



# Public Health Surveillance

*Towards a Public Health Surveillance  
Strategy for England*

## Public Health Surveillance: Towards a Public Health Surveillance Strategy for England

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# Public Health Surveillance

## *Towards a Public Health Surveillance Strategy for England*

Prepared by the Public Health England Transition Team

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# Executive summary

## Introduction

This document has been prepared for the Public Health England Information and Intelligence Working Group. It provides an overview of the vision, rationale, and plans for delivery of a surveillance strategy for Public Health England, as part of a broader information management strategy for Public Health England, and sets out the key benefits and challenges in delivering such a strategy.

## What is surveillance?

Surveillance is a core public health function that ensures the right information is available at the right time and in the right place to inform public health decisions and actions.

## What will success look like?<sup>1</sup>

In line with the Information Strategy for health and care '*The Power of Information*', this strategy will deliver systems that enable users within Public Health England and its partner organisations to view the latest information required to inform public health decisions and actions and receive alerts of incidents and adverse trends. Shared ambitions include capturing and using information to drive integrated care, improving interoperability between systems and using new technologies to improve outcomes.

A Director of Public Health who is inputting into Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) undertaken through health and wellbeing boards will be able to view and download outputs that provide an up to date analysis of morbidity or mortality, for diseases of public health importance along with an integrated analysis of surveillance data on environmental or behavioural risk factors for those diseases. Information from surveillance systems (e.g. primary care reports on asthma consultations, blood lead level measurement reports from pathology services), disease registers (e.g. congenital anomaly registers, cancer registers, GP asthma registers), and analyses of hospital episode statistics (e.g. acute asthma admissions) will be linked with information on potentially remediable risks from environmental tracking (e.g. radon measurements, air quality monitoring reports, measurements of lead levels in local water supplies) and made available at a local level, with national benchmark comparators.

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<sup>1</sup> Examples for illustration purposes

Public Health England will support policy and commissioning through the production of integrated outputs, drawing on surveillance and other data, which will provide an assessment of the need for, and the impact of, services. The Secretary of State for Health will be able to make decisions about how to prioritise resources based on the best available evidence about existing control programmes, the effectiveness and cost-effectiveness of such programmes, and the relative outcomes for different groups within the population. For example, it will be possible for Public Health England to link primary and secondary prevention activities (HPV immunisation and cervical screening uptake rates) with surveillance of outcomes (cervical cancer registrations, HPV infection rates) and risk factors (incidence of other sexually transmitted infections, sexual behaviour survey results), at a population level.

### The scope of surveillance

Surveillance may be used to inform health protection, health improvement and health service delivery, and is equally applicable to assessing acute and chronic disease occurrence and risks.

Surveillance encompasses the processes of data collection, analysis, interpretation and dissemination that are:

- (a) undertaken on an ongoing basis (i.e. there is a defined but not time-limited cycle of processing),
- (b) provide measures of population or group health status or determinants of health (hazards, exposures, behaviours) against historical or geographical baselines/comparators or defined levels/triggers for action, and
- (c) for which there is an agreed and explicit set of actions, timeframes and accountabilities for taking those actions, that will be initiated or informed by the outputs.

Surveillance is one part of an integrated public health information management function. Its relationship to other public health information management activities and the wider information strategy for health and care is described in the main body of the strategy.

### What is it used for (purpose)?

Public health surveillance can be used to inform public health action, programme planning and evaluation, and formulating research hypotheses. For example, data from a public health surveillance system can be used to:

- guide immediate action for cases of public health importance, such as ensuring that meningitis contacts are provided with appropriate prophylaxis
- measure the burden of a disease, and the identification of new or emerging health concerns e.g. providing measures of childhood obesity in different population groups along with indices of dietary behaviour and physical exercise
- monitor trends in the burden of a disease and changes in related factors, including the detection of epidemics and pandemics e.g. the detection of a localised increase in congenital abnormalities that might reflect a new environmental exposure, or a national increase in influenza
- guide the planning, implementation, and evaluation of programmes to prevent and control disease, injury, or adverse exposure e.g. identification of areas of high incidence of lead poisoning or road traffic accidents, or the evidence to inform and evaluate vaccination programmes
- evaluate public health policy e.g. monitoring obesity within the population to assess policy on improving diet and exercise levels
- detect changes in health practices and their effects, such as monitoring provision and uptake of screening and the incidence or prevalence of the target disease/outcome e.g. infectious diseases in pregnancy and outcomes such as hepatitis B, or bowel cancer screening and bowel cancer incidence
- prioritise the allocation of health resources e.g. local and national measures of the prevalence of diabetes and diabetic retinopathy
- describe the clinical course of disease e.g. surveillance of hepatitis C cases to assess long term outcomes and the impact of interventions
- provide a basis for epidemiologic research e.g. the identification of an apparently new risk factor among cases of a condition that is the subject of surveillance.

### Who are the outputs for?

Users of Public Health England surveillance outputs will include:

- Directors of Public Health, local authorities and health and wellbeing boards
- Public Health England staff
- commissioning bodies
- clinicians and NHS managers
- government departments
- Regulatory, advisory and professional bodies e.g. Medicines and Healthcare products Regulatory Agency (MHRA), Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infections (ARHAI), Royal Colleges

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- National Institute of Health and Clinical Excellence (NICE) to support monitoring of implementation of their evidence based guidance
- academic bodies
- international organisations e.g. World Health Organization (WHO), European Centre for Disease Prevention and Control (ECDC)
- industry e.g. food producers/retailers, pharmaceutical companies
- the public.

Outputs will include online interactive databases, regular and ad hoc epidemiology reports, environmental hazard maps (e.g. radon maps), prevention programme monitoring reports, population-based health profiles, and situational analyses.

### Current position

Figure 1 summarises the key data sources, outputs and outcomes of surveillance and allied public health information and intelligence systems. This shows how data collected and collated for surveillance are used, in combination with data collected and collated primarily for other purposes, for primary analysis to inform public health response and deliver operational public health intelligence, and for secondary analyses that inform more strategic decisions and actions. The strategy will focus particularly on strengthening current areas of weakness.

### How will the strategy be delivered?

The strategy will deliver systems to support and enable the key policy and operational goals set out in *Healthy Lives, Healthy People* and the subsequent *Update and Way Forward*, making best use of modern technology and the synergies offered by Public Health England. It will establish strong leadership and management arrangements that will bring together and, where appropriate, integrate relevant sender organisation systems, outputs and workforces to deliver outputs that meet current best practice. It will address gaps and weaknesses that have been highlighted through stakeholder consultation, developing new systems, and particularly establishing new linkages and new partnerships that the creation of Public Health England offers. The value and quality of surveillance will be assured through a quality framework encompassing: clearly stated objectives in terms of outputs and outcomes; standard operating procedures and quality standards for inputs, processes and outputs; explicit governance systems, stakeholder engagement, and system-level audit; and workforce development plans.



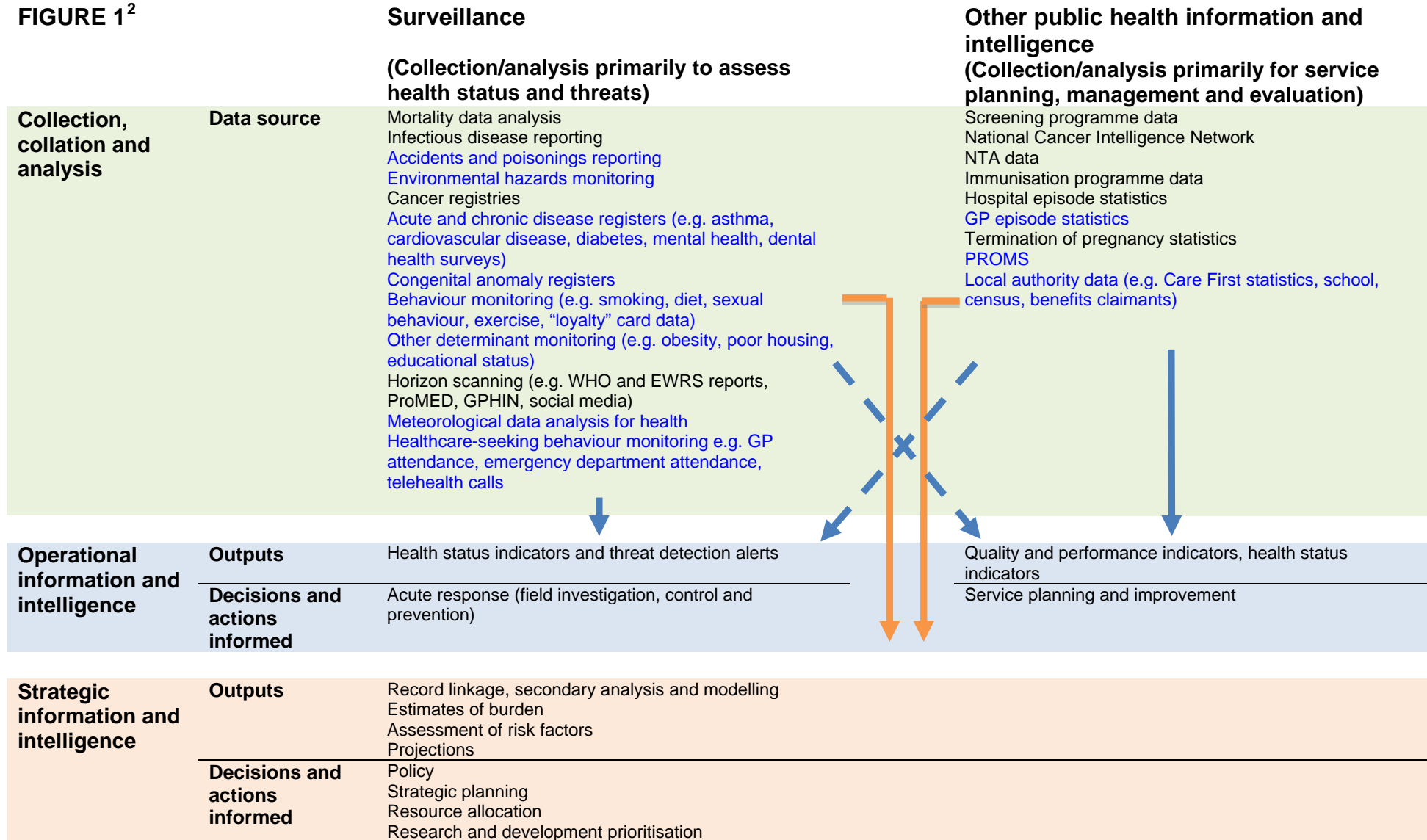
## What are the key challenges and opportunities?

- exploiting the expertise in Public Health England to ensure high-quality peer review, expert advice, professional standards and quality assurance
- improved use of data holdings, where appropriate, through linkage of datasets already collected by Public Health England to improve the evidence base and support local decision makers – the governance and organisational issues around this linkage requirement must be addressed as soon as possible. As described in the Information Strategy, *the Power of Information*, opportunities provided by the new status and functions of the Health and Social Care Information Centre regarding data collection and linkage need to be explored
- developing outputs using common tools, definitions and quality indicators across all public health areas, with evidence on the value of interventions and the impact and cost of short, medium and long term interventions
- streamlining data collections, supported by the development of a common public health minimum dataset and associated information standards
- identifying and exploiting novel sources of information and analytical approaches that can be used across the whole of Public Health England
- maintaining and developing the specialist workforce required to deliver the vision.

## Next steps (2012/13)

- implement a transparent quality and governance framework for surveillance
- identify best practice in surveillance methods and outputs nationally and internationally, and identify priorities for data linkage and/or information system integration for public health surveillance in England
- ensure core outputs for health protection, health improvement, and PHOF indicator production are available before April 2013; these could also be used to inform JSNAs
- define the technical infrastructure (with informatics colleagues) for the provision of surveillance systems
- develop business cases for new developments required to deliver priorities identified in *Healthy Lives, Healthy People* and through stakeholder consultation
- establish mechanisms for ongoing review of, and response to, user requirements of surveillance and key gaps in current outputs.

FIGURE 1<sup>2</sup>



<sup>2</sup> Data sources in blue text are currently less well integrated/exploited for surveillance than those in black text. See also Annex 3 for more detailed analysis

# 1. The vision

- 1.1 This paper sets out a vision for an integrated public health surveillance system that will be delivered by Public Health England<sup>3,4</sup>. It identifies opportunities to realise the benefits that the creation of Public Health England offers in respect of strengthening surveillance as a component of its public health knowledge and intelligence function within the changing organisational context of public health delivery systems.

## The vision

- 1.2 Public Health England will operate efficient, world-leading surveillance services that provide a robust evidence base for decision-making and action-taking in respect of both acute and chronic diseases and health determinants. Surveillance will underpin the protection and improvement of health and service delivery, through outputs that are timely, accurate, accessible and meaningful to users of this information at the local, national and international level.
- 1.3 There will also need to be consideration of the implications of equality and this will be a key principle underpinning the vision.

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<sup>3</sup> The paper has been developed through consultation with organisations represented on the Public Health England Information & Intelligence Working Group, the Association of Directors of Public Health, and with a wider stakeholder group attending a stakeholder engagement event. It also incorporates findings and

<sup>4</sup> recommendations from a paper on “Improving public health surveillance systems” produced by a South East and Eastern England Public Health Surveillance Working Group.

## 2. What is surveillance?

- 2.1 Surveillance has been defined as “the systematic regular collection, analysis, interpretation and dissemination of data for a given population to detect changes on patterns of disease or disease determinant with action taken if a predefined criteria or thresholds are met”<sup>4</sup>, or more succinctly as providing the right information at the right time and in the right place to inform decision-making and action-taking.
- 2.2 A defining characteristic of surveillance is that there is a direct and immediate link between the outputs of surveillance systems and operational or policy response. There should be an explicit mechanism whereby surveillance outputs feed into operational response, usually in real time and ideally with defined criteria (trigger points) for response, or planning and policy making, usually through analyses undertaken over longer time periods.
- 2.3 The Information Strategy, *the Power of Information*, focuses on how health and care professionals “can use connected information and new technology to join up and improve services, to inform the decisions they make and to help deliver safer, more integrated care”, for example through faster access to test results. The combination of robust information to inform action and improved health and care is therefore a fundamental ambition set out in the Strategy.

## 3. Scope of surveillance

- 3.1 Surveillance encompasses the processes of data collection, analysis, interpretation and dissemination that are:
- (a) undertaken on an ongoing basis (i.e. there is a defined but not time-limited cycle of processing),
  - (b) provide measures of population or group health status or determinants of health (hazards, exposures, behaviours) against historical or geographical baselines/comparators or defined levels/triggers for action, and
  - (c) for which there is an agreed and explicit set of actions, timeframes and accountabilities for taking those actions, that will be initiated or informed by the outputs.
- 3.2 This definition of scope, which is irrespective of disease type (i.e. is equally applicable to assessing acute and chronic disease occurrence and risks), clearly distinguishes surveillance from (most) research, which is usually time-limited and for which there is not generally an a priori agreed set of actions, and accountabilities for taking those actions, based on the outcome of the research. The continuous or ongoing nature of surveillance also differentiates it from other ad hoc surveys and analyses (particularly secondary analyses) that are often undertaken to inform the initial stages of policy development or planning, or the re-evaluation of policy. It distinguishes surveillance from clinical audit and service evaluation because surveillance generally provides health status (or health determinant status) measures related to a defined population, irrespective of whether or what interventions that population might be in receipt of, rather than provides measures against standards for individuals defined in terms of a specific health service intervention.
- 3.3 Clearly, not only is there some overlap in the characteristics of these different knowledge and intelligence activities, but also there is overlap in the data that are used for these various activities (see Figure 1). There is a relatively limited set of health data sources, and so inevitably these same sources will often be used for a number of different knowledge and intelligence purposes e.g. vaccine uptake data may be used for the evaluation of immunisation services, but also used as a measure of health status (vulnerability) for surveillance. The development of common standards, and even common systems, for data collection and collation for such overlapping uses of the same data should provide important efficiencies and opportunities for synergies (such as in secondary analyses).

- 3.4 It is also the case that data collected and collated for one purpose might additionally be used for another purpose after it has been collated and/or analysed for the initial purpose. Thus, data collected and collated primarily for the purpose of surveillance, such as the collation of clinical notifications of infectious disease, may also be used for research or secondary analyses for policy. Similarly, data collected for health service evaluation might subsequently be used to assess health status as part of a surveillance process.
- 3.5 This strategy therefore not only makes reference to inputs, systems and outputs that are wholly or largely used and disseminated for the purpose of surveillance (as defined above), but also makes reference to inputs, systems and outputs that are largely used and disseminated for other public health information management purposes, such as service planning and performance management or strategic planning. It is outside the scope of this strategy to prescribe how those other public health information management systems will be designed or operated, other than to identify where there is a need to ensure that systems may be integrated or interoperated through the application of common standards. In broad terms, the data sources and information management systems that are within scope of this strategy in terms of system design and operation are those listed as “surveillance” in Figure 1, which include:
- analysis of mortality data
  - infectious disease reporting and analysis
  - accidents and poisonings reporting and analysis
  - environmental hazards reporting and analysis
  - acute and chronic disease registers (e.g. asthma, cancer, cardiovascular disease, diabetes, mental health, dental health surveys)
  - congenital anomaly registers
  - behavioural monitoring and analysis (e.g. smoking, diet, sexual behaviour, exercise, “loyalty” card data)
  - monitoring systems for other determinants (e.g. obesity, poor housing, educational status)
  - horizon scanning systems (e.g. WHO and EWRS reports, ProMED, GPHIN, social media)
  - analysis of meteorological data for public health purposes
  - monitoring and analysis of healthcare-seeking behaviour, e.g. GP attendance, emergency department attendance, telehealth calls.

- 3.6 There are a wide range of other public health knowledge and intelligence functions that generate outputs that will be used for public health surveillance, and may use “surveillance” data as an input, but do not have surveillance (as defined above) as their primary purpose. Typically these functions will inform the planning, management and evaluation of services, e.g.:
- screening programme data collection and analysis
  - the work of the National Cancer Intelligence Network
  - the National Drug Treatment Monitoring System’s data collection and analysis systems
  - the collection and analysis of immunisation programme data
  - the collection and analysis of hospital episode statistics and (in the future) GP episode statistics
  - the collection and analysis of data on terminations of pregnancy
  - the collection and analysis of Patient Reported Outcome Measures
  - local authority data collections and analyses (e.g. Care First statistics, school, census, benefits claimants).
- 3.7 These functions/systems are within the scope of this strategy with respect to the definition of standards required to facilitate sharing or exchange of data and information, and with respect to the analysis and outputs that provide measures of population health status or health threat status. All other aspects of the design and operation (other than in identifying common standards for data and information sharing or exchange) of these functions/systems are out of scope of this strategy.

## 4. The role of surveillance – the policy context

- 4.1 Surveillance is an essential part of the public health toolkit. In making surveillance a core function across all of its areas of activity, Public Health England will not only ensure a robust evidence base for public health decision-making, but will also demonstrate its commitment to continuously monitoring and assessing the need for public health action.
- 4.2 The Information Strategy, *the Power of Information*, describes a number of ambitions to realise the potential benefits of information to improve our care and health outcomes.
- 4.3 Supporting this, *Healthy Lives, Healthy People: Update and Way Forward* sets out a clear vision for a public health system that will be driven and informed by the best available knowledge and information, and that will provide robust arrangements for the protection of health. Strong surveillance systems will be essential to delivering this vision. Surveillance, as part of a wider knowledge and intelligence function that will be delivered by Public Health England, underpinned by the ambitions and principles within *the Power of Information*, will deliver outputs that will enable:
- strategic direction and monitoring at the national and local level, by providing the information for many of the Public Health Outcomes Framework indicators, e.g. deaths and injuries on roads, alcohol-related admissions to hospital, people presenting with HIV at a late stage of infection
  - support local leadership of strategic planning of services, by inputting into JSNAs undertaken by health and wellbeing boards, and also providing the information required for assessing local population health status and needs for use by Directors of Public Health annual reports e.g. childhood obesity, excess winter deaths, food poisoning rates
  - commissioning of services, by providing measures of population health status and information for monitoring the impact of commissioned services, e.g. information on the incidence of sexually transmitted infections and vaccine preventable diseases, completion rates for treatment of tuberculosis patients
  - Directors of Public Health to provide advice to clinical commissioning groups (CCGs) e.g. dental health indices, measures of acute asthma incidence from GP and emergency department attendances



- robust health protection and emergency preparedness, by providing epidemic intelligence e.g. rapid alerts of outbreaks of infectious disease, maps of environmental hazards such as radon or landfill sites, and early warning of emerging threats from syndromic surveillance and international surveillance.

## 5. The role of surveillance – information for action

- 5.1 Implementation of a Public Health England Integrated Surveillance Service should deliver an outputs-based intelligence service that informs public health policy and practice. It will achieve this by ensuring that the right information is available at the right time and in the right place to inform decision-making and action taking. Public health surveillance can be used to inform public health action, programme planning and evaluation, and formulating research hypotheses. For example, data from a public health surveillance system can be used to:
- guide immediate action for cases of public health importance, such as ensuring that meningitis contacts are provided with appropriate prophylaxis
  - measure the burden of a disease, and the identification of new or emerging health concerns e.g. providing measures of childhood obesity in different population groups along with indices of dietary behaviour and physical exercise
  - monitor trends in the burden of a disease and changes in related factors, including the detection of epidemics and pandemics e.g. the detection of a localised increase in congenital abnormalities that might reflect a new environmental exposure, or a national increase in influenza
  - guide the planning, implementation, and evaluation of programs to prevent and control disease, injury, or adverse exposure e.g. identification of areas of high incidence of lead poisoning or road traffic accidents, or the evidence to inform and evaluate vaccination programmes
  - evaluate public health policy e.g. monitoring obesity within the population to assess policy on improving diet and exercise levels
  - detect changes in health practices and their effects, such as monitoring provision and uptake of screening and the incidence or prevalence of the target disease/outcome e.g. infectious diseases in pregnancy and outcomes such as hepatitis B, or bowel cancer screening and bowel cancer incidence
  - prioritise the allocation of health resources e.g. local and national measures of the prevalence of diabetes and diabetic retinopathy
  - describe the clinical course of disease e.g. surveillance of hepatitis C cases to assess long term outcomes and the impact of interventions
  - provide a basis for epidemiologic research.

- 5.2 An integrated public health surveillance function will be essential, not only to informing Public Health England in respect of its own public health functions, but also in enabling it to support the statutory duties of Directors of Public Health and the local authorities within which they will be based as well as the NHS. It will do this by providing timely and locally relevant surveillance outputs and analytical services that can be used by, and will be complementary to, public health intelligence teams working in local authorities. Examples of the range of data that will be used in surveillance to inform local public health delivery are given in Annex 3.
- 5.3 At the national level, Public Health England will need to have excellent and robust integrated surveillance systems to provide comprehensive and authoritative intelligence for policy and for the management and evaluation of services. Such systems will also ensure that international reporting and risk assessment obligations, as specified in the International Health Regulations and Decision No 2119/98/EC<sup>5</sup> of the European Parliament and of the Council, are met.
- 5.4 At both the local and the national level, Public Health England will provide surveillance outputs that will help members of the public make informed choices with respect to their health, by providing comprehensive information and advice on the health status of their local area as well as guidance on how to make positive changes. The outputs will also seek to inform decision-making and action-taking by public health professionals, staff working in partner organisations, and policy makers. Wherever appropriate, surveillance outputs will provide indicators that have been specified in the Public Health Outcomes Framework.

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<sup>5</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:1998:268:0001:0006:EN:PDF>

## 6. Who are the users of surveillance outputs?

- 6.1 The strategy will aim to deliver systems that enable users at all levels within Public Health England and its partner organisations to view the latest information and receive alerts of adverse trends and incidents, and will also provide relevant denominator and intervention information that will aid interpretation of case or event reports.
- 6.2 This information will be made widely and readily accessible through the best use of developing technologies, including the use of mobile devices, requiring only appropriate access permissions.
- 6.3 Users of Public Health England surveillance outputs will include:
  - Directors of Public Health, local authorities and health and wellbeing boards
  - Public Health England staff
  - commissioning bodies
  - clinicians and NHS managers
  - government departments
  - regulatory, advisory and professional bodies e.g. MHRA, ARHAI, Royal Colleges
  - NICE to support monitoring of implementation of their evidence-based guidance
  - academic bodies
  - international organisations e.g. WHO, ECDC
  - industry e.g. food producers/retailers, pharmaceutical companies
  - the public.

## 7. The current state

- 7.1 Figure 1 summarises the key data sources, outputs and outcomes of surveillance and allied public health information and intelligence systems. This shows how data collected and collated for surveillance are used, in combination with data collected and collated primarily for other purposes, for primary analysis to inform public health response and deliver operational public health intelligence, and for secondary analyses that inform more strategic decisions and actions. The strategy will focus particularly on strengthening current areas of weakness (as identified in Figure 1) and on developing and exploiting the linkages and new partnerships that will be facilitated by the creation of Public Health England.
- 7.2 Annex 3 provides an analysis of surveillance activities that currently inform public health policy and operations in England. These include many systems that are managed by Public Health England sender organisations, but also include systems that are operated by other organisations e.g. systems operated by professional organisations, such as the RCGP weekly returns service, the British Paediatric Surveillance Unit and the British Ophthalmological Surveillance Unit, and systems operated by organisations such as the Office for National Statistics, the Health and Safety Executive, Defra and the Drinking Water Inspectorate. The Information Strategy, *the Power of Information*, encourages interoperability between systems and organisations through promoting consistency in use of standards and technologies.
- 7.3 Surveillance has been most extensively developed in the field of health protection, with reporting and analysis systems that date back to the nineteenth century for infectious disease notifications and even earlier for mortality monitoring. Many of the infectious disease surveillance systems in operation in England are recognised as world leading, such as the national reporting system for surveillance of infections identified by microbiology laboratories and the disease or topic specific surveillance systems for HIV and for other sexually transmitted infections, and those for healthcare associated infection and antimicrobial resistance. There is a long history of innovation in England in surveillance, such as the unlinked anonymous HIV prevalence monitoring systems, and the British Paediatric Surveillance Unit, set up through a collaboration between the former Public Health Laboratory Service and the Institute of Child Health, which provided the

evidence that demonstrated the link between the use of aspirin in children and the development of Reye's syndrome, and which has since been used as a model for surveillance systems for rare disease across the globe. In more recent time, the HPA has successfully implemented new syndromic surveillance systems for patients seen in emergency departments and in walk-in centres, which will be a cornerstone of surveillance during the 2012 Olympics.

- 7.4 There are many examples of the public health value of surveillance, such as the identification of the extent of undiagnosed HIV infection in pregnant women, which led to changes in antenatal testing and reduction in neonatal HIV infections, the early detection of many outbreaks of foodborne infection that has enabled rapid control measures to be undertaken, and the extensive use of surveillance data in modelling and other analyses that have informed national policy on vaccination. Monitoring the use of new drugs within the population that seek treatment so that the dangers associated with new and emerging drugs are better understood has not only provided an early warning mechanism for new threats, but has also been helpful in establishing that some new drugs (methamphetamine) are not spreading as quickly, or causing the harms as was once feared.
- 7.5 There are, however, also examples of public health surveillance where there remain significant gaps or weaknesses. One example is that of surveillance congenital abnormalities. Arrangements around the country for this important function have been highly variable and insecure for a number of years. Registers operate from a mixture of university and NHS bases with funding from various local and national sources. As a result, despite some very good work by these individual registers and by BINOCAR, at present we do not have what could be described as a stable national system for surveillance of congenital anomalies in England. Only half the births in England are covered, data are not fully collated nationally (although progress has been made on this) and the systematic integration of data collection, with analysis leading to action, is not securely established.
- 7.6 The Information Strategy, *the Power of Information*, commits to fill those gaps in provision through enabling "better sharing of information and joining up of services" and this ambition will be shared by Public Health England, underpinned by a comprehensive strategy for surveillance.

- 7.7 Other areas of weakness, as was highlighted at a recent public health surveillance stakeholder workshop, is the paucity of surveillance of determinants of disease, particularly of behavioural determinants of chronic disease, such as smoking, alcohol consumption and exercise levels. This is of particular concern given that these are determinants that are linked to diseases associated with significant socioeconomic health inequalities, and that will need to be addressed if we are to deliver the commitment in *Healthy Lives, Healthy People: Update and Way Forward*, to reduce health inequalities as a priority for all parts of the public health system, drawing on the Marmot review to address the wider determinants of health. The challenge will be to not only develop or extend systems for the surveillance of the determinants of disease, but also to establish linkage between determinant and outcome data, such as alcohol and liver disease, or infection (such as human papillomavirus) and cancer (such as cervical cancer).
- 7.8 As noted, a defining characteristic of public health surveillance is that there is a direct and explicit link between surveillance outputs and public health decision-making or action-taking. While this is well established in some areas, such as in infectious disease outbreak detection and response, there is a need to strengthen these links in other areas.

## 8. Achieving the vision – the priorities

8.1 The vision set out in this paper is consistent with the direction of national policy and in particular the proposals and recommendations in *Equity & Excellence: Liberating the NHS; Healthy Lives, Healthy People*; the Information Revolution consultation document and the 2010 Arms Length Body Review. The key implications of these proposals and recommendations are that new systems should be focused on outcomes, capable of efficient and consistent delivery, responsive and flexible (particularly to local needs), excellent in performance and delivery (with high quality outputs) and operated transparently. The aim of the surveillance strategy is to ensure that the design and operation of Public Health England surveillance systems, and the quality of the workforce and outputs, can deliver this vision. It will achieve this through a programme of work that will deliver service transformation, service improvement, robust quality systems, and an outputs system that is responsive to user needs.

### Service transformation

8.2 Bringing together the functions and expertise that exists in the Public Health England sender organisations provides a unique opportunity to transform existing services, including surveillance. A set of transformational priorities were identified through a stakeholder workshop that was held to define the key requirements of a wide range of users of public health surveillance systems and outputs. The workshop participants considered a range of topic areas, covering a wide breadth of public health issues, including heart disease, asthma and air pollution, congenital anomalies, sexually transmitted infections, healthcare associated infections, and drugs, alcohol and health behaviours. A consistent set of priorities for addressing current gaps and weaknesses were identified for each of the topic areas, and delivering these will be a major focus of the strategy.



- 8.3 The key priorities to be addressed and implemented through the Surveillance Strategy will be informed by and reflect the ambitions set out in the Information Strategy, *the Power of Information*. The implementation plan will comprise of three main components:
- strengthening PHE's delivery of surveillance from day one
  - developing a national strategy for public health in England
  - strengthening surveillance for the future.
- 8.4 Priorities that have been identified to be delivered in the first year of PHE include:
- the establishment of a surveillance oversight committee
  - the development of a national surveillance strategy for public health in England to be agreed with partners and stakeholders, underpinned by the vision described in this document
  - the creation of a directory of the range of public health surveillance activities, mapped to policy and public health delivery priorities
  - a gap analysis of existing surveillance systems and the identification of strategic gaps
  - the publication of surveillance standards, including a quality framework, as part of an information management strategy, underpinned and informed by the *Power of Information*
  - the identification of priorities for development such as new surveillance systems or opportunities for integration and rationalisation of surveillance systems and outputs
  - data linkage of identifiable datasets
  - the development of common methodologies, interpretation and analysis tools.

### Service improvement – best practice

- 8.4 As well as identifying gaps and opportunities for strengthening existing surveillance systems, the strategy will promulgate examples of best practice. Public Health England will maintain an inventory of examples of best practice that will provide system-level models that can be adopted or emulated across a range of surveillance systems. Best practice examples will include, in particular:
- a) Examples of effectiveness
- systems and outputs with clear evidence of public health impact
  - systems and outputs with clear evidence of providing added value to users
  - systems with clear evidence of successfully dealing with real world issues e.g. solutions to “small number/cell size” constraints.

- b) Examples of efficiency
  - systems with clear evidence of achieving efficiency savings through technological or organisational design.

### Quality assurance – quality framework

- 8.5 Public Health England's commitment to excellence must be underpinned by sound quality systems. Their goals and objectives need to be consistent with other quality improvement and assurance initiatives and reflect policy frameworks such as the NHS Quality Framework which was developed to support quality improvement in the NHS.
- 8.6 Public Health England must also work with the National Quality Board to support their role in providing strategic oversight and leadership for quality in the NHS and at the interface with social care. Public Health England must also work with commissioners, regulators and others who have an information role to share their respective information and intelligence on the quality of services being delivered at local and regional level. This should be linked to the network of Quality Surveillance Groups that are being established across the NHS.
- 8.7 The surveillance strategy will put in place systems (through a Public Health England Surveillance Framework for Quality) that seek to guide and inform practice and thus improve the quality of surveillance.
- 8.8 Robust quality systems will be essential to realising the benefits that the creation of Public Health England offers within the changing organisational context of public health delivery systems. The Public Health England Surveillance Framework for Quality will reflect and support the vision for surveillance and provide a framework to deliver the high quality data and information that are required to underpin and inform public health response. It will provide a model within which there will be explicit standards and statements of governance arrangements that might apply to all or parts of Public Health England's surveillance systems. The structure for the framework will encompass:
- a) System objectives  
Each surveillance system should have a clear statement of its objectives in terms of outputs and outcomes.
  - b) System operations  
Each surveillance system should have an explicit standard operating procedure, which should include clear standards and quality indicators in respect of:

- inputs
- collation and storage of data
- analysis
- interpretation
- outputs.

### c) System governance

Public Health England will have robust governance arrangements for all of its surveillance activities, with governance arrangements that might be specific to a particular system or to many systems. The quality framework will require that for each system there is a clear description of the following governance arrangements:

- information governance
- stakeholder engagement
- audit and/or evaluation of the system against its objectives and operational standards
- workforce competence and capacity assurance.

## Delivery of a responsive, outputs-based service

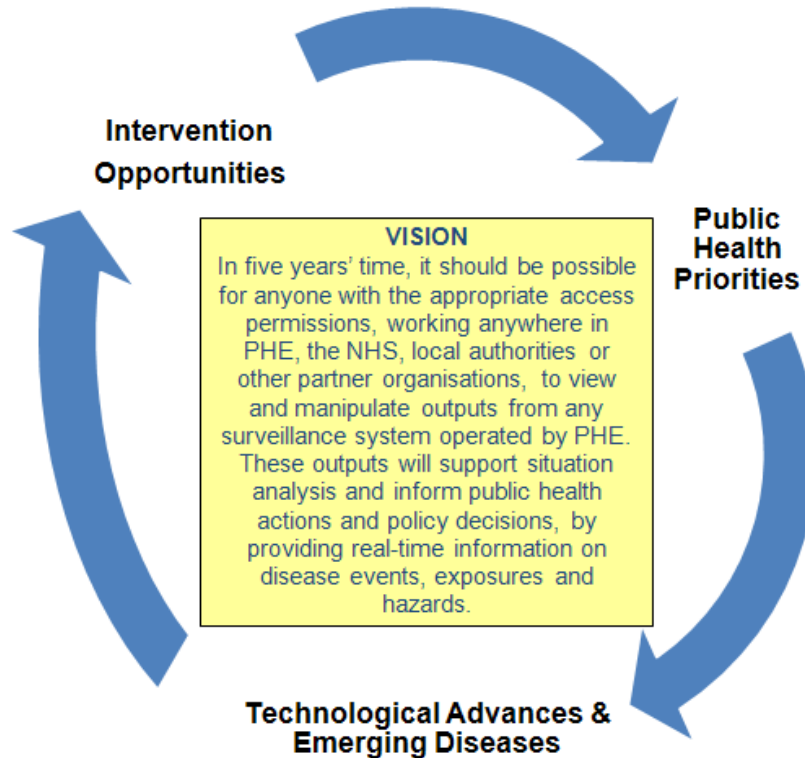
- 8.9 The strategy will deliver systems that enable users at all levels within Public Health England and its partner organisations to view the latest information and receive alerts of adverse trends and incidents, and will also provide relevant denominator and intervention information that will aid interpretation of case or event reports. This information will be made widely and readily accessible through the best use of developing technologies, including the use of mobile devices, requiring only appropriate access permissions.
- 8.10 The strategy will deliver national consistency and expert analysis capacity through national coordinating and delivery functions, while also being responsive to the needs of users, particularly at the local level, through the outreach and local knowledge provided by distributed and local teams. A common set of surveillance tools and methods, which can be applied to health protection, health improvement and service evaluation activities, will be developed through collaboration between the various information and intelligence teams that will be brought together in Public Health England. Particular areas in which synergies and new developments might be expected include data linkage for monitoring the chronic disease consequences of environmental exposures or behavioural risks, and advanced analytical approaches, such as mathematical modelling and spatial analysis.

- 8.11 Core surveillance outputs will include: on-line interactive databases, regular and ad hoc reports on the epidemiology of diseases and health determinants, environmental hazard maps (e.g. radon maps), prevention programme monitoring reports, population-based health profiles, and situational analyses (including threat assessments and outbreak investigation reports). Outputs will need to be useful and clear to professionals and the public alike. Wherever appropriate, these outputs will provide indicators that have been specified in the Public Health Outcomes Framework. The outputs from surveillance will also constitute an important component of the Public Health England Knowledge Management portal. Secondary uses of surveillance data will include burden of disease analyses and intervention impact assessments based on the synthesis of data from multiple sources.
- 8.12 A set of key surveillance data, covering the breadth of public health, which need to be actively reviewed by public health teams in local authorities, and, where necessary, action implemented, should be developed and published on the Public Health England website so as to offer a degree of assurance, both locally and to Public Health England, that the health status of the local population is being appropriately monitored and public health services delivered adequately e.g. area specific tables linking disease outcome information from surveillance systems (e.g. measles incidence) with inputs from prevention monitoring systems (e.g. immunisation coverage).
- 8.13 At a national level, Public Health England will produce surveillance outputs to support policy and priority setting, to detect and monitor trends in disease and exposure, to provide benchmark data for local analyses, and will provide reports and risk assessments in compliance with international reporting obligations. It will also undertake global threat tracking of emerging infections and other threats to health, and will disseminate alerts received from WHO, ECDC and other international and national organisations, including, as necessary, an assessment of the threat posed to the citizens of England and the wider UK.

## 9. Delivering the strategy – the core elements

- 9.1 Implementation of integrated surveillance systems within Public Health England should deliver an outputs-based epidemic intelligence service that informs clinical and public health policy and practice. It will achieve this by ensuring that the people and systems are in place to deliver the right information (including appropriate interpretation) at the right time and in the right place to inform decision making and action taking. The following sections briefly describe the core elements of a modern public health surveillance system that the strategy will deliver: the operating model (organisational structure); the key external partnerships; the methods and standards to be adopted; the quality framework; and the outputs.
- 9.2 Implementation of the vision will also need to be undertaken within a changing environment, where public health priorities, technological advances, organisational changes, and emerging diseases and threats will all have an impact on the way surveillance will need to be undertaken and the outputs that it will need to deliver. This will mean that the systems and solutions that Public Health England implements will need to be flexible, with the capacity for rapid change (Figure 2).
- 9.3 The Information Strategy, *The Power of Information*, clearly identifies the need to make use of modern technologies “to make health and care services more convenient, accessible and efficient” as well as acknowledging the need to change cultures relating to accessing data and encouraging interoperability between systems.

Figure 2



### Operating model for surveillance

- 9.4 The guiding principle in establishing arrangements within Public Health England for delivering surveillance and situational analyses should be to meet the needs of users in terms of usefulness, timeliness and responsiveness to local requirements and situations while also achieving efficiencies and a common approach across England. Local knowledge and expertise in service delivery and field epidemiology needs to be informed by national expertise in disease-specific determinants and interventions.
- 9.5 Surveillance should inform public health policy, planning and operational delivery – to do that it needs to be both timely and interpreted and presented in a way that those delivering front line public health services can use. The guiding principle in establishing arrangements within Public Health England for delivering surveillance should be to meet the needs of users in terms of local relevance, timeliness and responsiveness to local needs while also achieving efficiencies and increased consistency and a common approach across England. Local knowledge and expertise in service delivery needs to be informed by national expertise in disease-specific determinants and interventions, and in methods in quantitative methodologies (e.g. statistics and modelling).

9.6 It is proposed that, in the main, surveillance, particularly for health protection, be delivered through a national distributed system, with central organisation and direction of the work programme, but with geographically distributed teams based around the country. This will enable surveillance to be integrated with response functions at the local and national levels, while ensuring coherence and consistency in approach across the country. The national distributed model will also provide a mechanism for achieving economies of scale, for setting and implementing national standards, and will ensure that expert analysis capacity at the national level is informed by, and responsive to, the needs of users, particularly at the local level. Other surveillance activities, particularly those that inform health improvement and delivery of services other than health protection services, may be more efficiently delivered through networked teams at a sub-national level.

- there will be centralised national surveillance centres for the core public health domains and/or topic areas, e.g. infections or congenital anomalies, with the specialist knowledge, expertise and critical mass necessary to undertake rapid risk assessments across a wide range of diseases, determinants and threats, to provide evidence-based support for policy development and monitoring, and to discharge international surveillance obligations
- staff working at a sub-national level will have a key role in contributing to nationwide surveillance, taking a lead role in quality assurance by working with local data providers to improve the quality of data that are submitted (e.g. for cancer registration, or providing information on treatment of drug and alcohol misuse), and providing capacity to support local information and intelligence staff, and emergency response structures
- Public Health England centres will contribute to the surveillance function through the application of their local knowledge in interpreting locally and nationally generated surveillance information, and will also undertake additional local analyses where required. Equally important will be the role of Public Health England centres, working with Directors of Public Health and their staff, in ensuring that the intelligence that surveillance provides is appropriately mobilised to inform local public health action, and ensuring that user needs at the local level are understood and reflected throughout Public Health England's systems.

9.7 For health protection, surveillance and response are tightly integrated functions, wherein the same professional staff that are responsible for the interpreting and determining whether response is required on the basis of intelligence derived from real time data flows and analysis, are

also responsible for immediate response; decision-making requires first hand knowledge, at either the local or national level, of the strengths and weaknesses of what is often “soft” intelligence. Staff whose responsibilities are primarily related to health protection surveillance should therefore be co-located with staff responsible for response. Distributed surveillance teams for health protection will therefore be based in Public Health England centres (with line or professional reporting to the national coordinating centres for surveillance), as will Field Epidemiology teams. Co-location, though, will also benefit those staff involved in surveillance and response functions subject to longer timeframes, such as for issues of health improvement (e.g. trends in obesity, or rates of lung cancer related to tobacco smoking). Public Health England will endeavour to ensure staff working across the spectrum of surveillance and response are co-located wherever possible and appropriate.

- 9.8 For health protection, a centralised national surveillance function, with the expertise and critical mass necessary to undertake rapid risk assessments across a wide range of infectious and other environmental threats (including threats of uncertain aetiology), is essential. This is because outbreaks and emerging threats may be first detectable through the collation of data at a national level, but also because such capacity is a requirement under the International Health Regulations (2005). There will therefore be national surveillance capacity and expertise to deliver national analyses and support for the response to national incidents, public health threats and other emergencies, and international reporting, risk assessment and coordination obligations.
- 9.9 Surveillance activities that can be “done once and shared” should be delivered at the highest organisational level possible, to facilitate synergy between different systems (e.g. between environmental hazard tracking systems and chronic disease monitoring systems), and to ensure consistency, economy of scale, and resilience.

### Partnership working

- 9.10 Public Health England centres will be working with Directors of Public Health and their teams based in local authorities. It is essential, therefore, that Public Health England surveillance systems should provide Directors of Public Health with direct access to data and analyses that are relevant and useful for all health determinants, diseases and exposures, at all levels of analysis (local, sub-national, national). Ensuring that outputs are timely and sufficiently detailed



enough to meet local needs, according to the nature of the determinant or disease under surveillance, will be a priority for Public Health England. The mix of knowledge and intelligence skills required within Public Health England centres and within the teams supporting Directors of Public Health in local authorities will need to reflect the operating model for surveillance at the local level.

- 9.11 National partnerships will also be essential to the delivery of Public Health England's surveillance function. Both internal and external public health surveillance stakeholders have identified improved use of data holdings through immediate linkage of identifiable datasets as a priority. While there are a number of data sets that Public Health England sender organisations currently collect, and that will continue to be collected by Public Health England, that were identified as being a priority for linkage, there are also data sets held by other organisations that it would be beneficial to link to. A key partner in developing such linkages will be the Health and Social Care Information Centre. Other partners will include ONS, MHRA and Defra.

### Methods, systems and standards

- 9.12 Across the sender organisations there is a wealth of expertise in all aspects of the surveillance process from collection of the raw data, through cleaning and quality assurance, analysis, quality assurance of analysis, output production and quality assurance of outputs. The strategy will put in place mechanisms that will foster sharing of this expertise and learning from best practice e.g. building on evidence of cross-fertilisation of ideas where teams work on joint projects or in close proximity, and through the establishment of communities of practice among surveillance and other information and intelligence staff.
- 9.13 Synergies with other skill sets and tool sets available within Public Health England should be identified and exploited to realise the added value of creating a unified Public Health body with a responsibility for public health surveillance. In particular, further exploitation of the ability to integrate clinical outcomes data on chronic diseases, such as cancer registrations and hospital episode data, with risk factor and acute exposure data, offers significant added value. Staff working in local and in national distributed services should work together to develop new, and/or exploit to a greater extent existing, epidemiological and other quantitative methodologies (e.g. statistics, modelling). An inventory of specialist information and intelligence skills and tools should also be

created as soon as possible, so that potential synergies can be identified and exploited.

9.14 Standards (in terms of content and coding) should be defined for the recording and reporting of all data that are used for surveillance and other public health purposes, building on work that has been done, for example, with regards to cancer and sexual health data sets. There should therefore be a strong central information standards setting function within Public Health England, which brings together the relevant expertise from the sender organisations; the surveillance function also needs to be supported by information systems that facilitate the implementation of information standards and the development of interoperability between systems.

### Quality framework

9.15 Quality must not be seen as a discrete issue but rather part of the complete information lifecycle with the principles needing to be applied at all stages of the data management process, from capture to presentation and use. So as to fully assure the process, there must, therefore, be a quality element to all aspects of the surveillance loop (Figure 3) with quality measures being implemented where appropriate. A quality framework will be developed that will provide a tool to allow the assessment of the quality of surveillance data as well as the robustness of any interpretation contained within outputs based on these data. Data providers will also be able to use it as a reference document so that they can understand and comply with requirements that assure the quality of surveillance data.

9.16 The surveillance quality framework will:

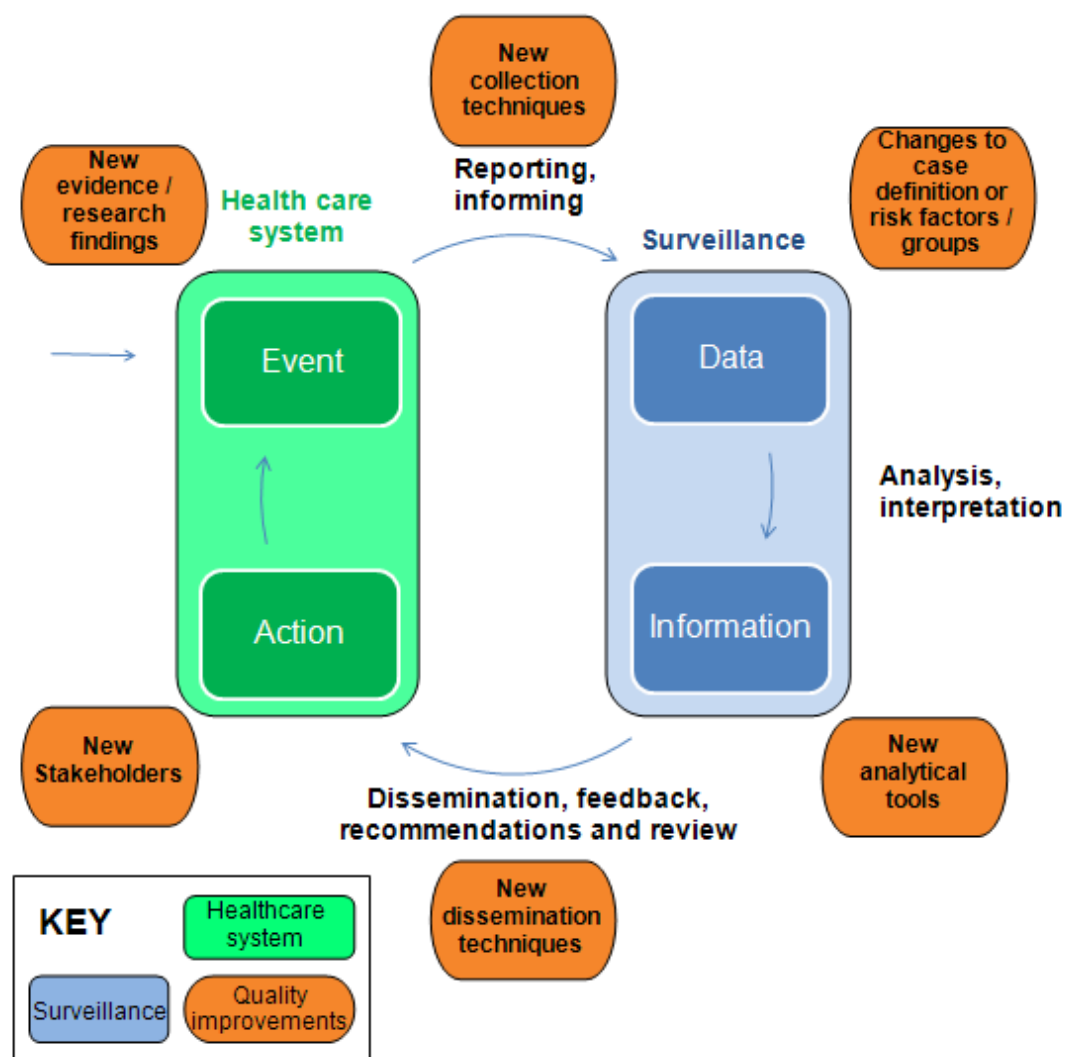
- describe the relevant definitions, principles and standards with regard to data collection, collation, processing (including disposal), analysis, interpretation and broadcasting (reporting, exposure, presentation and publishing). This will include standards on surveillance activity set-up and commissioning, and standards on workforce competencies and capacities
- define quality indicators to contribute to the assurance process to provide an indication of fitness for purpose and robustness of data collected or “inputs”. This will form part of a broader quality assurance framework which will include the development of an audit process to allow ongoing assessment and measurement
- provide assurance to data providers and recipients of the processes in place to promote rigor and integrity of the data. This will be

achieved through the establishment of an iterative process of formal engagement that will provide opportunities for continual feedback and review, as detailed in the surveillance loop

- describe an ongoing process of review.

9.16 This quality framework will identify the key stakeholders and users of surveillance outputs to enable the documentation of their requirements. This will also be informed by an established stakeholder engagement group and result in agreed mechanisms to ensure the continued improvement of data quality from point of collection to output.

Figure 3: The public health surveillance loop<sup>6</sup>

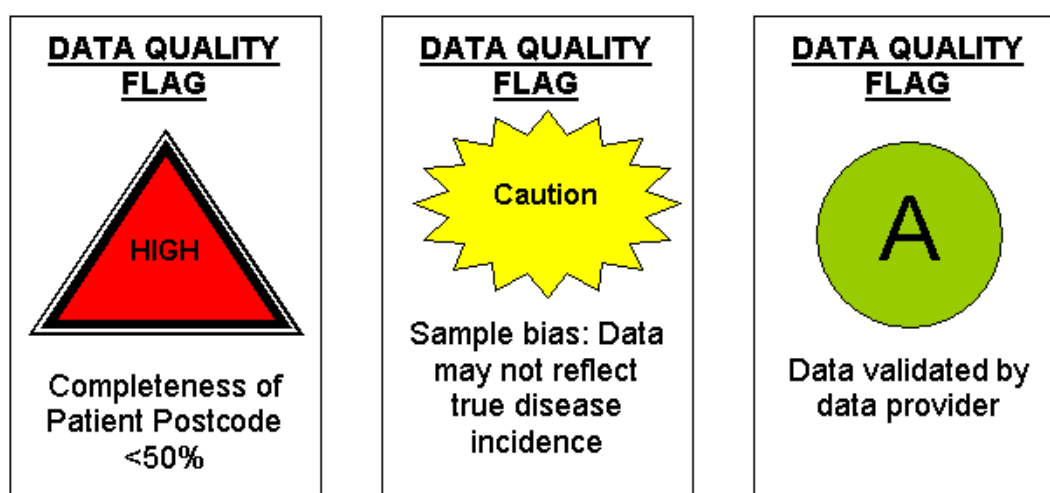


- 9.17 A quality statement for surveillance outputs will be developed, in consultation with stakeholders, which will include a quality flagging system for surveillance outputs. Possible quality flags include:
- metadata – all generic outputs that are generated should be presented in a standard format with their associated metadata. Metadata are data that provide information about other data. It can consist of details about a source of information, the length or timeframe of validity of an output, publishers etc.
  - statements – quality statements should accompany surveillance outputs. These should cover three categories:
  - coherence – the degree to which data derived from different sources or methods can be reliably combined or have been combined to build a picture of the phenomenon being studied

<sup>6</sup> Adapted from documents by CDC, J. Graber and ECDC

- accuracy and precision – the closeness between the value finally retained (after editing, estimation, imputation etc) and the true, but unknown, value. The larger the error the lower the accuracy
- comparability – the degree to which data can be compared over time, domain and to similar data from different sources.
- symbols – symbols that provide a quick assessment of quality (Figure 4).

Figure 4: Example quality flags



## Outputs – promulgating best practice

9.18 Each sender organisation has evolved surveillance mechanisms and outputs from these to support its specific needs and those of its stakeholders (recipients of the outputs), often following extensive consultation. While this has provided valued and bespoke outputs, it has also resulted in a multiplicity of web-sites and variations in outputs e.g. variation in the geographical levels of outputs (national, old region, primary care trust, local authority and general practice). As a result, from the perspective of local decision makers, especially Directors of Public Health, the multiplicity of websites presents significant challenges in terms of being aware of their existence and the need to extract data from many to piece together the entire profile of their local population. The strategy will deliver greater consistency of outputs, while retaining data, analytical and disease specific expertise and responsiveness to users needs. It will do this through the adoption of best of breed common tools for analysis and presentation of information, and by establishing stakeholder engagement processes that for regular review of needs and audit of delivery.

- 9.19 There is also scope for further harmonisation and rationalisation, and the strategy will build on the convergence that already exists in terms of the adoption of best practices in processes and output formats e.g. e-Atlases and profiles using spine charts.

## 10. Achieving the vision – service transformation projects

10.1 The creation of Public Health England provides a significant opportunity to bring together systems and expertise from a range of sender organisations in a way that will result in the sum of those systems and expertise being greater than their parts. This will need to be achieved through service transformations that exploit the synergies and capitalise on the potential efficiencies that come from bring together the systems and the workforces from the sender organisations. The preceding section outlined the organisational structure and the core elements of the Public Health England surveillance system, while this section outlines the transformational projects that will deliver the added value that Public Health England will offer over and above that currently offered by the sender organisations.

### Governance, methods and operational standards development

10.2 Realising the potential benefits of bringing together the systems and expertise from the different sender organisations and domains of public health will require that there is strong leadership and coordination of surveillance activities across all domains of activity, and that there is sharing of expertise and learning from different operating models. This will be achieved through the establishment of the following systems and structures:

- establishment of a Public Health England Surveillance Oversight Committee, that will be responsible for ensuring coordination of surveillance resources and activities, for identifying and directing the adoption of best practice and system rationalisations, for ensuring that systems meet agreed quality and governance standards, and for overall delivery of the surveillance strategy and development of future strategy. It will be accountable to the Public Health England Executive/Board
- establishment of a Surveillance Quality Framework Task & Finish Group, which will be responsible for sign off of the design and for implementation and promulgation of the Public Health England Surveillance Quality Framework
- the Public Health England Surveillance Oversight Committee will convene a Surveillance Methods Conference/Workshop and a seminar series to follow the conference/workshop. The purpose of the workshop and seminars will be to identify best practice in terms of

surveillance methods and to identify opportunities for delivering added value through the application of new or existing methods (from other systems) to existing surveillance activities, or through new linkages between existing systems or data. The output of these seminars will be a set of recommendations to the Surveillance Oversight Committee on possible service developments

- knowledge sharing tools, such as SharePoint and Intranet sites, and seminars will be established to encourage the development of communities of practice among the surveillance workforce.

### Data sharing and linkage

10.3 The most commonly identified priority by stakeholders for strengthening the public health surveillance function was that greater use be made of existing data through linkage of those data and analyses of those linked data sets. Bringing together the Public Health England sender organisations, and the extended mandate for the Health and Social Care Information Centre as the custodian of the national data repository for health and social care, provides a significant opportunity to develop more and improved linkages between exposure and/or acute disease surveillance data and chronic disease data. Realising this opportunity, however, is likely to require investment in developing standards and technical solutions, and clarifying issues related to ownership and sharing of data, and also related to confidentiality of personal data. The strategy will address these issues through the following projects:

- criteria for establishing record linkage will be defined, and these will be used to prioritise proposals for data linkage (which will be invited from stakeholders and system owners)
- a catalogue of all surveillance activities and outputs will be compiled and published
- an analysis of the legal and intellectual property issues related to data linkage and data sharing within Public Health England and between Public Health England and partner organisations (such as the Health and Social Care Information Centre) will be commissioned (this work has already been undertaken in part by the Public Health England Transition Team). It is important that public health surveillance functions are clear about the legal basis of each case wherever they access patient identifiable information for specific purposes. The recommendations from the independent review into information governance arrangements (expected in 2013), led by Dame Fiona Caldicott, must also be considered
- service level agreements or memoranda of understanding on data sharing and linkage will be developed with external partners



- a common data set and associated data standards will be defined to facilitate record linkage and analysis of linked data sets i.e. an extended common public health data set
- a task and finish group will be established to identify potential duplication and redundancy in data collections currently managed by Public Health England sender organisations, in liaison with the Review of Central Returns (ROCR) team in the Health and Social Care Information Centre, and will make recommendations on rationalisation of data collections and holdings
- a common information architecture for Public Health England information (surveillance and other public health data collections) will be developed and an options appraisal undertaken to identify the most appropriate technical infrastructure to support that architecture and to provide on-line tools that will provide access for Public Health England and the wider Public Health workforce to Public Health England data holdings.

10.4 We recognise that much of the data that are required for public health surveillance is highly sensitive and that PHE will need to ensure that the privacy and confidentiality of citizens is maintained and that PHE will hold data securely in line with published information governance standards set out in the Department of Health's Information Governance Toolkit.

### Outputs

10.5 The vision set out in this paper is consistent with the direction of national policy and in particular the proposals and recommendations in Equity & Excellence: Liberating the NHS, Healthy Lives Healthy People, the Information Revolution consultation document, and the 2010 Arms Length Body Review. The key implications of these proposals and recommendations are that new systems should be focused on outcomes, capable of efficient and consistent delivery, responsive and flexible (particularly to local needs), excellent in performance and delivery (with high quality outputs) and operated transparently. Outputs will need to be useful and clear to professionals and the public alike. Wherever appropriate, these outputs will provide indicators that have been specified in the Public Health Outcomes Framework. The strategy will address these expectations, and address weaknesses and gaps highlighted by stakeholders at the Public Health England Surveillance Stakeholder Workshop, through the following projects:

- a minimum standard model for surveillance outputs will be defined, that will set out criteria for outputs to include relevant denominator

data, national or “neighbour” comparators, interpretative commentary, and quality flags

- the feasibility and added value of developing outputs that present surveillance findings in terms of burden of disease and/or that include estimates of preventable morbidity or mortality (based on best evidence for effectiveness of interventions) will be assessed and recommendations made to the Surveillance Oversight Committee
- standards and systems for the detection of clusters and significant trends will be developed
- a standard quality marking system will be developed and implemented for all surveillance outputs (this will be done as part of the work of the Quality Framework Task & Finish group)
- standards for geographical analyses and outputs (maps, spine-charts, etc) will be defined (local authority, CCG, SOA)
- surveillance outputs required to produce Public Health Outcomes Framework indicators will be delivered (this work is already ongoing)
- a publication schedule for all of Public Health England’s surveillance outputs will be published.

### New data sources

10.6 A number of key weaknesses and gaps in surveillance data sources will need to be addressed, particularly to support local strategic decision making through JSNAs and JHWSs, and also for reporting such as the Director of Public Health’s annual report. The strategy will address these expectations, and the associated weaknesses and gaps highlighted by stakeholders at the Public Health England Surveillance Stakeholder Workshop, through the development of costed proposals for surveillance that will provide the information required to support and inform local stakeholders on public health priorities such as:

- smoking
- sexual behaviour
- diet
- exercise
- alcohol consumption.

# 11. Organisational and operational challenges

- 11.1 **Linkage of data and systems (particularly for chronic disease surveillance)** - There is a need for both acute event surveillance and chronic exposure surveillance. There are different challenges with each, particularly with linking exposure to chronic disease outcome. Bringing together the HPA, the public health observatories and the Cancer registries provides a significant opportunity to develop more and improved linkages between exposure and/or acute disease surveillance data and chronic disease data, but realising this opportunity is likely to require investment in developing standards (see below) and technical solutions, and clarifying issues related to confidentiality of personal data (see below).
- 11.2 **Working with data providers** - Public Health England will be reliant on the continued timely provision of data by others, particularly staff working in the NHS, in its surveillance function. The range of data providers may change as a result of Commissioning, and initiatives such as Pathology Modernisation, and changing technologies, such as point of care testing. Public Health England will need to work closely with providers and Commissioners, to identify future changes that might impact on reporting (e.g. reductions in laboratory specimen submissions from primary care) and to ensure that not only are systems streamlined to minimise the burden on reporters, but also that systems deliver benefits in terms of useful outputs and feedback. In particular, the impact on data providers, and the costs to Public Health England, of the data collection process needs to be minimised as far as possible. In some cases this might be achieved by rationalising data collections, where the same, or similar, data are being collected more than once for different purposes. The greatest priority, however, will be to develop IT solutions that reduce the effort and cost of reporting.
- 11.3 **Integration of surveillance with frontline response** - The close integration of surveillance and epidemiology functions, and the staff that deliver them, with frontline response, particularly, but not uniquely, in the field of health protection, needs to be preserved or strengthened in the formation of Public Health England. For other areas of surveillance, this link is less strong, but Public Health England needs to find ways of ensuring that review of key surveillance data and appropriate response is a routine part of local public health functions.

Responsibility for much public health response will sit with Directors of Public Health and local authorities, and as such delivery and analysis of local surveillance outputs will require close working of Public Health England centres and public health teams in local authorities.

- 11.4 **Quality of data** - A significant barrier to the production of surveillance outputs with the geographical granularity and timeliness to meet the needs of local users, including Directors of Public Health, local authorities and health protection units, is the quality of data reported through the system (i.e. often lacks postcode or other geographical markers) and the timeliness of reporting to the team responsible for analysis and outputs. Public Health England will need to work with standards setting bodies, the NHS and the Health and Social Care Information Centre in promoting a culture that is committed to improving the quality of data available for surveillance. The surveillance strategy will enable the creation of a quality framework for surveillance which will support quality control and appropriate governance.
- 11.5 **Information standards** - A lack of explicit information standards and case definitions gives rise to the risk of misinterpretation of outputs or apparently conflicting outputs produced by different parts of Public Health England. Local strategic planning, such as through JSNAs and JHWSs and service delivery needs to take into account information from a variety of sources, including the HPA, public health observatories, and the NTA (among others) – this information is often available in different formats (e.g. different geographical or demographic breakdowns) and to different timescales. Public Health England will need to work with standards setting bodies, the NHS, the Health and Social Care Information Centre and health and wellbeing boards in defining and promulgating information standards for surveillance.
- 11.6 As acknowledged in the Information Strategy, *the Power of Information*, it should also be recognised that from April 2013 onwards, the legal provisions with the Health and Social Care Act 2012 will come in to force. These will ensure that standards to which all providers of health and social care should have regard, can be set once across the health and care system in England (by the NHS Commissioning Board for the NHS and by the Department of Health for public health and for care and support).
- 11.7 **Processing of personal data** - The processing of personal data without explicit consent is necessary for aspects of health protection

(including surveillance and outbreak and emergency response). The HPA currently has statutory support, under s251 of the NHS Act (2006) to undertake processing of patient data for specified purposes (as do the cancer registries). As part of the transfer into Public Health England it will be vital to reassess both:

- the need for Public Health England or other bodies to, themselves, hold and use patient-identifiable data for each specified purpose, rather than, for example, data which have been linked in a secure environment and then anonymised; and
- the legal basis for each case where Public Health England or other bodies will require access to patient-identifiable information for specific purposes.

11.8 The recommendations from the independent review into information governance arrangements (expected in 2013), led by Dame Fiona Caldicott, will be key to ensuring that the future public health environment has appropriate information governance processes in place, with a clear statutory basis for any use of data that could be used to identify an individual, so that people can be assured that their confidential health and care data are being kept safe and secure.

11.9 **Critical mass** - It will be important to ensure that Public Health England staff with scarce specialist expertise are readily accessible to local and distributed national teams, and do not work in isolation. A critical mass is required to ensure that services and expertise are sufficiently robust and can maintain and support the level of work required in emergency situations.

11.10 **Workforce** - The public health intelligence workforce is relatively small, and ongoing uncertainties around the transition to Public Health England have resulted in some attrition of that workforce, particularly among Public Health Observatories. There is a need to attract, develop and retain information and intelligence staff, supported by appropriate training programmes and professional accreditation systems, if the vision of strengthening public health surveillance is to be delivered.

## 12. Implementation plan

The programme of work for delivering integrated surveillance will include a number of work packages including (note that this ordering does not imply that the work needs to be undertaken in a particular chronological order):

<b>Define current and forward scope of surveillance activities</b>	<b>Timescale</b>
Define priorities for surveillance outputs, within context of public health delivery priorities of Public Health England	Completed
Create and maintain a register of surveillance activities and outputs (see Annex 3 for initial high level inventory).	Completed
Define and implement a stakeholder engagement model for identifying our users priorities	Completed
Perform a gap analysis between what our users (internal, external and corporate) need and what we already provide	Completed
Develop a set of key surveillance measures for public health outcomes, disease incidence/prevalence and hazard and risk factor occurrence to inform the design of systems	2012/13
<b>Establish operating model</b>	
Define the operating model for surveillance activities undertaken by Public Health England	Completed
Identify workforce capacity and development requirements to deliver effective public health surveillance, and implement workforce plan that will facilitate the recruitment, development and retention of surveillance staff; contributing to wider PHE workforce responsibilities for Knowledge and Intelligence staff	2012/13 (capacity definition) 2013/14 (workforce plan)
<b>Establish governance systems</b>	
Establish an overarching steering group for oversight of surveillance activity and for identifying new or changing stakeholder needs into the future	2012/13
Establish a Quality Framework Group and compile and/or develop a list of internally agreed and monitored standards or criteria relating to information quality that can be measured against and that we expect our surveillance activities and outputs to meet.	2012/13
Document current systems and establish a managed action plan to ensure existing activities meet the agreed	2012/13

quality criteria and develop framework for future audit.	
Develop mechanisms to ensure innovative developments are identified and propagated across the surveillance community (“do once and share” model)	2012/13
<b>Define and establish the information architecture and technical infrastructure</b>	
Develop an Information Management Strategy	2012/13 (draft)
Define criteria for establishing record linkage and use to prioritise proposals for data linkage	2012/13 or 2013/14
Work with the Health and Social Care Information Centre and other partners to develop standards and agreements for data sharing	2012/13
Identify opportunities for achieving rationalisation and/or exploiting synergies across the full range of surveillance systems operated by Public Health England (including common methods of data capture, quality assurance, analysis, and output)	2012/13 or 2013/14
Develop a (surveillance) information architecture (data model) for Public Health England.	2012/13 (initial model)
Undertake options appraisal of technical infrastructure to support information architecture and deliver on-line access to Public Health England and wider Public Health workforce	2012/13
Adopt common processes for new system development	2013/14
<b>Develop new (added value) inputs and outputs</b>	
Define a minimum standard model for surveillance outputs	2012/13
Establish programme of work to define and promulgate best practice for surveillance, in terms of surveillance methods, and to identify opportunities for delivering added value through the application of new methods to existing surveillance activities, or through new linkages between existing systems or data.	2012/13
Assess and make recommendations on the feasibility and added value of developing outputs that present surveillance findings in terms of burden of disease and/or that include estimates of preventable morbidity or mortality (based on best evidence for effectiveness of interventions)	2013/14
Develop standards and systems for the detection of clusters and significant trends	2013/14

Develop and implement a standard quality marking system for all surveillance outputs	2013/14
Define standards for geographical analyses and outputs	2012/13
Ensure production of outputs required for PHOF indicators	2012/13
Develop costed proposals for surveillance that will provide the required level of information on <ul style="list-style-type: none"> <li>• Smoking</li> <li>• Sexual behaviour</li> <li>• Diet</li> <li>• Exercise</li> <li>• Alcohol consumption</li> </ul>	2012/13
<b>Manage transition</b>	
Work with the National Information Governance Board to ensure that surveillance activities undertaken by Public Health England are supported through legislation (Section 251 of the NHS Act, 2006) as necessary and appropriate	2012/13
Strengthen the linkage between the systems, particularly those operated at the national or national-distributed level, currently managed by the sender organisations	2013/14/15
Manage a migration of existing surveillance systems into a new architecture.	2013/14/15



# Annex 1. Surveillance – definition and purpose

## Definitions

Surveillance has been defined as “The systematic regular collection, analysis, interpretation and dissemination of data for a given population to detect changes on patterns of disease or disease determinant with action taken if a predefined criteria or thresholds are met”<sup>7</sup>, or more succinctly as providing ‘information for action’. A defining characteristic of surveillance is that there is a direct and immediate link between the outputs of surveillance systems and operational or policy response. Thus, there should always be an explicit mechanism whereby surveillance outputs feed into operational delivery, usually in real time, or policy making, ideally with defined criteria (trigger points) for response.

Surveillance is an essential part of the public health toolkit, particularly in the Health Protection domain, although it also has, as yet incompletely unrealised, value in the other domains of public health. However, it is often portrayed as a ‘secondary use’ of information. In reality it is a distinct public health activity; for example, in the health protection field, it requires a high level of expert professional input into the real-time analysis and risk assessment of data, and frequently requiring active follow-up of reports with the reporting laboratory, clinician, or the cases themselves, or requiring other immediate public health response. The close integration of surveillance functions, and the staff that deliver them, with direct public health response, is one of the great strengths of the public health system in England. The close link between surveillance and acute response is analogous to the link between diagnostic testing and patient treatment, which is defined as a ‘primary use’ of health information; the analogue of patient treatment being public health interventions, which might be population or individual-based. Surveillance outputs may, and often do, serve other purposes that might be considered ‘secondary uses’, such as audit, estimation of the burden of disease, or resource allocation, but such uses are by-products of the surveillance process.

The aim of surveillance is to provide information that is required to inform, and monitor the effects of, public health action. Surveillance is a means to an end, rather than an end in its own right. It is often part of a larger toolset that is used to achieve a public health outcome; the production of surveillance

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<sup>7</sup> Public Health Surveillance Working Group for the South East and East of England.

outputs should be seen as an intermediate, rather than a final, deliverable in the business of public health. The potential roles for surveillance in informing public health actions and decisions include:

- Assessing public health status
  - To inform action (which might be taken by individual practitioners, health organisations, government, or members of the general public) in respect of the control and prevention of risk factors, including behaviours such as smoking, environmental hazards, exposures to potentially harmful agents, and the occurrence of disease – this is typically through the detection of acute changes in the frequency of disease, including the detection of outbreaks
- Defining public health priorities
  - To inform policy and planning in respect of the current and likely future impact of risk factors, hazards, exposures and disease – this is typically through the monitoring of longer term trends in incidence and distribution of disease and/or monitoring of outcomes
- Informing and evaluating programmes
  - To inform decisions regarding existing interventions e.g. vaccination programmes, disease management strategies, population based behavioural interventions – this is typically through the monitoring of longer term trends in incidence and distribution of disease and/or monitoring of outcomes
- Stimulating research
  - To generate hypotheses and inform methodologies – this is typically through the analysis of demographic and risk factor data collected through the surveillance process.

Broadly speaking, surveillance systems can be categorised according to the type of event that is being monitored, which also generally reflects the primary purpose of the surveillance activity. Using this approach, public health surveillance systems largely fall into the following categories:

- Case, or indicator-based, surveillance, which forms the mainstay of disease surveillance in most countries, particularly for ‘acute’ diseases, and which is used for monitoring of trends and distribution (tracking) of specific diseases in the population;
- Syndromic surveillance, which may be based on reporting of clinical syndromes or potential correlates of disease activity in the population, such as over the counter sales of ‘flu remedies’; typically this form of surveillance will be used for early detection (alerting) of public health

threats, or may be used where the cause of illness is unknown or multi-factorial (e.g. following flooding incidents);

- Risk factor surveillance, examples of which include monitoring of behaviours (e.g. smoking, alcohol consumption, sexual behaviour), monitoring weight/BMI in children, monitoring air quality;
- Environmental public health tracking/monitoring, wherein acute and chronic environmental hazards or exposures, particularly non-infectious hazards, are monitored and the collated results (or risk maps) correlated with data sets on human morbidity or mortality e.g. congenital malformation registers;
- Outbreak and incident, or event-based, monitoring, which may provide unique intelligence on risky situations or emerging threats (where the aetiology of the reported incidents or clusters is unknown), and may also provide information on the effectiveness of interventions;
- Programme monitoring, such as vaccine uptake monitoring (which also provides a measure of population susceptibility), or cancer screening coverage.

## Public Health Surveillance: A strategy for Public Health England

<b>SURVEILLANCE</b>	<b>RESEARCH</b>	<b>CLINICAL AUDIT</b>	<b>SERVICE EVALUATION</b>
May contribute to knowledge but is primarily about measuring what is already known, in order to assess priorities, evaluate interventions, and detect and manage outbreaks and identify associated risks	The attempt to derive generalisable new knowledge including studies that aim to generate hypotheses as well as studies that aim to test them.	Designed and conducted to produce information to inform delivery of best care.	Designed and conducted solely to define or judge current care.
Not usually based on a specific hypothesis. Designed to answer: is there a need to start, continue or stop defined public health interventions, or the need for further investigation?	Quantitative research – designed to test a hypothesis. Qualitative research – identifies/explores themes following established methodology.	Designed to answer the question: “Does this service reach a predetermined standard?”	Designed to answer the question: “What standard does this service achieve?”
Measures against historical (or geographical) comparators and/or defined levels (triggers) for action	Addresses clearly defined questions, aims and objectives.	Measures against a standard.	Measures current service without reference to a standard.
May involve evaluating outcome of interventions, but may also be used to assess the need for an intervention when/where none is being taken currently	May involve evaluating or comparing interventions, particularly new ones, or studying how interventions are experienced.	Audit involves an intervention in use ONLY. (The choice of treatment is that of the clinician and patient)	Evaluation involves an intervention in use ONLY. (The choice of treatment is that of the clinician and patient)
Often involves collecting only those data collected for routine care, but may involve collection of data on hazards, exposures and other data to enable interpretation of issues relevant to the population rather than the individual.	Usually involves collecting data that are additional to those for routine care but may include data collected routinely. May involve treatments, samples or investigations additional to routine care.	Usually involves analysis of existing data but may include administration of simple interview or questionnaire.	Usually involves analysis of existing data but may include administration of simple interview or questionnaire.
Never involves experiments or purposive allocation of subjects to different interventions	Study design may involve allocating patients to intervention groups, or uses a clearly defined sampling framework.	No allocation to intervention groups: the health care professional and patient have chosen intervention before clinical audit.	No allocation to intervention groups: the health care provider/commissioner and patient have chosen intervention before service evaluation.
Ongoing, and usually open-ended, collection and analysis of data, with regular dissemination	Time-limited collection and analysis of data, usually with defined end-point and outputs	May be regular repeated or ‘one off’ activity	May be regular repeated or ‘one off’ activity
No randomisation	May involve randomisation	No randomisation	No randomisation
Findings should influence clinical or public health practice. Responsibility to act should always be clear	Findings may influence clinical or public health practice as a whole. Responsibility to act on findings is not always clear	Findings should influence clinical (or public health) practice. Responsibility to act should always be clear	Findings should influence clinical or public health practice. Responsibility to act should always be clear
Actions informed by findings usually taken soon after findings reported	Actions informed by findings often taken considerable time after findings reported	Actions informed by findings may be taken soon after findings reported	Actions informed by findings sometimes taken soon after findings reported

## Annex 2. Implications of key policy documents for Public Health England's surveillance function

The future model for surveillance undertaken by Public Health England must be consistent with the direction of national policy and in particular the proposals and recommendations in the NHS White Paper, *Equity & Excellence: Liberating the NHS*, the Public Health White Paper, *Healthy Lives Healthy People*, the *Information Revolution* consultation document, the Information Strategy, *the Power of Information*, and the 2010 Arms Length Body Review. The key implications of these proposals and recommendations are that:

a. Status quo is not an option.

b. Focus on outcomes

The whole system is aligned to deliver improvements in health outcomes. Surveillance outputs should be available to support the delivery of the Public Health Outcomes Framework and locally determined public health priorities.

c. Capable of efficient and consistent delivery

The creation of Public Health England provides a significant opportunity to bring the systems and expertise developed for the surveillance of health protection issues to bear on wider public health subject areas, including health improvement and service evaluation. Similarly, the expertise and systems used in other areas of public health information and intelligence activity (e.g. cancer intelligence, health profiling) should be harnessed to enhance the value of existing and future surveillance processes and outputs. The surveillance processes required to generate epidemic intelligence should be undertaken once only, at the most appropriate level of the organisation, and the outputs made available for use widely in a consistent format.

This will:

- avoid duplication
- ensure consistency of underpinning evidence/information, but permitting audience-specific tailoring, particularly at the local level

- facilitate clarity of accountability for the accuracy of information and evidence produced/used by Public Health England teams
  - provide consistent and easy to use summary information at local level to simplify local working and to form a base for more detailed local analysis.
- d. Responsive and flexible
- Outputs and the requirement for a particular surveillance system should be determined by needs of those using them to inform their decisions and actions, and should be subjected to regular evaluation
- systems must support the greater focus on local priority setting, planning and delivery of health and public health services
  - local determination of public health priorities and actions, led by the Director of Public Health within local authorities, must be supported by Public Health England information and intelligence functions, including surveillance outputs
  - Public Health England will need appropriate engagement/consultation mechanisms with users to ensure that its outputs meet, and continue to meet, their needs.
- e. Excellence
- Public Health England staff managing surveillance systems and producing surveillance outputs will be provided with the leadership, infrastructure, resources, training and development necessary to provide them with the skills for the job. Surveillance systems should comply with a defined set of good practice principles, which will include that surveillance outputs are useful, timely and accurate, and the systems used are robust. There will be good information governance, with stringent safeguards to protect the confidentiality of person-identifying information, including compliance with the appropriate statutory and professional frameworks for processing of such information when it is necessary for the protection of health.
- f. Quality
- Outputs should be fit for purpose, which will include being timely, reliable, and accessible and comprehensible to the audience and necessary to the purpose supported.
- g. Transparency
- Outputs should be accessible and user-friendly. All surveillance systems should be fully documented, with a clear statement of: objectives, intended audience for outputs, contact details of system owner, data sources used and outputs produced, governance and

quality arrangements, stakeholder engagement and evaluation arrangements.

## Annex 3. Inventory of surveillance activities

### Inventory of surveillance activities

Organisation	National Treatment Agency
<b>Comments</b>	<ul style="list-style-type: none"> <li>• The term ‘surveillance’ is applied slightly differently to the conventional (HPA) sense</li> <li>• The NTA ‘monitor’ drug and alcohol treatment, and collect information about individuals drug/alcohol use.</li> <li>• Most of their reporting is performance management related, however they also supply data to various groups and bodies who are more directly involved in surveillance such as the Advisory Council on the Misuse of Drugs (ACMD), HPA etc</li> <li>• The NTA monitor individuals receiving treatment, with particular reference to:               <ul style="list-style-type: none"> <li>– Type and frequency of drugs used</li> <li>– Effectiveness of treatment</li> <li>– Health and social status of individuals</li> <li>– Long term outcomes</li> <li>– BBV.</li> </ul> </li> <li>• They also monitor and assess the effectiveness of a number of programmes across government in tackling individuals with a substance misuse problem. This includes initiatives within the Department of Work and Pensions, the Home Office, Ministry of Justice and Department of Education.</li> <li>• They also monitor the activity level and type at needle exchanges.</li> </ul>
Organisation	Public Health Observatories and Cancer Registries
<b>Comments</b>	<p>The PHOs/Cancer Registries are involved with:</p> <ul style="list-style-type: none"> <li>• Monitoring regional PIs e.g. Health Profiles</li> <li>• Cancer Registry surveillance - incidence, mortality and survival data. This incorporates national (NCIN) and sub-national data with annual bulletins</li> <li>• Environmental cancer – at a sub-national level e.g. monitoring aluminum in the water supply, looking at sites like Hinkley Point where there are significant impacts or ongoing work</li> <li>• Congenital anomaly register – using InstantAtlas to look at quality and performance issues and providing QA to providers</li> </ul>



- End of Life Care Intelligence Network – looks at trends of deaths by disease and place and patterns of care. Also includes profiles at local authority level

<http://www.endoflifecare-intelligence.org.uk/home.aspx>

<b>Organisation</b>	<b>Public Health Surveillance Working Group for South East and Eastern England</b>
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<b>Comments</b>	Non-communicable disease public health surveillance activities (some also collect infectious disease data as well as non-infectious disease data) include:
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**Disease surveillance**

- 4CHILD (Four counties database of cerebral palsy, vision loss and hearing loss in children) (National Perinatal Epidemiology Unit)
- British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS) (National Perinatal Epidemiology Unit)
- British Ophthalmological Surveillance Unit (BOSU) (Royal College of Ophthalmologists)
- British Paediatric Neurology Surveillance Unit (British Paediatric Neurology Association)
- British Paediatric Surveillance Unit (BPSU)
- Cancer registries (Cancer Registries)
- Child death overview panels (being introduced) (Local Safeguarding Children Boards)
- Confidential enquiry into maternal and child health (CEMACH)
- GP research database (GPRD)
- Health surveillance at work (Health and Safety Executive)
- Mortality data (Office of National Statistics)
- National Congenital Anomaly System (NCAS) (ONS/BINOCAR (British Isles Network of Congenital Anomaly Registers))
- National Drug Treatment Monitoring System (National Treatment Agency)
- Promed (USA) - international health protection surveillance (Promed)
- QSurveillance (QResearch)
- Quality & Outcomes Framework (QOF) disease registers (DH/ Health and Social Care Information Centre)
- RCGP weekly returns service (Royal College of General Practice)
- Road accident statistics (Department for Transport)
- Survey of Prevalent HIV Infections Diagnosed (SOPHID) (HPA)
- Syndromic surveillance (NHS Direct)

- UK Obstetric Surveillance System (UKOSS) (National Perinatal Epidemiology Unit)

**Determinant surveillance**

- Drinking water inspectorate (Drinking Water Inspectorate)
- Labour Force Survey (Office of National Statistics)
- National Child Measurement Programme (Health and Social Care Information Centre)
- National Reporting and Learning System - patient safety incidents (National Patient Safety Agency)
- Serious Untoward Incidences (SUIs) (Local organisations)
- Teen pregnancy (Office of National Statistics)
- UK Air Quality Monitoring Networks (Defra)
- Weather alerts (Meteorological Office)

**Disease & determinant surveillance**

- Annual Population Survey (Office of National Statistics)
- General Household Survey (Office of National Statistics)
- Health Survey for England (Office of National Statistics)

**Organisation Health Protection Agency**

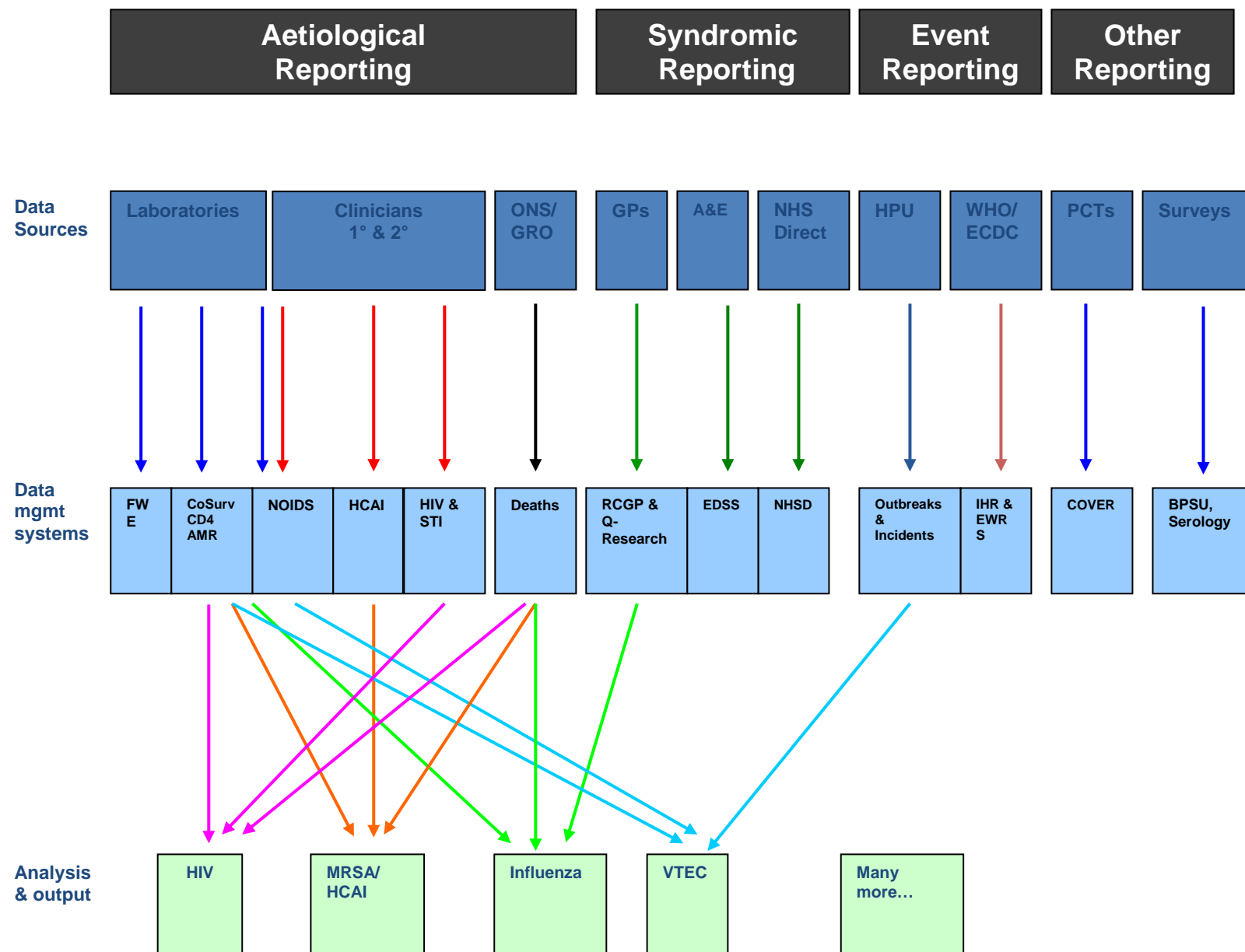
**Comments**

- Surveillance is the ongoing systematic collection, collation, validation and analysis of data and its timely dissemination to all those who need to know (including those that provided the data), along with interpretations and conclusions. There is overlap between the sources and types of data (the inputs), the collation and analysis processes (process), and the dissemination mechanisms used for the surveillance of the various different hazards, exposures and events that the HPA monitors (Figure 5).
- In broad terms the types of data that HPA collects for the purposes of infectious disease surveillance include the following:
  - Clinical Case Reports
  - Laboratory Reports
  - Primary Care Diagnosis Statistics
  - NHS Direct Call Statistics
  - Genitourinary Medicine Clinic Reports (STI Diagnoses)
  - Vaccine Coverage Statistics
  - Active Surveillance for Rare Diseases
  - Hospital Episode Statistics
  - Mortality Reports
  - Outbreaks & Incident Reports (UK)
  - International Outbreaks & Incident Reports
  - International Surveillance - ECDC DSN Reports

- Infectious Disease Screening Activity Data
  - Food, Water, Environmental Laboratory Reports
  - Serological Surveys
  - Epidemiological Surveys and Studies.
- 
- Taking infectious diseases as the example, some of these data types are collected and collated through a single data management system (e.g. NHS Direct data, LabBase) whereas others are collected collated through a variety of different systems (e.g. clinical case reports, some of which are received through the notifications of infectious disease system, others through the mandatory healthcare associated infection system, and others through dedicated ‘enhanced’ reporting systems such as that for tuberculosis). Some of these data collection systems collect data on only one type of disease (e.g. the system for ‘enhanced’ tuberculosis surveillance), while others collect data on wide variety of different diseases (e.g. the national laboratory reporting scheme). Analysis and outputs tend to be according to specific diseases (e.g. tuberculosis) or disease groups (e.g. sexually transmitted infections), and may draw on a variety of data types held in different data management systems.
  - An inventory, compiled in 2008, of surveillance database and analysis systems operated at the national level within the HPA, included 106 “systems”, of which 72 supported the surveillance of specific diseases or disease groups, 32 supported the surveillance of a variety of different types of disease or surveillance of outbreaks, one supported the surveillance of radiation-related hazards, and one supported the surveillance of chemical incidents and hazards
  - The surveillance outputs that inform public health decision making and action taking, including statistics, graphs, maps, interpretation and commentary, are increasingly based on a synthesis of data and analyses related to a single disease or a related group of diseases. Some surveillance systems are mandated by international agencies as part of global control programmes (e.g. polio). These combinations of data collections, analyses and outputs could be said to represent the surveillance “system” at a public health programme level.
  - The main outputs produced by the HPA fall into the following categories:
    - Antenatal Screen-detected infections
    - Antimicrobial resistance

- Blood donation related infections
- Chemical incidents
- Genital Chlamydia infection
- E. coli O157
- Influenza and influenza-like illness
- Group A Streptococcal Infection
- Gastrointestinal Disease (including salmonella, campylobacter, etc)
- General infectious disease
- Healthcare Associated Infections
- Hepatitis (A, B, C, E)
- HIV/AIDS
- Legionnaires' disease
- Infections in blood donors (hepatitis B, C, HIV, HTLV, syphilis, malaria)
- Invasive bacterial infections (meningococcal, pneumococcal and haemophilus infections)
- Norovirus infections and outbreaks
- Occupational exposure-related infections
- Other Infectious Disease
- Outbreaks & Incidents
- Primary Care and NHS Direct Syndromic Data
- Radon (maps)
- Respiratory Disease (including respiratory virus and bacterial infections)
- Sexually Transmitted Infections
- Tuberculosis
- Vaccine coverage
- Vaccine preventable diseases (diphtheria, pertussis, tetanus, polio, measles, mumps, rubella, congenital rubella, SSPE)

Figure 5: Health protection surveillance data flows



Denominator and reference data sources<sup>8</sup>

Data item description	Source type	Examples of where information would be used (not exhaustive)
English Indices of Deprivation	Government Department	The Indices of Multiple Deprivation (IMD) quintiles used as inequality groupings for trend analyses, e.g. mortality, L.E; identifies small areas of need within larger areas. Income deprivation also useful for children (IDACI) and older people (IDAOP)
Local Postcode Lookup	Local authority	Primary source used to maintain health intelligence Kirklees postcode to higher geographies gazetteer
Digital Mapping Datasets	Local authority	Needs analysis to highlight populations in need and location of services
GP registered population	NHS Local	Denominators in rates/prevalence for trend monitoring; Supporting targeted interventions and social marketing; Population forecasting and deprivation analyses; Identifies registered and resident populations; Used in life-expectancy calculations
GPs	NHS Local	Used for linking patients to practices
GP practices	NHS Local	Practice level population analyses; used in planning of targeted interventions
NHS Postcode Directory	Health and Social Care Information Centre	Secondary source used to maintain health intelligence Kirklees postcode to higher geographies gazetteer; Underpins population aggregations by geography
Various administrative lookups	Health and Social Care Information Centre	Lookup data such as communal establishments are update bi-annually
Predictive Risk Smart Registry	Health and Social Care Information Centre	To calculate age standardised disease prevalence for area comparisons.
Mid-Year Population Estimates	ONS	Used in denominators for regional and national rate comparators
Mid-Year Ethnicity Estimates	ONS	Currently only complete dataset for ethnicity by person and single years of age across Kirklees; Not available at lower levels of geography
Registered births (incl. Annual Death Extracts and Public Health Birth Files)	ONS	Denominators in rates such as infant mortality and low birth weight to support trend analyses; Infant mortality audits
Mosaic Public Sector - Geodemographic classification system	Private sector	Classification used to create local indexes using population (base) and service or questionnaire (target) data to identify target groups and their characteristics to support intelligence led commissioning

<sup>8</sup> Based on an analysis provided by Dr J Hooper, DPH Kirklees

**Examples of data used to inform local public health needs assessment, planning and service delivery<sup>9</sup>**

Data item description	Source type	Examples of where information would be used (not exhaustive)
Cancer incidence/ mortality/ survival	Cancer Registry	Monitoring 3 yearly rolling average incidence rates for different cancer sites, at PCT and local area level, etc.
Cancer screening data	Cancer Screening	Screening analysis - uptake and coverage.
Congenital Abnormalities	Congenital Anomaly Register	
Seasonal influenza vaccination uptake	Government Department	
British Crime Survey	Government Department	WHIST Programme indicator
The English Housing Survey - EHS	Government Department	WHIST Programme indicator
Communicable Diseases	HPA Local	To inform JSNAs
Communicable Diseases	HPA National	To inform JSNAs
Immunisations	HPA National	To inform JSNAs to inform HPV programme
Enhanced Infectious Disease Surveillance e.g. STI/HIV, TB, HCAI	HPA National	To inform JSNAs
Termination of pregnancy data	Independent sector and NHS Local	Audit of TOP pathway
Council tax benefit claimants	Local authority	Useful proxy for low income can be used to inform JSNA, etc.
School census	Local authority	Free school meals, SENs, persistent absence rate can be used to inform JSNAs, CYP plan, etc.
LA Data Collection	Local authority	Achievement at Early Years Foundation Stage (FSP) can be used to inform JSNAs, CYP plan, etc.
Key Stage 2/ Key Stage 4 Attainment	Local authority	Achievement at KS2 and KS4 can be used to inform JSNAs, CYP plan, etc.
Care First System	Local authority	Achievement at KS2 and KS4 can be used to inform JSNAs, CYP plan, etc.
Benefits claimants	Local authority	Disability Living Allowance, Incapacity Benefit, Severe Disablement Allowance, Attendance Allowance, etc, can be used in inform JSNAs, etc.
Household income	Local authority	To inform JSNAs
Police recorded crime data	Local authority	Household, vehicle, violent, robbery and 'all' crimes can be used to inform JSNAs, etc.
Fuel poverty	Local authority	To inform JSNAs
Miscellaneous consultation data	Local authority	Ad hoc consultations, evaluations, exploratory research to identify needs of 'harder to reach' groups
NEET Data	Local authority	To inform JSNAs; WHIST Programme Indicator, NI117

<sup>9</sup> Based on an analysis provided by Dr J Hooper, DPH Kirklees

## Public Health Surveillance: A strategy for Public Health England

Local Surveys	Local authority & NHS Local	Needs assessment; prevalence of; and relationships between population health and wellbeing indicators; identification and analysis of perceptions, experiences and satisfaction with local place and services; collection of baseline, medium and long-term public health outcomes to evaluate impacts of programmes/ interventions. Social marketing and behaviour change projects, evaluations, and exploratory research to compliment surveys. Can be used to inform JSNAs.
Smoking on delivery	NHS Local	
Breast feeding at 6-8 weeks	NHS Local	Monitoring breast feeding at 6-8 weeks.
Community Services Data	NHS Local	Used to support intelligence led commissioning; creating local indices e.g. Chlamydia screening data with Mosaic, Informs health equity audits e.g. specialist stop smoking service.
Clinical and Health Outcomes Knowledge Base	Health and Social Care Information Centre	National calculated rates for standard large areas to LA level. Numerators and denominators available, for different age groups and sexes depending on indicator.
Secondary care dataset	Health and Social Care Information Centre / PHOs	Currently being used to work out alcohol and smoking attributable admissions; rates of emergency admissions; creation of indices in needs assessments when using Mosaic.
Accident and Emergency	Health and Social Care Information Centre	Proxy for accident reductions if reliable and complete.
GP Patient Survey	Health and Social Care Information Centre	WHIST Programme indicator NI124
Dental Health Surveys (various age groups)	Health and Social Care Information Centre	
Registered deaths (incl. Annual Death Extracts and Public Health Mortality Files)	ONS	Numerators in mortality rate calculations; Excess winter deaths; Used in life-expectancy calculations; Suicide audit; monitoring of SQU02; Infant mortality audits
Official labour market statistics	ONS	IS/ DLA/ JSA claimant rates can be used to inform JSNAs
Teenage conceptions data	ONS	To inform JSNAs, teenage conception health intelligence summaries
National Childhood Measurement Programme	PHO	Prevalence of BMI indicators for Reception and Year 6 children at various levels of geography