APPENDIX A: OUR ENGAGEMENT JOURNEY IN MORE DEPTH

This appendix provides more detail on our engagement journey.

Discussions held during the pre-election period. We encouraged key stakeholders to tell us which business questions or problems needed to be addressed by secondary uses data. This resulted in headline focus areas for any proposed enhancements in the secondary uses data landscape. Views were provided by six key stakeholder organisations during this period when wider discussions were limited by purdah restrictions. These organisations were: the Care Quality Commission, Department of Health, the Health and Social Care Information Centre, Monitor, NHS England, and Public Health England. We organised these views according to the priorities of the 5YFV in relation to prevention, quality, and sustainability. These formed the basis of our early priority areas recommendations for new/enhanced datasets.

The following are key examples of the perceived ‘problems’ from this group, which all agreed would be resolved by an improved secondary uses data landscape:

Health and Wellbeing

- How can we identify those at risk of admission? (e.g. elderly patients)
- What is the impact of workforce levels on the quality of care?
- How can we develop an understanding of the quality of mental health services?
- How can we better understand the link between GP appointments and A&E attendance?
- How can we use wider determinants to better understand risk factors?
- How can we understand the prevalence and incidence of key diseases?
- How can we track patients better in the community when discharged to adult social care?
- Can we link community and demographic data to give us a better understanding the prevalence of dementia?

Funding and Efficiency

- How can we generate patient level costs for integrated care across health and social care?
- How cost-effective is a treatment? i.e. how can we link the cost of treatment with its effectiveness?
- How can we measure the performance of GP practices?
- What data is available to look at adult social care support from GP to community?
- What are the best models of primary care?
- How can we avoid another winter crisis?
- How can specialised commissioning co-ordinate with other care better?
- How can we understand what drives cost and variations in cost?

Care and Quality

- How can we better understand the link between GP appointments and A&E attendance?
- Is the level of death and severe harm attributable to problems in healthcare improving?

- How can we develop an understanding of the quality of mental health services?
- What is the impact of workforce levels on the quality of care?
- How effective are re-ablement services in social care and what is the patient experience of these?
- How can we track the unexpected effects of new drugs?
- Is premature death reducing in people with mental illness or learning disabilities?
- How can we improve the provision of care, safeguarding and protection of adults across health and social care?

Focus groups and national workshops (face-to-face). These included a wide selection of stakeholders from our engagement list to support the development of our recommendations, with the aim of:

1. Identifying how and when secondary uses data is currently used.
2. Identifying the limitations of this data and possible solutions.
3. Determining the benefits of these recommendations.
4. Mapping current secondary uses data initiatives.
5. Providing an overview of the work undertaken so far and the vision for the future.
6. Reviewing the emerging priority areas for new data sets and enhancement of current information.
7. Understanding what new information would help the priority areas and how easy it would be to obtain this information.
8. Identifying any other existing initiatives that should influence our NIB 2.2 recommendations.

We also provided attendees with an overview of the emerging vision for the secondary uses data landscape to give them an opportunity to comment and influence proposals.

Subject Matter Expert (SME) one-to-one conversations. These were designed to both consult and inform key stakeholders or primary users of secondary uses data in our top priority areas, including representatives from adult social care, hospital trusts and ambulance services, community care data SMEs, and patient level costing experts (PLICS). We have also spoken to representatives within NHS England about the priority focus required on genomics and are providing joint development of proposals with our colleagues in care.data to support the linking and expansion of information around the GP primary care arena.

A word on patient representation. We engaged at a high level only with patient representatives. This engagement has been limited as users of secondary uses data are not patients generally. However, to ensure we have obtained a patient view and captured some of the issues they perceive in the use of secondary uses data, we did invite patient representation in the form of a representative of Action on Hearing Loss and nursing staff to our engagement workshops. In addition, we asked attendees at our national events to 'think like a patient' and give us their views on how they wanted to see their data used for the purposes of secondary uses.

Rapid Review Group: This body reviewed our emerging proposals and helped shape what became our final recommendations for programmes of work. This group consisted of representatives from NICE, the clinical community, academics, and policy developers.

APPENDIX B: KEY THEMES FEEDBACK

This appendix provides more detail on the key themes raised at the NIB 2.2 National Workshops and the NIB 2.2 focused working groups.

NIB 2.2 National Workshops

Feedback from the two national workshops identified five broad themes in relation to data for secondary uses and Table 1, overleaf gives an overview of those themes.

Table 1: Themes from National Workshops

THEME	EXAMPLE FEEDBACK
Breadth of data	Gaps in the data picture across care settings can compromise decision making: An example for ‘breadth of data’ is the lack of data available from the private or voluntary sectors. Without visibility of this data, there is an incomplete picture of the continuity of care for a patient. For some patients, such as elderly patients, this can be a sizeable gap as they may be making use of private/self-funded services or voluntary services for health/social care needs. Another example is that of gaps within an existing dataset. Data relating to prescriptions in primary care are widely available, but there is considerably less data available on those dispensed and taken. These gaps make it challenging to identify whether patients are making the best use of the prescriptions provided by the NHS and also whether the NHS is getting the best value for money.
Quality of data	Issues with quality can often affect how the data can be used: An example for ‘quality of data’ is the lack of capturing patient morbidities (such as LD or MH) when a patient is admitted to secondary and unplanned care. Without this information it is difficult to assess hospital admissions for patients with LD or MH to determine such things as inequalities of care for patients. Another example is the lack of a common identifier at a person level across the different care settings. This makes it challenging to obtain the true data picture of a patient journey where it crosses care settings.
Linkage of data	Linking data (with shared access) across care settings can reduce burden of data collections: An example for ‘linkage of data’ is the sharing of information between health and social care settings. With the increasing age of the national population, more people are making use of both health and social care services. By sharing and linking data between these two care settings, the data will support more informed decisions in both of these care settings. A similar benefit would apply to other data linkages, such as between primary care and secondary care. Another example is the recognition that data regarding wider determinants of health are available from sources beyond the care settings, such as from DWP and DoE. By creating data links between those sources and the care settings, the data available in the care settings would be enriched and could improve accuracy in predictions of demand.

THEME	EXAMPLE FEEDBACK
Standards for data	Full enforcement of standards can improve data quality: An example for ‘standards for data’ is the presence of national minimum data set exists, but no national data flow exists, such as Community Care. Without a national data flow, local collections may not conform to the national minimum data set standards. Another example is about the standards processes themselves where it was commonly felt that they were unclear and burdensome. In some cases by the time a standard was introduced, it was felt that the world have moved on and the standard was already out of date.
Granularity of data	Data at a greater level of detail would be helpful to meet service needs: An example of ‘granularity of data’, and by far the most commonly raised, is that person level data is not available on a national basis for secondary uses. This makes it impossible to analyse individual patient journeys, to determine such things as costings, progression though a particular pathway, or comparators of care against national or local benchmarks. It also prevents secondary users aggregating data up to meet their own criteria.

NIB 2.2 Focused working groups

Feedback from the four focused working groups identified a number of common themes in relation to data for secondary uses. Although each focused group gave a slightly different context based on their own perspectives, Table 2 below gives an overview of those themes across all the focused working groups. These themes have been considered when developing our recommended four programmes of work.

Table 2: Themes from focused working groups

THEME	OUTLINE & EXAMPLES
Not sighted on existing data	Data exists in parts of the health and care system, is inaccessible for a number of reasons. For example, unaware that the data even exists, the data is known to exist but access is not granted, system providers charge for access to non-contracted data.
Gaining access to data	After recent legislation changes, the application of Information Governance rules has significantly impaired access to secondary uses data in a significant proportion of cases for many of our stakeholders that attended our workshops. The application of Information Governance rules and Caldicott principles is seen as confusing and inconsistent. A clearer steer is needed on implied vs. explicit consent, on what can be seen /can be shared.
Poor data standards/ interoperability	There is a lack of secondary uses data standardisation, poor definition of data standards, and a lack of adherence to those standards. Consistent patient identifiers are lacking, as well as variation in validation of data across care settings, local development and support from national bodies of new data sets. Data sets are incompatible across local, national and international boundaries.
Strategy, policy & implementation	Requirements are often confusing and not joined up across organisations. There is a lack of a cohesive strategy on how or what secondary information should flow to local providers. Information is requested in too short a timescale to deliver. There is no clear national view of what information is required or how to address geographical boundaries.

THEME	OUTLINE & EXAMPLES
Poor Data Linkages Across Patient Journey	A lack of standardised unique ID makes data linkage across patient journey particularly challenging (e.g. NHS Number is not utilised across all care settings).
Data quality and accuracy	Poor data quality hinders benchmarking, and costing figures are unreliable; data includes incomplete records, national datasets don't reconcile to ledgers, hospital site codes are poorly and inconsistently recorded, and there are various inaccuracy issues in the HES publications (e.g. hospital discharge dates don't match HES view). The root cause may originate in the data source (i.e. SUS inputs to HES). Data creators are not motivated or understanding of the need for quality data beyond direct care purposes. Data is inconsistent and cannot be reconciled across systems/needs. There are multiple data entries and data collections across the various care settings. When trying to obtain a joined up picture, there can be variations of values for the same thin, i.e. not a 'one truth' system.
Timeliness of data	There are time lags resulting in out of date data, e.g. the HES publication is 3 months old by the time it is available.
Poor breadth of data	Data sets are missing in many key areas, e.g. winter pressures, social care (including 'hard to reach' individuals), community data, unplanned care, mental health, national transplant data, local authority data models, and patient demographics. Specific data values are missing such as post code, births and deaths, geography, and age of mother.
Outdated systems and technology	Implemented technology doesn't meet the current/predicted business needs. Fragmented systems have limited interoperability. There is little sign of new technologies (such as apps and mobile devices) being exploited.

THEME	OUTLINE & EXAMPLES
Burdensome collections	There are far too many manual collections and not enough automatic extractions.
Poor education or awareness	There are not sufficient training on the value, benefits and use of the data that is available. This applies to both the staff across the wider care settings and also to the general public.

APPENDIX C: PROGRAMMES OF WORK

This appendix provides more detail on the objectives for the programmes of work being recommended by NIB 2.2.

PROGRAMMES OF WORK	OBJECTIVES
Programme 1: Enhancing Existing Secondary Uses Information	1. Improve data quality across health and care to meet business needs 2. Streamline and accelerate the information standards processes including reducing time for introducing standards 3. Enforce data quality and data standards through the governance of NIB and coordinated use of levers across ALBs 4. Improve timeliness of existing data flows to meet business needs and with consideration of burden issues 5. Improve data linkage for secondary uses data assets across health and care, prioritising: • National Clinical Audits • Wider determinants of health 6. Decommissioning collections of data when extractions are flowing reliably 7. Considering ways of making better use of existing data assets, e.g. developing tools and undertaking analysis in response to business needs and exploring predictive modelling.
Programme 2: Enhancing Existing Secondary Information	1. Creation of new minimum core general data sets for the following initial priority areas, in the following priority order: 1. Adult Social Care (care homes) 2. Community 3. Unplanned Care 2. Creation of new minimum core specific data sets for the following initial priority areas, in the following priority order: 1. PLICS 2. Genomics 3. Endorsement and consolidation of efforts in areas where existing programmes of work are already underway to bring about data improvements: 1. Primary care (GP data) 2. Mental Health Data

PROGRAMMES OF WORK	OBJECTIVES
Programme 3: Improving Information Accessibility	1. Publish a known and agreed standardised set of 'rules of access' that can be operated by secondary users and systems and is conformant with laws and regulations 2. Develop and issue a focused access and information governance approach that more effectively supports users and staff across all health and social care settings to execute their business function accurately, efficiently and in a timely manner 3. Provide transparency to the public/patient on how their data is being used for secondary purposes across health and care 4. Provide appropriate access to the data to users for secondary purposes. This may be by a variety of means, dependent on the actual information needed and recognising user needs, including: • Via physical and/or virtual secure data facility/ies, for example - in a secure data facility - where the user accesses the data from a hosted secure environment; the data does not leave this facility • Via analytical tools which allow the user to manipulate and view the data without being able to access the underlying data itself • An extract of the data which is provided to the user 5. In order to facilitate Programme 4 effectively, the user's details and needs must be recorded and understood, irrespective of whichever route they may take to request access to data. i.e. analogous to a Customer Relationship Management (CRM) solution common in other industries 6. Rationalise data linkages initiatives that have grown as a result of onerous information governance requirements: • Primary care data initiatives (CPRD, care.data, etc.) • ALB initiatives (e.g. data repositories and dashboards)
Programme 4: Ensure Secondary Data has the Patient as the Central Beneficiary	1. Ensure patient needs are met through use of secondary uses data initiatives to support greater understanding of their care pathways and make better use of patient centric data generation 2. Ensure secondary uses data remains focused around what can be done to improve the patient experience, improved treatment and innovations in care, reduce the service cost to the public (thus securing the future of services), and provide patients with maximum personalised choice

PROGRAMMES OF WORK	OBJECTIVES
	3. Secondary uses data always created using the patient / person as the central identifier (i.e. match the service provided to the patient, not vice versa) 4. All health and care providers to use a master patient index as the basis around which to gather data (whether it be secondary or primary data) 5. Patient secondary uses data delivery messaging system is standardised using a 'triple standardisation' approach: • defining consistent, patient-centric standards of secondary uses data (modularity for different types of care) • defining the transport mechanism for secondary uses data between care settings (standardised technical wrapper), e.g. use of XML and SNOMED-CT • defining headings for free text (modularity for different types of care) via Professional Standards Records Bureau (PSRB).

APPENDIX D: PROGRESS ON THE 11 FRAMEWORK FOR ACTION OBJECTIVES

This appendix provides a progress statement on the 11 commitments, monitored through the National Information Board's published 2020 Personalised Health and Care Framework for Action.

Table 3: Progress on delivery of the 11 objectives (public commitments made) in the NIB Framework for Action 2020

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
i	By June 2015, the NIB will agree a core 'secondary uses' dataset that all NHS-funded care providers have to make available to support commissioning, regulation and transparency. The dataset will be reviewed regularly and developed in line with general and specific confidentiality requirements, for example those applicable to fertility treatments as regulated by the Human Fertilisation and Embryo Authority (HFEA).	June 2015	April 2016	Deadline met. A roadmap of the core secondary uses datasets was released at the June NIB Leadership Summit which included a list of the 13 priority datasets that were recommended to be implemented. These datasets will support the implementation of the secondary uses information vision and were listed as part of the Vision Roadmap for NIB Work Stream 2.2. Further work to develop the final recommendations for the first suite of secondary uses data to be delivered via the care.data programme was undertaken. Details of which are included in this work stream published at the end of September 2015.
Ii	The NIB will, as part of that initiative, consult with care providers in social, domiciliary and residential care on the development and publication of appropriate data sets, to provide an effective insight into the safety and quality of their services.	N/A	N/A	Care providers are currently being consulted with and will continue to be engaged to delivery appropriate care providers' data sets. CQC's Adult Social Care (ASC) Provider Information Return (PIR) will change as a result of this consultation, as many of the items included will exist as a minimum data set to be collected at the point of registration. CQC's ASC Questionnaire for community services is being reviewed to consider how best to get views of service users and friends/relatives.

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
iii	Subject to on-going evaluation, and with full safeguards, the care.data programme to link hospital and GP data will be extended nationally to other care settings to enable safe data-sharing for better analysis of care outcomes.	N/A	N/A	Good progress continues to be made across all aspects of the care.data programme. The programme is continuing to work with the National Data Guardian (NDG) to agree how the programme can support a review of the arrangements and safeguards in place across each of the pathfinder areas prior to data extraction. Initial assessment is being undertaken to determine the impact of the work to be undertaken by Dame Fiona Caldicott to develop new wording for consent/opt out to be tested in care.data pathfinders as announced by Secretary of State on 2 September. CCG pathfinder project leads have been briefed on the measures announced by Secretary of State and initial implications for the pathfinder stage. Regional Voices events have taken place in all pathfinder areas, with the exception of Leeds (planned for September). These sessions have been well attended and good feedback gathered from each event.
iv	NHS England and Monitor will develop data standards to support new costing, pricing and payment systems to incentivise new models of care and deliver better outcomes for patients.	Five Year Programme continuing into 2020		The Costing Programme is a five-year programme that includes developing costing data standards. The first milestone of the programme is to develop the IT solution to collect PLICS data, for which the project brief and business case are currently in development. There is a plan to have this in place to collect PLICS in the new format from five providers in September 2016. This is led by Monitor and supported by HSCIC and SCCI.
v (a)	The NIB with clinical leaders will review how best to improve coverage and quality of clinical audits in all care contexts.	N/A	Plans available March 2016	NHS England commissions NCAPOP through HQIP which is a rolling programme of 30+ clinical audits. Plans will be shared from March 2016 to address the contribution that audit can make to the 5YFV commitment to measure all pathways of care by 2020.

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
v (b)	PHE will establish a single comprehensive national rare disease registration service that collects and quality-assures data on all rare diseases across the whole populations.	N/A	April 2016	The National Congenital Anomalies and Rare Disease Registration Service was launched 1st April 2015. Initially, PHE will expand the coverage of congenital anomaly registration for all births nationally as this will ensure a robust public health surveillance system is in place. This is a significant step towards achieving a national rare disease registration service as over 70% of rare diseases are present or detected at birth. Systems to collect late onset rare diseases will be rolled out from April 2016 onwards.
vi	DH will publish, by December 2015, proposals to ensure that all central data requirements will be collected once, and that, in future, the vast majority of all central requirements will be through extractions at sources.	December 2015	TBC	This area is to be reviewed as part of the future programmes of work being proposed across NIB work streams as there is still some confusion whether Work Stream 2.2 would be reporting progress on this area, or if it should be considered elsewhere within the NIB. Currently this is a ‘gap’ in our objectives oversight.
vii	The HSCIC will work with NICE to create a new Indicator Library service, which provides access to all the quality-assured nationally agreed indicators, and details the statistical methods that are used to construct them.	N/A	March 2016 – deadline set in HSCIC Business Plan	An existing interim Indicator Library is published on the HSCIC website. There is a recognised need for a permanent solution which is properly work flowed and presented. A project brief has been developed - it has been reviewed by the HSCIC corporate approvals board and an amended version is due for final sign off in mid Sept enabling this work to progress. A senior manager has been appointed within the HSCIC that will own and lead delivery of the library, supporting the Indicator Assurance Service. This is a key deliverable within the HSCIC 2015/16 business plan with an estimated delivery date of March 2016.

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
viii	By 1 April 2015 the HSCIC will publish for consultation its proposals to deliver an enhanced suite of data services, which could provide a core element for the collection and sharing of data and records and the national level.	April 2015	Interim outline proposals published Sept 2015. On-going.	HSCIC proposals in outline for the data service platform have been published in the roadmap for NIB work stream 8. This includes some outline proposals for the types of data services that we anticipate in the future. A number of internal discussions are on-going which need to be completed before consulting more widely e.g. on how the data services platform will align to other corporate programmes which are currently underway or planned.
ix (a)	The HSCIC, CQC, Monitor and the NHS Trust Development Authority (NHS TDA) will publish by October 2015 data quality standards to all NHS care providers, including the progressive improvement in the timeliness accuracy and completeness with which data is entered into electronic records and made accessible to carers and patients.	October 2015	December 2015	The Data Quality Working group of NIB 2.2 has developed proposals that could form the core content for a data quality standard. The aim is to define standards initially for a small set of data items that appear commonly in many data sets - this can then be built upon over time. An outline delivery plan has been developed that aims to make recommendations for the first set of data items and thresholds by Dec 2015 (a small delay from the original Oct 15 date). A draft list of data items has been circulated by HSCIC and Monitor has proposed a scoring mechanism to prioritise these. At the next meeting these will be agreed with a further meeting required to develop the corresponding thresholds. It is important to recognise that this work underway will develop the core content of a data quality standard. Once this is completed a further piece of work is needed to embed and roll out data quality standards including communication and support for providers who will need to implement them. This will require funding and appropriate governance.
ix (b)	The CQC will from April 2016 take performance against these data quality	April 2016	April 2016	Dependent on proposal ix(a) meeting its revised deadline.

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
	standards into consideration, as part of its regulatory regime.			
x	NHS England, will lead on a new Insight Strategy, to be published by April 2015, which will set out proposals for making better use of patient outcomes and experience data, including Friends and Family Test, public surveys, Patient Reported Outcome Measures (PROMs) and related measures, social media analysis, online ratings and feedback.	April 2015	Late 2015/ Early 2016	Insight Strategy Steering Group reviewed the latest draft of the Insight Strategy in September 2015. Positive feedback was received. Next milestones are: • Further 'deep dive on the Insight Strategy' with key stakeholders towards end of September. • Sign off from Simon Stevens, NHS England will be required before publication.
xi	NHS England will work with provider and patient groups to launch new experiments during 2015 to develop patient-centred outcome measures in specialised services and in maternity, and test the potential for their use in reimbursement for services, giving patients a role in determining how much a provider is paid, in part, on their view of the outcome.	End of 2015	TBC	Initial exploratory phase has completed - culminating in the convening of the inaugural programme board, where a recommendation to use the FY15/16 to establish the programme fundamentals was accepted. Stakeholder engagement has continued with the influential leaders in the field (Health Foundation, Private firms, representatives from the Scottish Health Service). Awareness of the programme has been successfully raised through it being the subject of a pop-up workshop at NHS Expo 2015. Next Steps: • The immediate deliverables are; a Pathfinder Site Learning Exchange, an evaluation of the Pathfinder Sites, Exploration and eventual

NO.	COMMITMENT	ORIGINAL DELIVERY DATE	REVISED DELIVERY DATE	UPDATE
				facilitation of a PCOMS summit and; wider evidence scan of the PCOM domain. • A board recommendation to explore a convergence of PCOMS/PROMS programmes continues.

APPENDIX E: ORIGINAL PRIORITY AREAS IDENTIFIED IN JUNE 2015 VISION ROADMAP

This appendix provides the original priority areas published as emerging proposals for new secondary uses data creation by NIB 2.2 in our Roadmap June 2015. At that time, these priority areas were perceived as the ones that if improved, would achieve the biggest benefits across the secondary uses data landscape. The table below was published as provisional proposals (subject to further stakeholder engagement and ratification) within the NIB Work Stream 2.2 Roadmap in June 2015 as “Table 2: Initial assessment of data for secondary uses”. It is replicated (as Table 4) in this updated version of the document for comparison and completeness purposes.

Note: the table below has been updated in terms of updates in the ‘current data’ and ‘key gaps’ columns to provide further clarity. The priority order and rankings remain as originally published.

Table 4: Initial assessment (as published in original June 2015 Roadmap document)

DATA	HEALTH & WELLBEING	CARE & QUALITY	FUNDING & EFFICIENCY	CURRENT DATA	KEY GAPS
Mental health	***	***	***	MHLDDS[1] collects record level data on adults and older people using secondary mental health, learning disabilities or autism spectrum disorder services. It includes services in hospitals, outpatient clinics and in the community. Further improvement work is underway to develop and consolidate various adult and children’s mental health data sets	Waiting time information – work is underway to address this

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[1] MHLDDS = Mental Health and Learning Disabilities Data Set

DATA	HEALTH & WELLBEING	CARE & QUALITY	FUNDING & EFFICIENCY	CURRENT DATA	KEY GAPS
Primary care (GP activity)	***	***	***	GP data is currently used for secondary uses through various initiatives already. For example, CPRD is used when GP data is focused on research. Aggregate level extracts of GP data are used for secondary purposes such as QOF.	There is a lack of information at a personal level from GP practices which would help determine the effectiveness of treatments from this care setting. Additionally, there is no information available about key GP activities such as the number or length of GP consultations taking place.
Adult Social Care	*	***	***	Aggregate adult social care data is currently collected from local authorities on areas including activity, costs and safeguarding. Data is also collected at a record level from experience surveys and DoLS.	Secondary uses data is missing on local providers outside the council network e.g. care homes, and the patient experience of re-ablement services[2].
Community	**	**	***	There is a locally drawn dataset called CIDS[3]. This is a patient level, output based, secondary uses data set on patients who are in contact with Community services.	CIDS flows locally only. There are currently no national flows of community information.
Specialised commissioning (Inc. Systemic Anti-Cancer Therapies)	*	***	***	Different areas of specialised commissioning currently collect their information in different ways through contractual schedules and local differences in contractual requirements.	A current gap exists in the form of national standards for the collection of data on specialised services, both for use in commissioning and in other secondary uses. Better understanding of the existing data landscape is needed to develop proposals which will further use and join this data up across specialised fields and areas.

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[2] Any changes to Local Government data is required to be fully funded

[3] CIDS = Community Information Data Set

DATA	HEALTH & WELLBEING	CARE & QUALITY	FUNDING & EFFICIENCY	CURRENT DATA	KEY GAPS
Unplanned Care (Inc. A&E, NHS111, Out of Hours)	**	**	***	Currently data collections are specifically focused on unplanned settings for payment of services use only (e.g. A&E CDS).	Data collections for unplanned care have gaps in coverage across Out of Hours care, NHS 111, walk-in centres. Secondary uses data provision covering a wider suite of unplanned care would allow the joining up of information to support predictive modelling of demand across the full range of unplanned care settings. In addition, person-level dataset introduction would provide an ability to track people receiving advice and review the follow up care received and impact on their health outcomes. Patient level data flow from main providers of out of hours services could yield approx. 80% of data[4].
Drugs (Prescribing/ Dispensing)	*	**	***	GP practice level prescribing data is available. This covers prescriptions by GPs and non-medical prescribers that are dispensed anywhere in the UK in the community.	Data on prescribing and dispensing for secondary patient care is limited. There is also a gap in patient level data on the provision of prescribing and dispensing drugs within hospitals. This prevents effective secondary purposes data use.
Learning Disabilities	*	***	**	The mental health and learning disabilities dataset(s) (MHLDSS) has been updated and is in the process of being replaced by the new MHMDS which has greater commonality of national information, and has been expanded to include learning disabilities around the autism spectrum disorder.	The mental health minimum data set has yet to be finalised and released into general operation (MHMDS[5]). The lack of this dataset is seen as a key gap in terms of the provision of secondary uses analysis in this area.

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[4] Prior to health restructure, negotiations were underway to deliver this.
[5] MHMDS = Mental Health Minimum Data Set.

DATA	HEALTH & WELLBEING	CARE & QUALITY	FUNDING & EFFICIENCY	CURRENT DATA	KEY GAPS
Costing (Patient Level)	*	*	***	Currently Reference Costs are collected at a high level.	Reference cost data are perceived to be at too high a level to incentivise best practices, support benchmarking, and develop an accurate tariff. Patient Level Information Costing systems (PLICS) is under development to fill this gap proposes to replace the Reference costs collection to provide a more granular set of costing data to support future tariff and benchmarking tools.
Diagnostics	*	**	**	DID[6] collects information about diagnostic imaging tests extracted from local radiology information systems. This captures patient level information and includes referral source, details of test, and waiting times.	Diagnostic pathology (blood tests)[7] data collections are a current gap. Also diagnostic physical examinations and endoscopy data for secondary uses is not available.
National Clinical Audits	*	***	*	A range of clinical audits are currently commissioned in primary and secondary care related to specific diseases. Other Audits are commissioned separately on a case-by-case basis.	National Clinical Audit data should be included in other data sets rather than having to commission a specific audit. Further consideration on how quality improvement activity could be captured in other data sets should be made.
Wider Determinants of Health	***	*	*	Data on wider determinants of health are requested at a local level for ad hoc purposes e.g. smoking data, exercise levels across a region, air quality, etc.	No national minimum data set exists on key aspects of the wider determinants of health. If this existed it could be linked with other data for secondary purposes e.g. to provide a better picture of health and its influencing factors to the government and interested parties.

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[6] DID = Diagnostic Imaging Dataset.

[7] Originally part of care.data but was paused.

DATA	HEALTH & WELLBEING	CARE & QUALITY	FUNDING & EFFICIENCY	CURRENT DATA	KEY GAPS
Workforce	*	*	**	The national workforce data set ensures that all suppliers of NHS funded care provide workforce information in an agreed format. Some issues with quality and completeness of this data exists, particularly for data related to primary care staff. There is also only limited information available about bank staff.	More data needs to be provided on Agency staff. The only data available is via a return from Trusts to DH about overall agency expenditure. No data exists on numbers of agency staff, staff groups, where they work or their cost. Improvements in the quality and completeness of primary care and bank staff would also be a benefit.