IMPRESS GUIDE TO INFORMATION

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Siân Williams IMPRESS Project Manager
Dr Julian Flowers, Director Eastern Region Public Health Observatory/Quality Intelligence East IPH
Dr Matt Kearney, Primary Care Clinical Advisor, Respiratory Programme, Department of Health
Dr Louise Wilson, Consultant in Public Health, NHS Torbay
Dr Steve Connellan, Consultant Respiratory Physician and Respiratory HRGs Expert Working Group (EWG) Lead
Jane Scullion, Respiratory Nurse Consultant Glenfield Hospital and Respiratory Lead, East Midlands SHA

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IMPRESS GUIDE TO INFORMATION

Purpose

This is a practical guide from IMPRESS for clinicians and commissioners about data and information related to respiratory care: what is there, why would you use it, where to find it, and pros and cons. It brings together sources from the NHS, commercial and voluntary sectors and across primary, secondary and community care. There is more information available from more sources than ever before, but it is only useful if you understand:

- Where it comes from
- What it does or doesn't say and why it says what it does
- How to act on the information
- What information we don't have eg unless practices or PCTs have done their own audit, we do not know how many people smoke in a PCT.

We use information to help us improve and to help us address three kinds of question:

1. Is there a problem? How do we compare? What would we expect for our population or patients, and does what we see match up to it. The information we need for this question is comparative - we need to compare local information with external information such as national or other standards, evidence based criteria, or other comparators. It helps for this kind of analysis to understand some very basic statistics so we don't chase random variations and instead act on genuine problems.
2. Are we improving? This involves looking at how things are changing over time within our population – we often need trend data
3. Are we the best we can be? We may be improving but if everyone else is improving faster we may not be offering the best care we could.

This guide explores these questions in two sections: needs assessment and performance. There is also a companion guide to information about the use of medicines in the NHS also downloadable from the IMPRESS website.

Needs assessment

What is the respiratory health status of our population and what action is needed to improve it? What is the prevalence (total cases) and incidence (new cases) of people with respiratory diseases, what services have they used and how frequently, how does that compare to what we might expect, what are the trends, how many might we expect to diagnose, treat and rehabilitate in the next year?

What is the uptake of effective care? How much do we have to spend? How much have we spent, on what, and with what return on our investment: analysis of costs, programme budgets and outcomes (eg the Spend and Outcome Tool SPOT – see Needs Assessment Section below).

See page 8 for more detailed guidance.

Performance

1. Are we doing things right, how are we doing compared to our peers? Comparative information on clinical care, including variation: how does your performance compare to your UK and international peers?
2. What value are we as commissioners getting for our money, how do we know? Are we commissioning the right things? What should we decommission? What should we invest in?
3. Prescribing and use of medicines information (separate section)
4. Are patients with respiratory disease dying in their location of choice

This guide does not cover information for patients.

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Principles

First, some basic principles when using information:

1. It is important to understand the difference between data and information. We *collect* data. They are facts about patients recorded in clinical notes or electronic systems such as a peak flow, blood tests, whether or not someone smokes or a diagnosis or what resource they have used. Data becomes information that can help us make decisions when it is considered *in context.* A clinical example: recognising that someone's peak flow is low requires knowing what it should be for a given age, sex and height. Using it to make a diagnosis of asthma requires other data that might be gathered from history or examination, or from blood tests.
2. There is a difference between data about individuals and information about populations. When attempting to assess need, performance, review services, or plan services we are usually interested in population based information. This is aggregated from data about individuals but the sum of individual patient needs is not the same as the population need – there maybe unmet or over met need.
3. Without knowing how things are now, you cannot know if your interventions are making a positive difference, so data and information and measurement are core to all stages of health care delivery.
4. Information can be a powerful communication tool. Healthcare professionals are motivated by knowing how they are doing and also by knowing someone down the road does it better. Information can highlight when something appears out of the ordinary. Therefore data and information are a very good way to engage healthcare professionals in discussions about variation: is it warranted – due to patient need - or unwarranted – that cannot be explained by type or severity of illness or by patient preferences[1]?
5. Clinical engagement is likely to be greater if the data commands the confidence of the clinicians. Therefore a quality assurance system is required (for example, the Audit Commission's reports on Payment by Results data quality).
6. When producing information, be clear what question you want to ask first and be very specific. Involve clinicians in this so that they agree the questions before being confronted with the answers!
7. Think about how you want it presented - graphics can increase the level of engagement significantly and a brief commentary is essential. The aim is for recipients to understand and act on the data, not to feel overwhelmed.
8. If you want to measure a new intervention, know your baseline and what improvement you expect, and consider a balancing metric. That is, the impact on the whole health economy (eg readmissions, prescribing rates for combination inhalers).
9. Make sure you have access to someone who understands the information sources, who can interrogate the data and who can answer queries: engage your Medicines Management team, and your Public Health Department. Find out who in your local Public Health Department holds the respiratory remit.
10. Be sure you understand what assumptions underpin it.
11. If you discover that the data suggest you are not doing as well as you had thought you should consider: is it due to chance? Is it due to differences in the way data are collected or coded ("data artefact"); if neither is the case it could be a real issue.
12. Follow information governance rules. See the Care Quality Commission reports. (see Appendix).
13. Coding should first and foremost be used to support patient care. However, it is also incumbent on professionals to account for their time. The method to do this is to code the activity and this is the basis for the analysis of most activity. So, our message is this: if there are codes use them and use them correctly, and ensure your team do the same. We would recommend that clinicians, coders and finance should consider such issues within a forum which meets regularly e.g Respiratory Governance Committee.
14. Collecting new data is expensive and often unnecessary. Be aware of what is already collected.
15. When sharing information, consider this: "People who are confronted with data that presents a less-than-favorable picture of their organization's performance generally go through four stages of coping. These stages are inevitable, and we encourage you to journey through them all, one at a time…but please do it fast,[2]
    - The data are wrong
    - The data are right but they are not a problem
    - The data are right, it is a problem, but it's not MY problem
    - The data are right, it is a problem, and it is my problem

[1] Wennberg John E Unwarranted variations in healthcare delivery: implications for academic medical centres. BMJ. 2002 October 26; 325(7370): 961–964

[2] http://www.ihi.org/IHI/Topics/OfficePractices/Access/ImprovementStories/ImprovementTipTaketheJourneytoJiseki.htm

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Medical records and coding

In order for information collected clinically to be made available as usable data for further analysis it has to be clinically coded which then enables the data to be stored in electronic databases in consistent formats. There are a number of coding systems used depending on what the source of the data is. The NHS has a range of data dictionaries for different data collections.

1. Patient diagnoses are usually captured with the International Classification of Diseases version 10 – ICD10. This system is used to code hospital activity as part of Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) and cause of death certificates. It is used in some but not all A&E departments and is an integral part of SNOMED
2. In primary care there is a different system called Read coding that has more than one version. The use of Read Codes may be variable in different practices, and may make comparison of practices difficult. Templates can help prompt for data and code automatically. PCTs in Hampshire have detailed the Read codes that may be used in COPD as part of an integrated care record initiative, following success in establishing an integrated care record for diabetes – across primary and secondary care.
3. Operative procedures and other interventions are largely coded according to the Office of Population, Censuses and Surveys Classification (OPCS), which is now in version 4.5.
4. Ambulance services use dispatch codes (AMPDS) which are problem based e.g. breathing problems rather than asthma.
5. For payment purposes hospital care uses Healthcare Resource Groups (HRGs) – these are now in version 4. They are based on HES data and are based on primary diagnosis and primary procedure codes and sometimes patient age. HRGs are bundles of coded activity with similar resource use. These are used to derive tariffs for Payment by Results (PbR). For information about resource implications, you may need to specify HRG4 codes.

For information about coding see Guide to Respiratory Coding http://www.impressresp.com/Portals/0/IMPRESS/Aguidetorespiratorycoding.pdf See Appendix). The IMPRESS Jargon Buster also lists HRG4 codes, and QOF targets.

A little more on asking the right questions, and coding

Information Departments will probably require you to specify

- Time period,
- Post codes,
- Ages,
- Gender
- ICD10 diagnostic codes and
- Possibly procedural codes OPCS4
- Possibly complications and comorbidity

A note on primary care coding

As a result of the increased use of structured care and the use of templates and electronic records, primary care Read-coded records contain very useful data. However, apart from QMAS analysis of QOF data, there is a lot that cannot currently be accessed nationally to provide useful benchmark or comparative data. Therefore a significant amount of work is happening nationally to improve the extraction of these data in anonymised, unintrusive ways. For more information on the General Practice Extraction Service GPES see: http://www.ic.nhs.uk/gpes

When looking at QOF performance by practice, ensure you also have the exception report (see http://www.ic.nhs.uk/statistics-and-data-collections/audits-and-performance/the-quality-and-outcomes-framework/the-quality-and-outcomes-framework-exception-reporting-2008-09 and also http://www.erpho.org.uk/viewResource.aspx?id=17497 Practices may exclude specific patients from data collected to calculate QOF achievement scores within clinical areas. The GMS contract sets out valid exception reporting criteria. Exception rates can vary

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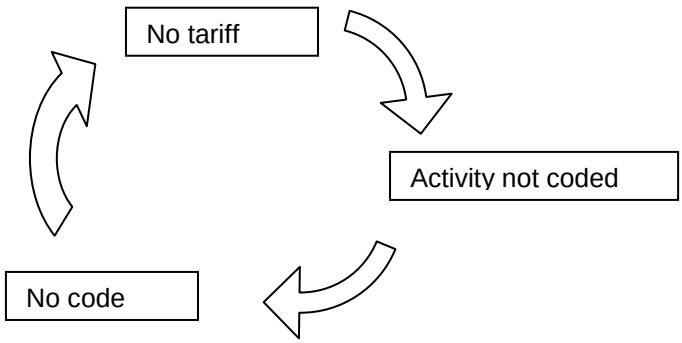
considerably, and this means that the datasets will not be complete: this will affect your denominator. Benchmarking practices on exception codes, showing the often dramatic variation in exception reporting can be a very productive way of starting a dialogue with high exception practices – a role for the QOF assessment teams if they are provided with the data.

A note on coding for secondary care clinicians

In secondary care, new codes are developed each year. These are the outcome of a lobbying process to ensure real activity is counted and paid for. The BTS, through the Respiratory Expert Working Group and Information Centre is actively involved in this process. Having a code does not necessarily mean there is a tariff. A tariff is developed once there is sufficient data to develop a reference cost which is currently based on the average cost of historical activity (this may change to be the minimum, or market price, but currently the average is used). So, if you don't use codes (even if there is no tariff), then there will be insufficient data to develop a reference cost and if there is no reference cost there will be no tariff. This creates a vicious circle:



For example, there are new codes for "ambulatory care less than 1 day" (used to be called "planned same day"). This can be used to recognise respiratory activity that is more than outpatients but not inpatients. Eg, NIV/CPAP assessment/monitoring/fitting of masks and setting up of cardio-pulmonary sleep studies and ambulatory oxygen assessments.

These were included in Payment by Results 2010/11 but were only assigned a mandatory tariff on the basis of daycase/elective interventions and discussions are on-going with regard to formally recognising such activity as daycase.

Direct access spirometry has a non-mandatory tariff of £40 which should form the basis for local discussions regarding development or consolidation of such a service.

There is a code for oxygen assessments that includes LTOT and ambulatory oxygen assessments. The tariff is under negotiation to ensure it reflects the complexity and resources required. There has also been written support from the Payment By Results team, in the Expert Working Group (EWG) submission to Connecting for Health (CfH), for a code to recognise pulmonary rehabilitation. A decision is awaited at the time of writing.

And a note for commissioners

You will understand that the vast majority of the information that is regularly used is derived from three main sources – clinical information collected by clinicians in the course of patient contact and fed into administrative, audit or research datasets; data required by law such as death certification which provides us information on how many people die from respiratory disease; and surveys which collect specific data (eg smoking data). Data derived from patients' notes or from registration is collected by clinicians and then interpreted by coders and therefore its quality is highly dependent on the actions of both. The Audit Commission has published comparative profiles of coding accuracy for all Strategic Health Authorities, primary care trusts and trusts and can be downloaded from http://www.audit-commission.gov.uk/health/audit/paymentbyresults/pbrresults200809/pages/default.aspx Further information http://www.audit-commission.gov.uk/health/nationalstudies/pbr/pbrdataassuranceframework200809/Pages/default_copy.aspx

The June revision to the DH In England Operating Framework for 2010/11 highlights the need to focus on this: *"PCTs must put a stronger emphasis on using Secondary Uses Services as their data source, which requires providers to improve the quality and completeness of data, in line with the information transparency agenda."*

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Presenting the data
When data are presented to clinicians and commissioners, they need to be interpreted and packaged for the non-specialist information user. Therefore graphs and charts should be accompanied by a brief commentary that explains the data and highlights the key findings and messages. The information should be focused – more is not the same as better! The aim should be for recipients to understand and act on the data, not to feel overwhelmed.

Indicators
Most of what is available are *indicators.* These are summary measures that capture the concept we are interested in either directly or indirectly and typically need to be understood in context, and considered together with other indicators. For example, we might use the proportion of people who are trained in inhaler technique as an indicator of the quality of asthma care. (In fact what we really want to know is the proportion of people with asthma who use their inhaler correctly but those data aren't captured). Or we might use prevalence adjusted bed days for COPD per 1000 population as a measure of the success of managing patients with COPD in the community.

Small numbers, variation and the play of chance

Wherever you look in healthcare there is variation. Admission rates to hospital vary almost two-fold for COPD for example. Some degree of variation is normal and to be expected. The question is how much variation is acceptable. This in part depends on the numbers and the numbers depend on the frequency of the event you are interested in and population at risk. If for example, you are looking at the variation in the prevalence of COPD between general practices you might see something like Figure 1that shows the prevalence of COPD using QOF registered patients for each practice in one PCT. There is apparently considerable variation in prevalence from 0.2% in lowest to 2.1% in the highest practice (the national average is 1.5%).

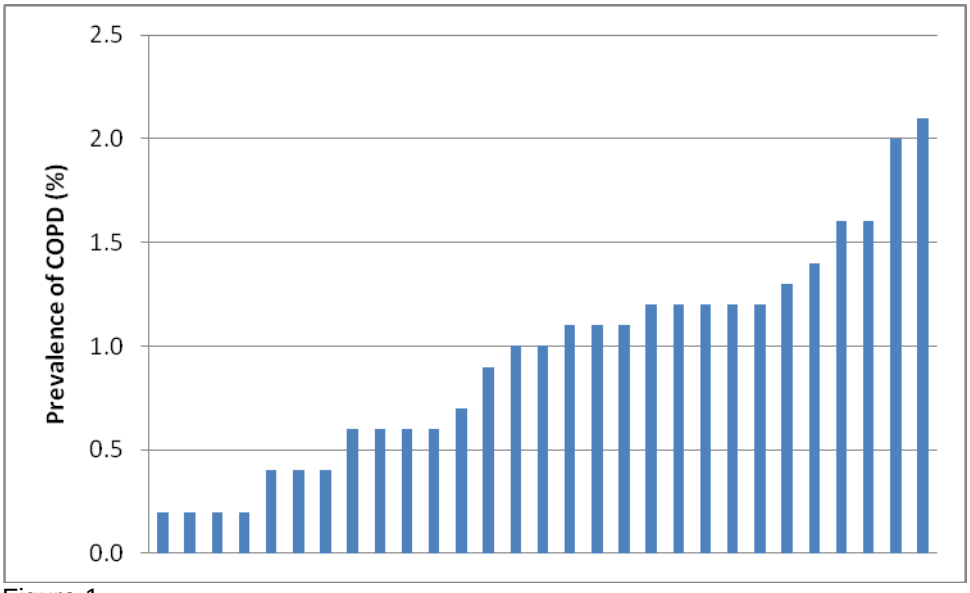

Figure 1

However the number of cases of COPD varies from 3 to 200 per practice – these are relatively small numbers and basing prevalence on these numbers is subject to statistical uncertainty or the play of chance. For this reason we often calculate an *uncertainty interval* for the estimates - usually called a 95% confidence interval – to show this uncertainty. This is reflected in the whiskers in Figure 2 below. If we take the practice with the second highest prevalence which has an observed prevalence of 2%, the uncertainty interval ranges from 1.5% - 2.8%. This means we are 95% sure that the true prevalence lies between these values - which is quite a range. (We could also say we were pretty sure it is not below 1.5% or above 2.8%). From this presentation the only practice with a rate statistically higher than the national average is the practice at the far right of the chart where the whiskers of the confidence interval do not contain the national average value of 1.5%.

A recent development in providing pictures of variation is the funnel plot – this is shown using the same data in Figure 3. A spreadsheet tool for drawing the plot can be found at

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http://www.apho.org.uk/resource/view.aspx?RID=47241. The funnel shapes show the amount of variation expected due to chance. In the chart below we have compared the practices in the PCT area with the national average – we can see the one practice with a high rate (closed circle) which lies above the upper dotted line, and there are a lot of practices which lay below the lower dotted line that have a lower prevalence than the national average.

We could also look at the variation within the PCT – this is shown in the funnel plot Figure 4 where practices are compared to the PCT average prevalence of 1%. Despite small numbers there is appreciable variation as evidenced by the number of practices outside the funnel – there are five practices with statistically higher prevalences than the PCT average – they are unusual for the PCT (they may have an older population – QOF prevalence is not adjusted for age; or have higher levels of smoking or be better at recording COPD in practice registers).

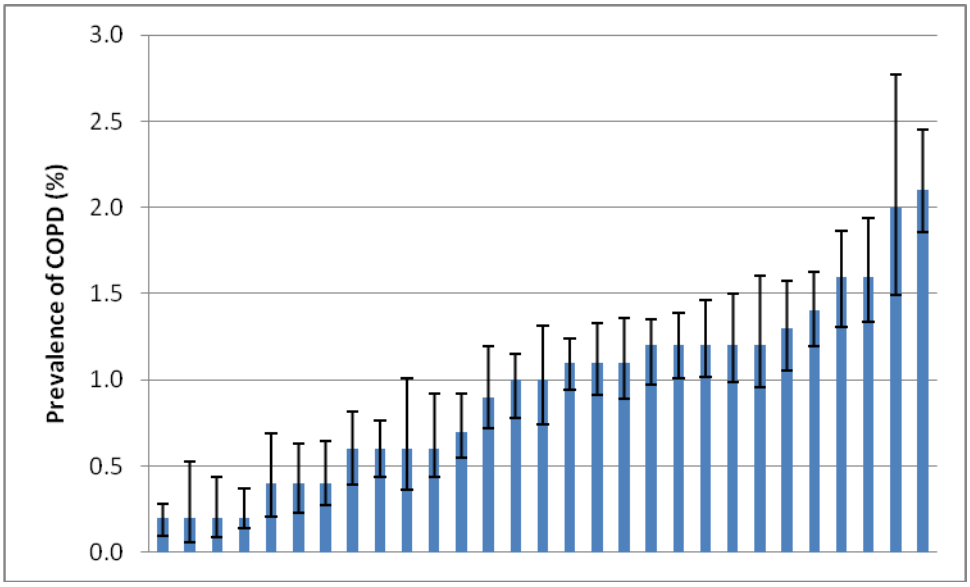

Figure 2

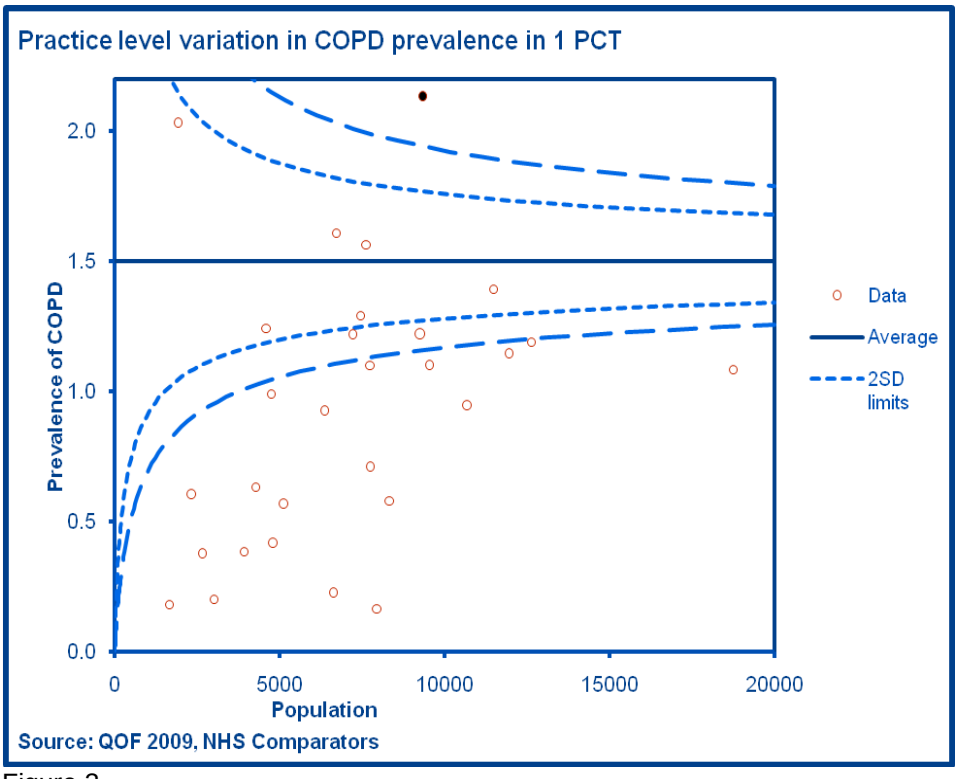

Figure 3

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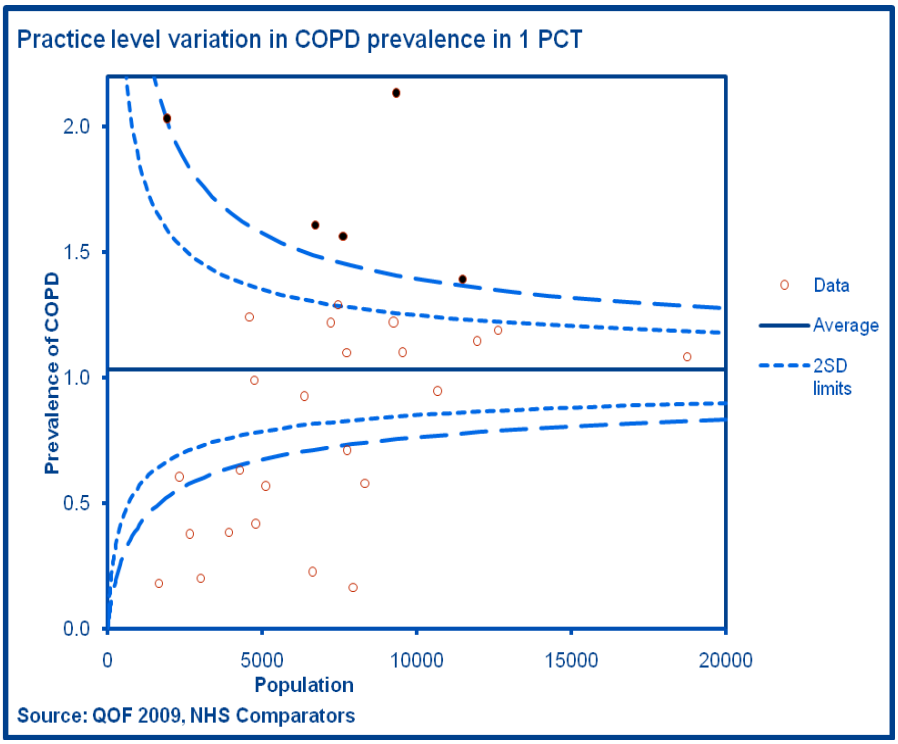

Figure 4

The map

Here are some of the key resources available, identifying which source, whether paid for or free, and any other relevant information. The appendices contain further summaries of some of the analyses and services, and some examples of the graphical formats that can be provided.

Your choice will depend on what analytical tools or companies your organisation may already be using; what local capability you have to interrogate the raw data yourselves; how important the graphical presentation is; local clinical preferences.

Inclusion of a source does not necessarily imply endorsement of the source by IMPRESS. In addition, this cannot be a comprehensive map, because the field is constantly changing. We will always consider updates if we are presented with further information.

If you use more than one tool, you may find some small discrepancies between the findings produced by different analytical tools, but these are unlikely to be significantly different.

For a full list of data sources including surveys, see http://www.laia.ac.uk/sources.htm

As part of the work in England to support the introduction and implementation of the National Strategy for COPD, there will be three workstreams:

1. Developing indicators, benchmarking data and audit criteria
2. Building the data infrastructure - supporting input, extraction and processing of data
3. Coding/tariff, reward and economic modelling

Therefore this guide does not cover this ground. It provides a map of information sources and leaves you to ask the questions relevant to your situation.

There is also a regular Royal College of Physicians (RCP) committee that comprises the Registrar and representatives from professional specialist societies, the Payment By Results team, British Medical Association, Audit Commission, Connecting for Health and the Information Centre which considers all issues such as PbR, coding, HRGs, best practice tariffs and so on. It also links with the Clinical Advisory Panel.

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THE IMPRESS MAP

NEEDS ASSESSMENT

The aim of needs assessment is to help prioritise or provide a rational basis for commissioning or planning services or the balance of services. It can help to think of:

- **Health needs assessment** – this is concerned with helping prioritisation and resource allocation. The sorts of information used relate to the overall impact of respiratory disease on health and how it compares to other issues. To understand the impact of respiratory disease we might use measures like:
  - Disease incidence (the rate of new cases)
  - Disease prevalence (total number of cases)
  - Mortality rate (the rate at which people die from the disease) or survival
  - Year of life lost (a measure of premature death)
  - Disability adjusted life years
  - Inequalities in outcome or disease frequency - for example COPD is more common in more deprived population as a result of higher levels of smoking and has a higher mortality rate
- **Healthcare needs assessment** which is concerned with looking at the uptake of effective care for example, the use of NIV in COPD. The information requirements here are different because we need to understand the effectiveness of treatment and the incidence not of all COPD but of more severe cases who are likely to be eligible for, and benefit from, NIV.

Understanding measures of disease frequency and mortality

The common measures used to estimate disease frequency are:

- **Incidence** – the number of new cases of disease in a defined population in a given time (e.g. per 100,000 per year).
- **Prevalence** - the number of cases of disease in a population at a given point in time.

Incidence and prevalence are related. For diseases like asthma and COPD that are chronic diseases the prevalence is much higher than the incidence (there are relatively few new cases per unit of population time but they are not cured). For pneumonia, the opposite is true: the incidence will be much higher than prevalence– people recover or die. For lung cancer the incidence and prevalence are roughly the same – most cases die within a year or two of diagnosis.

The importance of the distinction and the relationship is related to:

- **Prevention** – we might be able to prevent incident cases e.g. smoking cessation to prevent COPD but once a case becomes established they need to be managed
- **Cost** – prevalent disease (long term conditions) have life time costs whereas acute diseases only cost for the duration of the illness
- **Management and care planning** – long term conditions need care over long periods taking into account say for COPD long term deterioration and acute episodes.

The most commonly used measure of mortality is the *mortality rate* that is the number of deaths *from the disease* per unit population. It is not the same as survival or case fatality that is the death rate in people *with the disease*. For COPD, for example, the former counts the number of people who have an underlying cause of death of COPD on a death certificate and divides by the number of people in total in that population; the latter follows up a cohort of patients with COPD and measures the frequency with which they die or survive over a given time.

It is much easier to estimate mortality rates than survival and there are many published mortality statistics. However, if there is a high death rate in your population there may be three reasons:

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1. A higher incidence or prevalence of disease
2. A lower survival
3. A combination of 1 and 2
4. Higher levels of coding on death certificates.

One important issue in comparing mortality rates between populations is the effect of **age**. Age is the most powerful determinant of death rates and unless age is taken into account we can be misled into thinking a problem exists when in reality it does not. For example, if there are two populations of the same size which have the same death rates for every age group but one is much older than the other, there will be more deaths in total in the older population and therefore the crude rate will be higher.

To adjust for the age differences a process of **age-standardisation** is usually undertaken. There are two versions:

- **Indirect** - this compares the number of deaths observed in the local population with the number that would be expected if the death rates in the national population applied locally. This usually produces a ratio – the SMR or standardised mortality ratio. If there is no difference between the local number of deaths and the expected number of deaths then this ratio is 100. Below this means mortality is lower than expected compared to the national average; above this means mortality is higher. The HSMR is a topical version of an indirectly standardised mortality index. [NOTE: at the time of writing a standard definition for HSMRs is due from the Department of Health England 2010]
- **Direct** – for this the death rates in the local population are applied to an external standard such as the England population or the European Standard population to give a rate known as a DSR or directly standardised rate. Public health practitioners and epidemiologists generally prefer this as a summary measure of mortality.

The pros and cons and further details are outlined in East Region Public Health Observatory InphoRM 6: Standardisation and other Association of Public Health Observatories technical briefings.

The table begins on the next page.

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Supplier	Prevalence and incidence of respiratory diseases and predictive risk	Map of local services	Spend and outcome
NHS	**QOF Disease registers** from Information Centre NHS Comparators and also http://www.gpcontract.co.uk/browse.php **General disease prevalence** site: http://www.apho.org.uk/resource/view.aspx?RID=48308 and respiratory: Eastern Region Public Health Observatory (erpho) http://www.erpho.org.uk/topics/copd/copd.aspx The RCGP Research & Surveillance Centre publishes annual prevalence rates by age and sex for every ICD diagnosis derived from about 100 practices in England and Wales. http://www.rcgp.org.uk/clinical_and_research/rsc.aspx Estimates of age and sex specific asthma and COPD prevalence by region derived from analysis of the THIN database (2.7 million patients in 300 practices) are available from: http://www.erpho.org.uk/viewResource.aspx?id=20574 **Modelled estimates and projections of COPD** for PCT, Local Authorities in England also remodelled for urban and suburban areas (updated Oct 08) THIN http://www.erpho.org.uk/viewResource.aspx?id=20574 And for general practices http://www.apho.org.uk/resource/view.aspx?RID=77180 Disease management information toolkits – one on **paediatric asthma:** http://yhpho.york.ac.uk/IADataServer/dmit/modules.asp Data on certain infectious respiratory diseases and vaccination uptake are available from the Health Protection Agency www.hpa.org.uk/ and local and regional Health Protection Units www.hpa.org.uk/ProductsServices/LocalServices/LocalAndRegionalServices/ Information on lung and related cancers is available through local cancer networks	**Joint Strategic Needs Assessments** are available from local Public Health Departments. Public health reports are available from PCTs – these cover health status, including smoking statistics, and local priorities. Some are written jointly with local authorities and so provide information from more than NHS data. The Director of Public Health's annual report may also provide useful information on local population health status Environmental hazards – Radon : www.hpa.org.uk/Topics/Radiation/UnderstandingRadiation/UnderstandingRadiationTopics/Radon/radon_Map/ Air quality http://www.environmental-protection.org.uk/air-quality-and-climate/air-quality/particles/ www.airquality.co.uk/	**The PCT Spend and Outcome Factsheets and Tool** (SPOT) provides an overview of programme budgeting expenditure and outcomes for every PCT in England. The tool allows for further exploration of the data. http://www.apho.org.uk/resource/view.aspx?RID=76246 Last published Dec 2009 The Compendium of Health and Clinical Indicators at www.nchod,nhs.uk or nww.nchd.nhs.uk contains counts and deaths rates for asthma and COPD and has data going back to 1993. It has data for local authority areas, PCTs and SHA regions. Your local PHO or ONS will have access to mortality files – the raw data from which mortality rates can be calculated and could help if more specific or other kinds of data are required.

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Supplier	Prevalence and incidence of respiratory diseases and predictive risk	Map of local services	Spend and outcome
	www.cancer.nhs.uk/networks.htm End of life – patients dying in their place of choice is now an important metric for PCTs ww.endoflifecare.nhs.uk/eolc/mch.htm		
IMPRESS	Guidance and examples of needs assessment at http://www.impressresp.com/Commissioning/NeedsAssessment.aspx		
Commercial – free	AstraZeneca, GlaxoSmithKline and Boehringer Ingelhim/Pfizer have free tools available at SHA/PCT and practice cluster level that calculate the prevalence of COPD and asthma (some of these are based on the APHO models). These can be accessed via the companies' non-promotional teams. Other companies may not have tools but might offer funding for data analysis as a service to the NHS to increase awareness of their company in the respiratory field.		
Voluntary sector	Predictive risk software to identify likely high users of services: http://www.kingsfund.org.uk/current_projects/predictive_risk/index.html Both PARR and the Combined Predictive Model were commissioned by the Department of Health and Strategic Health Authorities and developed by the King's Fund in partnership with New York University and Health Dialog (now part of Bupa). Other paid-for predictive risk tools also exist – used by the FESC companies – see below.		The Nuffield Trust has been commissioned by the DH to develop a predictive risk tool to predict future costs of social care – pilot work is underway. See http://www.nuffieldtrust.org.uk/projects/index.aspx?id=221 for updates
Voluntary sector	British Lung Foundation social marketing analysis of hot spots for COPD Invisible Lives, supported by analysis from Experian using its Mosaic software that includes retail and other non-health datasets. http://www.lunguk.org/media-and-campaigning/special-reports/InvisibleLivesKeyFindingsASummary.htm		
Voluntary sector	Experience of BME patients with COPD: Picker Report http://www.impressresp.com/LinkClick.aspx?link=75&tabid=83		
Voluntary sector	Lung and Asthma Information Agency http://www.laia.ac.uk/ Academic unit in the Department of Community Health Sciences at St George's Hospital Medical School. Established in 1990, LAIA's sponsors are the Asthma UK , British Lung Foundation and the British		

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Supplier	Prevalence and incidence of respiratory diseases and predictive risk	Map of local services	Spend and outcome
	Thoracic Society. It provides information sheets		
Universities	Department of Medicines Management, Keele University, has provided analysis about COPD and asthma prevalence for all 17 PCTs, practices and Practice-based commissioning groups in the West Midlands using the QOF database, prescribing data from Prescribing Analysis and Cost Tool (PACT), the ERPHO prevalence model, and emergency hospital admissions. URL: http://www.keele.ac.uk/schools/pharm/pctsla/files/COPD&Asthma(Apr08).pdf and http://www.keele.ac.uk/schools/pharm/pctsla/files/respiratory.pdf	Department of Medicines Management, Keele University, has provided analysis about COPD and asthma prevalence for all 17 PCTs, practices and Practice-based commissioning groups in the West Midlands using the QOF database, prescribing data from Prescribing Analysis and Cost Tool (PACT), the ERPHO prevalence model, and emergency hospital admissions. URL: hospital admissions. URL: http://www.keele.ac.uk/schools/pharm/pctsla/files/COPD&Asthma(Apr08).pdf and http://www.keele.ac.uk/schools/pharm/pctsla/files/respiratory.pdfx	
Commercial – paid for	A number of the FESC companies have predictive risk tools: eg United Health http://www.unitedhealthuk.co.uk/our_services/Information_tools.htm Humana http://www.humana.co.uk/approach/documents/Humana-LeafletHRA.pdf and Bupa Health Dialog http://bupahealthdialog.co.uk/html/risk.html Aetna UK also offers relevant tools. http://www.aetna-uk.co.uk Tribal recommends John Hopkins University Baltimore Adjusted Clinical Groups (ACG) Case-Mix System http://www.acg.jhsph.edu/html/AboutACGs.htm For a guide to what the FESC companies can offer to commissioners, see their joint response to the House of Commons Health Select Committee http://www.publications.parliament.uk/pa/cm200809/cmselect/cmhealth/1020/1020w251.htm		

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PERFORMANCE
Are we doing things right? Are we doing the right things? How are we doing compared to our plan? How are we doing compared to our peers in terms of patient safety and experience, cost and standards? How much can we rely on the quality of the data?

	Primary and community care	Secondary care	Spend and outcome
NHS			
NHS (Information Centre, NHS Institute, APHO). Note the Information Centre works in partnership with other providers such as Doctor Foster Intelligence Ltd, IMS Health and Northgate	NHS Comparators http://www.connectingforhealth.nhs.uk/systemsandservices/sus/delivery/comparatorsfrom the NHS Information Centre provides comparative data from QOF and SUS. QOF data is also available from the Information Centre: www.ic.nhs.uk/webfiles/QOF/2008-09/Practice%20tables/QOF0809_Pracs_ASTHMA.xls IMPRESS has been given permission to show some examples of how the comparators service works: http://www.impressresp.com/Commissioning/NeedsAssessment/NHSComparators.aspx QOF Exception rates: http://www.erpho.org.uk/viewResource.aspx?id=17497	NHS Institute offers PCTs analysis for the 19 ambulatory care sensitive conditions that includes asthma, COPD and pneumonia, how, compared to the top quartile of performers in terms of cost and activity, their PCT is doing, and what potential there is for saving admission cost and volume http://www.institute.nhs.uk/opportunitylocator/default.aspx. Asthma information: eg admission data from Information Centre http://signposting.ic.nhs.uk/?k=ASTHMA&f=indexgroups%3ANHS+IC COPD data: http://signposting.ic.nhs.uk/Default.aspx?k=COPD&f=indexgroups%3ANHS+IC	The PCT Spend and Outcome Factsheets and Tool (SPOT) provides an excellent overview of programme budgeting expenditure and outcomes for every PCT in England. The tool allows for further exploration of the data. http://www.apho.org.uk/resource/view.aspx?RID=76246 Last published Dec 2009
NHS Regional public health observatories	All PHOs provide a HES analysis service for their regions and are familiar with other potentially useful information sources like NHS Comparators and SHAPE. NHS comparators (www.nhscomparators.nhs.uk) is run by the Information Centre and has GP practice and PCT level information on admissions for COPD, rates per 1000 QOF registrations and so on.		Each has a role in different disease areas and East of England is now the lead for respiratory diseases (see above under needs assessment). However in addition your local PHO may have produced a special report eg SEPHO (South East England Public Observatory) Clinical Standards indicators in South Central. Report 6: COPD. May 2009 SEPHO that aimed to identify significant quality issues in the prevention and clinical care of COPD that could be revealed from existing routine data sources: death registrations, QOF data, Hospital episode statistics
NHS NpfIT http://www.connectingforhealth.nhs.uk/	Clinical dashboard toolkit http://www.connectingforhealth.nhs.uk/systemsandservices/clindash/toolkit		
Third sector			
eg Keele	Department of Medicines Management, Keele University, has provided analysis about QOF indicator achievement, prescribing, hospital admissions, referral	Department of Medicines Management, Keele University, has provided analysis about QOF indicator achievement, prescribing, hospital	

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	Primary and community care	Secondary care	Spend and outcome
	methods and deaths for asthma and COPD for all 17 PCTs, practices and practice-based commissioning groups in the West Midlands using the QOF database, prescribing data from Prescribing Analysis and Cost Tool (PACT), the ERPHO prevalence model, and emergency hospital admissions. It also includes a series of questions to start discussions. URL: hospital admissions. URL: http://www.keele.ac.uk/schools/pharm/pctsla/files/COPD&Asthma(Apr08).pdf and http://www.keele.ac.uk/schools/pharm/pctsla/files/respiratory.pdf	admissions, referral methods and deaths for asthma and COPD for all 17 PCTs, practices and practice-based commissioning groups in the West Midlands using the QOF database, prescribing data from Prescribing Analysis and Cost Tool (PACT), the ERPHO prevalence model, and emergency hospital admissions. It also includes a series of questions to start discussions. URL: hospital admissions. URL: http://www.keele.ac.uk/schools/pharm/pctsla/files/COPD&Asthma(Apr08).pdf and http://www.keele.ac.uk/schools/pharm/pctsla/files/respiratory.pdf	
Audit Commission			Its national clinical coding audit programme quality assures the data used in Payment By Results. The Year 2 report analysing every acute trust's performance 2008/09 shows that the number of errors made by NHS trusts under the PbR system is falling, but there are continuing concerns about the poor quality of some medical records. Comparative profiles for all Strategic Health Authorities, primary care trusts and trusts and can be downloaded from http://www.audit-commission.gov.uk/health/audit/paymentbyresults/pbrresults200809/pages/default.aspx Further information http://www.audit-commission.gov.uk/health/nationalstudies/pbr/pbrdataassuranceframework200809/Pages/default_copy.aspx
Royal Colleges	Report of the National Chronic Obstructive Pulmonary Disease Audit 2008: Survey of COPD care within UK General Practices http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/ncrop/Documents/Report-of-The-National-COPD-Audit-2008-survey-of-COPD-care-within-UK-General-Practices.pdf	Report of the National Chronic Obstructive Pulmonary Disease Audit 2008: Resources and Organisation of care in Acute NHS units across the UK http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/ncrop/Documents/Report-of-The-National-COPD-Audit-2008-resources-and-organisation-of-care-in-acute-NHS-units-across-the-UK.pdf	Quality indicators used in the audit: http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/ncrop/Documents/NCROP-Quality-Indicators.pdf Report of the National Chronic Obstructive Pulmonary Disease Audit 2008, UK Primary Care Organisations: Resources and Organisation of Care http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/ncrop/Documents/Report-of-the-National-COPD-Audit-2008-UK-Primary-Care-Organisations-Resources-and-Organisation-of-Care.pdf COPD audit data from Report of the National Chronic Obstructive Pulmonary Disease Audit 2008:

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	Primary and community care	Secondary care	Spend and outcome
			Patient Survey http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/ncrop/Documents/Report-of-The-National-COPD-Audit-2008-Patient-Survey.pdf
IMPRESS, BTS and PCRS-UK	PCRS has funded or part-funded a number of audit tools: eg for COPD diagnosis and spirometry http://www.guideline-audit.com/pcrsuk_copd_dx/ (free) and chest infection http://www.guideline-audit.com/chest_infection_audit/ and Unscheduled attendance at general practice surgeries for asthma episodes (UNSAFE) Audit http://www.guideline-audit.com/unsafe/ which are part of a collection available from http://www.guideline-audit.com/index.htm	British Thoracic Society (BTS) National Audits are included on the list of NCAAG approved audits for 2009/10 Quality Accounts . http://www.brit-thoracic.org.uk/audit-tools.aspx COPD: work is underway to provide access to the European COPD audit in autumn 2010. Other information: Guide to respiratory tariffs http://www.brit-thoracic.org.uk/Portals/0/Delivery%20of%20RespCare/resp_tariffs_guide.pdf And guide to Respiratory Coding http://www.impressresp.com/Portals/0/IMPRESS/Aguidetorespiratorycoding.pdf	
Voluntary sector	QOF data from http://www.gpcontract.co.uk/ Creative Commons licence. Produced using publicly available data, but analysed by SHA, PCT, and by PCT clusters. Produced by Gavin Jamie		
Commercial			
Commercial – free/low-cost	The pharmaceutical companies with respiratory products including AstraZeneca, GlaxoSmithKline, Boehringer Ingelhim/Pfizer, Novartis and Chiesi offer audit services supplied either as computer programmes or services supplied by a third party. These may show performance against a standard such as QOF or NICE or compare the costs, use and trends in prescribing of inhaled medications. Approach their local teams for more information. If you work with these companies, you should follow the DH/ABPI guidelines on partnership working and be very clear about ownership of the information, and how it can		

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	Primary and community care	Secondary care	Spend and outcome
	be used.		
Commercial - free	There are some pilot schemes of primary care data extraction and audit tools, with additional services such as patient questionnaire and feedback that are funded in tripartite arrangements. For example, Optimum Patient Care offers AsthmaTrak and COPDtrak in PCTs in England, paid for partly by OPC and partly through pharmaceutical company sponsorship and partly in exchange for anonymised patient data		
Commercial – paid for – clinical	There are a number of clinical systems available that will, as a by-product, produce performance data. These include http://www.tpp-uk.com/systmone.htm that has the capability to cross primary and secondary care and is compliant with the summary care record.		
	Lung Health. Guided consultation software produced by Mike Pearson Not yet compatible with GP systems, but work is ongoing.		
Commercial – paid for non-clinical	There are a number of commercial data extraction tools.		
Commercial – paid for non-clinical	The DH has produced a Framework for procuring External Support for Commissioners (FESC) Many of these suppliers offer tailored analytical services.	The DH has produced a Framework for procuring External Support for Commissioners (FESC) Many of these suppliers offer tailored analytical services.	The DH has produced a Framework for procuring External Support for Commissioners (FESC) Many of these suppliers offer tailored analytical services.

Presentation

Department of Medicines Management, Keele University, has been commissioned by West Midlands SHA to provide information drawing from both prescribing and activity datasets. For examples of how this is presented by PCT see http://www.keele.ac.uk/schools/pharm/pctsla/files/COPD&Asthma(Apr08).pdf and http://www.keele.ac.uk/schools/pharm/pctsla/files/respiratory.pdf

Connecting for Health http://www.connectingforhealth.nhs.uk/systemsandservices/clindash/toolkit/metricsrep is piloting a number of clinical dashboards: for example, Salford Care of the Elderly service

Other pilots for the clinical dashboard include:

Northumberland Tyne and Wear NHS Trust	Ben.Scorer@ntw.nhs.uk
Bradford and Airedale Primary Care Trust	
Norfolk and Norwich University NHS Foundation Trust	Nick.Jaciuk@NNUH.nhs.uk
Mid Staffordshire NHS Foundation Trust	STEVEN.SHAW@midstaffs.nhs.uk
Nottingham University Hospitals NHS Trust	matt.howden@nuh.nhs.uk
The Homerton University Hospital NHS Foundation Trust	Petra.Cox@homerton.nhs.uk

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Salisbury NHS Foundation Trust	carole.perren@salisbury.nhs.uk
Portsmouth Hospitals NHS Trust	Claire.Dyson@porthosp.nhs.uk
South East Coast Ambulance Service NHS Trust	Mike.Plowman@secamb.nhs.uk
Bolton Primary Care Trust	dashboard@BOLTON.NHS.UK
Salford Royal NHS Foundation Trust	Helen.Rooney@srft.nhs.uk
Imperial College Healthcare NHS Trust	Neil.Macdonald@imperial.nhs.uk

The following pages of appendices give further examples.

We will also publish this paper as an html document online and will update as we find or are presented with updated information.

19 July 2010

Siân Williams IMPRESS Project Manager,
Dr Julian Flowers, Director Eastern Region Public Health Observatory/Quality Intelligence East IPH,
Dr Matt Kearney, Primary Care Clinical Advisor, Respiratory Programme, Department of Health,
Dr Louise Wilson, Consultant in Public Health, NHS Torbay,
Dr Steve Connellan, Consultant Respiratory Physician and Respiratory HRGs Expert Working Group (EWG) Lead,
Jane Scullion, Respiratory Nurse Consultant Glenfield Hospital.

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APPENDIX
Care Quality Commission – information governance

"The term "information governance" refers to the policies and practices in place to ensure the confidentiality and security of the records of patients and service users to help deliver the best possible care. The acronym HORUS is often used to sum up how personal information should be:

* Held securely and confidentially
* Obtained fairly, efficiently and lawfully
* Recorded accurately and reliably
* Used effectively and ethically
* Shared appropriately and lawfully.

Our study of information governance in healthcare organisations aimed to build on the increased scrutiny and profile of this aspect of healthcare, following well-publicised losses of personal data. However, we wanted to look beyond the headlines on data security. The study looked at wider aspects of information governance including the quality of information, how it is shared, and how clinical and non-clinical information about individual people is used to shape their care. This is because these are also key measures of good information governance and have an impact on the quality of care that patients experience."

Another useful phrase to remind NHS employees about data confidentiality is "**Nothing about me without me**" (Diane Plamping[3]) now included in the government white paper Equity and excellent: Liberating the NHS[4].

[3] Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan S, Ollenschläger G, Plamping D, Rockefeller RG. Healthcare in a land called PeoplePower: nothing about me without me.Health Expect. 2001 Sep;4(3):144-50.

[4] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353 Downloaded 12 July 2010

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APPENDIX – Examples of commercial and free tools

Illustrations of tools from pharmaceutical companies: to follow.

Asthmatrak

In Surrey the PCT is working in partnership with the social enterprise Optimum Patient Care, with the support of the University of Surrey Postgraduate Medical School, to provide a management review service for people with asthma and COPD. The service stratifies patients according to risk by collecting and linking data from the patient in the form of questionnaires, and from the practitioner, in the form of extracted routinely-collected clinical data from electronic patient records, into three streams:

1. High risk – needs referral for specialist review
2. Not considered to be high-risk, but whose asthma is not well controlled and their care could be better optimised – healthcare team offered NICE-based points to consider
3. Low-risk and well controlled.

The data extraction is done with minimal disruption to the practice and feedback is given to both the patient, practice and PCT in the form of a summarized questionnaire together with electronic data current treatment; adherence to therapy; level of asthma control; patient-reported concerns and beliefs; and asthma management considerations, based on rulesets approved by a local steering committee and inline with NICE guidance.

Overall the scheme aims to enhance the consultation process and reduce time spent reviewing patients with well-controlled asthma and for those who are not well controlled, identify reasons for poor control.

Confidentiality of patient-identifiable data is maintained through a robust process of linked-anonymisation before transfer and de-anonymisation in the doctors' surgery when the report is received.

The management review services are supported by Research in Real Life, in exchange for anonymised patient data for research purposes and the asthma service is in Surrey is also supported by an unrestricted grant from Novartis. The services are therefore provided free of charge across the PCT.

The impact of the service has not yet been assessed as it is in the early stages of practice engagement and data extraction.

Source: OPC, April 2010

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APPENDIX Extract from Guide to Respiratory Coding

INPATIENT GUIDING PRINCIPLES

In this section the aim is to consider those Healthcare Resource Groups (HRGs) which are high in volume and have been further divided to provide greater definition of resource consumption. We will consider examples of typical acute admissions and the related coding.

Acute exacerbation of COPD:
A patient with known COPD is admitted acutely following an exacerbation. He also has a background of Diabetes (Type 2) and chronic AF (on aspirin). He does not require any form of assisted ventilation and is in hospital for 10 days. In view of symptoms of haemoptysis, he has a bronchoscopy (fibreoptic) prior to discharge with no need for washings, brushings or biopsy.

Diagnoses:
COPD with acute exacerbation (ICD10 code **J44.1**)
Atrial fibrillation (ICD10 code **I48.X**)
Non-insulin-dependent diabetes mellitus without complications ICD10 code **E11.9**)
Haemoptysis (**RO4.2**)
Procedures:
Diagnostic Fibreoptic Bronchoscopy lower respiratory tract NOS (**E49.9**)
Grouped to:
HRG **DZ21J – COPD or Bronchitis without NIV without intubation with CC**
Reimbursement:
There would be no reimbursement for the bronchoscopy in this case as it was part of an acute admission > 1 day. If this had been carried out electively, as a day case procedure, it would group to HRG **DZ07Z** and be reimbursed separately.

Acute exacerbation of COPD requiring NIV support:
Acute exacerbation of COPD which required NIV support during the first 3 days and following this was complicated by Clostridium Difficile colitis. Discharged after 2 weeks.

Diagnoses:
COPD with acute exacerbation (ICD10 code **J44.1**)
Enterocolitis due to Clostridium Difficile (**A04.7**)
Procedures:
Non-invasive ventilation NEC (**E85.2**)
Grouped as:
HRG **DZ21E – COPD or Bronchitis with NIV without intubation with Major CC**

Acute exacerbation of COPD requiring intubation and ventilation:
Acute exacerbation of COPD requiring intubation soon after admission followed by 10 days in ITU complicated by aspiration pneumonia during the convalescent period. Discharged after 4 weeks.

Diagnoses:
COPD with acute exacerbation (**J44.1**)
Pneumonitis due to food and vomit (**J69.0**)
Procedures:
Invasive ventilation (**E85.1**)
Grouped to:
HRG **DZ21B – COPD or Bronchitis with intubation with Major CC**

Acute exacerbation of COPD discharged home within 24 hours:
Acute exacerbation of COPD admitted to the Medical Admissions Unit and seen by specialist Respiratory nurses soon after admission. No evidence of pneumonia on CXR and checklist suggests that he is suitable for discharge home. Confirmed by responsible clinician and discharged to Hospital at Home (HaH) pathway with daily visits and assessment as per ICP for the next 7 days.

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Diagnosis:
COPD with acute exacerbation (**J44.1**)
As the length of stay is < 1 day and discharged home this episode will be grouped as:
HRG **DZ21A – COPD or Bronchitis with length of stay 1 day or less discharged home.**
FESC – see Jargon Buster

NpfIT – see Jargon Buster

END