NATIONAL INFORMATION BOARD

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Personalised Health and Care 2020

WORK STREAM 2.2 ROADMAP

Giving the right people access to the health and care data they need

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

June 2015

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1 CONTEXT

The National Information Board (NIB) Work Stream 2.2 has been established 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)". This in turn will support the NIB objective of "Give the right people access to the health and care data they need."

At the NIB leadership meeting in March, two objectives for Work Stream 2.2 were agreed:

1. To provide oversight of the delivery of the commitments in relation to comprehensive data in the NIB Framework[1] and;
2. To deliver, by June 2015, a plan for developing the core secondary uses dataset development (rather than specifying the dataset itself).

Over the next 12 months the Work Stream has three deliverables[2]:

1. *June 2015: Vision roadmap* – which will outline our vision for secondary uses data in health and social care.
2. *September 2015: High priority roadmap* – which will specify programmes of work for those areas of the vision roadmap identified as high priorities (e.g. who will deliver, by when, cost, etc.).
3. *May 2016: Detailed roadmap* – as above, for the medium and low priority areas.

The Work Stream will also review existing programmes to improve the collection of data, with a view to rationalising them (e.g., to reduce unhelpful duplication, streamline access, reduce the burden professionals, and improve efficiency).

The Work Stream is guided by the three principles set out in the Five Year Forward View:

1. Health and Wellbeing (prevention)
2. Care and Quality (quality)
3. Funding and Efficiency (sustainability)

The purpose of this document is to set out this Work Stream's 'vision' for the data needed by the NHS and social care. This vision has been developed through an initial round of engagement with a selection of arms-length bodies (ALBs). Over the course of the summer we will refine our data recommendations through a series of workshops and focused discussions with wider stakeholders.

2 RESEARCH AND EVIDENCE

2.1 Issues with current data provision

At the moment, much of the health and social care data in England is fragmented, incomplete and often inaccessible. A great deal of information is held in silos where its full potential cannot

[1] Commitments i-xi on pages 34-35 of the NIB 2010 Framework For Action
[2] A mock-up of these deliverables is provided in Appendix A

be realised. Often the information is collected in aggregate forms, which are insufficiently detailed to meet the business needs of a modern health and social care service.

As a result:

- Commissioners lack essential information about the quality of the services they are securing for their population, including the safety, efficiency and compassion of those services and how well each service is joined up to provide seamless care for patients.
- Other users, including clinicians, managers, regulators and researchers, lack complete and accurate information about the outcomes, quality, efficiency and equity of the services being provided, often having to rely on re-using data that were recorded primarily for financial purposes.

In our 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, 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.

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	• How can we better understand the link between GP appointments and A&E

Quality

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 reablement 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 a learning disability?
- How can we improve the provision of care, safeguarding and protection of adults across health and social care?

The Work Stream will now need to build upon this initial round of engagement. In the second phase of our work, we shall be examining these requirements in more detail. This engagement will occur through a series of focused work groups and workshops, which will be complemented by a web consultation and the input of a rapid review group.

1. Focused work groups – we will hold four focused work groups (two each in Leeds and London) aimed at collecting the views from four stakeholder groups: member organisations of the NIB; providers, local government and social care; charities, academics, researchers, think tanks and data intermediaries; and commissioners). These work groups will be aimed at those who are working in analytical or operational roles.
2. Workshops – two workshops (in Leeds and London) will be held after the focused work groups to provide all national organisations and other interested parties, including patient groups, with the opportunity to contribute to the roadmap.
3. Web – throughput the summer, we will use the web as a platform to engage with the wider public in relation to our vision roadmap.
4. Rapid Review Group (RRG) - a collection of subject matter experts and interested parties who will provide rapid turnaround and comments on the Work Stream proposals as they are developed.

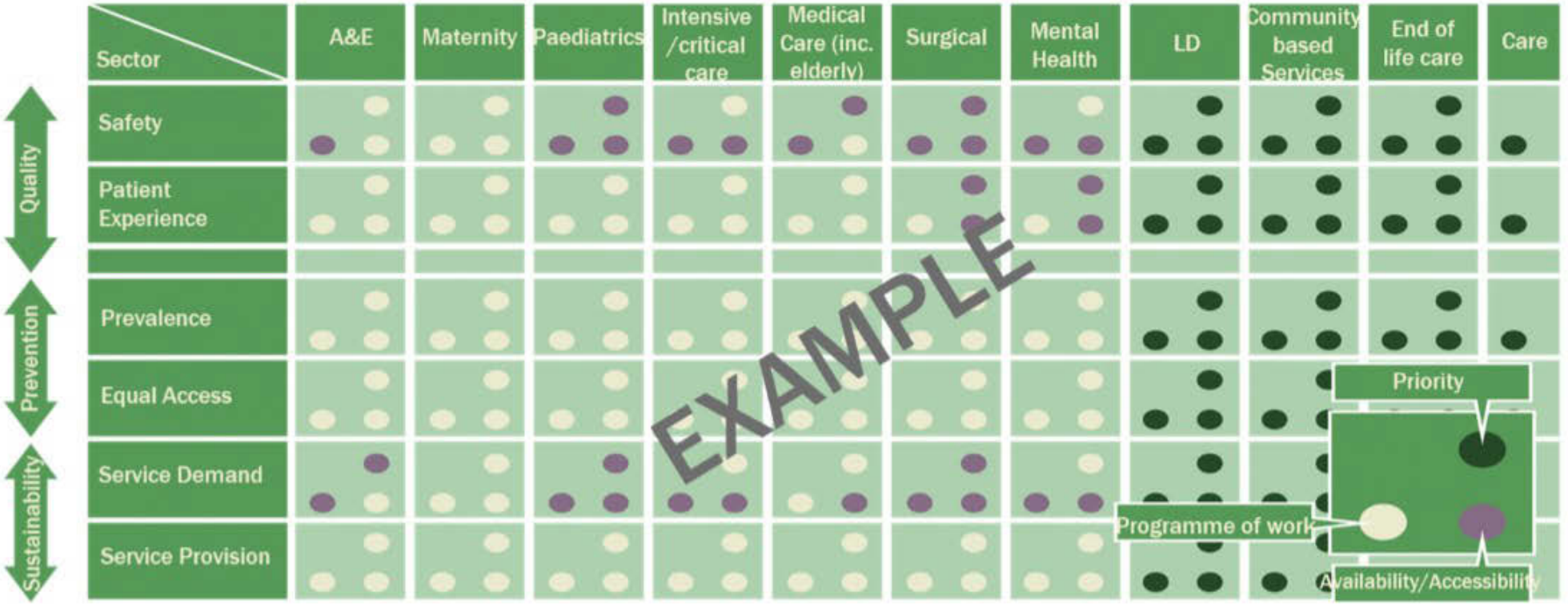
We will structure our next round of engagement around the generation of a “heat map” that reflects views across the stakeholder community.

We will list each potential data area on the heat map. Based on the findings of our engagement, we will assign three RAG ratings to each data area to reflect (1) its relative priority; (2) whether or not a programme of work currently exists in this area; and (3) the current availability and accessibility of data. Table 1, overleaf, defines the ‘RAG’ for each of these three dimensions and Figure 1, overleaf, provides a mock-up of how the heat map might appear once populated.

Table 1: RAG ratings for the heat map

RAG Rating	Priority	Programme of work	Data availability and accessibility
Red	High	No programme exists	No data available
Amber	Medium	Programme exists but needs development	Data available but not used
Green	Low	Programme exists and is active	Data available and used.

Figure 1: Mock-up heat map (each data area is assigned three RAG ratings)



2.2 Next Steps

Our 'high priority roadmap' and our subsequent 'detailed roadmap' will specify the current status for each data area including any programmes of work underway to improve them.

Based on the contents of these documents, we will propose a rationalised set of programmes to improve secondary uses data for health and social care. Each such programme will be led by a NIB organisation and will be responsible for delivering that programme, liaising with the HSCIC and other ALBs, as well as the central NIB 2.2 team.

In addition there are several issues that cut across all areas of the NIB, including infrastructure, coding, data quality, and liaison with other work streams. We will establish a separate group to deal with these cross-cutting issues.

3 BUILDING THE PICTURE FOR DELIVERY

Our initial round of engagement identified 29 potential data areas covering the whole of health and social care including:

- Adult Social Care
- Ambulance
- Births
- Child & Adolescent Mental Health Services (CAMHS)
- Children's
- Community
- Costing (patient level)
- Deaths (ONS mortality data)
- Diagnostics
- Drugs (prescribing/dispensing)
- GP Prescriptions (Dispensing)
- Hospital activity (extension to PbR)
- Learning disabilities
- Maternity
- Mental health
- National clinical audits
- Unplanned care (including A&E, NHS111, Out of Hours)
- NHS health checks
- Other primary care (Ophthalmology, Dental)
- Pathology (GP requested: results of investigations)
- Primary care (GP activity)
- PROMs/PREMs
- Psychological therapies (including IAPT)
- Referrals
- Registries

- Screening
- Specialised commissioning (including Systemic Anti-Cancer Therapies)
- Unplanned
- Wider determinants of health
- Workforce

Through this initial round of engagement, we constructed Table 2, overleaf. We ranked the 29 potential data areas. For the 13 highest ranking data areas we assigned a priority for further investigation based on the likely impact/benefits achievable in support of the 5YFV and NIB strategic priorities.

Table 2 assigns a 'star rating' indicating the potential impact that having high quality data would have across the health and care sector if this data area were improved. It also incorporates, an assessment of data quality, as it stands today for each of these 13 data areas versus the ambition for that required data quality. So, for example, where a data area was judged to have a high degree of impact on funding and efficiency, but required significant investment to reach the desired quality, coverage and consistency, then it was assigned three stars. Conversely where a data area was not essential, or where it is already well provisioned, then it was assigned one star.

Table 2 Initial assessment of data for secondary uses

Data	Health & Wellbeing	Care & Quality	Funding & Efficiency	Current Data	Key Gaps
Mental Health	***	***	***	MHLDDS[3] 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 underway to develop and consolidate various adult and children's mental health data sets.	Waiting time information – work underway to address this.
Primary Care (GP Activity)	***	***	***	There are uses of GP data through various initiatives such as CPRD which are currently focussed on researched. Aggregate levels extracts of GP data are used for programmes such as QOF.	There is a lack of information at a person level from GP practices which would help us to determine the effect of treatments from this care setting. Additionally, there is no information available about the number or length of GP consultations taking place.
Adult Social Care	*	***	***	Aggregate data collected on areas including activity, costs and safeguarding from local authorities. Record level data collected on experience surveys and DoLS.	Local providers outside council e.g. care homes etc., and patient experience of re-ablement services.[4]
Community	**	**	***	There is a national data standard CIDS[5]. 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 national flows of information.

[3] MHLDDS = Mental Health and Learning Disabilities Data Set
[4] Any changes to Local Government data is required to be fully funded
[5] CIDS = Community Information Data Set

Data	Health & Wellbeing	Care & Quality	Funding & Efficiency	Current Data	Key Gaps
Specialised Commissioning (Inc. Systemic Anti-Cancer Therapies)	*	***	***	The areas of specialised commissioning currently collect their information in different ways through contractual schedules.	National standards for the collection of data on specialised services both for use in commissioning as well as other secondary uses. There is a need to better understand the data landscape to develop proposals to better use and join this up.
Unplanned Care (Inc. A&E, NHS111, Out of Hours)	**	**	***	Currently collections specifically focussed on unplanned settings focus on use for payment (e.g. A&E CDS). Plans for developed for	Predictive modelling of demand across a range of settings & NHS 111 person level dataset to track people receiving advice and follow up for their health outcomes. Better understanding of the pathways patients are taking to services. Patient level data flow from main providers of out of hours services could yield approx. 80% of data[6]
Drugs (Prescribing/ Dispensing)	*	**	***	GP practice level prescribing data is available which covers prescriptions by GPs and non-medical prescribers that are dispensed anywhere in the UK in the community.	Data covering secondary care is limited. Also a gap related to hospital prescribing data at a patient level.
Learning Disabilities	*	***	**	MHMDS[7] was replaced by MHLDSS following an expansion of the scope to include learning disabilities and autism spectrum disorder payments.	Key gap in terms of analysis.
Costing (Patient Level)	*	*	***	Currently reference costs are collected, these are too high level to incentivise best practices and develop an accurate tariff.	Patient Level Information Costing systems (PLICS) will replace the Reference costs collection to provide a more granular set of costing data to support future tariff and benchmarking tools.

[6] Prior to health restructure, negotiations were underway to deliver this.
[7] MHMDS = Mental Health Minimum Data set

Data	Health & Wellbeing	Care & Quality	Funding & Efficiency	Current Data	Key Gaps
Diagnostics	*	**	**	DID[8] 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)[9], diagnostic physical examinations & endoscopy.
National Clinical Audits	*	***	*	Range of clinical audits currently commissioned in primary and secondary care related to specific disease. Audits are commissioned separately.	Consider how quality improvement activity could be captured in other data sets rather than having to commission an audit.
Wider Determinants of Health	***	*	*		Health data is not currently linked with wider cross governmental data sets and/or with local government data.
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 for information related to primary care staff, limited information about bank staff.	Agency staff – the only data is a return from Trusts to DH on agency spend. No data on numbers of agency staff, staff groups, where they work or their cost.

[8] DID = Diagnostic Imaging Dataset

4 BENEFITS

Our vision for data for secondary uses is inextricably linked to the outputs of the other NIB work streams. As part of this collective ambition, we aim to improve the scope, quality, and standardisation of the information exchanged, during transfers of care up to the point where separate flows of data for secondary uses are no longer required.

By extending the standardisation process and by ensuring that software is able to generate information about each significant care episode, the current collections and extractions of data for secondary purposes should no longer be needed. There will always be some new collections required to support changing priorities; however, the vast majority of the information required by regulators, commissioners and managers etc. could be met by analysing the information that clinicians/professionals generate and use in the giving of care.

In the short term, we need focus on

- extracting data that are already held electronically (e.g. pathology data);
- promoting the use of existing standards;
- linking data (e.g. linking clinical audit data routinely to HES).

4.1 High-level benefits

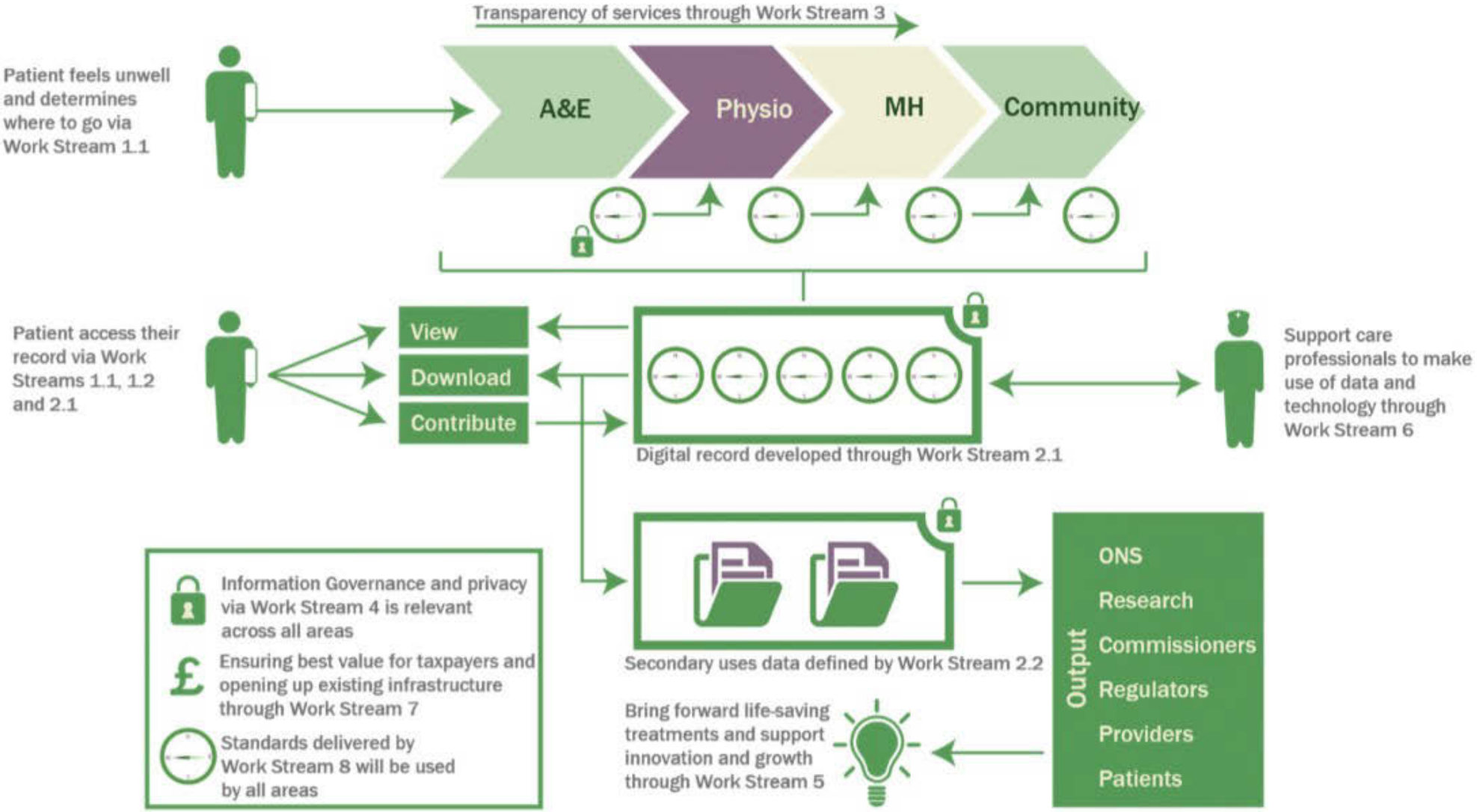
- Provision of linked data sets to researchers and organisations who undertake academic or health service improvement research – thus helping to identify the numbers, needs and experiences of people affected by illnesses.
- Improved data will result in smarter commissioning which will mean improved health outcomes for citizens and users.
- Clinicians/professionals will be able to access data on the key clinical activities that each care professional has been involved in, so that professionals are able to benchmark themselves and generate evidence for revalidation and for continuous improvement.

Our collective ambition for the future state can be summarised in Figure 2, overleaf.

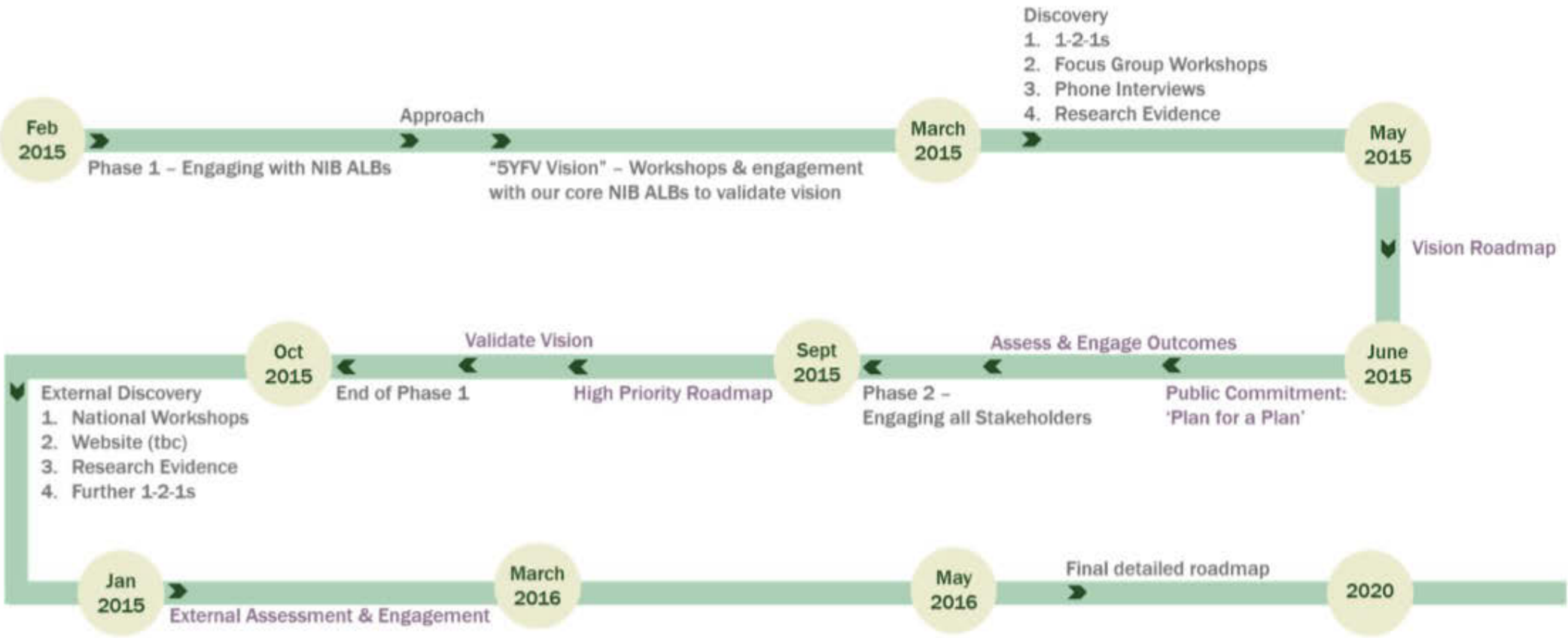
Appendix A sets out the time line for our work stream to deliver further detailed roadmaps to achieve our collective ambition.

Appendix B provides mock-up illustrations of our September 2015 and May 2016 NIB 2.2 Roadmap deliverables.

Figure 2: Overview of our vision for secondary uses data



APPENDIX A: TIMELINE FOR WORK STREAM 2.2



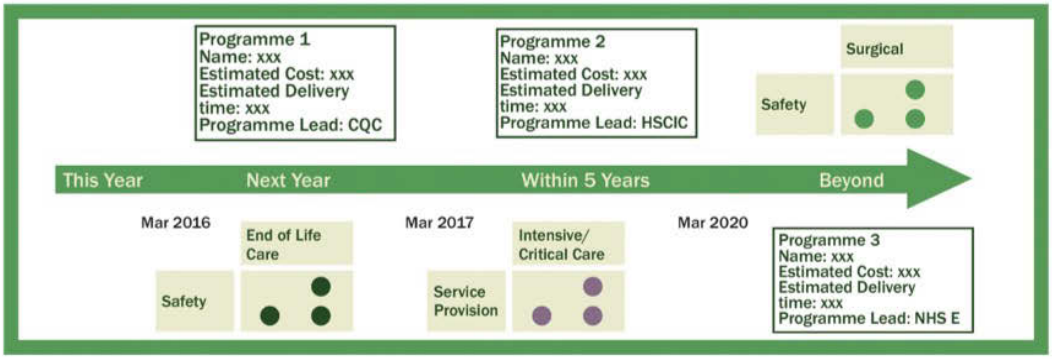
APPENDIX B: MOCK-UP ROADMAPS

High Priority Roadmap (September 2015 Deliverable)

The focus of the High Priority Roadmap will be to specify the High Priority data sets. It will outline programme recommendations to plug the gaps in the current landscape, including suggested owners.

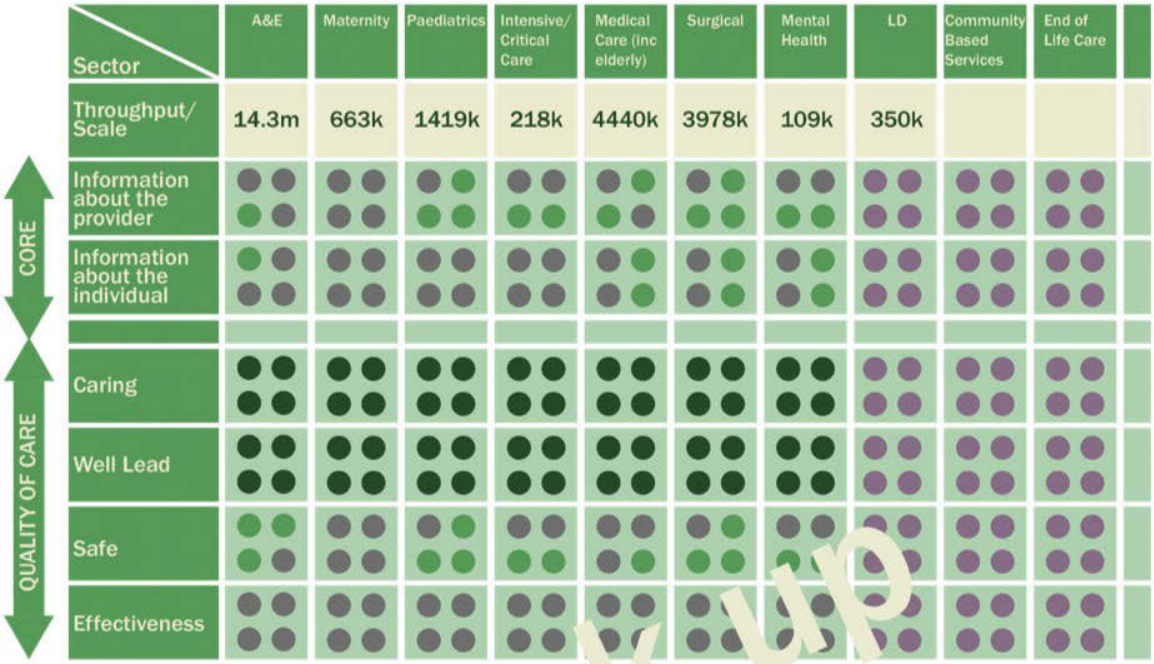
Mock up

Programme number	Priority (H, M, L)	Programme	Heatmap score	Programme Lead	Timeframe for Delivery
1	H	Increase the amount of data available to monitor the safety of end of life care	End of Life Care / Safety	CQC	1 Year
2	M	Begin collecting data about the service providers intended critical care	Intensive/ Critical Care / Service Provision	HSCIC	2 Year
3	L	XXX	Surgical / Safety	NHS England	3 Year



Detailed Roadmap (June 2016 Deliverable)

This will build on the High Priority Roadmap and all remaining data landscape requirements will be included. It will provide outline programme recommendations for the Medium and Low data priority areas.



Mock up

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3	L	XXX	Surgical / Safety	NHS England	3 Year