote 37
[57] http://www.nrls.npsa.nhs.uk/
[58] See footnote 16

- pressure ulcers
- falls
- urinary tract infections in patients with a catheter
- new venous thromboembolisms

These were selected as the focus because they are common and because there is a clinical consensus that they are largely preventable through appropriate patient care. Patients are assessed in their care settings, and measurement is intended to focus attention on the elimination of patient harms. More than one indicator in *The NHS Outcomes Framework* is to be calculated from these statistics. HSCIC told us that, as the statistics are new, it has no current plans to request the Statistics Authority to assess them.

Other official patient outcome statistics scheduled for assessment

32. The Statistics Authority is currently scheduling and conducting assessments of other official patient outcome statistics used to inform *The NHS Outcomes Framework*, where producer bodies have already placed requests. The designation of these statistics as National Statistics is expected within a reasonable timescale after their assessment. The National Bereavement Survey[59], produced by ONS on behalf of NHS England, and the healthcare associated infection statistics[60] (HCAI), produced by Public Health England[61], are among those statistics currently being assessed.[62].

Conclusions

The Statistics Authority recommends that HSCIC, NHS England and CQC put forward the patient outcome statistics listed in paragraph 10 for assessment against the *Code of Practice* (Recommendation 1, paragraphs 18 to 31).

Part 2:

33. Part 2 of this Monitoring Review examines the use made of the patient outcome statistics and provides a summary of feedback from users about improving these statistics.

Patient outcome statistics in the independent sector

34. Following the organisational changes in the NHS from 1 April 2013[63], NHS England is responsible for commissioning publicly-funded healthcare in England, whether provided by the NHS or the independent sector. When accessing the NHS Choices portal, there are very few key facts data for independent-sector care providers, and no explanation is given for not presenting these statistics[64]. It was also confirmed to us that there are differences in the information available from NHS providers and from independent sector providers which make it difficult for comparable statistics to be released.

[59] http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/index.html
[60] http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HCAI/EpidemiologicalDataHCAI/
[61] https://www.gov.uk/government/organisations/public-health-england
[62] http://www.statisticsauthority.gov.uk/assessment/assessment/programme-of-assessment/index.html
[63] Under the *Health and Social Care Act 2012:* http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted
[64] For instance the NHS Safety Thermometer data at http://www.hscic.gov.uk/catalogue/PUB11382/nati-safe-tool-jul-2012-jul-2013-datv2.xlsm

Conclusions

The Statistics Authority sees a vital need for HSCIC and NHS England to disseminate patient outcome statistics from all publicly-funded healthcare providers (whether NHS or the independent sector), and, in the interim, to state clearly whether the current statistics do so (Recommendation 2, paragraph 34).

Uses and accessibility of patient outcome statistics

35. A frequently cited use of patient outcome statistics is to allow patients and their representatives (MPs and GPs) to hold the NHS and the Government to account. However, we have found that much of the information about patient outcomes presented in statistical reports is neither readily accessible nor designed to be understood by the less-expert user. The Statistics Authority's Monitoring Review *The accessibility of official statistics on health*[65] called for the introduction of an easily understood framework of concepts, categories and terminology. We were told that patient representatives often want to make further enquiries of official statistics producers to satisfy their enquiries at the appropriate healthcare provider level and in terms those patients' representatives can understand. These comments echo those gathered during the Statistics Authority's review of health statistics and suggest that a fundamental change in attitude and culture within the bodies producing such health statistics is still needed. In particular, the recognition that supporting the beneficial use of official statistics outside the NHS, whether by Parliament, business, the voluntary sector or by patients and their families, is just as important as supporting the use within the NHS and within government. The Statistics Authority will continue to work with the statistics producers to bring about that change in attitude.

36. Another use of statistics about outcomes from patient care is by healthcare providers themselves to improve their quality of care. We were told that there is scant evidence that public reporting improves clinical outcomes, except in the case of cardiac surgery[66]. Healthcare providers collect management information at the time they give care to patients, and use this information more intensively and frequently than outcomes statistics published some time after the information are collected. Aggregated official statistics are more often used by care providers to benchmark performance or examine trends. Healthcare providers find that the publication of official, aggregated statistics are not timely enough to act upon and are not at sufficient clinical detail to analyse adequately. These limitations of the official statistics mean that they have less value for individual healthcare providers.

37. Healthcare regulators also use patient outcome statistics since the official, aggregated datasets allow them to make estimates that are less uncertain and build up trend analyses from the time series information they present. For example, CQC, Monitor[67] and the National Audit Office[68] use the statistics to inform assessments of the quality of care given, to make risk assessments for the purposes of scheduling their audit functions and for allocating resources. CQC told us it is developing a quality ratings scheme for healthcare providers.

38. As part of this review, we examined the access to, and presentation of, eight sets of patient outcome statistics which are used to produce measures in *The NHS Outcomes Framework*[69].

[65] See footnote 21
[66] http://www.kingsfund.org.uk/publications/getting-measure-quality
[67] http://www.monitor-nhsft.gov.uk/
[68] http://www.nao.org.uk/
[69] The statistics examined were statistics on *SHMI*; *Emergency Re-admission Statistics* and *PROMs* from HSCIC; statistics on *Cancer Survival* from ONS; and statistics on the *Number of patients assessed to prevent venous*

With the exception of cancer survival statistics, we did not examine patient outcome statistics which are already designated as National Statistics as compliance with all aspects of the *Code of Practice* has already been assessed by the Statistics Authority. The statistics examined measure not just objective outcomes but also patients' experiences. Our analysis included, for example:

- the extent to which the entry points to the statistics from the producer bodies' principal web pages are straightforward
- the existence of clear links to information about methods, quality and reliability
- the capability to re-use the data
- the publication of clear metadata[70] about the statistics
- a published forward timetable for the release of the statistics

Also examined was the accessibility of the statistics from other key web access points such as the National Statistics Publications Hub[71] and NHS Choices. We compared access to these official statistics with access to other relevant, non-official, patient outcome statistics produced by, for example, academic and research organisations.

39. It is not always apparent from the statistical reports what the context and likely uses are for the statistics contained in the reports. For example, in England, prospective patients are encouraged to use a limited range of statistics, through the NHS Choices[72] website to choose a provider for their treatment. Upon searching for a particular healthcare provider or procedure, various 'Key Facts' are presented to patients, some of which are statistics such as mortality rates or readmission rates. NHS Choices explains the methodology used to calculate the mortality statistics and the data source, but the information could be more clearly explained for the less-expert user.

40. The issues associated with 'accessibility' centre on being able to identify, locate and then acquire the required statistics, as well as being able to understand their meaning. The less-expert user, as well as the expert, needs to know what statistics are available on the topics of interest to them and how to find the figures and the advice relating to them. The vast range of information about patient outcomes, which this review has highlighted, now means that this has become increasingly challenging. It is clear that the answer has to lie with well designed websites as well as cooperation between producers and those available to help the less-expert user, such as charities and voluntary groups, to adopt shared approaches to optimise people's likelihood of finding what they want[73].

41. This review has found that of those patient outcome statistics we examined, many did not present accompanying commentary[74] which would be essential if they were to become designated as National Statistics. This contrasts with official statistics classified as National Statistics which include commentary to aid interpretation (an example of the latter is ONS's cancer survival statistics). Some patient outcome statistics that we examined presented only

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thromboembolisms; *Friends and Family Test*; *Patient Experience of hospital care from the national inpatient survey*; and *Patient Experience of GP Services* from NHS England

[70] http://epp.eurostat.ec.europa.eu/portal/page/portal/statistics/metadata

[71] http://www.statistics.gov.uk/hub/index.html

[72] www.nhs.uk

[73] This is set out in Principle 8, Practices 1 and 2 of the *Code of Practice*

[74] Commentary adds contextual detail to allow the reader to make sense of the figures represented. The commentary should explain what the statistics mean and make clear the nature and implications of uncertainty associated with the statistics

numbers or data tables, with no contextual information and little explanation about the significance or importance of the statistics.

42. In terms of statistical comparability[75], this review found that different statistics producers release patient outcome statistics about similar aspects of care, but the existence of the complementary statistics and how to access them are not always made clear. One set of statistics may present an 'objective' measure of an outcome, such as, access to GP's Out of Hours services, by measuring waiting times for responses to telephone calls, while another producer body provides statistics based on patients' reports of the response times to their calls from an experience survey. Access to both sets of statistics would be more informative if links were provided to the comparable statistical reports. For example, we found that NHS England's statistical bulletin *Overall Patient Experience Scores* provided the overall statistics for England and noted that CQC also disseminates the statistics at a more detailed healthcare provider level. Conversely, CQC's website does not refer to the complementary set released by NHS England.

43. Statistical coherence is the degree to which data about the same phenomenon are similar although derived from different sources or methods. The concept of 'death following a spell in hospital' is presented in a manner that does not appear to be coherent across the various statistical sources. Table 1 shows results for mortality at the same NHS trust that are published by four different sources. There is no explanation of coherence given with the official statistics, which is confusing for data users. SHMI statistics are sourced and calculated differently to the HSMR as it appears in the Dr Foster Hospital Guide[76] and to the RAMI[77] as it appears in some of the NHS healthcare provider Quality Accounts[78]. To meet the requirements of the *Code of Practice*, producers should ensure that the official statistics explain coherence with other relevant statistics in a straightforward manner[79].

Table 1 Comparison of sources, definitions and figures for mortality for an example NHS trust

Source	Definition as published	Results as published
HSCIC's Indicator Portal	SHMI – deaths associated with hospitalisation	January 2012 to December 2012 = 0.9146
Dr Foster's Hospital Guide	1 year hospital standardised mortality ratio	September 2011 to August 2012 = 78.28 out of 100
Trust Quality Accounts	RAMI	Rolling 12 months = 61
NHS Choices	Mortality ratio: deaths in hospital and within 30 days of discharge	0.9146

[75] Statistical comparability is the degree to which data can be compared over time and domain
[76] http://www.drfosterhealth.co.uk/hospital-guide/
[77] http://www.ncbi.nlm.nih.gov/pubmed/3143868
[78] http://www.nhs.uk/aboutNHSChoices/professionals/healthandcareprofessionals/quality-accounts/Pages/about-quality-accounts.aspx - DH has instructed Trusts to use SHMI from 2012/13
[79] This is set out in Principle 4, Practice 2 of the *Code of Practice*

What users told us about access and presentation

44. Expert users often find the patient outcome statistics to be sufficient for their needs, in terms of their accessibility and the clarity of the data presentation and supporting information. There were some specific suggestions for improvement. For example, one user highlighted the difficulties of accessing cardiac surgical outcome data for both paediatrics and adults, as well as problems experienced in finding material on the ONS website. Another user highlighted the issue of large volumes of data that are put in the public domain for transparency purposes and the difficulties that can be encountered in making sense of the data, particularly for the public in making choices. We were told about an example in which data are released through nearly 17,000 web pages on the Central Cardiac Audit Database[80], with the consequence that meaningful comparisons were found to be 'almost impossible'[81].

45. We were told that clinical commissioning groups[82] and healthcare providers seek assistance from commissioning support units[83] (which from 2016 will be independent private businesses) to interpret patient outcome statistics. The House of Commons library provides analytical support for Parliamentary users. Third sector organisations publish their own material, drawing on the official patient outcome statistics, to support the public in understanding the nature of various health conditions and their related treatments. NHS England told us that it sees NHS Choices[84] as the tool for the public to access health information, including statistics about patient outcomes, hospital performance and the quality of care.

46. We were told that third sector organisations want better support in order to obtain those statistics they require in formats that are accessible to their members and supporters. The use of an alert facility was proposed; HSCIC has a feature where users can register, via its website, to be alerted when there has been a new release of statistics. There appears to be scope for HSCIC to advertise such features more broadly. It was suggested to us that there is potential for official statistics producer teams to work collaboratively with third sector organisations on the interpretation and presentation of patient outcome statistics, as well as providing feedback on the usefulness and accessibility of previously published statistics.

47. The published presentations of the hospital mortality indices SHMI[85] and HSMR[86] raised concerns among some users that such presentations do not clearly support appropriate interpretations of the figures. A misunderstanding by some media organisations about the terms 'excess' and 'avoidable' deaths as equalling 'needless' deaths was highlighted in a BMJ article[87] by Professor David Spiegelhalter. He emphasised the need for hospital information packs including SHMI and HSMR statistics to provide clear guidance about the measures used, to aid their appropriate interpretation. He discouraged statistics producers and others from using the term 'outliers', suggesting they adopt alternative descriptions such as 'above the expected range'. He also advised against the translation of the standardised mortality rates into the numbers of excess deaths.

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[80] https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument

[81] The Statistics Authority is fully supportive of the view expressed by the Public Administration Select Committee, that transparency is not always or necessarily achieved merely by publication of data. 'Data dumping' can be inimical to transparency and good government. See the Authority Chair's letter to the Right Honourable Francis Maude, MP, Minister for the Cabinet Office of 11 October 2011 at http://www.statisticsauthority.gov.uk/reports---correspondence/correspondence/letter-from-sir-michael-scholar-to-rt--hon--francis-maude---open-data---11102011.pdf

[82] http://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/c/clinical_commissioning_group_de.asp

[83] http://www.hsj.co.uk/home/commissioning/csu-structures-and-how-they-will-operate/5055935.article#

[84] See footnote 72

[85] See footnote 9

[86] See footnote 10

[87] See footnote 41

Conclusions

The Statistics Authority recommends that:

- **HSCIC and NHS England engage closely with expert users such as in third sector organisations with a view to improving the clarity and accessibility of current patient outcome statistics for less-expert users** (Recommendation 3, paragraph 46)
- **HSCIC provide more straightforward guidance about hospital mortality statistics directed towards less-expert users** (Recommendation 4, paragraph 47)

Users' feedback about improving patient outcome statistics

48. Users raised a number of issues about patient outcome statistics in addition to those about access and presentation. We approached some known and potential users of patient outcome statistics and invited comments via an open note on the Statistics Authority's website and through the Royal Statistical Society's StatsUserNet[88] forum. We received comments from ten users about their use of patient outcome (official and non-official) statistics and we met or spoke with four official statistics producers.

Statistics should present greater detail

49. Users identified a wide range of aspects of patient outcomes for which they want more detailed information than is currently published, and highlighted information gaps where statistics are not available. Annex 1 gives a list of the information gaps identified by users. It highlights that further information is wanted on specific health conditions, such as cancers; on patient characteristics, such as ethnicity and disability, and about the outcomes themselves, such as providing more types of PROMs, and granular level surgery outcomes, for example at speciality and surgeon levels.

50. Cancer Research UK told us that further information is wanted about: the stage of cancer in those registered as newly diagnosed cases of cancer; hospital information about emergency presentation and treatment for cancer patients; information from the screening programmes, and about patient experience of hospital care. They also emphasised the importance of maintaining existing cancer survival statistics published by ONS.

51. A lack of information was highlighted in the Chief Medical Officer's 2011 annual report[89] about some musculoskeletal disorders[90], sensory disorders[91] and skin diseases. Arthritis Research UK has also identified a number of information gaps relating to musculoskeletal disorders. It told us that it is working to address some of the information gaps by funding research. An example of one result from this research is the development of a new tool, the Musculoskeletal Calculator[92], which aims to produce reliable estimates of the incidence and prevalence of the major musculoskeletal conditions at both local and national levels. It is also funding the development of the musculoskeletal patient reported outcome measure[93] (M-PROM) for inclusion in *The NHS Outcomes Framework*. We were told that, historically, the lack of

[88] http://www.statsusernet.org.uk/Home/
[89] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141771/CMO_Annual_Report_2011_Chapter_2a.pdf
[90] http://www.hse.gov.uk/MSD/
[91] http://www.spdfoundation.net/about-sensory-processing-disorder.html
[92] http://www.arthritisresearchuk.org/policy-and-public-affairs/policy-priorities-and-projects/musculosketal-health-services/the-musculoskeletal-calculator.aspx
[93] http://www.arthritisresearchuk.org/research/grants-you-can-apply-for/types-of-grant/special-strategic-awards/musculoskeletal-patient-reported-outcome-measure.aspx

information available on musculoskeletal disorders has not helped to focus policy makers on measures to alleviate the associated issues and consequences of these conditions. Such conditions carry a significant burden in addition to the implications for people's health – only mental health issues are cited as causing more days lost from work[94].

52. Historically, data generated from primary care have been difficult to obtain with the exception of conditions included in the quality and outcomes framework[95]. This is set to change with the new General Practice Extraction Service[96] (GPES), managed by HSCIC, which will extract data from GP information systems. It will collect data for NHS England's new data system 'care.data'[97] on a wide range of diseases and conditions. The intention is to link the data from GPs with other health and care data and produce the care episode statistics (in place of the current hospital episode statistics). No diagnostic codes relating to musculoskeletal conditions have been included in the GPES extract, so no primary care data on any musculoskeletal disorders can be drawn into 'care.data'.

Conclusions

The Statistics Authority recommends that: HSCIC, NHS England, and CQC further research and publish the views of a wide range of users about their needs in respect of: (a) ensuring that the presentation of relevant statistics is accessible, clear and at a level of detail that supports their further use; and (b) extending the range of patient outcome statistics to address currently unmet needs (Recommendation 5, paragraphs 38 to 52).

The methods and modes of collecting data should be improved

53. We were told of concerns about the methods for producing some specific patient outcome statistics. In particular, these concerns related to FFT but also about the use of the HSMR for measuring quality of care in hospital trusts. FFT[98] was criticised as not having a sound conceptual basis. Concerns expressed related to the different methods and the modes of data collection used by trusts in gathering the views of patients. NHS England did not adjust the statistics for factors such as age, gender, co-morbidities or social disadvantage despite strong evidence that some patient characteristics will influence the responses. Combined with low response rates and a significant risk of response bias, there are serious concerns around the robustness of these statistics. The lead statistician for NHS England told us that he chose to release the new statistics as experimental statistics as this will give an opportunity to enable users to have access to new statistics and provide feedback on their suitability. We were also told that NHS England has begun a review of FFT, including the nature of data collection by NHS trusts, and will determine whether the method of collection should be more specifically mandated.

Conclusions

The Statistics Authority considers that the results from the review of the FFT would be significantly enhanced if NHS England gathered the views of a wide range of users and published its findings (Recommendation 6, paragraph 53).

[94] http://www.fitforworkeurope.eu/press-releases.htm
[95] http://www.hscic.gov.uk/qof
[96] http://www.hscic.gov.uk/gpes
[97] http://www.england.nhs.uk/ourwork/tsd/data-info/
[98] http://www.england.nhs.uk/statistics/statistical-work-areas/friends-and-family-test/friends-and-family-test-data/

Patient outcome statistics in the devolved administrations

54. Health policy and the management of national health services are devolved to the countries of the UK. We spoke to patient outcome statistics producers in Wales and Scotland who told us that the relevant authorities in Wales[99] and in Scotland[100] have considered their respective responses to the *Francis Inquiry Report*. In Wales, early in 2013, all NHS organisations published their acute hospital level risk adjusted mortality figures and these are now routinely made available through a website called *mylocalhealthservice*[101]. The Welsh NHS and Welsh Government want to build on this approach and have established a transparency and mortality taskforce[102] to help implement this. The approach to develop Welsh hospital mortality statistics has been published in a series of statistical articles[103]. The intention is to develop a range of mortality indicators, including, but not limited to, deaths in hospitals. The *National Health Survey for Wales*[104] provides patient experience statistics for Wales and is designated as National Statistics.

55. The Scottish Patient Safety Programme[105] (SPSP), which is coordinated by Healthcare Improvement Scotland[106], has just completed its first five years of operation, and directly promotes patient safety in NHS Scotland. The programme uses real time data, collected unit-by-unit, often by the staff caring directly for patients, to improve the reliability and safety of healthcare systems and processes. The SPSP was recently relaunched and we were told that the Keogh Review has been influential in assessing safety in Scottish hospitals. Scotland has produced Hospital Standardised Mortality Ratio (Scottish HSMR) statistics as official statistics since 2008, and these were recently assessed and conditionally designated as National Statistics[107]. We could find no published hospital standardised mortality statistics for Northern Ireland.

56. There are no explicit rights given to patients in Wales which provide for patient choice in respect of where they access services. In Wales, statistics are not produced and presented for the purpose of independently assisting patient's choices. Statistics collected in Wales on patient outcomes are primarily used for the purposes of health policy development and monitoring, assessing patient experience and outcomes, and holding the NHS to account for its performance and for quality and safety improvement.

57. In Scotland, patient outcome statistics are primarily used for the purposes of health policy and clinical monitoring, for performance management and holding the NHS in Scotland to account and for quality and safety improvement. A Quality Measurement Framework[108] is being developed in Scotland which collects and publishes data at three levels. Level 1 is high level and monitors progress against large-scale government aims for healthcare improvement at a national level. Level 2 is used for performance management and to hold NHS in Scotland to account and includes specific Scottish Government HEAT targets[109]. Level 3 is principally management information that are rarely aggregated and published as national statistics. The

[99] http://wales.gov.uk/topics/health/publications/health/reports/safecare/;jsessionid=975C25228FADF23E1B161A45B3C0B638?lang=en
[100] www.nhsnss.org
[101] http://mylocalhealthservice.wales.gov.uk/#/iaith=ENG
[102] http://wales.gov.uk/topics/health/nhswales/organisations/mortality/?lang=en
[103] http://wales.gov.uk/topics/statistics/articles/mortality-statistics-in-wales/?lang=en
[104] http://wales.gov.uk/statistics-and-research/welsh-health-survey/?lang=en
[105] http://www.scottishpatientsafetyprogramme.scot.nhs.uk/programme/about
[106] http://www.healthcareimprovementscotland.org/home.aspx
[107] http://www.statisticsauthority.gov.uk/assessment/assessment/assessment-reports/assessment-report-249---statistics-on-hospital-standardised-mortality-ratios-and-nhs-complaints-in-scotland.pdf
[108] http://www.isdscotland.org/Health-Topics/Quality-Measurement-Framework/Resource-Use/
[109] http://www.scotland.gov.uk/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance

NHS in Scotland told us that it regards the published statistics at Levels 1 and 2 as official statistics and may put these statistics forward for assessment for designation as National Statistics, although it has no immediate plans to do so.

58. The provision of health and social care services is the responsibility of each of the devolved administrations and there are consequently differences in the way these services operate and also in the methods used to monitor and report on them. The Statistics Authority understands that a review of statistics comparable across the four countries of the UK, including healthcare, is being undertaken by the Government Statistical Service Inter Administration Committee[110].

[110] http://www.statisticsauthority.gov.uk/about-the-authority/board-and-committees-documentation/minutes-and-papers/papers-from-the-committee-for-official-statistics-meeting-on-16-may-2013.pdf

Annex 1
Specific information highlighted as needed by users in responses to the Authority

Information gap
The rapid inclusion of musculoskeletal outpatients and community care data in Care Episode Statistics (CES), through effective use by Public Health England and local authorities of the prevalence and incidence estimates that emerge from the Musculoskeletal Calculator
Adoption of the Musculoskeletal-Patient Reported Outcome Measures by the NHS for routine clinical use in a wide range of settings
Further work on standardisation of diagnostic recording and coding of musculoskeletal disorders
Helping charities to more easily be able to request, acquire and process data into formats that are more accessible to their members and supports
HSCIC could increase awareness of existing published timetable of release and alert facility that will email when new statistics are published
Working collaboratively on interpretation and display of data, to collect feedback on usefulness and accessibility of previously published statistics
Cancer survival: We strongly urge the Statistics Authority to ensure the ongoing publication of this data
Cancer staging: We would like to see the publication of staging data for every possible cancer site as an official statistic. This would help identify areas where there may be scope for improving early diagnosis and allow progress to be tracked over time
Emergency presentations: Nearly a quarter of all cancers are diagnosed via an emergency presentation, often resulting in poor outcomes. Reporting emergency cancer diagnosis data would highlight this issue and allow progress to be tracked
Treatment: Reporting outcomes data linked to treatment modality would allow for more in-depth analysis of cancer outcomes and allow more effective service planning
Patient experience: The Cancer Patient Experience Survey should be carried out every year. It provides an extremely valuable insight into the aspects of cancer treatment not easily captured in outcomes data and has been shown to drive improvements in NHS Trusts
Screening data: The NHS Bowel Cancer Screening Programme should report detailed statistics in the same way as the NHS Breast and Cervical Screening Programmes
Interpretation of data: More interpretation of statistics would be welcome to make the context the data are presented in clear. However, we would rather see more statistics published than more interpretation of currently published statistics
In-patient survey technical details report: provide some references for the techniques discussed, for the readers who don't have a good background in statistics
There is potential for developing more sophisticated outcome statistics other than death/length of stay/readmissions
Would like to see greater transparency
Underlying data could be made more accessible
Although Hospital Episode Statistics record A&E attendance by age, ethnicity and gender, breakdowns are only published by age and gender. We would like to see improvements made to the coverage of ethnicity
It would be helpful if breakdowns were published for hospital admissions due to injury for under-18s by age, ethnicity and gender

Patients are routinely asked for their religion when attending A&E or admitted to hospital and we would like to see consideration given to publishing these data if the quality is sufficient
Patients' views on how they are treated in hospital: Adult Inpatient Survey has the potential to provide national data broken down by age, disability, ethnicity, gender, religion and/or sexual orientation, subject to data quality
Data broken down by equality characteristics to be published from the GP Patient Survey, the Maternity Survey and the Community Mental Health Service User Survey
Publication of data from the Mental Health Minimum Dataset by equality characteristics, such as age, ethnicity and/or gender
PROMs after surgery for cancer at a granular level for surgery outcomes – currently no disaggregated clinical outcomes are published
More statistics on childbirth mortality: perinatal, neonatal and stillbirths – by trusts

Annex 2

Aspects of materiality used to determine priorities for assessment against the *Code of Practice for Official Statistics*[111]

'We determine priority on the basis of whether:

i. The statistics are used to inform economic or social policy making, the importance of those policies in the national context, and the potential impact of making of poor decisions because of poor quality, or poorly presented statistics;
ii. The statistics are used in allocating substantial amounts of public resources, or other significant operational decision-making by central or local government, or other users;
iii. The statistics are used as part of high profile indicators, or have been used in setting, calibrating or measuring progress against government targets;
iv. The production of the statistics is required by legislation either in the UK or Europe;
v. The statistics are used in the production of other sets of statistics, for example the use of population statistics as the denominator for other statistical series;
vi. The publication of the statistics typically generates significant media reporting or other public attention; and
vii. The statistics have been the subject of recent Parliamentary scrutiny, for example by the Public Administration Select Committee, other Select Committees or equivalent scrutiny in the devolved administrations or the EU.'

[111] See footnote 13

Annex 3

List of Official Statistics used to inform the 2013/14 NHS Outcomes Framework, as at August 2013

(Indicators in italics are 'placeholders' pending development or publication)
HSCIC regards the quarterly update report for the NHS Outcomes Framework as official statistics

Domain 1: Preventing people from dying prematurely

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
1ai	Potential years of life lost from causes amenable to healthcare	Avoidable mortality in England and Wales	ONS	England and Wales	Age, gender, region	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
1aii	Potential years of life lost from causes amenable to healthcare-children and young people	Mortality data by cause	DH	England and Wales	Age, gender, local authority	Official Statistics
		Mid-year population estimates of the population aged 19 years and under	ONS	England	Age, gender, local authority	National Statistics
1b	Life expectancy at age 75 (i) Males ; (ii) Females	Period and cohort life expectancy tables	ONS	England	Gender, region	National Statistics
1.1	Under 75 mortality rate from cardiovascular disease*	Mortality data by cause	ONS	England and Wales	Age, gender, local authority	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
1.2	Under 75 mortality rate from respiratory disease*	Mortality data by cause	ONS	England and Wales	Age, gender, local authority	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
1.3	Under 75 mortality rate from liver disease*	Mortality data by cause	ONS	England and Wales	Age, gender, local authority	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
1.4	Under 75 mortality rate from cancer*: One-year and Five-year survival from cancer (i) (ii) colorectal (iii) (iv) breast (v) (vi) lung	Mortality data by cause	ONS	England and Wales	Age, gender, local authority	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
		Cancer survival reference tables	ONS	England and Wales	Gender, age standardised, cancer network	National Statistics
1.5	Excess under 75 mortality rate in adults with serious mental illness*	Mental health minimum dataset	HSCIC	England	Mental health provider organisation	Experimental Statistics

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
1.5 (cont)	Excess under 75 mortality rate in adults with serious mental illness* (cont)	Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
1.6i	Infant mortality*	Mortality statistics childhood, infant and perinatal	ONS	UK and countries	Strategic health authority, local health board, gender, age band	National Statistics
1.6ii	Neonatal mortality and stillbirths	Mortality statistics childhood, infant and perinatal	ONS	UK and countries	Strategic health authority, local health board, gender, age band	National Statistics
1.6iii	*Five-year survival from all cancers in children*					
1.7	*Excess under 60 mortality rate in adults with learning disability*					

Domain 2: Enhancing quality of life for people with long-term conditions

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
2	*Health-related quality of life for people with long-term conditions^*					
2.1	*Proportion of people feeling supported to manage their condition^*					
2.2	Employment of people with long-term conditions^	Labour Force Survey	ONS	England	Age band, gender, local authority	National Statistics
2.3i	Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)	Hospital Episode Statistics	HSCIC	England	Gender, provider, some procedures	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
2.3ii	Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s	Hospital Episode Statistics	HSCIC	England	Gender, provider, some procedures	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
2.4	*Health-related quality of life for carers^*					
2.5	Employment of people with mental illness+	Labour Force Survey	ONS	England	Age band, gender, local authority	National Statistics
2.6i	Estimated diagnosis rate for people with dementia*	Quality Outcomes Framework	HSCIC	England	Practice level	Official Statistics
		Estimated prevalence of dementia by age	London School of Economics	UK	Age band	Non-official Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
2.6ii	*A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life^*					

Domain 3: Helping people to recover from episodes of ill-health or following injury

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
3a	Emergency admissions for acute conditions that should not usually require hospital admission	Hospital Episode Statistics	HSCIC	England	Gender, provider, some procedures	National Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
3b	Emergency readmissions within 30 days of discharge from hospital*	Hospital Episode Statistics Continuous Inpatient Spells	HSCIC	England	Gender, provider, some procedures	Official Statistics
3.1	Total health gain from patients who reported an improvement in health status following elective procedures: (i) hip replacement, (ii) knee replacement (iii) groin hernia and (iv) varicose veins	PROMs dataset	HSCIC	England	Gender, age, disability, ethnicity, deprivation, provider	Experimental Statistics
3.1v	*Psychological therapies*					
3.2	Emergency admissions for children with lower respiratory tract infections (LRTIs)	Hospital Episode Statistics Continuous Inpatient Spells	HSCIC	England	Gender, provider, some procedures	Official Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
3.3	*Proportion of people who recover from major trauma*					
3.4	*Proportion of stroke patients reporting an improvement in activity / lifestyle on the Modified Rankin Scale at 6 months*					
3.5	Proportion of patients with a fragility fracture recovering to their previous levels of mobility at (i) 30 days and (ii) 120 days	National Hip Fracture Database	British Geriatric Society and British Orthopaedic Association	England	Count of patients, country	Non-official Statistics
3.6i	Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services^	Adult Social Care Combined Activity Return (ASC-CAR)	HSCIC	England	Age, gender	Official Statistics
3.6ii	Proportion offered rehabilitation following discharge from acute or community hospital^	Adult Social Care Combined Activity Return (ASC-CAR)	HSCIC	England	Age, gender	Official Statistics
		Hospital Episode Statistics	HSCIC	England	Gender, provider, local authority	National Statistics

Domain 4: Ensuring that people have a positive experience of care

NHS Outcomes Framework Domain number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
4ai	Patient experience of GP services	GP Patient Survey	NHS England	England	National	Official Statistics
4aii	Patient experience of GP out of hours services	GP Patient Survey	NHS England	England	National	Official Statistics
4aiii	Patient experience of NHS dental services	GP Patient Survey	NHS England	England	National	Official Statistics
4b	Patient experience of hospital care	National Inpatient Survey	CQC	England	Provider	Official Statistics
4c	Friends and Family Test	Friends and Family Test Survey	NHS England	England	Ward, provider	Experimental Statistics
4.1	Patient experience of outpatient services	National Outpatient Survey	CQC	England	Provider	Official Statistics
4.2	Responsiveness to inpatients' personal needs	National Inpatient Survey	CQC	England	Provider	Official Statistics
4.3	Patient experience of accident and emergency services	National Emergency Department Survey	CQC	England	Provider	Official Statistics
4.4	Access to (i). GP services (ii). NHS Dental services	GP Patient Survey	NHS England	England	Practice	Official Statistics

NHS Outcomes Framework Domain number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
4.5	Women's experience of maternity services	National Maternity Services Survey	CQC	England	Provider	Official Statistics
4.6	Bereaved carers' views on the quality of care in the last 3 months of life	National Bereavement Survey	ONS and DH	England	Country	Official Statistics
4.7	Patient experience of community mental health services	Community Mental Health Survey	CQC	England	Provider	Official Statistics
4.8	*Improving children and young people's experiences of healthcare*					
4.9	*Improving people's experience of integrated care^*					

Domain 5: Treating and caring for people in a safe environment

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
5a	Patient safety incidents reported	Patient Safety Incident Reports	NHS England	England	Provider	Official Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
5b	Safety incidents involving severe harm or death	Patient Safety Incident Reports	NHS England	England	Provider	Official Statistics
		Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
5c	*Hospital deaths attributable to problems in care*					
5.1	Incidence of hospital related venous thromboembolism (VTE)	NHS Safety Thermometer	HSCIC	England	Provider	Experimental Statistics
5.2	Incidence of healthcare associated infection (HCAI): (i) MRSA bacteraemia; (ii) Clostridium difficile	Mandatory surveillance of (i) MRSA bacteraemia and (ii) C. difficile	Public Health England	England	Provider	Official Statistics
5.3	Incidence of newly acquired category 2,3 and 4 pressure ulcers	NHS Safety thermometer	HSCIC	England	Provider	Experimental Statistics
5.4	Incidence of medication errors causing serious harm	Patient Safety Incident Reports	NHS England	England	Provider	Official Statistics

NHS Outcomes Framework number	Name of indicator	Name of statistics used to populate the indicator	Producer body	Coverage	Level of disaggregation	Status of source statistics
5.4	Incidence of medication errors causing serious harm	Mid-year population estimates	ONS	England	Age, gender, local authority	National Statistics
5.5	Admission of full term babies to neonatal care	Number of babies on the National Neonatal Research Database	Neonatal Networks	England	Provider	Non-official Statistics
		Number of term births in England	ONS	England and Wales	Local authority	National Statistics
5.6	Incidence of harm to children due to 'failure to monitor'	Patient Safety Incident Reports	NHS England	England	Country	Official Statistics

* *Indicator shared with Public Health Outcomes Framework*

^ *Indicator complementary / shared with the Adult Social Care Outcomes Framework*

\+ *Indicator complementary with the Adult Social Care Outcomes Framework and the Public Health Outcomes Framework*

Annex 4 Glossary

Berwick Review of Patient Safety	Donald Berwick chaired the National Advisory Group on the Safety of Patients in England and reported on 6 August 2013
Care Episode Statistics	Planned official statistics about healthcare in England
Chief Medical Officer (CMO)	The CMO acts as the UK government's principal medical adviser and the professional head of all directors of public health in local government
Clinical Commissioning Groups	These are organisations that commission hospital and community NHS services in England
Francis Inquiry	Robert Francis, QC, chaired the Mid Staffordshire NHS Foundation Trust Public Inquiry
Friends and Family Test (FFT)	These official statistics assess the quality of care delivered to NHS patients from the patient perspective
Healthcare Improvement Scotland	This official body supports healthcare providers in Scotland improve care
Hospital Standardised Mortality Ratio (HSMR)	This is an indicator of healthcare quality that measures whether the death rate at a hospital is higher or lower than expected
Mortality rate	A measure of the number of deaths in a given population
National Patient Safety Agency (NPSA)	This Agency was abolished in October 2012 and the majority of its functions transferred to NHS England
National Reporting and Learning System (NRLS)	This is a software system set up to collect information about patient incidents reported by the NHS in England
NHS Choices	This is a portal for patients in England at www.nhs.uk
NHS England	This is an executive non-departmental public body of the Department of Health
The NHS Outcomes Framework	This Framework is published by the Department of Health and sets out the outcomes and corresponding indicators used to hold NHS England to account for improvements in health outcomes
NHS Safety Thermometer	These official statistics measure incidents of harm to patients

Patient Experience Survey	These official statistics assess the quality of care delivered to NHS patients from the patient perspective
Patient Reported Outcome Measures (PROMs)	These official statistics assess the quality of care delivered to NHS patients from the patient perspective
Patient Safety Incident Reports	These official statistics measure incidents of harm to patients
Public Health England (PHE)	This is an executive agency of the Department of Health
Quality Measures Framework	This official Framework is published by Information Services Division Scotland and will measure health and social care quality in Scotland
Risk-Adjusted Mortality Index (RAMI)	This is a statistical tool by which an estimate is made of probability of death for all admitted patients
Scottish Patient Safety Programme (SPSP)	This is a framework to steadily improve the safety of patient care in Scotland
Stats User Net	This is an online community for all users of official statistics and can be found at www.statsusernet.org.uk
Summary Hospital-level Mortality Indicator (SHMI)	These official statistics report mortality at trust level across the NHS in England
Third sector organisations	Organisations undertaking voluntary or charitable activities
Trust Quality Account	This is an annual report about the quality of services by an NHS healthcare provider