



NATIONAL INFORMATION BOARD

Personalised Health and Care 2020

WORK STREAM 8 ROADMAP

Enabling information standards

Provides a 'standard-setting' service to underpin all other work streams

June 2015



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1 CONTEXT

The Terms of Reference for Work Stream 8 centre around work on Standards and on Technical Platforms. The intent is to provide a roadmap in these areas which brings together the needs articulated by the other work streams into a coherent plan. The key objectives are:

- To ensure that standards required by the system as a whole, and specifically by the NIB work streams, are developed and agreed
- To provide an outline architecture for the Technical Platforms to support services defined in the other work streams to deliver the NIB Framework commitments

1.1 Current state

1.1.1 Information standards

Information Standards enable both interoperability of information, and consistency of data for comparability. These are both vital to the efficacy of the increasingly interconnected systems in the health and care sector.

The NIB Framework for Action calls for “*All patient and care records will be digital, real-time and interoperable by 2020.*” This can only be achieved if there is widespread adoption of key standards.

The information standards team in the HSCIC is responsible for managing the development of a set of fundamental standards. These standards define the way that clinical information should be described, coded, structured into records and communicated. They are not static. As care develops and changes, new releases of these standards have to be built and published together with a comprehensive set of mapping tables and tooling. Depending on the pace of change, the various standards are updated on a regular schedule which ranges from weekly to 3-yearly.

Some standards are well accepted (e.g. ICD and OPCS classifications in acute care, and Read Codes in primary care) since they drive payments and mandatory reporting; other standards, although equally important, lack these drivers and are less well used.

The development and approval of standards and data collections are managed by SCCI (pronounced ‘sky’) – the Standardisation Committee for Care Information. The SCCI process tracks the development of new standards and collections, ensuring that the statutory obligations of consultation, burden assessment and implementation guidance are adhered to.

SCCI then provides a recommendation for approval to NHS England or to the Department of Health and oversees the issue of an Information Standards Notice which effectively places the approved standard into the list for which providers are required by their contracts to have ‘due regard’. This is the mechanism by which providers are required to implement the data collections which are approved.

1.1.2 Technical platforms

The Technical Platform scope for this work stream is primarily for national systems which will support the ambitions and plans for the other work streams. Existing national systems which



were built under the National Programme for IT are being progressively re-procured as the national contracts come to an end.

There is a growing set of regional systems being built to join up care across communities. Some of these bring data together to create an integrated record, while others rely on building an index or register of data records without actually moving them.

There is currently little support for the citizen-centred services envisaged in the NIB Framework beyond a programme for patients to have access to their GP record which is in progress. Support and services to third party apps and service providers is very limited.

1.2 Drivers for change

1.2.1 NHS Number

The NHS Number is a unique identifier used to represent a patient across all of health and social care as well as in wider contexts of care.

The NHS Number is a fundamental standard which places a requirement on other standards and specifications on how to represent patients by their identifier.

It defines how the NHS Number must be used in identifying people receiving health and care services, and in locating and communicating their health and care records and other information pertaining to the planning and provision of their care. The standard sets out how information systems must accept, store, process, display and transmit the NHS Number, and what organisations must do to ensure that they use the NHS Number correctly.

Adoption has been widespread across the Health system, but is still by no means universal with many local identifiers still in use. In social care, the NHS Number is virtually unused, but it is a fundamental pre-requisite for the growing drive for integration of care across the sectors.

The use of NHS Number is governed by the Interoperability Programme Board which has a specific stream which works with stakeholders to encourage the adoption of the NHS Number. The programme has worked with a range of providers to understand how the NHS Number is used by NHS organisations and is actively working with those organisations with the lowest uptake to bring them into line with the top organisations. Work is currently underway to understand how to increase the use of the NHS Number in social care.

1.2.2 Clinical terminology

Terminologies are standardised clinical vocabularies for use by clinical staff to capture data about patients. They are used without a pre-existing record to express statements about the patient or treatment in a standard way.

The adoption of standards for coding of clinical records is vital for accurate transmission of patient information, for improved decision support for patient care, and for greatly enhanced analysis and research.

In primary and community care, versions of the Read Codes have been in use for many years. However, Read Codes have now been deprecated and V2 will not be updated after April 2016, and Read V3 will not be updated after April 2018.



In secondary care, other than for mandatory reporting, there has been no national standardisation of coding in patient clinical records/notes. SNOMED CT was mandated by the National Programme for IT, but take up has been poor because:

- Key national data collections still require Read or ICD/OPCS coding
- Secondary care software providers have been slow to provide easy and practical SNOMED CT functionality
- Benefits are limited when coding is confined to individual providers
- There has been no co-ordination of implementation such that systems and care settings could move to SNOMED CT in a planned way to allow interoperation

SNOMED CT is the de facto international standard for coding of clinical terms. The UK (like many countries) has a variety of existing standards which create inertia against adoption, but the direction of travel towards SNOMED CT usage is almost universally accepted.

However, SNOMED CT can be complex and there are choices to be made around adoption which balance the power of the structure with simplicity of implementation. There is as yet little guidance in this area.

The Power of Information strategy defines the Dictionary of Medicines and Devices (dm+d) as the NHS medicines and devices terminology of choice. It is the SNOMED CT implementation of a standard drug dictionary, with pricing information developed with the Business Services Authority. The older Read Codes V2 Drug and Appliance Dictionary is still used significantly in primary care but is not scalable for use in other health care sectors. The current mixed environment of dm+d and Read Codes V2 Drug and Appliance Dictionary is unsafe and prevents interoperability. The Electronic Prescription Service (ePS) however, does mandate the use of dm+d.

In secondary care there is little standardisation as software providers generally use their own coding systems.

1.2.3 Classifications

Classifications are categorisations of episodes of care for population monitoring, payment, business-planning and epidemiology purposes. 'Coding' into classifications is done from a pre-existing record.

The UK is obliged to provide healthcare statistics to the WHO using ICD classifications. The use of ICD-10 and OPCS-4 is already embedded in the reporting of acute care since the current payment mechanisms depend on it.

Classifications are likely to be required for many years to come, but should become more accurate and easier to derive automatically once records are coded in SNOMED CT at the point of care, and ICD-11 is implemented which is more aligned with SNOMED CT.

1.2.4 Pathology

Pathology is a key part of most patient pathways and effective NHS pathology services are the foundation for high quality diagnosis, treatment and care. GPs and hospital doctors rely on



accurate and reliable information from pathologists to help them make the right treatment decisions that will deliver the best outcomes for their patients.

The pathology results service, implemented some 10 years ago, provides for the electronic communication of results from laboratories to GPs, and has been a great success.

However, the service relies on the Pathology Bounded Code List (PBCL) which is difficult to keep pace with new tests and results, and also on outdated EDIFACT messaging. There is no electronic requesting of tests, only the transmission of results. There are no standards for requests and results to be reliably communicated between pathology labs or across acute care settings.

The National Laboratory Medicines Catalogue (NLMC) is a standard for tests and results that has been developed jointly by the HSCIC, the Royal College of Pathology and the National Pathology Programme at NHS England. At present, the completeness and usage of NLMC is limited. Funding for its development has been cut.

1.2.5 Communications of Patient Records

The rising demands on healthcare systems and associated costs require a much more efficient and transparent means of recording, transmitting and accessing reliable clinical information in order to manage and deliver high quality care to patients, and populations.

The definition of electronic health records (EHR) standards has been attempted before, but the scope has been wide and the 'clinical endorsement' has sometimes consisted of the approval of a few doctors on the programme.

The challenges can only be met by the development and use of EHRs in which data are recorded consistently across all contexts. The implementation of national standards for the clinical structure and content would facilitate shared care, enable interoperability between locations and contexts, and yield comparable data to support the management and monitoring of services realising benefits for patients, clinicians and services.

The Professional Records Standards Body (PRSB) was set up by the Academy of Royal Medical Colleges for the purpose of clinical endorsement. The Transfer of Care documents which they have defined inherently provides the correct necessary scope for the information needed to be communicated across providers.

The current definition, however, is limited to textual headings and content specification. It requires significant effort to provide the coded content and message definitions which are needed for software vendors to be able to safely implement the standards.

1.2.6 Standards governance

In reviewing the standards governance processes for the Work Stream 8 deliverable, a number of issues have already emerged, although this is a preliminary list:

- There are gaps in the governance of standards, in particular the governance of information standards into National Programmes and the governance of technical and



some information standards into provider IT systems. There is often no sanction available if standards are not followed.

- There is a need for additional standardisation of data models. The NHS Data Dictionary provides a comprehensive view of existing data items, but there are many instances where alternatives exist, and there is a lack of coverage for some items including reference data.
- SCCI is seen as a slow and cumbersome process. Although some of this is based on a misunderstanding of SCCI as just processing approvals (in fact it oversees the whole development process), there is more that could be done to streamline its working and improve its representation.
- There is no forum to debate standards strategy and set priorities for standards development. NHS England has just set up a Data Board to do this for standards driven by NHS England, but there remains no process to set these in the context of standards driven by other ALBs.
- Part of the SCCI statutory work is burden assessment for data collections and standards. Although the burden is assessed, there is no forum to decide whether a given collection or standard is 'worth' the burden it imposes on providers.
- There is no forum or resources anywhere in the system to promote desirable standards. SCCI currently has a long list of really good ideas but, as yet, no-one can be found to sponsor them.
- There are no health-related cross-government standards, although some aspects of care do cross the boundaries of departments. We are just starting to engage with the Cabinet Office's Open Standards Board on this.

1.2.7 IT systems and platforms

Over recent years, new national IT systems have been mostly procured in a piecemeal way, with each programme separately justified, funded and governed. This has resulted in a lack of interoperability and a sub-optimisation of the benefits that could have been achieved.

There is a need for a system-wide roadmap which specifies the planned changes and shows how they can develop as part of an overall architectural vision for the sector. Business Architects from HSCIC and NHS England have work underway to bring this view together into the Enterprise Architecture which is managed by the Informatics Design Authority.

The systems in the HSCIC which receive and disseminate patient level data have grown over the years and require significant re-design to be able to cope with the challenges of increased data volumes, more complex rules about citizen objections and consents, better ways of handling confidential data and new ways of providing information to users.

In addition to HSCIC systems, CPRD and PHE also have platforms that hold patient level data for specific purposes and provide good facilities for managing and using it. However, the capabilities are fragmented across the ALBs and do not match the DH intention to manage patient level data in a single organisation.

Systems owned and run by care providers are the responsibility of the provider trusts. Of key interest is whether they are able to capture clinical data in an accurate and timely way, and



whether they adhere to the information standards in their communications. Secondary care and social care have some well-implemented systems, but in general the digital maturity is low – very low compared with other industries, and not yet high enough to deliver the ambition of the NIB Framework.

The regional systems being built are innovative and diverse. There is a need to provide some help and guidance to those considering building new systems. They are looking for ‘cookbooks’ which set out best practice from previous experience and show which options are effective and which standards are needed for overall interoperability.

2 RESEARCH AND EVIDENCE

The research on data and standards has been run by Work Streams 2.1 and 2.2 and is not reproduced here.

This was preceded by extensive consultation done during the development of the NIB Framework for Action. The detailed findings in this area were published separately as “Framework for Action: Data and Standards Version 1.0”, which sets out in particular the case for the PRSB Transfer of Care Documents to be adopted.

3 BUILDING THE PICTURE FOR DELIVERY

The following sets out the overall ambition of Work Stream 8:

1. Fundamental standards are adopted with full adherence across health and social care sectors

Other work streams are working on aspects of this ambition, but for Work Stream 8 this means for each of the fundamental standards that implementation plans are agreed and the relevant programmes of work are defined and funded.

2. The processes for the development, approval and governance of standards are complete, fit for purpose and accessible

This will help to ensure that the right standards are available for use in a timely way and that they are up-to-date with clinical developments. Details and full relevant guidance must be published in an accessible form so that the standards are well understood, including the benefits of adoption. There must also be ongoing processes and adequate resources for the maintenance of the standards.

3. Integrated technical platforms, securely hosted and professionally managed, provide a high quality and responsive service

The technical platforms must provide services to achieve the ambitions of the NIB Framework for Action across the following areas:

- Data collection, processing and onwards provision for commissioning, research and regulation
- Published Data and Transaction interfaces for app providers
- Citizen access and authentication



- Preference (objection and consent) setting

4 BENEFITS

There are considerable benefits from standardisation. These are being considered and documented in detail by the other work streams.

This work stream can be considered as the engine room aimed at ensuring that the required standards are agreed, available, implementable and properly governed into use.

The benefits arise not from simply having a standard, but from its careful implementation along with the associated business processes. The interoperability and consistency that the standard enables will only be achieved if the overall change programme is successful.

Likewise, the benefits which arise from the applications and services called for by the other work streams are documented in their own deliverables.

The purpose of the Technical Platform work in Work Stream 8 is to ensure that the various requirements are brought together into a coherent architecture, and to ensure that the various systems envisaged across the NIB Framework for Action are designed efficiently and practically.

5 FOLLOW-ON PROGRAMMES, PROJECTS OR TASKS

5.1 Standards

5.1.1 Transfer of care documents

A programme of work is required to transform the headings in the PRSB standards into fully defined messages with coded content, and to define the communications methods and protocols to be followed.

Once the implementable standards are available, work will be needed with the software vendors in all sectors to promote the use of the standards and get them implemented in software packages used by providers.

When the software is available, a programme of marketing and support will be needed with providers to implement the new versions of software and to work with clinicians, carers and support staff to adopt the working practices and processes which will enable effective use.

5.1.2 Replacement of Read Codes with SNOMED CIT and dm+d

The implementation of SNOMED CT in place of Read Codes (as mandated in the Framework for Action) now requires a significant programme of work to co-ordinate change to the many systems and processes which use Read Codes. These include all the GP systems, pathology results service and Quality Outcomes Framework (QOF) reporting.

A programme of work for this is already established within the GPSoc team, allowing co-ordination of changes to primary care systems and arrangements. Planning work is evaluating the appropriate dates for the various changes to ensure that there is a practical sequence of events with achievable milestones.



Moving away from Read Codes includes ending the use of the Read Codes V2 Drug and Appliance Dictionary and instead implementing dm+d across primary care.

5.1.3 SNOMED CT and dm+d in secondary care

In secondary care, SNOMED CT and dm+d implementation is not driven by a single compelling event as it is in Primary Care. Each Trust system must be implemented or upgraded on the basis that coding will be done using SNOMED CT.

Some Trusts have started doing this, but adoption will be accelerated by the use in primary care (and the need to interoperate) and also by the contractual and regulatory levers being exerted by NHS England and set out in Work Stream 2.1.

As in primary care, the implementation of preferred terminologies (SNOMED CT and dm+d) is closely related and must be done together

Wider implementation must be enabled through new detailed guidance and support material and events, encouraging the capture of SNOMED CT terminology and codes at each point of care. We must demonstrate the benefits to providers of moving statutory acute care reporting from manual ICD / OPCS coding to more automated classification based on accurately captured SNOMED CT codes.

We need to actively support software providers to design and implement enhanced SNOMED CT functionality that is simple to use, and actively engage with trusts and commercial organisations to increase awareness of dm+d and SNOMED CT. We also need to work with the relevant professional bodies to establish agreed sets of terms for their professional use.

5.1.4 Pathology

The resolution of the pathology requests and results issues requires a substantial programme of work, of which acceleration of NLMC development is a key factor.

The programme will also need to resolve issues surrounding the communication messaging formats and service, and build the required infrastructure to handle the type and volume of traffic from a fully-working service.

A proposal for such a programme is currently being developed by HSCIC with NHS England, and is under consideration by the Informatics Programme Management Board (IPMB). Funding will be required for the programme and specifically for the continued development of the NLMC.

5.1.5 Standards governance

The gaps identified in the work on Standards Processes need to be filled. The most significant elements of this are the full establishment of the Informatics Design Authority (IDA) and revisions to the SCCI processes and arrangements.

The IDA is planned to operate alongside the Informatics Portfolio Management Board (IPMB). It is intended that the IPMB would look to the IDA to provide technical review and support on proposals as it considers whether to approve them. The Terms of Reference for this and the working arrangements have been drafted and are awaiting IPMB approval.

The IDA will use the Enterprise Architecture (EA) to act as the definition of which standards should be governed into National Projects and how this should be done. The EA contains both



Technical Standards and Information Standards, and the IDA’s Technical Review Group has representation to cover each.

The SCCI processes are in the process of change for a number of reasons and there will be updates to the Board and panel representation, the development and assurance processes and the organisation of the supporting services. There is also a new SCCI governance board being planned to oversee the operation of the Board and processes, and there will be new interactions with the recently established NHS England Data and Services Board. It is intended that these changes will be co-ordinated together to minimise disruption and to facilitate communication to stakeholders and interested parties.

5.1.6 Standards strategy

It has become apparent that in addition to the deliverables planned for this work stream on Key Standards and Standard Processes, there is a need for an overall Standards Strategy to be developed and then maintained.

This will build on the existing deliverables, but will be extended to define the many types of standards, to set boundaries around what needs to be centrally mandated and to cover all the initiatives needed.

5.2 Technical platforms

Work is ongoing, primarily in the HSCIC and NHS England, on a number of IT projects which are being informed by the developing NIB work, and which will need to be further shaped and informed by the requirements and approaches being set out in the other work streams.

There are 3 major dimensions in considering IT platforms for data and services in health and social care. They may be summarised as offerings to:

- Citizens
- Clinicians and carers
- Secondary users, both ‘internal’ and ‘external’

5.2.1 The three basic user domains for data and IT services in health and care

The three basic user domains for Data and IT services

Who	Citizens and their apps suppliers	Clinicians, carers, their organisations and apps suppliers	Commissioners and Regulators Researchers, Academia, Pharma
Why	Empowering the individual	Direct Care	Secondary Uses
What	Individual’s information	Individual’s information	Bulk information
Status	New, to be built	In silos – some mature, some basic, some	Mature but in need of major overhaul



Each of these is concerned with essentially the same data, and many of the same services, but there are differences in:

- The extent of public concern over data sharing and storage
- How time-critical the information needs are
- The legal basis for holding data
- The quantity of information needed at a time
- The level of detail and layers of complexity involved
- The language used to discuss similar topics

The following sections discuss the IT platform and service needs for each of these user domains as envisaged by the other work streams. New IT work is needed in each area, and also some additional work on existing systems.

It is important that such work be co-ordinated to an overall design and plan. We do not do this currently - each programme has had its own scope and plan and budget. But the NIB Framework and its work streams have the ambition to build a much more coherent and integrated set of services, and the architecture and management of the whole system must reflect this.

5.2.2 Data Services Platform – for secondary uses of data

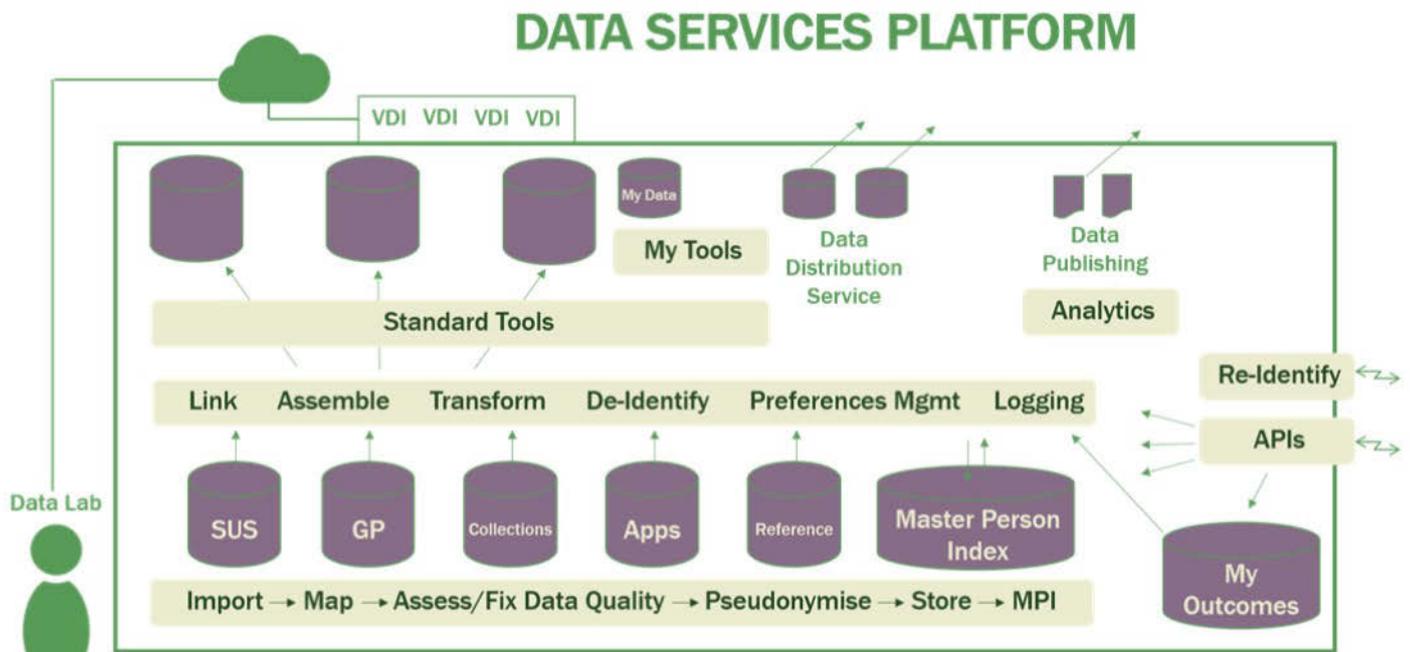
The key requirement for secondary uses of health and care data is the development of a Data Services Platform (DSP), which will provide the basis for the management of data for (primarily) commissioning, research and regulation.

There are several existing and planned programmes, including the National Tariff Service, and Data Services for Commissioners, that have similar requirements for importing data and cleansing it, processing it through a set of services and then making it available for the separate purposes. There is also a general need to re-platform the existing data services in the HSCIC to improve service to users, capability and capacity.

There are short term needs for each of the programmes which must be delivered alongside the design and build of the strategic service. Planning is underway to define the overall DSP and also the interception points with the other programmes.



The new Data Services Platform will support new and existing data services for secondary uses with improved services and a range of new safeguards:



A key feature of the new Data Services Platform will be the separation of the many data inputs, and the allocation of a pseudonym with de-identification on landing so data within the platform will be much less identifiable than current systems. A Master Person Index will be built to keep track of all the data in the system for each individual – what data we received about an individual, and what data we have given out, or made available in marts and databases for particular purposes.

As required (and only as required) data from the input sets will be built into databases and marts for the various end-user purposes. Each set will be carefully de-identified according to the minimum level of identifiers needed and will have a separate set of pseudonyms for each user group. Data will be linked only for specific purposes in different and mutually inaccessible data repositories.

A range of services (shown across the top of the diagram) will be provided to access data:

- For highly sensitive material, a physical data lab on HSCIC premises will be the only way to obtain access, with nothing taken in or out except for approved results.
- Less sensitive data may be accessed over the network through a virtual machine.
- In some instances, it will be possible to bring your own data to link and/or your own tools for analysis.
- The above facilities will probably mean that less data is physically disseminated, but this will still be possible for some data sets under an agreement.



- The HSCIC will continue to do analytical work, publishing results and aggregated information.

A re-identification service will be provided for circumstances where this is needed and where users can provide suitable credentials and reasons for access. Other Application Programming Interfaces (APIs) will support the access to Digital Services for the citizen and for third party apps and services providers provided they are authenticated.

In addition, other NIB Work Streams, particularly 2.1, 2.2 and 4, are defining and elaborating data and data services needs which will need to be incorporated into the platform. It is expected that the DSP programme will define a clear scope and relationship with other programmes by mid-2015.

One of the NIB Framework actions states: “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.”

The Data Services Platform will be capable of supporting central data collection, and will have a set of safeguards for protecting it beyond our current provisions:

- Data is de-identified while on the Data Services Platform
- Data is not linked until required
- Data can be accessed, analysed and linked with local data without leaving the Platform
- Highly sensitive data can be accessed very securely through a data lab
- Citizen preferences, consents and objections can be complied with in detail
- The uses to which a citizen’s data has been put can be tracked

Secondary uses are essentially concerned with the analysis of bulk data, where there are large numbers of records collected and linked together. The Data Services Platform is designed on the basis that for this type of work the data needs to be physically collected in one place. Technologies are emerging for analysis of bulk data which remains distributed, but these are not currently mature or scalable and will not be practical for secondary uses within the 5-year timescale. It is arguable that it will always be better to have data for analysis in one place, or at least most of it though there may be exceptions where large data items are better not copied, for example genomics information or images, but these are very dependent on the exact usage pattern.

5.2.3 Clinicians and carers – Direct Care Programme

The data for direct care is not centralised, but exists in care provider systems. The problem that has persisted over the years is to get the right information to a clinician or carer at the right time and with the appropriate level of detail.

GP systems are a key integration point due to the nature of general practice. But many regional systems are being built to answer the need for better integration of GP data with information from local acute hospitals, community hospitals, mental health trusts, social care and other settings. These regional systems are an excellent focus for promoting joined up care and should be encouraged and supported.



There have been a number of attempts to provide some kind of central service, most of which have been unsuccessful. An exception to this is the Summary Care Record (SCR) which is now approaching complete coverage of the population and is gaining momentum in usage. The SCR has very limited data but is available nationally for rapid access in emergency or out-of-area situations.

GP systems and regional systems can provide local and regional services and the SCR can provide a limited national patient view. However, there are still many barriers to fully joining up care and providing the right data and services to clinicians and carers.

The work streams have identified several initiatives which can address the problems currently experienced in direct care, and which would enable the interoperability required. These should be managed together as a Direct Care Programme:

1. **Transfer of Care standards implementation** - discussed in the Standards section of this document
2. **Best practice for Regional Integration initiatives** - Regional projects to build Integrated Digital Care Records (IDCRs) have been driven so far entirely through local initiatives. Consequently there is a wide variability in technologies, scope and approach, and new regional systems being planned are looking for advice and guidance for best practice. There is also a need for some elements of standardisation to enable improved interoperability between the regional systems and to therefore research, create and publish a set of guidance material – cookbooks, case studies, best practice, hints and tips – that will enable faster and better implementation with improved interoperability.
3. **Record Locator** – A key issue in joining up information for direct care is the obvious question of where the data is for any individual. For a clinician or carer deciding on a treatment or pathway, it is vital to be able to find out what records exist, which at least gives the possibility of seeing and using them. This is similar to the Master Person Index outlined above in the Data Services Platform, but the need is to keep track of what data is out there in local and regional systems rather than to track the data we hold centrally. It is possible that the same system could be used for both purposes. Such a record locator would need to be sent a notification by the distributed provider systems whenever a new person is set up with records there.
4. **Standard APIs into care systems** – Having found a record, the next challenge is to access it and retrieve or look at the data. There is no standard way for doing this today, and each system has its own methods of access, authentication arrangements, data sharing rules etc. We are running an initiative with a range of system providers to see whether it is practical to define and publish a set of standard interfaces – usually called Application Programming Interfaces or APIs. These would greatly improve the pace at which integration across the system could proceed as those who hold data and those who access it have a common mechanism.
5. **Integration hub for primary care data** – The GP Systems of Choice (GPSoC) programme has defined some ‘standard APIs into care systems’ as discussed above, but specifically for GP systems. The programme is currently defining an update providing a second generation of



interfaces. They have identified some issues relating to the process for accreditation to each of the different GP systems and other practicalities which could be addressed by building an Integration Hub. This will provide consistent, common interfaces into principal GP systems with open market access. It will standardise and streamline the integration of consumer systems and applications that need to access and transact with primary care data.

6. **Interfaces to central systems** – Clinicians and carers need the ability to access a range of services to make enquiries and do updates. Such services include central systems for demographic data about a person, viewing a Summary Care Record or making a booking. Using such services is discussed in more detail in the next section about citizen access. Clinicians and carers need access not only through the normal clinical systems in their organisations but also through a new range of mobile apps and systems. The APIs into these central systems need to be standardised and published for clinical users as well as citizens.

5.2.4 Digital Services – the offering to the citizen

We are working on the outline architecture for a set of services to support the ambition being developed in Work Streams 1.1, 1.2 and 4 for citizens as well as for third party apps and services. Figure 1, below, illustrates the kind of offerings which are being considered for citizens:



Figure 1: Concept of the kinds of Citizen Services to be provided. It is not intended to be complete or correct in its content. See Work Stream 1.1 for details.

This digital offer to citizens will have its ‘front end’ user interface (as illustrated above) on a web site in nhs.uk but will require the support of a set of ‘back end’ technical and platform services. We need to provide citizens with access to data that is held elsewhere and transactions that are managed elsewhere, and to underpin these with administrative systems for authentication, indexing, logging and preference implementation.

Such services must be built with access provided not only at a user interface level but also at a system level so that they may be called by other authorised systems. Some of these services



exist today, and have usable Application Programming Interfaces (APIs) that can be called by other systems. Others exist, but do not publish details of how they can be accessed. Some services have yet to be built.

Many of these services are (or will be) provided by national systems, but there will also be local and regional systems which will need to give and receive information.

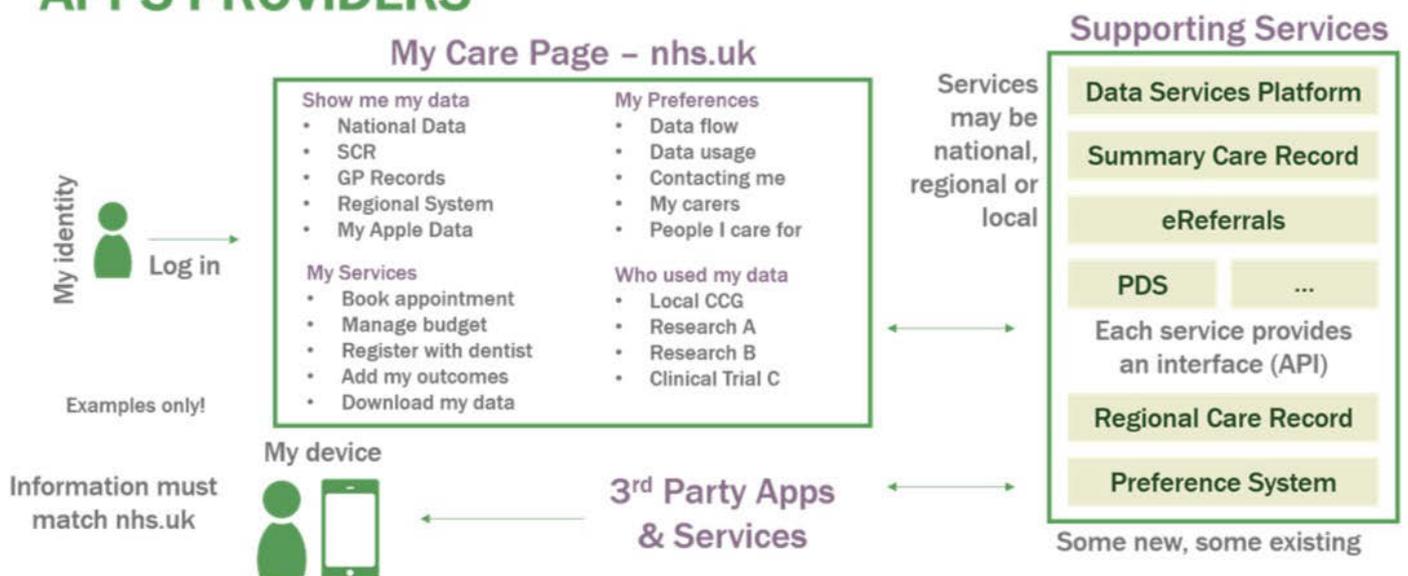
These same services will also be needed to support the growing market for apps and third party service offerings. While not every app will need every service, many will have similar needs for data access, transaction processing and administrative support. These must be essentially the same services as those provided directly to the citizen to provide a consistent experience and set of information, whether directly through our digital web interfaces, or through apps.

The successful stimulation of the apps market will depend upon such services being available and easy to deploy.

Third party apps and services providers will require a straightforward Directory of Services which publishes details of what can be accessed, the interfaces available and guidance on how to use the services, including how to manage user consent for the app or service to access the citizen's information.

The same set of services that support citizen access through a web site must also be available to apps providers, so that the user experience is consistent:

DIGITAL SERVICES FOR CITIZENS AND APPS PROVIDERS



User access to these services is planned to be on the nhs.uk website, with a new set of pages designed for the individual to access their personal information. Backend systems will be built to support:

- Authentication and login



At a scale of potentially 50 million users, protecting highly personal information, this is a non-trivial task. Arrangements may need to be tied in to other cross-government initiatives.

- **Access to and presentation of data held 'Nationally' in HSCIC**
These data relate to the individual. We currently hold person-level data in the Personal Demographics Service, Summary Care Record, Hospital Episode Statistics and several other data sets. Several initiatives are planned or underway which will extend the range of data held. With such a large range of information, much of it not designed to be understood by non-professionals, there will be a need to provide extracts and perhaps an understandable summary. For some purposes, however, the citizen may want to view or extract all the raw data. The listing of data for the user will be populated from the Master Person Index in the Data Services Platform.
- **Access to data held outside HSCIC**
Users will expect to be able to access all their data across the health and social care system. They cannot be expected to be familiar with the name HSCIC, or to know which organisation holds which data. Person-level medical and care records are held by GPs, hospitals, community medicine centres, regional integration systems, mental health trusts, local authorities, care homes and a host of other settings. We cannot expect to integrate all these together in the short or medium term, but we can provide at least a portal which would allow such care providers to register their holding of data, or perhaps for citizens to store their own links. Users would be able to click through to these systems, possibly with authentication credentials which they will have already provided to log on. The listing of outside data for the user will be populated by the Record Locator system discussed as part of the Direct Care Programme above, and may be supplemented by the citizen adding their own data repositories to the list.
- **Preferences**
Citizens will need a place to record their preferences (including objections and consents) about the use of their personal information. The Data Services Platform is the key gateway for the distribution of patient level data and is the obvious place where such preferences should be managed and implemented. There is a wide and dynamic range of uses, applications and services to which data can be put, and so the preference service must be capable of straightforward configuration – for example to allow me to consent to my data being used by a new app provider. Such preferences must then be actionable and traceable on the national data and transaction platforms.
- **Where has my data gone?**
This is a key issue (often the key issue) for patients who are considering objecting to some uses of their data. If they could be certain that they can see where their information has gone and what it has been used for then preferences can be considered on the basis of knowledge rather than fear. We need to be able to track each data usage or release for each citizen and to be able to present this information in a meaningful way.
- **My Services**



This represents the range of transactions available to the citizen. Such transactions will be made available on the web site but will interact with 'back end' systems such as booking systems or prescription systems.

These Digital services for citizens and for third party apps and service providers should not be viewed as a single IT system. The required data, transaction and administrative services will be delivered through a range of co-ordinated enhancements to existing systems and platforms together with some new facilities.

6 ESTIMATED OVERALL TIMESCALES

6.1 Standards

Most of the standards programmes are ongoing work with a final and complete implementation being some years into the future.

The replacement of Read Codes in Primary Care is currently being planned on an aggressive timescale to complete by the end of 2016. This is an ambition rather than a fully secured date and cannot be confirmed until more detailed planning is complete.

6.2 Data Services Platform

This is a phased programme, and again does not yet have a fully assured plan. Some of the elements will be delivered in 2015 for use by the Genomics England Programme, and some in early 2016 for use by the Data Services for Commissioners Programme.

It is expected that the current scope can be delivered by mid-2017, and a fully operational platform will have the existing services migrated by end-2017.

6.3 Direct Care Programme

This includes a range of projects which will deliver their objectives in the 1-3 year timeframe.

6.4 Digital Services

The digital services front end will be delivered by progressive enhancements to the NHS web presence over the next 2-3 years.

Many of the back end services are already in place and APIs are available to access them. A project to package and publish these should have a first pass done by September 2015 with ongoing updates as new services are completed.

The remaining backend services mostly need to tie in to the Data Services Platform, so are likely to be available in the same 2 year timescale.