NATIONAL INFORMATION BOARD
Personalised Health and Care 2020

WORKSTREAM 2.2 FINAL ROADMAP
Give professionals, patients and carers access to the data they need

Developing a roadmap for comprehensive data on the quality, efficiency, and equity of health and care services for secondary uses

September 2015

Final Version

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1 EXECUTIVE SUMMARY

In November 2014, the National Information Board (NIB) published a Framework for Action to transform outcomes of health and care for patients and the public by transforming the use of data and technology. It set out clear objectives to raise the performance of the NHS and social care system through the use of digital technologies.

NIB work stream 2.2 (NIB 2.2) was established in early Spring 2015, having a shared objective with work stream 2.1 to support the Framework For Action's objective of "Giving the right people access to the health and care data they need". NIB 2.2 is focused on enabling access to health and care data in the secondary uses data arena, specifically aimed to:

"Develop a roadmap for comprehensive data on the quality, efficiency and equity of health and care services for secondary uses (i.e. all uses that are not direct care)"

Secondary uses of information include commissioning, regulation, planning, performance management and research.

The work of NIB 2.2 has been guided by three principles set out in the NHS Five Year Forward View[1], namely by focusing on the role of data for:

1. Health and wellbeing ("prevention")
2. Care and quality ("quality")
3. Funding and efficiency ("sustainability")

This document sets out the Final Vision Roadmap of NIB 2.2 to improve the quality, consistency and coverage of secondary uses data. It does so by identifying the top priorities for data, setting out a five-year work programme to deliver these data, and describes the benefits to the sector that will be realised by having better data for secondary uses.

Text Box 1 summarises the core principles and dependencies of secondary uses.

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[1] www.england.nhs.uk/ourwork/futurenhs/

Text Box 1: Secondary uses data core principles and dependencies

VISION: SECONDARY USES DATA CORE PRINCIPLES AND DEPENDENCIES

All health and care information follows the patient on their journey.

Health and care data are captured in a digital patient record once at the point of care, throughout the patient pathway and across all health and care settings. These data will be generated as a patient moves around the system and will follow them between care settings.

Data quality will be improved by implementing standard data conventions including *triple standardised* formats, namely (1) standardised message wrapper, (2) standardised text and information capturing conventions, and (3) uniform coded information conventions. Data threshold definitions will also be applied, such as the validity of the data, data punctuality, etc.

A 'side feed' of the patient's data, are sent to the HSCIC for linkage at a patient level through a person index. Secondary uses data thereby become patient-centric. Eventually, these electronic flows of information will enable the majority of manual data collections and surveys to be withdrawn, which will also enable secondary uses data to be provided in a more timely way.

Access to secondary uses data by appropriate users will only be made in accordance with legal requirements and the patient preference models that will be recommended by Dame Fiona Caldicott's data security and data sharing review.

The resulting secondary uses data landscape must be flexible enough to support future needs and to enable data to improve the health and wellbeing of the nation.

Our ambition is to ensure that we can make the best use of the secondary uses data asset to deliver a full range of benefits to patients and the public.

Our vision is for

"The provision of a complete set of patient-centric information covering all episodes of care, regardless care of setting, that is maintained over time and contains all key data required for secondary uses purposes. This information will be generated as the patient moves around the system and will follow them in real time between care providers."

This complete set of patient-centric data will:

- generate as the patient moves around the system and will follow them in real time between care providers,
- cover all episodes of care, irrespective of care setting,
- be maintained over time,
- contain all of the data required for secondary purposes and
- be made more widely available for secondary purposes, in accordance with the legal and regulatory framework.[2]

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[2] Dame Fiona Caldicott,, as National Data Guardian, will provide public and transparent scrutiny on the safe use of personal health and care data

This vision is fundamentally different from the situation today, where data are largely organised around care settings and are not always linked together around the patient. This new approach will enable new insights that are simply not possible at present. For example, an ability to follow the care history of individuals, track activities that cross different care settings, diagnose the root cause of increasing A&E wait times, or determine the underlying reasons for financial pressures faced by NHS Trusts. It will also have the flexibility to support new models of care as they emerge. Data collected about an interaction between a patient and their care provider will, in future, follow standardised information protocols, irrespective of the setting in which that care was delivered (i.e., whether in a GP surgery, community hospital, walk-in centre, acute hospital, care home, or any other setting).

Our vision therefore requires secondary uses data to be of high quality: they must be collected consistently, covering all patients, settings and geographies. Today, the quality of data is highly variable. Certain data fields are often left blank or are set to default values; crucial information is sometimes omitted; in some cases, data are collected locally but do not flow nationally or do not adhere to national information standards; in other cases, issues with the quality of data are not conveyed back to the person who entered the data.

In order for us to achieve this new paradigm, we propose the following suite of programmes of work:

Programme 1: Enhancing existing secondary uses information – improving the quality, timeliness and linkage of data across all care settings; better analysis using existing assets; improving the quality of post-analysis information (assets and products); streamlining the data standards processes and decommissioning duplicated information.

Programme 2: Add new national secondary uses data – providing new secondary uses information flows. The top priority areas are (1) a comprehensive GP data set (2) an improved mental health datasets (3) adult social care, (4) unplanned care, and (5) community care. For all data sets, it will be important to collect information on the outcomes that matter most to patients. In addition, separate streams of work are recommended on genomic data and on Patient-Level Information Costing Systems (PLICS).

Programme 3: Improving information accessibility – improving existing access to data via secure data facilities and through the provision of appropriate secure data access tools. This work will be done whilst respecting legal and regulatory requirements and will be informed by Dame Fiona Caldicott's review of confidentiality and data security.

Programme 4: Ensure that secondary uses data have the patient as the central beneficiary – building a patient-centred culture for the provision of secondary uses data. The proposed mechanisms to support this approach include moving towards a master patient index and using 'triple-standardised' messaging conventions to ensure that data follow the patient on their journey through all parts of the NHS and social care.

This document begins by setting out our vision for secondary uses data. After explaining our process of engagement with a wide range of stakeholders, we go on to describe a five-year work programme to achieve our vision, including our recommendation for what should be the highest priority new data sets. We conclude by listing the benefits to the health and care sectors

that we believe will be achieved through these programmes for improving data for secondary uses.

2 OUR VISION FOR THE SECONDARY USES DATA LANDSCAPE

At the moment, much of the health and social care data in England is fragmented, incomplete and often inaccessible. A great deal of the data and information are largely organised around care settings and are not always linked appropriately around the patient. Often the information is collected or published in aggregate forms, For example, the Hospital Episodes Statistics (HES) publication is focused on information from acute (secondary) care only; the Mental Health and Learning Disabilities Data (MHLDDS) is focused solely on mental health and learning disabilities[3]; and the Community Information Data Set (CIDS) is focused solely on community care. For other important settings of care, such as GP practices and ambulance trusts, there are currently no nationwide dataset of patient-level data.

The quality of data currently captured is highly variable. For example:

- Hospital episodes data suffers from numerous quality issues: some fields are left blank, others may be filled with default values or have incorrect coding.
- The Mental Health data set is improving, but it currently omits key information, such as costs and outcomes, which limits its usefulness.
- Community data are collected locally but do not flow nationally.
- Some adult social care data are collected by local government, but social care data are inconsistent and do not adhere to any national information standards.
- Cost information is not available at the patient level, so there is no way of benchmarking value-for-money in any care setting.

In short the modern health and social care service is unable to exploit the full potential of the data and information available to it, to support in meeting its business needs.

The scope of care settings covered in our vision, described in this document, includes primary, secondary, and tertiary care settings as well as unplanned care settings, community care settings, and palliative care and social care. It covers all care settings regulated by the Care Quality Commission (CQC), including all care funded or provided by the NHS. The scope of users of secondary uses data includes Arm's Length Bodies such as CQC, Monitor, Public Health England; commissioners of care services; providers of care services; local authorities; and researchers.

A summary of our secondary uses data principles and dependencies is provided in Text Box 1.

Our strategic vision is to link data from all care settings, covering all episodes of care, using the patient as the key linkage point and to maintain this patient-centric data over time. This approach would enable analysts to achieve insight on a number of issues that are simply not possible at present. For example, to follow the care history of individuals, to track pathways of care that cross care settings, to diagnose the root causes of increasing A&E wait times in

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[3] The MHLDDS is due to be replaced from early 2016 with the Mental Health Services Data Set (MHSDS) this consolidates and replaces a number of existing information standards and incorporates additional requirements in support of learning disability services, waiting times and Children and Young People's Improving Access to Psychological Therapies (CYP IAPT). It covers both Children's and Adult mental health services and will gather data from a range of providers and settings.

different parts of the country, and diagnose the reasons for financial pressure on different parts of the health service. By implementing our strategic vision, we will achieve a secondary uses data landscape that reflects the changing environment and which better reflects the ways in which health and care services are now being provided. For example, there would be better support for those services that were traditionally provided in acute hospitals but which are now increasingly moving to community and primary care settings. This shift will accelerate as the new care models in the Five Year Forward View (FYFV) are piloted and then adopted at scale.

To achieve our strategic vision, secondary uses data will need to be of high quality, be consistently collected, and cover all patients, settings and geographies. We believe that data collected about a specific interaction between a patient and the health and care system should follow standardised information protocols, and should be collected and made available in standardised ways, irrespective of the setting in which that care was delivered.

Our strategic vision cannot be delivered overnight and will be met through a number of programmes of work focusing on different aspects of improvements to secondary uses data.

Short Term (<2 years)

By focusing, in the short term, on improving the quality of data already captured as well as extending the breadth to capture more information for secondary uses, early benefits can be realised through improved decision-making for secondary purposes.

Where tactical solutions are identified which could realise benefits quickly, then NIB2.2 will recommend that these are adopted.

Medium Term (2-5 years)

In the mid to longer term, we propose that improvements in the data recording at the point of care will include the date and time of the care activity, the care organisation(s) and the individual care provider(s) involved in the activity, the care activity provided (including investigations and treatments), diagnoses, and the outcomes of the care activity. These data will be recorded at the point of care and will be linked together for that individual patient in order to create a patient-centric set of data (once appropriate technologies are in place). Over time, a picture of care encounters will build up for millions of patients, which will be made available to analysts working to improve care services.

Long Term (>5 years)

In the longer-term, we propose that data for secondary uses be collected once at the point of care, and then made available to appropriate stakeholders in accordance with the legal and regulatory framework. We envisage that the patient-centric data will not necessarily be a single data set itself, but rather a collection of data sets linked at the patient level. Our vision will enable information about a patient to follow them on their care journey as they receive treatment across any of the care settings.

This requires the adoption of standardised approach for information flows across the care settings and a uniform capability to link patient-centred data. This could be achieved through the introduction of a master patient index and the use of 'triple-standardised' messaging conventions.

Figure 1 illustrates the triple standardised message wrapper described in our vision. This recommendation builds on principles of data capture recommended by the Professional Records Standards Body, which is supported by the Academy of Medical Royal Colleges.

Figure 1: Illustration of Triple Standardisation Messaging
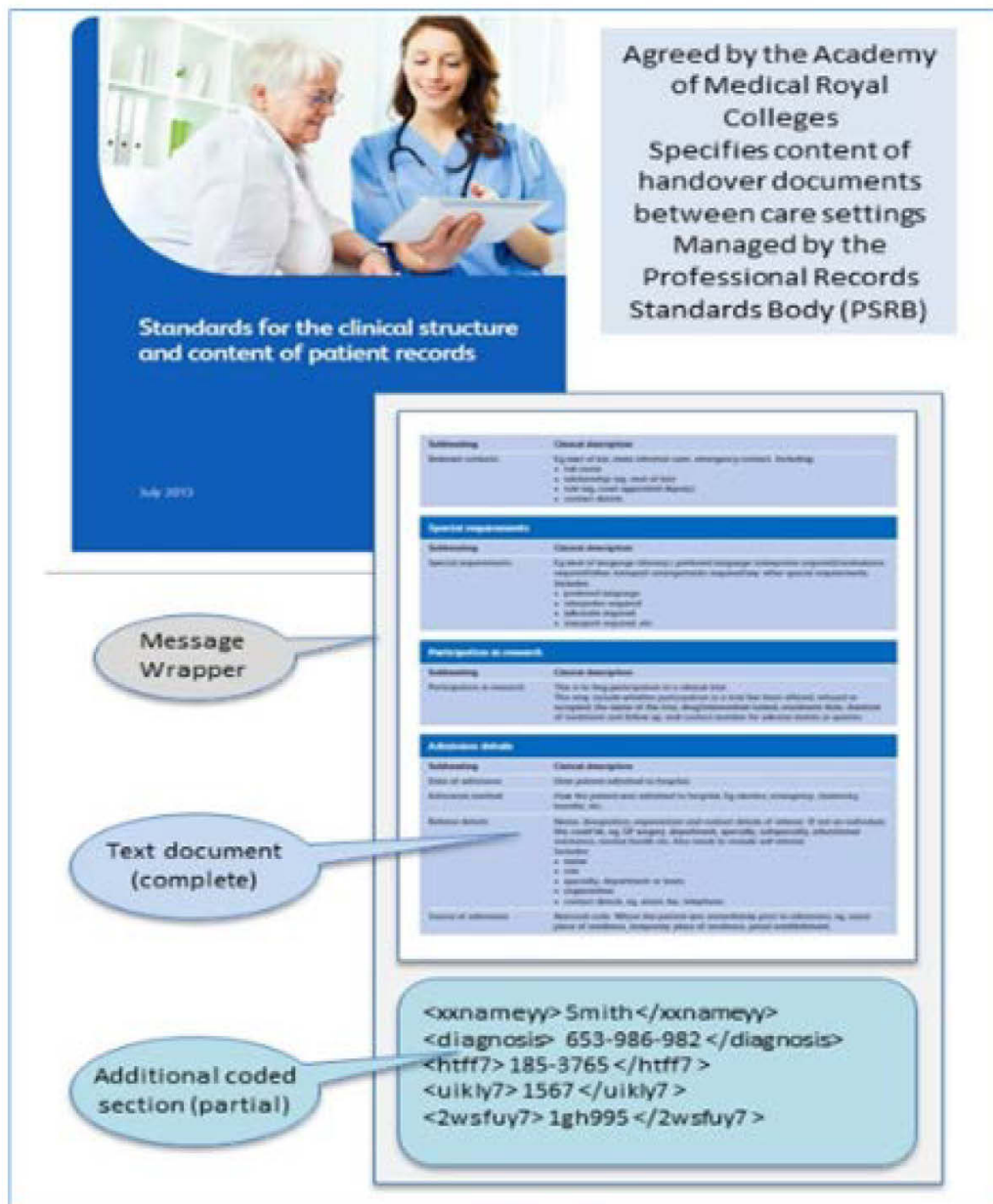
3   ENGAGEMENT ACTIVITIES

3.1   Overview of Engagement

Our vision for secondary uses data was developed in collaboration with a wide range of stakeholders. We asked stakeholders to identify any problem areas with secondary uses data and to suggest ideas for solutions. We incorporated their feedback into our programmes of work.

Further information about our engagement can be found in APPENDIX A.

Over the spring and summer of 2015, we engaged with over 200 people drawn from a wide range of stakeholder groups, including:

- Arm's Length Bodies of the National Information Board[4]
- Clinical Commissioning Groups
- Commissioning Support Units
- Health and care providers
- Social care teams
- Local government
- Clinicians
- Charities
- Universities
- Think tanks
- Public Health
- Adult social care
- Health and Social Care Information Centre
- Technical systems providers (via Tech UK)
- Patient and public representatives
- Voluntary Sector

As our recommended programmes of work move into the next phase of work, we will engage further with stakeholders.

3.2   Initial Engagement

During the pre-election period, we sought the views of six organisations in relation to secondary uses data, namely the Care Quality Commission, the Department of Health, the Health and Social Care Information Centre, Monitor, NHS England, and Public Health England. We organised our findings according to the priorities of the 5YFV (i.e. prevention, quality, and sustainability).

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[4] Arm's length bodies from within the National Information Board cover over 20 organisations from across the health and care sector including, health and care service providers including the Department of Health and Public Health England, technical information and systems providers such as the Technical Design Authority and HSCIC, Regulatory bodies such as Monitor and CQC plus charities, voluntary organisations and other organisations involved in information management across health and care. A full list can of NIB ALBs can be found in the National Information Board paper: 2020 Personalised Health and Care: A Framework for Action.

Working with these organisations, we developed a list of core business questions that need to be answered by an improved secondary uses data, for example

- "How can we identify those at risk of admission?",
- "How can we generate patient level costs for integrated care across health and social care",
- "How can we better understand the link between GP appointments and A&E attendance?"

For further details, see APPENDIX A.

3.3 Post-election Engagement

Once the pre-election restrictions on engagement were lifted, we engaged with a wider group of stakeholders through four focused working groups, two national workshops, a series of 1:1 meetings, and a rapid review group. See Figure 2.

Figure 2: Post-election stakeholder engagement

Engagement	Purpose	Target Audience
4 X Focused Working Groups: 1) Charities, Academics, Researchers + Think- Tanks 2) NIB ALB's 3) Providers, Local Government + Social Care 4) Commissioners (CCGs & CSUs)	• Understand current uses of secondary data • Understand limitations & solutions • Map secondary uses data initiatives • Map current data initiatives	Secondary uses data users
2 x National Workshops	• Gain a clearer understanding of specific new secondary datasets need to be developed to improve the landscape • Capture a list of initiatives that are currently underway to improve secondary uses data • Undertake an initial health check of 13 priority areas	All those interested in secondary uses data
Series of one-to-ones	To further information in relation to 13 'priority' data set areas	Those with a specialist interest in one of the 13 priority areas
Rapid Review Group	To receive comments and feedback from subject matter experts on emerging proposals and publications	'Tested' our early vision roadmap thinking and scope of secondary data uses

Stakeholder Categories Engaged

- Voluntary sector
- Patient and public representatives
- Citizens/patients
- Commissioners/CCGs
- Providers
- Social care
- Royal Colleges
- Clinicians
- Scientific bodies
- Researchers/academics
- Users/customers.
- Public health and social care teams in Local Authorities

200+ ✓

For further details of our findings, see APPENDIX B.

4 OUR RECOMMENDED PROGRAMMES OF WORK

As a result of the feedback from our stakeholder engagement, NIB 2.2 is proposing a number of programmes to deliver the key improvements that are required in secondary uses data. These recommendations include listing the care settings in which improvements in data are most urgently required.

4.1 Priority Setting

Our engagement has led us to focus on which areas of health and social care should be the priority for collecting data. Table 1 sets out the relative priorities of different areas according to the three 'lenses' of the 5YFV, namely prevention, quality and sustainability. Note that this list is by no means exhaustive: other data sets will be added after the delivery the initial priority data sets.

Table 1: Priority areas of data for secondary uses

FIVE YEAR FORWARD VIEW THEMES			
Data	Health & Wellbeing (Prevention)	Care & Quality (Quality)	Funding & Efficiency (Sustainability)
Adult social care	✓	✓	✓
Unplanned care	✓	✓	✓
Community	✓	✓	✓
Patient-level Information Costing Systems (PLICS)[5]		✓	✓
Genomics[6]	✓	✓	
Primary care (GP data)	✓	✓	✓
Mental health	✓	✓	
Wider Determinants of Health	✓	✓	
Drugs	✓	✓	
Specialised commissioning	✓	✓	✓
Learning disabilities		✓	
Diagnostics	✓	✓	
National Clinical Audits		✓	
Workforce		✓	✓

5 PLICS was included in the original Vision Roadmap entitled as 'Costing's

6 Genomics was a late addition to considerations as a result of one to one stakeholder discussions in potential 'hotspot areas'.

Figure 3 shows a RAG ratings 'heat map', which was created using the criteria defined in Table 2 and demonstrates the hotspot areas that stakeholders told us required new or significantly enhanced data sets.

Table 2: RAG criteria for heat map

RAG Rating	Priority	Programme of work	Data availability and accessibility
🔴 (red)	High	No programme exists	No data available, or data available with significant deficiencies
🟠 (amber)	Medium	Programme exists but needs development	Data available, with some deficiencies
🟢 (green)	Low	Programme exists and is active	Data , with no or minor deficiencies

	Adult Social Care	National Clinical Audits	Community	Costings (incl, PLICS)	Diagnostics	Drugs & Devices	Learning Disabilities	Mental Health	Primary Care	Specialised Commissioning	Unplanned Care	Wider Determinants	Workforce
Priority	red	amber	green	amber	green	red	amber	green	amber	amber	amber	green	red
Programme of Work	amber	amber	amber	amber	amber	amber	amber	green	green	red	red	amber	red
Data availability and accessibility	red	amber	red	red	red	red	red	amber	red	red	red	amber	amber

Figure 3: Heat map for priority areas of data for secondary uses[7]

Note: Genomics was not considered in the construction of the heat map, as the heat map based on the findings of the wider stakeholder engagement.

It should be noted that our four programmes of work are currently recommendations that are under review as part of the wider NIB proposals for the Comprehensive Spending Review 2015 to 2020. Their delivery depends on appropriate funding being secured as part of this process.

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[7] Genomics is not shown in the heat map, as it was not covered in the national workshops or focused working groups.

4.2 Proposed Programmes of Work

Based on our discussions with stakeholders, we have concluded that to improve the secondary uses data landscape we need to focus on four areas:
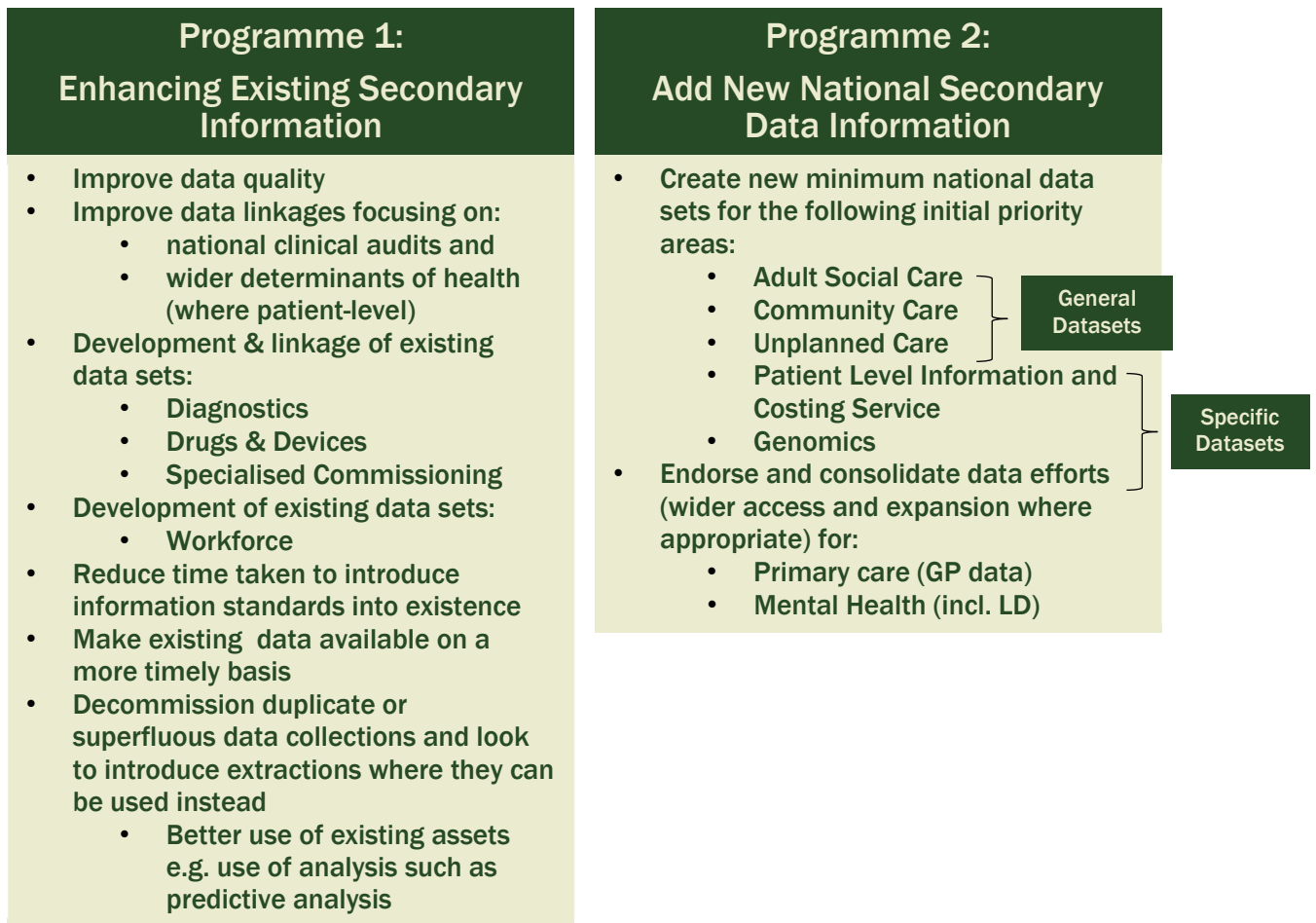
1. Enhancing the secondary uses data that already exist – making them more reliable and removing unhelpful boundaries. In addition, we need to ensure that the systems for approving new datasets are more streamlined.
2. Adding new datasets to improve the breadth of coverage of secondary uses data across health and care sectors.
3. Improving access to secondary uses data – our engagement revealed many instances where data are not flowing efficiently to those who need it in order to improve care services.
4. Ensuring that data are centred on the patient not the care setting. This represents a fundamental change in the way secondary uses data are generated, collected, and made available. It has the potential to provide the greatest benefit for patients and taxpayers, as it will ultimately provide a more holistic picture of the health and care of the population. In turn, this change will lead to improvements in entire care pathways and in the sustainability of high quality care services.

NIB 2.2 recommends these four programmes of work to move the health and care sector towards our vision – focusing first on a number of priority areas which our stakeholders tell us would deliver most benefits to the health and wellbeing of the nation.

Figure 4: Programmes of Work 1 & 2

Programme 1: Enhancing Existing Secondary Information	Programme 2: Add New National Secondary Data Information

• Improve data quality
• Improve data linkages focusing on:
   • national clinical audits and
   • wider determinants of health (where patient-level)
• Development & linkage of existing data sets:
   • Diagnostics
   • Drugs & Devices
   • Specialised Commissioning
• Development of existing data sets:
   • Workforce
• Reduce time taken to introduce information standards into existence
• Make existing data available on a more timely basis
• Decommission duplicate or superfluous data collections and look to introduce extractions where they can be used instead
   • Better use of existing assets e.g. use of analysis such as predictive analysis
	• Create new minimum national data sets for the following initial priority areas:
	   • Adult Social Care ⎤
	   • Community Care ⎬ General Datasets
	   • Unplanned Care ⎦
	   • Patient Level Information and Costing Service ⎤
	   • Genomics ⎬ Specific Datasets
	• Endorse and consolidate data efforts (wider access and expansion where appropriate) for: ⎦
	   • Primary care (GP data)
	   • Mental Health (incl. LD)

Programmes 1 and 2 (Figure 4) can be summarised as improving data content across the secondary uses data landscape. Programme 1 addresses issues with the current data landscape; Programme 2 looks to extend the data content by developing and implementing new data sets in key areas of the secondary uses data landscape. With the exception of genomics and PLICS, which have separate, existing programmes in place, we anticipate that these data sets listed will be delivered through the care.data programme. These datasets will therefore be provided as recommendations to care.data for incorporation in their future phases. They can be grouped as follows:

- Endorsing and consolidating efforts in two areas where programmes of work are already underway to bring about improvement to the data available:
  - o primary care (GP data, which constitutes Phase 1 of the care.data programme)
  - o mental health data (including learning disabilities)
- Creating new minimum core *general* data sets for, the three highest priority areas:
  - o adult social care
  - o unplanned care
  - o community care

- Improving the development and linkage of existing or emerging data:
  - o national clinical audits
  - o diagnostics
  - o drugs and devices
  - o specialised commissioning
  - o wider determinants of health (where patient level)
- Supporting the creation of new minimum core *specific* data sets for two priority areas, in their respective programmes:
  - o genomics
  - o patient-level information and costing systems (PLICS).

As some wider determinants of health and workforce data are not patient level data, these are excluded from any initial list given to the care.data programme.

Figure 5: Programmes of Work 3 & 4

Programme 3: Improve Information Accessibility	Programme 4: Ensure Secondary Data has the Patient as the Central Beneficiary
• **Publish and adopt an agreed and transparent set of standardised 'rules of access' for secondary users and systems, conformant with legal requirements.** • **Provide secure physical & virtual data access facilities and tools.** • **Provide a CRM (or equivalent) to track requestors of secondary uses data via secure facilities** • **Rationalise data linkages initiatives that have grown as a result strict information governance requirements.**	• **Secondary data to be built around following the patient on their journey.** • **Secondary data always created using the patient as the central identifier (match the service to the person, not vice versa)** • **All health and care providers to use the master patient index as the basis for data.** • **Secondary data to support the highest standards of care and safety for the patient.** • **Support transparency of secondary data transmission via triple standardised messaging, interoperable systems, and pseudonymisation.**

Programme 3 (Figure 5) can be summarised as improving accessibility to data. It is important to stress that patient trust and confidentiality remains a core principle and that any changes in access or use of secondary uses data will still conform to the appropriate laws and regulations.

Programme 4 (Figure 5) can be summarised as ensuring that any improvement to the secondary uses data landscape has the patient at its heart.

5 ANTICIPATED BENEFITS FOR CARE SETTINGS

This section provides details of the anticipated benefits of our proposed programmes of work. Against each of these benefits, we provide an indication of where they support the Five Year Forward View to show how our vision and roadmap supports the principles of Health and Wellbeing (prevention), Care and Quality (quality), and Funding and Efficiency (sustainability), and whether the benefits are primarily cash releasing, societal or qualitative.

5.1 Continual Improvement of Care for Patients

Our vision is that good data underpins continuous service improvement in care for patients and to ensure that the best care and treatment is available for all through empowering commissioners and providers of care. The improved identification of trends and removal of unwarranted variation will lead to better evidence-based decision-making.

Our vision can be achieved by extending the secondary uses data available through new data collections[8] where insight is lacking due to an absence of data; by enabling national collections where only local collections exist; and by ensuring data standards are introduced and mandated more quickly. Together, these will lead to a higher quality and more consistent national secondary uses data landscape.

5YFV principles met: health and wellbeing (prevention); care and quality (quality); funding and efficiency (sustainability) – primarily cash releasing benefits, qualitative and societal.

5.2 Improved Efficiency and Cost Savings across the Care Sectors

Our vision is to provide better and more efficient data to help release some of the several billion pound funding gap by supporting the improved design of services and increased productivity.

This vision can be achieved by more effective secondary uses data that focus on the activity, quality and cost of services provided to patients – thereby allowing the management of high value patient services to be improved, and the sustainability of the health and care system to be better supported into the future. Practical cost saving benefits will be released by improving productivity, the provision of more complete, accurate and detailed secondary uses information (including costs at a patient level); reduction in the overheads for data cleansing; reduction in the number of discrete data collections; increased use of automated data extractions; and improved data analysis tools that identify and benchmark solutions.

Together, these will lead to a more effective use of secondary uses data, enabling healthcare to be delivered efficiently through a better understanding of activity, cost and quality, driving high value services and enabling sustainability of the system as a whole.

5YFV principle met: funding and efficiency (sustainability) – primarily cash releasing benefits.

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[8] The use of collections here is meant to infer an automated extraction as the preferred mechanism to avoid the additional burden of more manual collections, wherever possible.

5.3   Improved Measurement of the Standard of Care Provided to Patients

Our vision is to enable informed decision-making, informed by measurable criteria along patient journeys (both activities and outcomes) through care pathways.

This vision can be achieved by ensuring that data sets support the measurement of patient care regardless of care setting; addressing gaps in secondary uses data along care pathways; and linking data across care settings and pathways. Together, these will lead to decision makers being able to identify, predict and respond more quickly to changing needs or to services that are failing along care pathways.

5YFV principles met: health and wellbeing (prevention); care and quality (quality); funding and efficiency (sustainability) – primarily qualitative and societal benefits.

5.4   Improved Treatment Outcomes for Patients

Our vision is to enable research studies to influence services and policies, in order to improve patient care and safety.

This vision can be achieved by improving the quality and breadth of data available to researchers; improving data linkage across care settings; and by improving access for researchers to the wider and more robust secondary uses data. Together, these will enable research of the whole population, help to identify the numbers, needs and experiences of people affected by illnesses, and increase the robustness of research geared towards improving patient outcomes.

This benefit is predicated on building and retaining public trust so that they are confident to allow their data to be used for these purposes.

5YFV principles met: health and wellbeing (prevention); care and quality (quality) – primarily societal benefits.

5.5   More Targeted Services for Patients and the Public

Our vision is to enable commissioners to provide better targeted services across the wider care settings and support opportunities for improved public health initiatives.

This vision can be achieved by improving data linkages across care settings; ensuring that secondary uses data supports varying levels of aggregation (for example supporting geographic boundaries); and ensuring that patients have greater access to information on the wider determinants of health; encouraging take up of public health initiatives. Together, these will lead to a more holistic, patient-centred view, supporting a broader and more complete picture of care pathways, and will identify the changing needs of patients on which to focus new or existing care services and public health initiatives.

5YFV principles met: health and wellbeing (prevention); care and quality (quality); funding and efficiency (sustainability) – primarily societal and qualitative benefits.

As further benefits continue to be generated, they will be assessed as we progress through to delivery of our recommendations. See APPENDIX C for further details.

6   NIB 2.2 FRAMEWORK FOR ACTION 11 OBJECTIVES

6.1   Progress to date

Within the NIB 2020 Personalised Health and Care Framework for Action, the NIB 2.2 work stream was tasked with overseeing the reporting of 11 objectives for improving the secondary uses data landscape. These objectives are each allocated to one or more ALBs. They represent milestones in the overall implementation roadmap for secondary uses data and support the improvement of the secondary uses data landscape. The role of NIB 2.2 is to provide an oversight of these objectives, report on their progress and provide a strategic steer where appropriate.

As a demonstration of the role of NIB 2.2 in relation to the delivery of these commitments, one of the NIB 2.2 Framework for Action objectives relates to oversight and reporting of the extension of the care.data programme. In this instance NIB 2.2 provides policy steers (in the form of the priority datasets that will be considered in future phases of the care.data programme) but is not responsible for the final delivery of care.data, which remains the responsibility of the care.data programme board.

A report on the progress of each of these initiatives can be found in APPENDIX D.

7   NEXT STEPS

Following the final NIB 2.2 recommendations detailed earlier in this paper, the next step is for the NIB 2.2 recommended programmes of work to be assessed under the umbrella of the National Information Board to agree if our proposals will be included in the 'target portfolio' of programmes to be delivered from April 2016 onwards. By the end of November 2015, the National Information Board anticipates that it will be in a position to announce which programmes of work will receive funding.