

# Review of Public Health England's data collection and data management functions

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## Executive Summary

This review was jointly commissioned by Public Health England (PHE) and NHS Digital (NHS D) under the aegis of the Department of Health (DH). Terms of Reference (ToR) for the review are included as annex A.

The review aims to provide an independent opinion as to the future disposition of the data held and used by PHE in carrying out its functions. All of the primary data collections undertaken by PHE have been considered as part of this review.

The review essentially breaks down to the question – should PHE data collections be transferred to NHS D, acting in its statutory role of safe haven for information for the NHS, and if so, how and when should that, or those, transfer(s) occur?

The review was conducted with the understanding that if any change or changes were recommended, any such change would:

1. As a minimum, not compromise or lead to a reduction in the ability of either organisation to discharge its respective functions and responsibilities, unless such change was universally agreed to be in the best long term interest of the health and care sector;
2. Be considered within the context of the capacity and capability of NHS D to assume any of the functions with regards to data collection, management and dissemination currently performed by PHE and of PHE to transfer that function;
3. Seek to maximise the benefits for the taxpayer, the health and care system and health outcomes, including the opportunity to enhance functionality and effectiveness of the data collection and analysis process, and enhance the overall outcomes underpinning the data collection rationale; and
4. Be fully cognisant of the cost implications, both in terms of potential savings over the longer term and any associated upfront or ongoing costs, while being clear that an implementation programme would need to develop detailed costings and agree future funding arrangements.

## Methods

Professor Keith McNeil, Chief Clinical Information Officer (CCIO) Health and Care, and Chair National Information Board (NIB), was asked to conduct the independent review. Information relevant to the decision making process was obtained from relevant documents, and from an extensive interview process canvassing the opinions of a range of stakeholders nominated by PHE, NHS D and DH. The list of interviewees can be found at annex B.

Conclusions were drawn from this information and recommendations made within the framework listed above.

## Conclusions and recommendations

1. There was consensus that the mechanistic aspects of how data is collected, and where it is aggregated and held were largely irrelevant if accessibility of the data to those who needed it was maintained or enhanced. This included the timeliness of access as well as consideration of the fundamental confidentiality and security requirements related to the data access.
2. All parts of the system should work together to gain maximum value from data, including maximising functionality and linkages across the system, securing best value for the taxpayer, and translating the data into actionable intelligence that improves health outcomes.
3. It was agreed that no changes should be embarked upon until such time as both organisations (PHE and NHS D) were assured that the capacity and capability to achieve the change without any degradation of quality and performance or any impact on core functions was in place, and that the likely costs were assessed and funding in place. To determine the best approach for each dataset, a transparent and robust “due-diligence” process should be used. PHE would act as the primary customer for any data collections transferred to NHS D and should work closely with NHS D to ensure both the availability of the required data allows PHE to meet its functions and the ongoing requirements and refinement of that data meets its ongoing needs.
4. As sponsor for both PHE and NHS D, DH should have oversight and assurance of implementation plans. The CCIO should also be assured of the benefits and value of any transfer. NHS D, PHE and DH should work together to carry out the “due-diligence” process, develop business cases and produce implementation plans.
5. Any changes that required additional funding or resource would require a business case and funding would be negotiated using standard mechanisms.
6. The individual databases involved should be considered in 4 separate tranches:
  - I. Those which could, subject to the satisfactory completion of a “due-diligence” process, potentially be transferred in short order (around 12 to 18 months) with minimum if any disruption to functionality (i.e. where the capacity, capability, and costs were already in place). There are several data collections currently involving both PHE and NHS D which could serve as a template for transition with added functionality.
  - II. Those data sets with more complex requirements where, subject to the satisfactory completion of a “due-diligence” process, a “medium term” (around 18 months to 3 years) plan would be required to ensure maintenance of functionality and time for capacity to be planned and built by NHS D to house the data sets.
  - III. The National Cancer Registry and the National Congenital Anomaly and Rare Diseases Registry, which owing to its size, complexity and intrinsic links to other strategic developments such as genomics, life sciences, and the availability of the Data services Platform, should be considered over a longer term (3 to 5 years).

- IV. Datasets that should remain with PHE. These will include: those that support the real-time or near real-time provision of patient or population facing public health services as part of PHE's core functions in areas such as health protection case incident management; data collections performed on the basis of contractual activities on behalf of other organisations (e.g. laboratory results); and, non- mechanistic/ non-automated data collections requiring significant public health expertise in identifying and entering the required data.
7. To test the approach, a pilot should be established by NHS D and PHE immediately. This should undertake a robust and realistic "due-diligence" process on a significant database. The approach should be evaluated and refined and the pilot should deliver a clear methodology that can be used for other data sets.
8. PHE and NHS D should also work together without delay to review all the primary data collections held by PHE and determine which tranche they should each fall into. They should develop proposals confirming how each collection should be considered, the timeline for carrying out the "due-diligence" process for tranches 1 and 2 and the next steps and share this with DH by the end of the calendar year. Until this work is completed the detailed timelines will remain uncertain.

## Introduction

There is a policy imperative of developing a centralised and / or co-ordinated data collection and management function to operate on behalf of the health and care system, which would collect and link identifiable health and care data from across the system. This would enable the effective and efficient sharing of that data wherever and whenever it is required for direct clinical care, population health management, and business intelligence and research. This directly aligns with the NIB 2020 programmes, the Life Sciences and genomics strategic agendas, and the broader Government Transformation Strategy.

This review looks at the primary data collections and data management functions carried out by PHE and examines how, and under what circumstances, some or all of those data collections could be transferred to NHS D. The review calls on both PHE and NHS D to provide leadership to the system by working closely together to demonstrate the value and power of data to the digital transformation programme and to deliver benefits to the whole of the health and care system and the wider UK PLC.

## Rationale for the review

At a bilateral meeting between the senior executives of NHS D and PHE in September 2016, it was agreed that the data collection and data management functions of PHE would be independently reviewed to assess future options. Professor Keith McNeil was asked as the CCIO for Health and Care, and Chair of the National Information Board, to conduct this review and make recommendations on whether, and subsequently how, the data sets could and should be managed in the future by NHS D, given its statutory responsibility as the national safe haven for health and care data.

The reviewer, first and foremost, adopted the position that any transfer of responsibility for collection of the existing datasets should, wherever possible, enhance the overall outcomes underpinning the rationale for collecting the data, with benefits delivered to the whole system through enhanced use, linkage and accessibility of the data. The mechanistic aspects of processing, including the collection, aggregation and hosting should be of second order importance, and designed so as to enhance and deliver accessibility, timeliness of information flow, information governance and security.

In addition to the formal ToR, the review was also considered within a wider framework including:

1. The relevant statutory responsibilities of both PHE and NHSD;
2. The policies regarding Information Governance (IG) and data handling across the NHS;
3. NIB's 'Personalised Health and Care 2020' portfolio, particularly related to domains D (interoperability) and Domain H (data);
4. The recent Tailored Review of PHE by DH; and
5. The proposed Life Sciences Strategy.

## Background to Public Health England

PHE was established as an Executive Agency of DH on 1 April 2013 through the merger of more than 100 organisations. It was set up to protect and improve the nation's health and wellbeing overall and, in particular, to address health inequalities.

PHE is the expert national public health agency that fulfils the Secretary of State for Health's statutory duties to protect health and address health inequalities, and executes the Secretary of State's power to promote the health and wellbeing of the nation. It undertakes a range of evidence-based activities that span the full breadth of public health working locally, nationally and globally and is responsible for four critical functions which are set out in its remit letter:

- PHE's first function is to fulfil the Secretary of State's duty to **protect the public's health** from infectious diseases and other public health hazards, working with the NHS, local government and other key partners in England and also working with the Devolved Administrations and globally where appropriate;
- PHE's second function is to **secure improvements to the public's health**, including supporting the system to reduce health inequalities;
- PHE's third function is to improve population health by **supporting sustainable health and care services** including supporting local government and the NHS with access to high quality data and providing data analyses to improve services and outcomes;
- PHE's fourth function is to ensure that the public health **system maintains the capability and capacity** to tackle today's public health challenges and is prepared for the emerging challenges of the future, both nationally and internationally.

The Framework Agreement sets out PHE's statutory functions delegated by the Secretary of State for Health.

PHE's Strategic Plan sets out its role in the public health system and its vision for better public health outcomes. This is underpinned by PHE's annual remit letter from the Minister for Public Health and its annual business plan which describe the actions PHE will undertake to achieve its vision. PHE promotes world-class science and evidence and, is at its heart, a knowledge based and intelligence driven organisation with a critical reliance on data and information to enable it to fulfil its statutory duties and accomplish its vision of achieving better outcomes. As such, PHE needs access to a wide range of data and information. PHE's ability to effectively and efficiently identify and respond to immediate threats and longer term challenges to public health fundamentally depends on it having timely and unfettered access to data and information on the health status of the population, the wider determinants of health across populations, and the provision of health and care services to the population of England.

The primary data collections that PHE currently manages can be classified as follows:

- a) Health protection incident/case management and outbreak control
- b) Vaccination and immunisation services
- c) Chemical, radiological and biological source and exposure monitoring
- d) Communicable and non-communicable disease surveillance

- e) Population disease screening programme management and quality assurance
- f) Microbiological and other specialist laboratory testing and reporting services
- g) Disease registration
- h) Patient- and population-level health and social care service monitoring and evaluation.
- i) Environmental, socio-economic, behavioural, and genetic health risk factor monitoring
- j) Health improvement service marketing and the provision of information, sign-posting and interventions

## Background to NHS Digital

NHS Digital is the new trading name for the Health and Social Care Information Centre. NHS D is the provider of national information, data and IT systems that support health and social care services. NHS D's key role is to improve health and care in England by enabling technology, data and information to work in the interests of patients, clinicians, commissioners, analysts and researchers in health and social care.

NHS D provide a range of technology and information services that are used by patients and service users, the public at large, and health and care professionals, as well as by research, industry and commercial organisations. These services support the commissioning, design and delivery of health and social care provision in England, and provide information and statistics that are used to inform decision-making and choice across the Health and Care system.

NHS Digital has statutory duties it discharges on behalf of the health and care system:

- a) Manage the collection, storage, processing and publication of national health and care information, as directed by the Secretary of State and NHS England.
- b) Deliver the national technology and infrastructure services that underpin the provision of health and care services.
- c) Manage the development and delivery of information standards, products and services needed to support health and care provision, and the commitments of the NIB.
- d) Fulfil data quality assurance responsibilities by expanding services provided to support improvements in data quality, and publishing the annual data quality report.
- e) Act as the national source of indicators by, for example:
  - Producing and publishing the NHS Outcomes Framework, the Clinical Commissioning Groups Outcomes Framework, and the Adult Social Care Outcomes Framework;
  - Managing the national library of assured indicators and their methodology;
  - Co-ordinating the assurance processes necessary to support the design and use of robust and meaningful indicators.
- f) Provide advice and support to health and care organisations on information and cyber security, standards and information governance.
- g) Develop the Information Governance Toolkit to support greater self-assessment for integrated services.



- h) Support system-wide management of administrative burden, providing the Secretary of State with an assessment of opportunities for reducing the impact of administrative burden (reporting) on the front line.

## Information governance considerations

The legal framework governing the use of personal confidential data in health care is complex. It includes the Data Protection Act 1998, the Human Rights Act 1998, NHS Act 2006, the Health and Social Care Act 2012, and the Care Act 2014, as well as the common law duty of confidentiality, the Caldicott principles and a range of national guidance for health and care organisations on data protection and information governance.

The law allows personal data to be shared between those offering treatment and care directly to patients but it protects patients' confidentiality when data about them are used for other purposes. These "secondary uses" of data are essential if we are to run a safe, efficient, and equitable health service, and achieve the "triple aim" of healthcare provision – better patient outcomes, better patient experience and affordability of healthcare services. For secondary uses where it is not essential to be able to identify patients, data that has been aggregated or anonymised must be used.

There are specific citations contained within policy documentation that set the strategic direction:

- The National Data Guardian Review, carried out by Dame Fiona Caldicott and published in June 2016, proposes "that data should be passed to the HSCIC, as the statutory safe haven of the health and social care system, to de-identify or anonymise and share it with those that need to use it." (Paragraph 1.34). In addition, it goes on to state that "the Review considers that the Secretary of State's objective of creating a trustworthy system with the minimum use of people's personal confidential data would be better achieved by allowing all data to flow into the HSCIC. This would allow the HSCIC to link and then de-identify personal confidential data to create comprehensive de-identified data sets." (Paragraph 1.36).
- The PHE Tailored Review recommends that, "Health data should be collected, stored, and managed to minimise costs, ensure data security, and maximise benefits to patients and the public. As with all other health and care data, NHS Digital should store and manage all relevant national sets of patient-identifiable public health data in line with the stringent requirements of the recent Caldicott Review."
- The 10 year strategy published in 2012, *The Power of Information: giving people control of the health and care information they need*, set the framework for transforming information for health and care, and made clear recommendations on information governance. It stated the ambition of "information recorded once, at our first contact with professional staff, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow (interoperability) between systems whilst keeping our confidential information safe and secure." The framework set an expectation that

NHS Digital would be created to undertake the main data collection and data linkage functions on behalf of the health and care system, becoming the safe haven for data storage, although it did also recognise that “Where there is a strong clinical case, specialised data collections will still exist in other organisations – for example the rich and widely respected cancer registries and national clinical audits”.

- In November 2013, PHE signed up to the concordat on reducing the burden of national requests for information. This states that PHE will “work with the Health and Social Care Information Centre (NHS D) as the national base for all information which is collected or extracted from local systems.”

## Personalised Health & Care 2020

The NIB’s framework for action, *Personalised Health and Care 2020*, set the vision to support frontline staff, patients and citizens to take better advantage of the digital opportunity. Two of the domains delivering this framework for action are particularly pertinent to this review.

The vision for *Domain D – Integrated care and social care* is to inform clinical decisions across all health and care settings and improve the experience of service users by enabling and enhancing the flow of patient information.

The interoperability strategy is based on local information flow for direct clinical care based on regional analytic hubs allowing also for local population decision making. In addition, this regional model aligns with the recently announced Life Sciences Strategy model of data sharing for research purposes. Over and above this regional data analysis, nominated national data flows would be continued / established where required and appropriate.

In reviewing the datasets currently collected by PHE, this interoperability strategy must be considered in terms of effectiveness and efficiency (including timeliness) of data flows and the IG around those flows.

The vision for *Domain H – Data availability for outcomes, research and oversight*, is to improve the quality, availability and integrity of health data so that frontline staff, researchers, and decision makers are better informed right across the NHS.

A key part of this vision is the development of the Data Services Platform (DSP), on which the designated national datasets will be managed (this also forms a key part of the interoperability strategy within Domain D). It is envisaged that many of the datasets currently managed by PHE will be national collections, thus any transition of said national data flows and functionality to NHS D would require the appropriate capability and capacity within NHS D to assume this role, with the DSP key to the capacity issue.

Delivery of both of these domains is fundamental to the future accessibility of data and information across health and care generally, and for the functionality of any of the datasets recommended for transfer from PHE to NHS D.

## Methodology

This review has been carried out independently of PHE, NHS D and DH, led by Professor Keith McNeil in his role as national CCIO and chair of the NIB.

Information relevant to the decision making process was obtained from relevant documents, and from an extensive interview process canvassing the opinions of a range of stakeholders nominated by PHE, NHS D and DH. The list of interviewees can be found at annex B. The key themes were drawn from all of the interview discussions and are included in the findings.

## Findings

This section sets out the primary concerns raised regarding any potential transfer of data collection and data management functions from PHE to NHS D. In addition, key themes for enhanced functionality, efficiency and effectiveness were also canvassed from the interviews with key stakeholders.

### PHE primary concerns

The full submission from PHE to inform this review is attached at annex C. One of the most significant statements is that “PHE strongly recommends that no transfers of any of the primary data collections it currently manages should occur where this will adversely affect its ability to effectively and efficiently discharge its core functions as the expert national public health agency and an emergency Category 1 responder.” As set out earlier in this report, PHE has a number of statutory functions to protect health and address health inequalities as well as a duty to promote health and wellbeing. As such, any transfer must not inhibit or adversely affect their ability to carry out these core functions in order to continue to protect the public from threats to health. PHE would act as the primary customer for any datasets that were transferred into NHS Digital and would therefore have unrestricted access to the data required, and would work closely with NHS Digital on the ongoing development and refinement of those datasets.

In addition, PHE have detailed four other fundamental principles that must be considered as part of determining whether transfer of specific data collections is appropriate.

1. Public health specialist input

Many PHE data collections are not automated or mechanistic collections. They rely on specialist public health input and any transfer must preserve this subject matter expertise to ensure operational effectiveness and strategic management. Much of this expertise is intrinsic to PHE’s delivery of its core functions rather than being standalone or specific to the data collection. Therefore, where the integrity of the data collection and the service that relies on it requires specialist public health input DH approval for any move must be sought and PHE’s remit and priorities appropriately revised.

2. Specialist clinical input

Similar to point 1 above, many of the screening programmes run through PHE rely on the specialist input of clinically qualified front-line staff. If therefore, there is any transfer to NHS D of contracts, service level agreements or other formal agreements

with clinicians, DH approval must be sought and PHE's remit and priorities appropriately revised.

3. Cost efficiency

Any potential transfer should not result in any net increase in the cost of providing the public health service or function reliant on the data collection and analysis. If additional costs or expense are required, specific DH approval will be required and the additional funding agreed prior to any transfer. Any additional costs associated with the transfer of a data collection should not result in additional (unbudgeted) costs to PHE, not agreed with DH and funded in advance.

4. Stakeholder support

Approval must be sought from the specific governance groups responsible for oversight of the data collections prior to any transfer. Consultation with broader partner, stakeholder and user groups should take place to gain broad support for any transfer.

In addition, as part of any implementation plan, PHE are keen that a structured business impact assessment (i.e. "due-diligence") will need to be undertaken on each of the data collections proposed to transfer to assess the impact on the effectiveness of the public health services and functions that rely on the data collection, and allow mitigation of any risks.

## Key themes from interviews

1. Accessibility of data

The primary concern of all interviewees was data accessibility; the maintenance thereof and the potential for enhanced accessibility, should a transfer to NHS D occur. There was consensus that any potential transfer of data collections and data management functions should not be disruptive and that any such transfer must allow the same level of access, or indeed enhanced access wherever possible.

The timeliness of access to data is crucial. PHE fundamentally relies on the timely and unconstrained access to the data and information it collects and processes, to enable it to carry out its statutory duties. PHE's ability to effectively identify and respond to immediate public health threats mandate that any potential transfer does not reduce access to the required data within the required timescales.

*Note: Such immediate access requirements describe the functionality of some "Tranche IV" databases, and as such would not be recommended for transfer to NHS D.*

There was concern expressed by the research community that any transfer may restrict timely access to datasets. There should therefore be a transparent process, collaboratively developed, as part of any dataset transfer to ensure timely access to data is maintained or enhanced. This concern was not solely that of the research community, but was shared by the majority of those interviewed.

*The majority of stakeholders interviewed however, stated that they were organisationally agnostic as to where data was collected and stored, as long as assurance was provided that access to data was maintained or improved, functionality enhanced, and data quality would not be compromised in any way.*

## 2. Cost / burden

There is a system wide requirement to reduce the burden and cost of data collections, particularly to health and care provider organisations. The 2013 concordat, signed by the Department and its Arm's Length Bodies, made clear that there is a public duty to collaborate in the interests of good care and outcomes, and in the interests of efficiency and productivity. As such, there is an imperative to remove duplicative data collections. This was cited by a number of interviewees, who noted that this review presented an opportunity to rationalise data collections where there was obvious duplication and also to examine those data collections where there was (significant) overlap.

It was however noted that an accurate assessment of burden, cost and interdependencies of each collection would be required on a case-by-case basis to ensure functionality is maintained in any transition. This would form a fundamental requirement of the business impact assessments (i.e. "due-diligence" process).

## 3. Capacity and capability of NHS D

All interviewees held the view that prior to any transfer of data collections, the capacity and capability of NHS D to take on and maintain the collection's integrity and current service levels would need to be assessed and agreed. This would need to form part of individual impact assessments (i.e. "due-diligence" process) for each of the data collections being proposed for transfer.

## 4. Data flows / linkages and enhanced functionality

There was strong feeling among interviewees that this review is long overdue, and that it presents a unique opportunity alongside the portfolio of NIB programmes to enhance data linkages and overall functionality across the system. Delivery of the portfolio of NIB programmes will enable for the first time, a markedly increased ability to link previously disparate datasets, and to provide enhanced functionality to the users of those datasets through the application of advanced analytics currently co-ordinated through NHS D.

*This enhanced functionality can only be provided by NHS D in the context of the current information governance landscape and legislation.*

Interviewees opined that improved functionality as part of any potential transfer that provides real-time (or close to) access to data would be very desirable. However, there was recognition that a balance would need to be found between the cost implications of improved access and the functional benefits.

## 5. Data quality

There was agreement that data quality needs to be maintained or enhanced and any transition must not put this at risk.

## 6. Transparency

A number of interviewees commented that this review provides a much needed opportunity to address the issue of increasing the transparency of how, why and by whom data is being used.

## 7. New data collections

Any new data collections approved subsequent to this review should be considered in line with the recommendations of this review and the overall strategic intentions of the NIB. As far as possible, they should be planned to be managed by PHE and NHS D in partnership

## 8. National Cancer Registry

The National Cancer Registry and associated data management functions were central to discussion in many of the interviews. There are historical and political sensitivities around the cancer registries, which were subsumed into PHE when it was formed as an organisation in April 2013.

The collection of cancer data and the analytic functions were originally split when taken on by PHE. A previous review recommended the functions be brought back together, which is the situation today. There was some concern expressed about a future separation of these functions.

It is clear from all of the interviews conducted that there are many dependencies on the cancer registry data and there must not be disruption to its current high level of function. In particular, the delivery of the cancer taskforce recommendations is dependent on use of the data, as is deriving the full value of the 100,000 genome project and the recently announced Life Sciences Agenda.

## **Conclusions (from the interview process)**

There was consensus that the mechanistic aspects of how data is collected, and where it is aggregated and held were largely irrelevant if accessibility of the data to those who needed it was maintained or enhanced. This included the timeliness of access as well as the fundamental confidentiality and security requirements related to data access.

There was universal agreement that, if through this process, it was easier to link currently disparate data sets that would be a very desirable outcome, and all parts of the system should actively engage in this opportunity for delivering tangible benefits including maximising functionality and linkages.

PHE needs a range of data to allow it to carry out its statutory and core public health functions. PHE will continue to lead on public health analytics. PHE should therefore act as the primary customer for any datasets transferred to NHS D and should work closely with NHS D to ensure both the availability of the required data allows it to meet its functions and the ongoing requirements and refinement of that data meet its ongoing needs.

No changes should be embarked upon until such time as both organisations (PHE and NHS D) were assured (objective and validated) that the capacity and capability to achieve the change without any degradation of quality and performance or any impact on core business was in place and that the likely costs were assessed and funding in place. Any changes requiring additional funding or resource would require a business case and be negotiated using standard mechanisms.

To determine the best approach for each dataset (or sets thereof where appropriate), a transparent and robust “due diligence” process should be used. NHS D, PHE and DH should work together to carry out the “due-diligence” process, develop business cases and produce implementation plans and the CCIO should be assured of the benefits and value of any transfer, both in terms of quality and performance outcomes (to be defined) and overall value for money.

The databases involved should be considered in 4 separate tranches. PHE and NHS D should work together without delay to review all the datasets held by PHE and determine which tranche they should fall into. This agreement should be based on the input of the relevant clinical, population health and data specialists and should form the first piece of work following the acceptance of the recommendations of this review. At a high level, these tranches are defined as:

- I. Those which could, subject to the successful completion of a “due-diligence” process, potentially be transferred in short order (around 12 to 18 months) with minimum if any disruption to functionality (i.e. where the capacity, capability and costs were already in place). There are several data collections currently involving both PHE and NHS D which could serve as a template for transition with added functionality.
- II. Those data sets with more complex requirements where, subject to the successful completion of a “due-diligence” process, a “medium term” (around 18 months to 3 years) plan would be required to ensure maintenance of functionality and time for capacity to be planned and built by NHS D, and relevant capability be established to house and manage the data sets. This is likely to be linked to the development of the Data Services Platform (NIB Domain H) and the regional interoperability model for data sharing (NIB Domain D).
- III. The National Cancer Registry and the National Congenital Anomaly and Rare Diseases Registry, which owing to its size, complexity and intrinsic links to other strategic developments such as genomics, life sciences, and the availability of the Data services Platform, should be considered over a longer term (3 to 5 years) and should take into account the developing context. There is an opportunity to use the considerable functionality contained within the registry as it stands as either a model for the Data

Services Platform, or indeed as the Data Services Platform with a scaling up of the current infrastructure.

- IV. Datasets that should remain with PHE. These will include: those that support the real-time or near real-time provision of patient or population facing public health services as part of PHE's core functions in areas such as health protection case incident management; data collections performed on the basis of contractual activities on behalf of other organisations (e.g. laboratory results); and, non- mechanistic/ non-automated data collections requiring significant public health expertise in identifying and entering the required data.

## Recommendations

It is the recommendation of this review that, in line with legislative responsibilities and information governance considerations, all datasets except for those related to The National Cancer Registry and The National Congenital Anomaly and Rare Diseases Registry (Tranche III) and those determined/ agreed to be in Tranche IV, should be transferred to NHS D, subject to the satisfactory completion of a "due-diligence" process and the production of an implementation plan agreed between PHE, NHS D and DH. The next steps should incorporate the following:

1. PHE and NHS D should work together without delay to review all the datasets held by PHE and determine which tranche (as set out in the conclusion of this report) they should each fall into. They should develop a report confirming how each collection should be handled, the timeline for carrying out the "due-diligence" process for tranches I and II and the next steps by the end of the calendar year. A due diligence process for subsequently determining the process and timing of transfer of each data collection, or set thereof, is set out in annex D. Until this work is completed the detailed timelines will remain uncertain. However, they should avoid undue delay and consider the achievability of the indicative timelines above. In parallel, those data sets described requiring highly specialised PH input for the management of disease outbreaks etc. (Tranche IV) should be agreed with appropriate stakeholder input as soon as possible and uncertainty in these critical areas.
2. Agree and co-create with stakeholders an implementation plan for each of the datasets (either singly or where appropriate in functional groupings). This will necessarily include a review of the capability and capacity of NHS D to host and manage the datasets and any cost implications arising from any transfer agreements. A joint working group from NHS D and PHE should agree the approach to transferring data sets and how to meet the indicative timescales for transition outlined above in the conclusion.
3. As part of 2. (above), ensure the visibility and transparency of the cost implications of any transfer of function and agree these, their mitigation, and the mechanisms for reaching agreement on funding arrangements with DH as sponsor for both organisations.
4. Review as an integral part of the "due-diligence" process the opportunities for:



- a. Increased transparency of data usage
  - b. Additional linkages and functionality for each and every dataset
  - c. Reducing duplication of collections and the burden of reporting for provider organisations
5. To test the approach, a pilot should be established by NHS D and PHE immediately. This should test the “due-diligence” process to develop a robust and realistic implementation plan for a significant database. The approach should be evaluated and refined and the pilot should deliver a clear methodology that can be used for other data sets.

As sponsor for both PHE and NHS D, DH should have oversight and assurance of the implementation plans, including involvement in their development and sign-off.

It is recommended that the plans be developed and delivered in conjunction with Domain H of the NIB 2020 portfolio (or its successor board), and that, working with DH, business plans be developed and the usual mechanisms used for securing resources to fund and carry out this work.

It is recommended that at this time no change to the National Cancer Registry and the National Congenital Anomaly and Rare Diseases Registry be considered, until such time as the satisfactory transition of the functions in tranches I and II has been completed. At such time, and with the caveat that there will be a significantly different landscape to consider as the interoperability, genomic and life sciences agendas progress and mature, a further specific review of the opportunities for the Registries be undertaken.

It is recommended that the data collections agreed to fall into tranche IV be retained by PHE, and that those specific data sets be identified and agreed by PHE and NHS D as a matter of priority so as to create certainty amongst those responsible for managing said datasets.

## Annex A: Terms of Reference for the review

### Background

1. At a bilateral meeting between senior executives of PHE and NHS Digital on 27th September 2016, and in a subsequent confirmatory e-mail between Chief Executives, it was agreed that PHE's data collection and management activities would be reviewed independently to assess future options. It was agreed that Professor Keith McNeil would be asked as chair of the National Information Board to undertake an independent review of the data PHE holds and make recommendations on whether any of these datasets in full or in part be better managed in future by NHS D. This is reflected in the recommendations of the PHE Tailored Review.
2. On the creation of Public Health England (PHE) in April 2013, a large number of functions were brought together to provide an efficient and effective focus for public health in England. The policy background for these changes was set out in 2010 in the Government White Paper entitled *Healthy Lives, Healthy People: our strategy for public health in England*. As the new national public health agency, PHE was expected to draw together a number of functions previously provided by multiple agencies including data collection, analysis and provision of evidence directly to support local action, while also delivering a 30% cost saving compared with the predecessor arrangements in this aspect of its work.
3. A later policy paper, entitled: *The Power of Information: giving people control of the health and care information they need* (2012) set out the government vision for an information-led health and social care system. This was then followed by the National Information Board Paper *Personalised Health and Care* (2014). The main objective was to establish a system based on more automated compilation of data with much more extensive linkage between data sets. Anonymisation could then be applied so that the data could be safely and widely shared.
4. NHS D's statutory powers with respect to data are defined in the Health and Social Care Act 2012, and further defined in the Care Act 2014. The most pertinent to the current review are the requirements to:
  - Manage the collection, storage, processing and publication of national health and care information, as directed by the Secretary of State and NHS England.
  - Manage the development and delivery of information standards products and services needed to support health and care provision, and the commitments of the National Information Board.
  - Fulfil data quality assurance responsibilities by expanding the services provided to support improvements in data quality, and publishing our annual data quality report.
  - Act as the national source of indicators
  - Provide advice and support to health and care organisations on information and cyber security, standards and information governance.
  - Support system-wide management of administrative burden, providing the Secretary of State with our assessment of opportunities for reducing its impact on the front line.

5. The Power of Information anticipates the creation of the body now known as NHS Digital as the central agency with new powers under the Health and Social Care Act 2012. There was clearly an expectation that the new body would be undertaking the main data collection and linkage functions on behalf of the system. However the benefits of specialist clinical oversight of certain data collections were also recognised explicitly including some of those currently carried out by PHE, but that there would need to be a strong clinical case for specialised data collections to exist in other organisations.
6. The current situation is that NHS Digital undertakes large scale administrative data collections from NHS secondary care providers, primary care providers and also from the social care sector. The main data linkage activities are to secondary care data to allow more research and insight into care provided across care settings. Personal data also flow to other organisations for specific purposes, for example NHS Business Services Agency and PHE. In addition there are a variety of specialist organisations managing large scale national clinical collections such as the National Joint Replacement register, NICOR and the national Renal Register. There are also substantial local data flows to DSCROs and other bespoke NHS partnerships.
7. More recently the work of the National Information Board (NIB) and the information and technology portfolio to implement *Personalised Health and Care 2020*, a strategy for information and associated technology in the NHS identified an entire Domain to focus on *Data for Research and Oversight*. Within this, Programme 26 defines objectives to reduce the burden of data collection, increase timeliness and seek to extract data directly rather than collect it manually.
8. Most recently, Dame Fiona Caldicott's review of data security and consent / opt-outs was published on 7 July 2016. It said (paragraph 1.36) 'The Review considers that the Secretary of State's objective of creating a trustworthy system with the minimum use of people's confidential data would be better achieved by allowing all data to flow into the HSCIC. This would allow the HSCIC to link and then de-identify personal confidential data to create comprehensive de-identified data sets'.
9. The review is taking place within a context where data linkage of NHS D, ONS and PHE data already occurs, and development work is already underway on elements of system-wide capability including:
  - Data Linkage
  - Review of information governance hurdles and legal basis for data linkage
  - De-identification
  - Remote access to data to obviate data sharing in many cases
  - Mapping of current data collections in NHS D to minimise burden, reduce duplication and open opportunities for automated extraction
10. In summary, there is an underlying policy objective of developing a central data collection and management function that would operate on behalf of the whole health and social care system to collect and link identifiable health data from all parts of the system. Those datasets could then be made available in anonymised form to bona fide organisations for legitimate purposes. This objective has been partially achieved in the creation of NHS Digital and its associated functions. The underpinning functions are not

yet fully implemented although there are plans to develop additional elements as part of Personalised Health & Care 2020. The PHE Tailored Review in 2016, which will be published in the first quarter of 2017, recommended that, “Health data should be collected, stored, and managed to minimise costs, ensure data security, and maximise benefits to patients and the public. As with all other health and care data, NHS Digital should store and manage all relevant national sets of patient-identifiable public health data in line with the stringent requirements of the recent Caldicott Review. Given the need to ensure this does not disrupt the important work of PHE and local health services, Professor Keith McNeil, Chief Clinical Information Officer for the health and social care system and chair of the National Information Board, will review the practical steps necessary to achieve this, and will report by May 2017.” PHE has argued that many of those data collections and data management processes (e.g. disease registration) require specialist clinical oversight and may not be within the current capability of NHS Digital to deliver.

### **Aim of the review**

11. To understand current arrangements for data collection and data management in PHE and NHS D and to evaluate various options for delivering these functions in future. In particular to assess whether some or all of the data functions currently carried out by PHE would be better carried out by NHS D. In assessing options the review should take account of government policy, data security and data sharing in accordance with the National Data Guardian Review, information governance considerations, the current and likely future capability of the different organisations, burden on organisations of data collection, benefits for patients and the public, financial cost, and the views of other interested parties including users of the data.

### **Remit**

- The review will be overseen and directed by Prof Keith McNeil the CCIO and Chair of the National Information Board.
- The review will report to the Chief Executives of PHE and NHS D. The decisions are to be taken by the Chief Executives and the Department of Health.
- The review recommendations will be shared with the Department of Health to ensure they are consistent with Ministerial policy decisions on the management of Health & Care personal data.
- Timescales for implementation of the recommendations are to be agreed with the Department of Health.
- Both organisations will co-operate fully with the review in making information available about current arrangements.
- Tasks will include:
  - Summarise the policy context and intended direction of travel.
  - List and briefly describe the main primary data collections currently undertaken by PHE and any comparable and relevant datasets in NHS Digital
  - Summarise the purposes and identify the end-users of the main data collections
  - Assess the burden of data collection on providers and potential duplication of data sets between the two organisations

- Summarise governance arrangements for the data collections including legal basis, restrictions on access, data sharing oversight and relevant data security arrangements (including assurance) in PHE and NHS D.
- For a set of illustrative “exemplar” data collections or defined classes of data collections describe in more detail the approach taken and the methods used in order to understand the capabilities and capacities required to undertake the respective data collections or classes of collection (in PHE and NHS D) and whether any changes in data location would require transfer of staff.
- Identify a set of future options for data collection for the exemplars including wholesale transfer to NHS D or involvement of NHS D in supporting part of the processes.
- Evaluate those options and test that evaluation with users of outputs and interested parties.
- If data collection functions are identified as transferable to NHS D set out a timeline for migration of data and staff
- Draw together some conclusions and recommendations based on the above.

### **Timescale and approach**

- The review needs to be as independent as possible from the two organisations.
- A small team to be identified by Prof McNeil to help him to describe and assess current arrangements, develop and evaluate options and draft conclusions and recommendations.
- The review should consider seeking advice from knowledgeable third parties such as Sir Alex Markham for cancer data sets, Prof John Watson (DCMO) for infectious disease surveillance, relevant patient groups and specialist charities, National Clinical Directors and other users of data and intelligence based on these data collections.
- The Department of Health will provide policy input and will be a member of the small team led by Prof McNeil.
- Final report to be available within four months, preferably sooner.

This remit has been agreed by Public Health England, NHS Digital and the Department of Health. Any questions should be addressed to John Newton (PHE), David Hughes (NHS Digital) and Simone Bayes (DH).

1 November 2016

## **Annex B: List of interviewees**

### Public Health England

Anne Mackie – Head of Screening  
Jem Rashbass - National Director for Disease Registration  
Derrick Crook, PHE director national infection service  
Anne-Marie O’Connell – Head Information Management, National Infection Service  
Nick Phin – Interim Deputy Director, National Infection Service  
Dr Mary Ramsay – Consultant Epidemiologist and Head Immunisation, Hepatitis & Blood Safety Department

### NHS Digital

Linda Whalley – Director of Strategy  
Dean White – Interim Strategic Account Manager  
Martin Servers – Medical Director and Caldicott Guardian  
David Hughes – Executive Director of Information & Analytics  
Matt Neligan – Director of Transformation  
Daniel Ray – Director of Data Science  
Jackie Shears – Programme Director for new data collections

### NHS England

Cally Palmer – National Cancer Director  
Morfydd Williams – Cancer Director  
Martin Gore – National Multi-Disciplinary Team clinical Lead  
Peter Clarke – Chemotherapy National Lead

### Department of Health

John Watson – Deputy Chief Medical Officer

### Healthcare Quality Improvement Partnership

Jane Ingham – Chief Executive  
Yvonne Silove – Cancer Audit Lead

### MacMillan

Lynda Thomas – CEO MacMillan Cancer support  
Declan Hunt – Executive Director of Technology  
Julie Flynn – Strategic Data Influencing Lead

### Care Quality Commission

Sir Mike Richards – CQC Chief Inspector of Hospitals

### Cancer Research UK

Sara Hiom – Director of Early Diagnosis and Cancer Intelligence  
Michael Chapman – Head of Cancer Intelligence and impact

### Office for National Statistics

Jennet Woolford – Deputy Director, Health Analysis & Life Events Division  
Nick Stripe – Head of Life Events Processing and Outputs

Additional interviewees

Sir Alex Markham – Director of Research and Professor of Medicine, Leeds University

Professor Eva Morris Senior Fellow leading the Cancer Epidemiology Group

Professor Alison MacFarlane - School of Health Sciences, University of London

David Forman – International Agency for Research on Cancer; author of the Forman Review

Chris Carrigan – UseMyData; former Cancer Registries Director

## Annex C: Suggested PHE principles and considerations

### Background

1. The Tailored Review of Public Health England (PHE) undertaken by the Department of Health (DH) in late 2016 considered, among other functions, PHE's data management activities. The review recommended that "health data should be collected, stored and managed to minimise costs, ensure data security and maximise benefits to patients and the public".
2. To support the implementation of this recommendation, PHE and NHS Digital (NHS D) commissioned Professor Keith McNeil, the NHS England chief clinical information officer, to "undertake an independent review of the data PHE holds and make recommendations on whether any of these data sets in full or in part might be better managed in future by NHS D".
3. PHE understands that the outcome of Professor McNeil's review will be a recommended framework for assessing in a balanced and objective way the relative advantages and disadvantages of transferring any of PHE's primary data collections to NHS D. PHE also understands that Professor McNeil will not be making recommendations on whether specific named data collections should transfer to NHS D. It will be for PHE and NHS D to work together, with support from DH, to agree plans to implement the recommendations of the review and agree the future handing of data collections and timelines for any agreed changes.
4. To support Professor McNeil's review, PHE has produced:
  - a) A catalogue of its primary data collections (i.e. all the direct collections of health status or health risk factor data from patients and the public, or from health and care providers and from environmental and healthcare equipment (exposure source) measurement, that are undertaken or commissioned from other organisations by PHE, or undertaken by PHE on behalf of other organisations); and
  - b) a suggested set of principles to inform Professor McNeil's framework for assessing whether or not any data collections should transfer to NHS D in the future.
5. Underpinning the approach PHE has taken when developing its suggested principles is an absolute commitment to optimising the use of the data collected across the health and care system to improve the safety and effectiveness of the health protection, health improvement and healthcare services provided to patients and the public. PHE has also considered the need to quantify need for preventative and treatment intervention, and to reduce inequality when developing the suggested principles.
6. PHE welcomes the review of its data collection and management functions as an opportunity to work collaboratively with NHS D and DH on a strategy for maximising the beneficial value and use of nationally-important public health data collections.
7. This document sets out the principles and considerations that PHE recommends should be taken into account as part of a balanced and objective framework for determining whether PHE data collections should transfer to NHS D. It sets out a number of



‘fundamental’ principles, which PHE considers to be of the highest importance, augmented by a number of supporting considerations. Finally, it recommends that a structured business impact assessment process should be used to ensure that all the relevant factors needed to determine the relative merits of individual data collections staying with PHE or moving to NHS D are considered in a comprehensive and systematic way.

## **Fundamental data collection transfer principles**

### Protecting the public health services provided to patients and the population

- 8. PHE strongly recommends that no transfers of any of the primary data collections it currently manages should occur where this will adversely affect its ability to effectively and efficiently discharge its core functions as the expert national public health agency and an emergency Category 1 responder.**
9. It is critical that PHE continues to be able to protect the public from threats to health and to work to improve public health and reduce health inequalities – the fulfilment of its remit from the Secretary of State for Health must not be adversely affected by any transfers of its data collections to NHS D.
10. Building on this, PHE strongly recommends that no transfers of any primary data collections that support the real-time or near-real-time provision of patient- or population group-facing public health services should occur. PHE must be able to take rapid action to protect and improve public health, including retaining the ability to dynamically adapt data collections to changing contexts and needs. PHE cannot agree to any transfers of its data collections that could increase the risk of patients being harmed or the level of harm being increased.
11. The primary data collections used by PHE to support direct care include its:
  - a) national and regional microbiological and other specialist laboratory information systems (LIMS) – which provide specialist diagnostic patient information to clinicians and other healthcare professionals;
  - b) health protection incident and case management, outbreak control and surveillance – which provide the patient information used to identify and manage communicable disease cases and radiological, chemical and biological incidents; and
  - c) disease screening programme quality assurance information systems – which provide the patient information used to ensure the provision of safe and effective population screening services, including responding to serious incidents.

### Specialist public health and clinical input, cost efficiency and stakeholder support

12. In addition to ensuring the ongoing provision of safe and effective public health services to patients and the population as whole, PHE strongly recommends that four other fundamental principles must be considered when deciding whether a primary data collection should transfer to NHS D:

#### **1. Public health specialist input**

Many PHE data collections are not automated or mechanistic collections. They rely on specialist public health input and any transfer must preserve this subject matter

expertise to ensure operational effectiveness and strategic management. Much of this expertise is intrinsic to PHE's delivery of its core functions rather than being standalone or specific to the data collection. Therefore, where the integrity of the data collection and the service that relies on it requires specialist public health input DH approval for any move must be sought and PHE's remit and priorities appropriately revised.

## **2. Specialist clinical input**

Similar to point 1 above, many of the screening programmes run through PHE rely on the specialist input of clinically qualified front-line staff. If therefore, there is any transfer to NHS D of contracts, service level agreements or other formal agreements with clinicians, DH approval must be sought and PHE's remit and priorities appropriately revised.

## **3. Cost efficiency**

Any potential transfer should not result in any net increase in the cost of providing the public health service or function reliant on the data collection and analysis. If additional costs or expense are required, specific DH approval will be required and the additional funding agreed prior to any transfer. Any additional costs associated with the transfer of a data collection should not result in additional (unbudgeted) costs to PHE, not agreed with DH and funded in advance.

## **4. Stakeholder support**

Approval must be sought from the specific governance groups responsible for oversight of the data collections prior to any transfer. Consultation with broader partner, stakeholder and user groups should take place to gain broad support for any transfer.

## **Structured business impact assessment**

13. For all the primary data collections currently managed by PHE, the combination of factors that will need to be taken into consideration when assessing the case for transfer to NHS D will be specific to the business and operational context in which each individual collection is currently managed. Alternatives to the wholesale transfer of the staff and technology supporting the collection – such as the provision by NHS D of data processing services, the implementation of interoperability features, and the sharing of data extracts – may be equally effective and potentially more efficient ways to optimise the value of a data collection and so should be considered as part of the transfer assessment process.
14. Whatever the nature of the transfer, there must be in all cases an explicit acknowledgement of the PHE requirement for timely and unrestricted access to the data collection and to the involvement of PHE in the development of the data collection to support the fulfilment of its remit and core functions.
15. To achieve this, PHE strongly recommends that a formal assessment should be undertaken of the impact of any proposed transfer on the effectiveness of any of the public health services and functions which, directly or indirectly and in whole or in part, rely on the data collection. This impact assessment must include consideration of the

fundamental principles set out above, as well as a series of other considerations, including those that are detailed below.

16. Any transfer proposal must be tested through an initial pilot and evaluated to ensure that the implementation plan is sufficiently robust, viable and fully costed before any full transfer of the data collection takes place.

### Supporting data collection transfer considerations

17. PHE recommends that the considerations listed below should be an integral part of the impact assessment process for any proposed transfer of a primary data collection to NHS D:
  - a) **Data collection expertise:** Consideration should be given to the specialist public health expertise that PHE has brought to the development of the data collections it currently manages and to its track record of enhancing a data collection – for example, by improving data quality or increasing the linkages to other data sets – and thereby enabling improvements in the public health service or function based on the data. PHE’s expertise in handling other types of non-patient data (eg. related to dwellings) should also be taken into account when deciding if a transfer is feasible or advisable.
  - b) **Public trust and participation:** Consideration should be given to any potential impact on the public’s consent to participating in data collections. Any proposal to move a data collection should take into account quantifiable and comparable public perceptions of PHE and NHS D in keeping personal data confidential and secure.

Public trust in NHS D’s custodianship of data collections will be influenced by both the public’s knowledge of past HSCIC information governance practices, and also current experience of NHS D’s practice and rapidly evolving re-use strategy. Data subjects may participate less if their trust in NHS D reduces and they have privacy concerns related to uncertainties over re-purposing of data collections. This would fundamentally impair the collections’ fitness for purpose and diminish their public health value.

Furthermore, where it is agreed that a data collection should be transferred, a collection assessed to be of particularly high risk in this regard should be scheduled for transfer later in the overall programme schedule, allowing time for NHS D to demonstrate good stewardship and for public sentiment and the impact on participation to be monitored as the programme develops.

- c) **Patient information:** A proposal to transfer any data collection should consider the patient information implications as part of the formal business impact assessment process. A transfer should not result in a reduction in the clarity and fitness-for-purpose of the information provided to patients on the processing of their personal data. The advice of the Information Commissioner’s Office should be sought where a data collection transfer will entail a substantive change to fair processing arrangements for the collection.

- d) **Data collection burden reduction:** Both NHS D and PHE should consider whether a transfer will reduce the data collection burden (for example, by merging a PHE collection with a similar NHS D one) as well as to whether the burden can be reduced without the collection being transferred (for example, through the rationalisation of duplicative data items across two or more separate collections).
- e) **Data use dependencies:** Many of the PHE primary data collections are used internally for multiple discrete purposes; many are also made available to external users with a lawful and legitimate basis for access. As part of the formal business impact assessment process for ensuring that public health service effectiveness is not adversely affected by a transfer, these internal and external dependencies should be fully mapped and impact-assessed. A transfer should not occur where this will negatively impact on the effectiveness and cost efficiency of any of the public health services and functions which rely in whole or in part of the data collection.
- f) **Statutory function:** Where PHE has a statutory responsibility to collect data – such as notifications of reportable infectious diseases – any transfer of the resulting data collection should not reduce PHE’s ability to discharge this duty.
- g) **Legal and regulatory basis:** The legal basis for PHE’s person-based data collections is derived variously from patient consent, Section 251 of the NHS Act 2006 and the Health Protection Regulations 2010. Other classes of information, including laboratory data, are subject to formal regulations. Any transfer must take account of the existing legal basis and applicable regulatory framework for the data collection and should only be implemented where this is consistent with the associated permissions, or where the legal basis has been altered to enable the lawful transfer of the data collection to NHS D. Formal legal opinion should be sought in instances where the legal basis implications of a transfer are unclear or complex.
- h) **Data access administration:** For any transferred data collection, the administrative process for re-obtaining access to the data and the financial charges associated with this should be minimised. The NHS D data access process should ensure that PHE and the wider public health system continue to have the same lawful and legitimate access to the data collection and that data is made available within at least the same timescales. The financial costs associated with administering access to the data collection should be minimised at all times, and any financial charges that adversely impact on access to the data should be reviewed and approved by DH.
- i) **Data collection development:** A proposal to transfer a data collection should consider whether there are any plans to substantively change the purpose, content, management or operation of the collection, including plans to change the IT platform. Any transfer should not adversely impact on the implementation of these plans unless there is agreement between PHE and NHS D, as well as any other collection sponsors, that these plans will be revised or modified in such a way that does not adversely affect the effectiveness of the public health services based on the data collection.

- j) **Data linkage dependencies:** Allied to the mapping and impact assessment of all the uses of the data collection, the extent to which these uses in turn rely on linkages to other data collections to provide a public health service or function should be taken into consideration. The business impact assessment process should consider whether the transfer will result in an established or planned future linkage between different data collections being made logistically infeasible or substantially more onerous.
- k) **Contracted collections and income generating services:** PHE undertakes some data collections under contract to other organisations. Some of its collections also underpin public health services that are income-generating. Both these considerations should be taken into account when assessing a proposed data collection transfer to ensure PHE will neither be in breach of contract nor experience a loss of income without this change being reviewed and approved by DH.

## Exclusions

18. While the terms of reference for Professor McNeil's review are not specific in this regard, PHE assumes that the definition of a primary data collection excludes management information collected and used by PHE to ensure its day-to-day operational effectiveness and performance. This includes information on corporate service provision (including budgetary information), service performance, human resources, and other aspects of service or function management. Accordingly, these information collections are not included in the PHE data catalogue.

## The role of data in PHE

19. PHE is the expert national public health agency which fulfils the Secretary of State for Health's (SoS) statutory duties to protect health and address health inequalities, and executes the SoS' power to promote the health and wellbeing of the nation.

20. To achieve both its primary function and the priorities set out in its annual remit letter from DH, PHE needs access to a wide range of data and information on the health of the nation. PHE is a data and intelligence-driven organisation – its ability to effectively and efficiently identify and respond to immediate threats and longer term challenges to public health fundamentally depends on it having timely and unfettered access to data and information on the health status of the population, the wider determinants of health and the provision of health and care services to the population of England.

21. The primary data collections PHE currently manages can be classified as follows:

- a) Health protection incident/case management and outbreak control
- b) Vaccination and immunisation services
- c) Chemical, radiological and biological source and exposure monitoring
- d) Communicable and non-communicable disease surveillance
- e) Population disease screening programme management and quality assurance
- f) Microbiological and other specialist laboratory testing and reporting services
- g) Disease registration
- h) Patient- and population-level health and social care service monitoring and evaluation.

- i) Environmental, socio-economic, behavioural, and genetic health risk factor monitoring
- j) Health improvement service marketing and the provision of information, signposting and interventions

22. Examples of such collections can be found on the [data.Gov.uk website](https://data.gov.uk). A more definitive catalogue of collections will be made available at the point the tranche allocations are baselined.

## Annex D: Due diligence checklist for pilot transfer

1. Background information including size of the data set, frequency of collection, time sensitivity of collection, processing and publication requirements.
2. Current issues with collection and processing platforms, including specific technical issues and/or requirements impacting on the transition.
3. Existing plans for development, increase or change in scope.
4. Legal, data security, information governance, legislative and consent considerations.
5. Value for money and benefits realisation including:
  - a. Opportunities for increased transparency of data usage
  - b. Additional linkages/functionality
  - c. Reduction of duplication of collections
  - d. Reduction of the burden of reporting on provider organisations
  - e. Full scale costs including one off transition and ongoing expenditure
  - f. Efficiencies arising and cash releasing opportunities
6. NHS D's capacity and readiness to take on responsibility for each data collection, including opportunities for upgrading and/or replacing existing systems and processes.
7. The capacity of both organisations to auspice the transfers whilst delivering current business requirements and core functions.
8. PHE's requirements as the prime customer regarding access to and timeliness of the data.
9. Interdependencies with any other data collections impinging on core functions of PHE or any other NHS organisation.
10. Alignment with PH&C 2020 initiatives regarding data and system standards, and interoperability.
11. Reasonable timeframes for transition with reference to the timeframes for the different tranches recommended in the body of the document.
12. Specific agreement to be reached around those data collections which will stay with PHE for the foreseeable future (tranche IV).