TARGET ARCHITECTURE

Outputs from the Interoperability and Population Health Summit

CONNECTING CARE SETTINGS AND IMPROVING PATIENT EXPERIENCE

Version 0.23

Message from Will Smart, CIO for Health and Social Care in England

This document summarises the outputs from the Interoperability and Population Health Summit that I convened in November 2016. The purpose of the summit was to bring together national and international experts to explore the challenges associated with enabling data to flow across the health and social care system to support the provision of the best possible care to our citizens.

Of course, in two days it was not possible to address in detail all the implications associated with the proposed approach. Consequently, I am therefore sending this out to a broad range of stakeholders for further review and comment in order to develop our thinking on the issues set out in this paper.

We would like to hear from as many people as possible, so please feel free to pass the document to colleagues. In order to maintain momentum, it would be appreciated if comments could be returned to england.interoperability@nhs.net by 20th January 2016. These comments will be incorporated into an updated version of this document early in the new-year.

Thank you for your support.

Will Smart
CIO for Health and Social Care in England

21/12/16

DRAFT

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1 Executive Summary

1.1 A two day summit, called by the CIO for Health and Social Care in England[1], was held in November 2016 to consider and discuss the following *problem statement*:

What is the target architecture that will support delivery of the Paperless 2020 ambitions that will enable us to:

- bring together care information related to the patient in near real-time[2] at the point of care
- create a normalised view for the citizen and those involved in their care
- perform near real-time analysis tailored to the needs of the population as well as enabling decision support for an individual

➔ to achieve more precise targeting of interventions for citizens as part of their care

1.2 This leads to a wider set of questions, including:

- at what scale should we operate to support local initiatives (e.g. Sustainability and Transformation Plans, Accountable Care Organisations) and the wider population?
- at what scale should the technical architecture operate to deliver this?

1.3 This paper introduces the emerging recommendations from the summit. These are to set out a series of regional self-organising communities[3] in line with existing planning guidance, with populations of 2-5 million[4]. It is anticipated that these communities will tend towards 5 million. These communities will be supported by a coterminous, scalable architecture based upon regional platforms that adhere to national standards, are underpinned by national capabilities and integrated seamlessly with the national data platform. This enabling data to be aggregated at a national level.

1.4 We are committed to discussing the aims, objectives, benefits and governance of this proposal widely to ensure that this approach benefits the whole population through better health and care services, and better outcomes for individuals. We are therefore sending this document to stakeholders for review and comment via england.interoperability@nhs.net by 20th January 2016.

[1] A list of attendees can be found at the back of this document.

[2] "near real-time" meaning that information can be accessed and used in an actionable period by citizens and professionals

[3] These supporting a large place-based population and initiatives within them, e.g. a single accountable care system or many accountable care systems, a hospital chain, a research network, public health programmes and integrated practice units.

[4] or potentially larger where self-organised

2 Context

2.1 The digital revolution in healthcare delivery is developing at pace across the world. Many health economies including those in developing economies are creating new opportunities by using data recorded in electronic health records as well as mobile devices, social media and other sources. This intelligence is generated from data streaming into cloud-based data stores, federating and linking data from medical services, pharma, scientific institutions and public services. This needing to happen in conjunction to protecting privacy and data rights, and improving the experience for individuals to control their data.

2.2 The Five Year Forward View (FYFV)[5] and the National Information Board[6] has set out a clear strategy for the adoption of technology and the realisation of a data-driven health and care service and includes a mandate to move to integrated, citizen-centric and outcomes-based care provision with the aim of improving the health and wellbeing of individuals and populations at large. The strategy for England is aligned to achieving the "Triple Aim"[7] of:

- improving the health and wellbeing of local communities
- providing a better experience of care for patients
- delivering lower per capita cost for the taxpayer.

2.3 The FYFV supports a local approach to innovation of care models to meet the needs of local populations, and to what the Kings Fund refers to as "place-based care". Taking this place based approach results in the potential for a significant improvement in care for the citizen (see Annex A for an example user journey).

2.4 To ensure sustainability, new models of care are beginning to use more real-time data that allows localities to better "predict and prevent" as well as "diagnose and treat". These new paradigms require patient and population-orientated data to be used in near real-time for decision support and advanced analysis. Users of the health care system are no longer prepared to wait weeks, months or even years to discover individual outcomes or describe collective performance. These new systems must be supported by real-time and near real-time accessible data flows that not only describe for the patient 'how am I doing today?' and 'how far do I still have to go to achieve my goal?', but also enable proactive clinical learning and decision-making with major impact on patient outcomes and system efficiency and safety.

2.5 What is increasingly evident from an international view point is that in order to move to improving the health of populations (such as in value-based payments), the informatics enablement is a critical underpinning to understand where to focus effort, and, also how to take action and engage citizens at an individual level. Furthermore, in providing more personalised care for the individual, we have to look beyond traditional health and care boundaries as understanding citizens and impacting behaviour requires us to address the fact

[5] https://www.england.nhs.uk/ourwork/futurenhs/nhs-five-year-forward-view-web-version/
[6] https://www.gov.uk/government/organisations/national-information-board
[7] https://www.england.nhs.uk/2016/09/geraint-lewis-2/

that wider determinants of health and wellbeing are from factors outside of the institutional health and care settings e.g. employment, education, housing.

2.6 A number of key concepts were discussed at the summit to address the problem statement set out in the executive summary. These are outlined below.

"Learning Health and Care" Systems

2.7 Friedman et al[8] outlined such a system in terms of 'the fundamental properties of a highly participatory rapid learning system that can be developed from use in part of electronic health records. Secured and trusted use of these data, beyond their original purpose of supporting health care of individual patients, done transparently and with high quality information for the public about the use of their data, can speed the progression of knowledge from the lab bench to the patient's bedside and provide a corner stone for healthcare reform.'

2.8 The characteristics of such a system require that data can be converted into knowledge which can then be used for and with patients to improve care. It has two components: first is the collective organisation of the institutions and people and second are the technical and governance arrangements to assemble and provide the data for use.

2.9 The arrangement of organisations, people and technology as part of this architecture is consistent with Making IT Work[9], in that use of data and IT should not be considered as a technology solution, but rather as a tool to support adaptive change led by those with the problem. So the overall approach needs to be as much centred on models of local leadership and governance; establishing the relationship between professionals and citizens and how the data is controlled - as it is about technology standards and systems.

	What's the Work?	Who Does the Work?
Technical Problems	Apply current know-how	The 'authorities'
Adaptive Change	Learn new ways	The people with the problem

Figure 1 – Adaptive change being led by those "with the problem"

2.10 A key metric of learning healthcare systems is the associated latency, this being a "two-delay" problem - data captured to data being available and then also data available to action being taken. "Current health data reuse is too little, too late, at too high a cost of information management."[10]

2.11 Consequently, whilst concepts such as 'interoperability' are fundamental in providing the basis for information sharing and "should be built in from the

[8] Friedman, Wong & Blumenthal, Achieving a Nationwide learning System, Science Translational Medicine, Nov 2010

[9],[11] https://www.gov.uk/government/publications/using-information-technology-to-improve-the-nhs

[10] Methods Inf Med 6/2015

start"[11], there is a need to link this same information for near real-time insight and delivery of actionable information at the point of need.

2.12 The architecture needs to outline how concepts such as 'interoperability', 'population health management', 'outcomes-based commissioning' and 'activated citizen' that may have historically been discussed separately come together into an overall approach.

The Purposes of Information

2.13 The summit outlined the key purposes of information that need to be covered by the target architecture.

Direct Care - "Interoperability"
Ability to exchange uncoded and coded data at point of care, access normalised "longitudinal record"
Ability to share views at point of care for professionals and citizens and enable decision-support
Ability to enable patient to be active participant in own record and to enable transactional services

Direct Care –Precision medicine and Case Finding
Ability to compare an individual against a population for more precise intervention
Ability to identify individuals at risk and provide personalised intervention alerts

Intelligence – Commissioning for service planning
Ability to provide a view at a whole population level from data garnered from multiple provider systems to understand demand and enable effective planning of service provision across providers

Intelligence – Payment, Regulation and Service Evaluation.
Ability to process data in support of payments for services
Ability to understand conformance of organisations to regulatory requirements
Ability to provide national benchmarking of providers and understand the effectiveness of services

Research - use of data for clinical and other research (identifiable/pseudonymised)
Ability to use data as part of consented trials
Ability to use data to undertake research on the effectiveness of treatments

Figure 2 - The purposes of information enabled by the target architecture

2.14 Below are a set of user statements of need for each of these purposes used to test out the proposed approach.

2.15 **Layer 1:** The basic level needed for fully interoperable information exchange in real-time to be able to bring together the longitudinal record for the patient.

- *"As a patient with diabetes, I want to be able to access my blood test results and share my home blood pressure readings with my GP"*
- *"As a surgical registrar, following consent gained, I want to be able to compare the medications prescribed for this patient by their GP against those currently in my hospital system"*

- *"As part of an integrated care team, I want to be able to work with the patient in creating, viewing and updating elements of their care plan and the associated care co-ordination we need to put in place."*

2.16 **Layer 2:** Information accessed in real-time for that patient can then be compared to information held about a wider population both to enable a more precise intervention but also used in near real-time to identify high-risk individuals.

- *"Before referring this patient for a heart operation, I want to understand the outcomes for patients who had similar characteristics"*
- *"As a GP, I want to be alerted to all patients eligible for a flu vaccination who have not yet had one provided at a care setting."*
- *"As a care home manager, I want to know that my patient was visited by the home physiotherapist as expected in their care plan and to be alerted if this does not happen."*

2.17 **Layer 3:** The same information captured for direct-care provision can be pseudonymised and linked (with appropriate legal basis) to other information sources from wider determinants of health and care, for near real-time service planning.

- *"As a commissioner I need to have an overview on whether the right chronic kidney disease patients are being seen in specialist clinics, versus being managed exclusively within primary care, and thus plan future capacity requirements"*

2.18 **Layer 4:** The same information captured for direct-care provision can be pseudonymised and linked with wider information sources, (with appropriate legal basis), and used for national benchmarking, national comparison and regulation, as well as payment of services - be they locally or nationally commissioned - including specialised commissioning services.

- *"As a commissioner, I want to ensure that I am paying for the services being provided".*
- *"As a regulator, I want to be able to compare organisations who are providing cancer services with their peers"*
- *"As a provider, I want to understand how my referral to treatment times compares with similar organisations"*
- *"As a regulator of clinical care, I want to be able to perform near real-time quality monitoring to detect variations in outcomes and clinical events across the entire population to determine which warrant further investigation"*
- *"As a regulator, I want to be able to ensure that evidence-based protocols are being followed for patients against national guidelines."*

2.19 **Layer 5:** The same information captured for direct care provision (pseudonymised or identifiable) can be linked with wider information sources, (with appropriate legal basis), for research purposes.

- *"As a patient who has recently had a cancer, I would like my data to be used to improve the cancer care pathway in my area"*

- *"As a patient with asthma, I want to signal my willingness to be contacted for future research into asthma treatments, and I've already agreed to link my genome to my GP and hospital data for research studies"*

2.20 There are initiatives at a local level already underway covering several of these purposes e.g. Cheshire Care Record bringing together information for direct care, as well as Kent and Leicestershire in linking information to provide improved intelligence and pathway analysis. The target architecture is not intended to stop progress on these approaches, but to show how we bring these activities together into an overall managed framework.

3 Target Architecture

Diameter of Trust

3.1 In considering how we enable these purposes across England, we were led by the work of Farr Institute[12] to consider the 'diameter of trust' concept as the way to gauge the size and characteristics of a learning, sustainable and trustworthy healthcare system. The concept of 'diameter of trust' arises from:

- studying the health data sharing initiatives that have succeeded or failed;
- interpreting focus group and questionnaire based evidence of public attitudes;
- interpreting responses to test cases in citizen's juries and other public involvement work.

3.2 Establishing the diameter of trust needs to take account of:

- The level at which reciprocity with the citizen can be established.
- The proportion of the patient's interactions that occur within a geographical area e.g. in supporting their long term condition management, care co-ordination.
- The size and scale that will enable data collected to be supportive of a learning system that is adaptive, and can be analysed to be statistically significant (although regions can be aggregated)
  - Too small will prevent sustainability and radical change to care models.
  - However, too large will inhibit the agility and flexibility to
    - bring data together from the wider determinants of health and care for that population in near real-time
    - establish the trusted relationships needed.

- The size required to have enough care provision and social asset to enable local innovation in care model design.
- Maintaining local data controllership (e.g. data controllers in common) in data services. This enables the rapid use of information locally within the

12 Combining Health Data Uses to Ignite Health System Learning

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appropriate contexts as well as the ability to agree sharing protocols for pathways, such as cancer, that straddle geographies with patients at the boundaries of regions.

- Establishing and embedding leadership and change with health and care professionals in that locality.

3.3 The trade-off is a population large enough to have substantial economies of scale in infrastructure and governance and small enough for the community to relate data linkage/sharing to local benefit. Approaches around the world which define the population size around which learning health systems are organised reflect an upper-band of approximately 5 million, and the size of small countries like Denmark, Israel, Ireland and Scotland that can enact laws and regulations over health data sharing without major push-back. Even with countries that have larger populations, regional approaches such as Catalonia (7 million) in Spain, Venice (5 million) in Italy have been more successful than their associated national initiatives (60 million, 47 million respectively).

3.4 This is also consistent with experience in the US with success in regional initiatives such as Intermountain Healthcare, Advocate HealthCare and the New York Collaborative (8 million). In any case, even with large successful implementations, there are no such systems operating at the scale of a 60 million population.

3.5 This regionalised approach is in line with the development of self-organising governance through the Sustainability and Transformation Plans (STP) and underpinning accountable care organisations and new care models. These STP footprints should form a minimum bar of expectation for these regional initiatives with the ability for STPs to collaborate together. The STPs are already highlighting service change that requires digital enablement – such as placed-based integrated care models commissioned on the basis of outcomes (e.g. Black Country STP) as well as new cross-sector pathways for diabetes with shared-care plans for the wider integrated team. Driving the target architectural approach from this regionalised business context and need for local leadership is important to ensure that this is business-led and not technology-led.

3.6 The Connected Health Cities[13] programme and initiatives such as the Great North Record[14] are already based on a 2-5 million scale and have demonstrated the benefit in engaging citizens to create a trust relationship at this population size. Furthermore, their engagement with Academic Health Science Networks (15 in England) as part of these regional initiatives provides an opportunity to link insight and research into this.

3.7 This recognises that the drivers for choice of architecture are as much about culture and governance as they are about technical aspects. These provide the business context and priorities and also governance processes in driving delivery.

[13] https://www.connectedhealthcities.org/
[14] https://www.greatnorthcarerecord.org.uk/

The need for national analytics and insight

3.8 At the same time as determining the approach to support local "learning health and care systems" is the need to be able to support national analytics and insight across a number of different stakeholders such as NHS England, NHS Improvement, CQC and PHE. Consequently, the architecture needs to facilitate the creation of a national "data-lake" that is based upon the information held at a regional level and to be able to perform near real-time analytics and provide insight at a national level.

What technical approach should be taken for establishing regional "learning health and care systems"?

3.9 A number of principles emerged at the summit that forms the basis of the technical approach.

Emerging Principles

- That sharing of information is based upon the local trusted relationship between citizens and health care professionals
- Data should be controlled as close as possible to source.
- Data specific and tailored to that population can be used to derive actionable insight on the fly, to enable near real-time intervention at a local level for that population's specific needs.
- Individuals play an active role in generating and using data, and controlling how health and care providers use their data
- Governance of data and services should be de-coupled from decisions on physical implementation.

3.10 Clearly there are options of the technical approach being a national one or a regional based one. However, the approach needs to be based upon a balance across governance, speed, cost, scale, flexibility, and deliverability and difference in need.

3.11 For example, for population health; a dynamic and flexible national Data Services Platform at country level will enable national and local flows to be consolidated and data aggregated at a national level and combined with other data available nationally (e.g. Cancer Registries) for analysis.

3.12 At the same time, there will still be the need to enable localities to innovate and analyse together richer and deeper data items and flows relevant to that population, and directly integrate these into the local workflow. This sharing being within the 'Diameter of Trust' and with local data controllership. This will enable them, with appropriate controls in place, to perform real-time local business logic relevant to population health management. It will also use near real-time information for public health, outcomes-based contract management and local service planning, including locally agreed CQUINs for example.

3.13 Consequently, as it is recognised that there will be a richer set of data gathered at a regional level than nationally, these above considerations and principles point to a regionally-based approach where data controllership is local, sharing of information is tailored to that localised clinical workflow and information is used for localised real-time analytics based upon tailored data. This regional approach supports subsequent sharing of information with a national data platform for the creation of a national "data-lake" to enable nationally performed analytics – all operating in line with the National Data Guardian Review recommendations. This regionalised approach also enables the focus on improving data quality to be managed at a local level and so support professionals who will have a direct local stake in this and, just as importantly, the conversation between professionals and citizens on how and what data is be used and shared.

3.14 By taking a regionalised architecture approach linked to a national platform, this can then enable regional–based analytics to be tailored with the ability to provide relevant data for aggregation at a national level and use in national platforms (e.g. for specialised commissioning) and enable the use of national data back at a regional level for wider comparison. This is consistent with emerging recommendations on the move to use of modular data that will enable consistency and flexibility in use of data at regional and national levels.

What do we need to deliver for citizens through this infrastructure?

3.15 We must not create an architecture that artificially constrains citizens to a particular geography or organisation against the expectation that 'I' (as the patient) am engaging with the 'NHS', as opposed to separate parts of it. To enable access to their care information, there needs to be the ability to support an entry point of engaging and accessing services with the 'NHS', e.g. through nhs.uk, that can link to relevant national or local services as well as the more contextualised local experience where citizen provided data can be shared, with their consent, along their integrated care pathway.

3.16 We also need to consider that patients' access and use of apps/wearables will be communicated with professionals on their care pathway across health and care organisations. Consequently, the sharing of wearables information with care professionals would seem to be synonymous with the trusted relationship of sharing of care record information, and so again in the "diameter of trust." This is based upon citizen's consent on where and with whom their data is shared as part of a seamless user experience, with this information to be brought together in a federated model using standards based Application Programme Interfaces (APIs).

3.17 In the future, we should look to provide the ability for citizens to be able to subscribe to a Personalised Health Record (PHR) service where all the data about them is available for apps of their choice to then use and access. This care record information being brought together and normalised from across the local platforms. At the same time, citizens having the ability to provide their information into this PHR service so that their professionals can call on this in

real-time and incorporate into their systems as part of their interactions with patients. This using the national record locator service (see national capabilities - 3.3.1) to locate and retrieve care record information for that citizen and this being used in "reverse" for the citizen provided information to be located and then incorporated as part of care records during professional and citizen interactions.

3.18 We can look to provide choice of PHR service used by the patient to hold their data along with national availability of this data for use by care teams, and across regions as determined by patient journeys. The key being the trust established with them on how their data is to be used and shared.

Proposed target architecture

3.19 The proposed approach is to establish a set of scalable regional platforms, underpinned by key national capabilities, standardised components and correlated with the learning health and care communities concept outlined above.

3.20 These are based upon rich data suited to that population at size and scale, using information shared for direct-care provision that can be integrated directly into the local workflow. These platforms will provide data that can be aggregated nationally with the national data platform to support local analysis and wider comparison.

3.21 **Expectations of the "platforms"**

These regional platforms will operate as an interoperable architecture. These working to a common 'design guide/blueprint' to provide a consistent approach to information sharing, whilst still enabling local innovation.

- These platforms will share information using a set of nationally defined APIs and datasets for citizen/patient data to flow across multi-vendor value chains without commercial impediments. This will enable information to be shared across care services (e.g. Ambulance) and pathways (e.g. Cancer) that cross regions/STPs boundaries.

- They would operate using a common consent architecture in line with Caldicott 3 recommendations so that, as a professional, I am able to get a normalised single view of the patient's data even when they have crossed borders without loss of data.

- These regional platforms aligning with existing local platform initiatives and enabling synergies to be identified whilst maintaining their "local buy-in".

- The platforms would use a consistent set of technical capabilities - with these potentially delivered at a larger scale and re-used across regions and therefore not 'tightly-coupled' to a specific geography. These include a number of 'do-once' national infrastructure capabilities for information

exchange (see 3.31). For example, the national record locator service that would bring together information from across regions. This also enables the single view of data for patients at the borders of geographies.

- These platforms operating on principles of “Privacy By Design”.

3.22 This target architecture approach provides the ability for regional initiatives to progress at a pace and agree sharing across regions based upon patient pathways, whilst at the same time utilising national capabilities and enabling learning at a national level - to aide continuous quality improvement.

3.23 This then enables the sharing of data from a local through regional to national level and reflects local accountability for service change, responsiveness and agility in implementation at a regional level, whilst still necessitating data being available nationally e.g. for specialised commissioning, benchmarking and comparison.

3.24 In driving consistency across these regional platforms, an additional national role would be in the development of common set of requirements for the core capabilities needed, including potentially national frameworks that would also drive the appropriate market dynamics and make greater use of cloud services. Also, the potential for re-use of open source capabilities.

3.25 An alternative approach would have been to look to provide new centralised data services for local and regional population health management. However, this does not take into account the significance of establishing trust and instilling local confidence in the confidentiality, security, agility and flexibility in nationally delivered data services.

3.26 What we learnt from the summit and previous programmes is that these trust and information governance aspects should be considered before technology in how data services should be delivered for regional/local use – be they a national document store or population health data linkage services.

3.27 The first step for national data services should focus on creating a responsive national data platform for core and statutory national functions. This national data platform being able to receive data in near real-time from regions and national sources and share this back in near real-time. This then demonstrating rapid delivery, flexibility and technology approaches that can be built upon. Furthermore, any decision on national provision of commodity services locally needs to be considered in the context of the wider market and implications on local innovation.

3.28 Consequently, this target architecture also provides the natural transition architecture through establishing and building on regional platforms already in place and/or identified through the STPs. For less mature localities, we should consider how these regional platforms can be re-used and scaled in conjunction with national infrastructure capabilities. This embedding the trust of

sharing of data at a regional level whilst national standards, governance, trust and flexibility is being defined for new national data services.

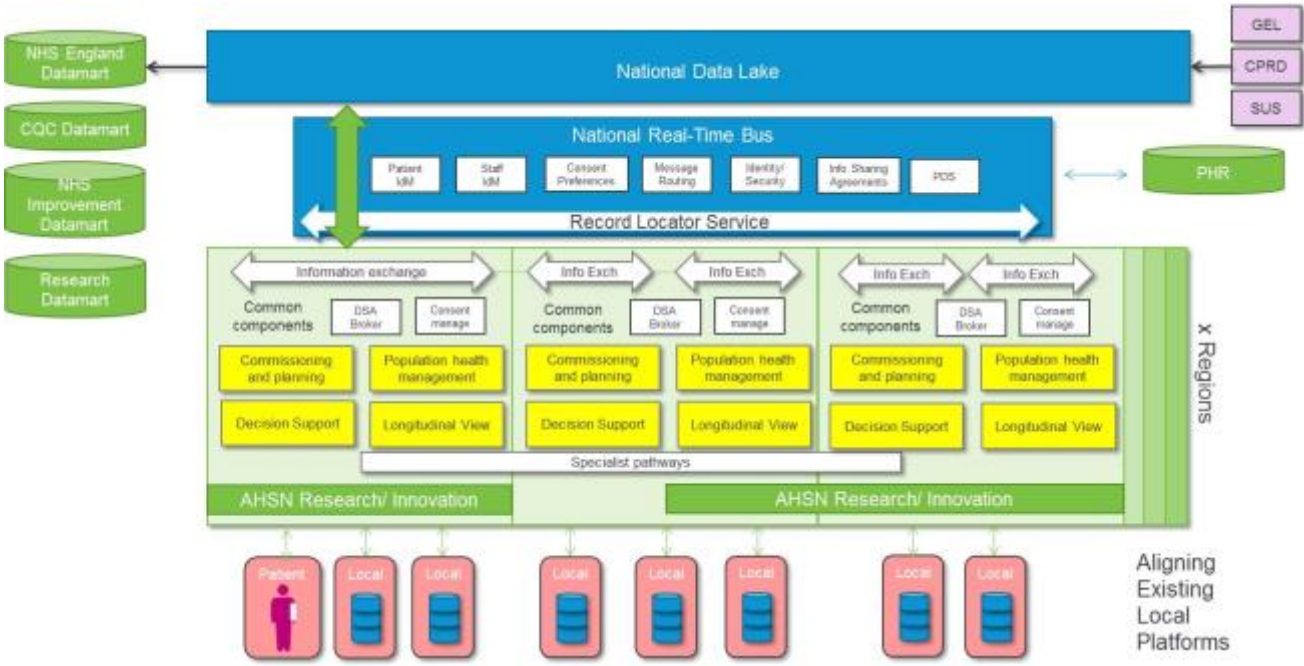

Figure 3 - The proposed target architecture

3.29 This regional architecture approach would provide the following capabilities:

1) The ability to combine identifiable structured data in real-time from local clinical systems and platforms and wider sources (such as the citizen themselves) to be able to bring together the “longitudinal record” for the citizen in support of decisions at the point of care, and available to view through local clinical systems with appropriate legal basis. The National Record Locator will ensure that information recorded about patients who receive care in more than one regional area can be called upon and collated into one place.

2) Citizens need to be able to able to access their longitudinal record through open interfaces from their PHR(s), but importantly need to be able to provide their data in the context of the local services they are using and along their integrated care pathways, e.g. a diabetes app used in conjunction with the diabetes service. Where there are use cases for provision of their data nationally, they should have the mechanism to provide this and so be able to ‘plug’ into national services through open interfaces.

3) The ability to combine structured data in near real-time from local systems, platforms and wider sources (such as the citizen, open data) into a normalised record that can support population health management requirements such as identifying gaps in the quality of care; care coordination; care planning and management; population health risk stratification; predictive algorithms and integrated care network management of outcomes-based commissioned contracts.

4) The ability to support service planning and commissioning as a derivation of the data that is being collected to manage care. To be able to provide extracts and de-identified information, add in local data flow content to perform local business logic and analytics for local service planning that can happen in near real-time

   Example: data flows frequency is improved to hourly where possible (only applicable to specific feeds), allowing STP level System Resilience to be achieved. This will also allow for pressure to be better understood and handled, influencing staffing (including working patterns) and pathways to improve patient care.

5) The ability to directly align research initiatives with availability of data locally, and the opportunity to engage citizens locally in research with the appropriate legal basis. Using this information directly within the learning health system to support research at local, regional or national levels in conjunction with national services.

6) Ability to better support national data requirements for central processes. To be able to provide extracts of this data to national services such as the Data Services Platform for payments, specialised commissioning, national benchmarking and regulatory requirements with near real-time feedback from the national platform to aid local service provision. This also enables the ability to upload and download a snapshot of the data from the regional architectures and so a local<->regional<->national flow and so mitigating the issue of multiple duplicate information flows being needed from local systems.

3.30 The regional architecture will be underpinned by nationally provided infrastructure capabilities providing an optimal approach for local learning health systems. It will also enable the alignment of existing local platform initiatives at a regional level whilst maintaining local buy-in.

3.31 In this way, the target architecture provides a set of regional platforms facilitated using scalable technical capabilities and a set of 'do-once' national capabilities. These include capturing patient preferences, flags (e.g. Child Protection Information Sharing), approaches (e.g. computational management of information sharing protocols) and a set of national platform components such as:

- National Record Locator Service – to enable the location of patient records
- Citizen and Staff Identity – the ability for a citizen to be verified once for access to digital services across their care pathway, including the ability for professionals to be verified once.
- Master Demographics Service - to enable to unique identification of a patient to link to their care records and data items.
- Messaging and Routing – ability to enabling the routing of messaging.

In addition, there is a need for a set of "standardised" components that should be used across the regional platforms to ensure that activities are done "in the same way". These include

- De-identification – ability for data to be de-identified. This will need to be a common service which can be deployed across national and regional platforms.
- Terminology and Translation – to provide linking rules, translations and normalisation of coding.
- Rules definition and engine – for nationally defined guidelines e.g. NICE guidance, we should look to develop re-usable components that can execute the same algorithm and in a consistent manner. This being available for national use but also local use with the ability for localities to then add their own additional local rules.
- Data Landing Platform –where locally, regionally or other data can be landed to be incorporated into the data held by the platform.
- Analytics engine – different analyses will need to be carried out locally, regionally and nationally and so an engine capable of analysing the data held will be necessary. Some of this analysis e.g. HRG generation will be shared components but some will be locality specific.
- Alerting – there are examples where an alerting engine will be needed to be able to detect areas within a CCG which require intervention e.g. winter pressures and there will be national ones e.g. Winterbourne View.
- Master Patient Index – this will ensure that a master list of patients being managed is available and that records about their care whether for direct care or secondary uses can be linked together.

4 Conclusion

4.1 To address the problem statement outlined in the executive summary, two main elements have emerged for the target architecture.

1) **Governance** based on a set of regional self-organising communities building upon the existing planning approach with a minimum STP level footprint (including the ability to extend to a combination of STPs), where each community operates as a learning health care system for its population. This will be supported by a digital roadmap that delivers a regional platform for shared services, information sharing for both direct care and population health management based upon privacy by design. This at a scale of approximately 2 to 5 million population. Leadership is key to driving delivery of information sharing and so the STPs as self-organising communities are key in driving local implementation and delivery and having the leadership in place.

2) The target architecture based on a number of **'regional platforms'** striking the balance between a single national approach and the current generally localised approach to provide an optimal hybrid. This being at a sufficient level to provide economies of scale, mirroring the approach in self-organising units of local delivery whilst not being tightly coupled to them and so able to flex around organisational constructs. It brings together the architectural

capabilities for information sharing for direct care and population health management as well as serving purposes for planning, commissioning and research - all based upon the sharing of the same structured data. It also enables the ability to move at pace" at a regional level, whilst using a set of nationally-provided capabilities, adhering to national standards and using standardised components. This enables learning across localities and potentially promoting these datasets/regional capabilities to then become available at a national level.

Next Steps and Considerations:

1) To engage on the proposed target architecture with the attendees of the interoperability summit and then to wider stakeholder groups.

2) To consider the approach and guidance on supporting the self-organising groups and their scale to establish learning health and care systems.

3) To outline the leadership and delivery expectations that would need to be in place locally to ensure that this implementation can be achieved and benefits realised.

4) Further work in outlining the information governance implications of the target architecture, including taking account of the work to develop anonymisation guidance/standards and incorporating privacy by design in early stages.

5) To outline the local 'design guide' for regional platforms - including the key capabilities needed and which ones will be delivered nationally.

6) To urgently accelerate the definition of the national standards - both in the common set of interfaces and also the national datasets required, as well as the delivery roadmap for 'do-once' national infrastructure capabilities based on open standards and open source approaches.

7) To investigate the optimal delivery approach for "standardised components" and also national procurement frameworks to drive consistency in the capabilities delivered and create appropriate market dynamics.

8) To work with the NIB portfolio, its programmes and the EAB on the implications of the target architecture. This includes further definition of the national capabilities and also detailed architecture definition for different uses cases on sharing of citizen provided data.

9) To outline next steps in moving towards the target architecture and the minimal viable approach needed for lower mature localities whilst taking account of market and innovation implications.

10) To outline the emerging needs for evolving national functions e.g. outcomes-based re-imbursement models, risk-based approach to quality regulation and the implications on the target architecture.

Annex A

What does this mean for me as a citizen?

The target architecture itself is purely an approach that enables us to outline a framework. Critically, it is what this means for the citizen as someone who has to engage with care services that is central to what the architecture is trying to achieve.

"I get very worried about being by myself when my breathing gets worse. When I called NHS 111 the lady knew about my emphysema and said she was sending a paramedic to see me. He knew about my problems, that I smoked and the treatment I was taking, so I didn't have to keep telling everyone the same story when I went into hospital.

My GP came out to visit me when I came home. He knew everything that had happened to me in hospital and told me I would need to reduce the dose of one of my tablets next week. I am not very good at remembering things so the nurse is going to call me on my iPad to remind me and to check that I am alright."

"As the call handler I know that Dot has a long-term problem with her lungs and that the nurse has been to see her at home three times in the past week. This information helps me decide that Dot needs someone to assess her at home and see whether she needs to be admitted to hospital. So I ask for a paramedic to be dispatched."

"As the paramedic attending Dot I can assess how much her current condition differs from when she was last seen by her GP. I can also see her previous blood results which lets me know her usual oxygen level and whether she is sensitive to treatment with oxygen. This means I can treat her safely."

"As the A&E consultant I can see that Dot was barely able to speak and was very wheezy when she was seen by the ambulance staff. She had a high temperature and very low oxygen level when she was first seen. I can compare the recordings taken in hospital with those taken by the paramedic and see that Dot has improved with the treatment she has received on the way to hospital. I can see that the chest x-ray she had done in A&E shows signs of an infection which wasn't there on her previous chest x-ray."

"As the Respiratory registrar I can see from Dot's previous hospital record that she was in hospital for 2 weeks last winter with a bad chest infection and took a while to recover. I can see the antibiotics she was given at that time so decide to prescribe the same ones. I am alerted that she has an allergy to this and when I look back at the notes from her last hospital admission I can see she developed a rash with the antibiotic, so her treatment was changed. Although she has not been in hospital for a year I can see from her GP notes that the nurse has been visiting her more frequently at home recently, as she has not been coping as well."

"Dot can't remember the name of all her medicines and inhalers. As the hospital pharmacist I can look at the information in Dot's GP record which tells me all the medications she usually takes so I can make sure these are prescribed. I can also see that Dot's GP prescribed her a course of antibiotics two weeks ago which she has recently finished, so I can discuss the best antibiotic treatment to give Dot while she in in hospital with the Respiratory Registrar.

I could see from Dot's care records that she hadn't had her annual flu jab. I administer Dot with a Flu jab and make a note on her care record."

"As the discharge nurse I can see from Dot's GP notes that she needed a lot of input after she was discharged from hospital last year and lost her confidence getting back on her feet after her chest infection. I speak to her daughter who lives 50 miles away. She is worried that Dot won't manage if she is discharged home quickly and she mentions that Dot has been struggling to get into the bath and to get out to the shops recently. I set up a conference call

with her GP, the community hospital consultant, social services and Dot's daughter. We decide that Dot should go to the community hospital for a while once her chest infection is improving. I record the outcome of the meeting in Dot's shared care plan."

"When I see Dot in the community hospital I can see the treatment she had in hospital and review the assessments made by the physiotherapist. I can also see from the GP record that Dot has not been managing well at home for a few months and will need some additional care at home when she goes home. I notify social services of Dot's likely discharge date so they can make sure her new care package can be put in place. I update Dot's shared care plan.

I can see from Dot's care record that she has not yet received the latest stop smoking kit. I give her a kit and mark her down as having received one."

"As Dot's GP I can see that Dot had phoned NHS111, been seen by a paramedic and then admitted to hospital. I know which ward she was admitted to and who was looking after her.

Now that Dot has been discharged home I can see all the treatment she has been given from her hospital records and the note from the hospital consultant to ask me to reduce the dose of one of her medications in a week. I can see that social services have arranged for a carer to visit twice a week and that the first visit is due tomorrow.

I know Dot gets a bit anxious and sometimes forgets to take her medications. Dot's daughter has recently bought her an iPad so she can stay in touch with her more easily. I tell Dot the nurse will arrange to contact her regularly on Skype to keep an eye on her now that she is back home."

DRAFT

Summit Attendees - The following were attendees at the summit.

Attendees Name	Role	Organisation
Adrian Byrne	Director of Informatics	University Hospitals Southampton NHS Foundation Trust. CIO Community Chair.
Andrew Eland	Engineering Director	DeepMind Health at Google
Andrew Fenton	Associate Director, Digital Transformation	NHS South, Central and West
Andrew Jaminson	Partner	PA Consulting Group
Andy Kinnear	Director of Digital Transformation	NHS South, Central and West CSU. BCS Health Chair
Benjamin Heap	Project Manager	NHS England
Cathy Kelly	Chief Clinical Information Officer	University College London Hospitals NHS Foundation Trust
Charles Gutteridge	Chief Clinical Information Officer	Barts Health NHS Trust
Cian Hughes	Applied Artificial Intelligence Researcher	DeepMind Health at Google
Cris Ross	Chief Information Officer	Mayo Clinic
Daniel Ray	Director of Data Science	NHS Digital
David Champeaux	Managing Director, Healthcare Strategy	Accenture UK
David Evans	Director of Policy and Community	BCS
David Stables	Chief Executive Officer	Endeavour Health Charitable Trust
Dr Carmelo Velardo	Senior Researcher in Digital Health	University of Oxford
Dr Dario Salvi	PostDoc Research Assistant	University of Oxford
Dr Henrique Martins	Chief Executive Officer	SPMS - Serviços Partilhados do Ministério da Saúde
Dr Justin Whatling	Vice President Population Health	NIB Independent
Dr Kambiz Boomla	Clinical Information Officer & Senior Lecturer	Waltham Forest and East London CCGs & Queen Mary University of London
Dr Rafael Richards	Director, VA VISTA Data Project	U.S. Department of Veterans Affairs
Emma Doyle	Head of Data Policy	NHS England
Geraint Lewis	Chief Data Officer	NHS England
Graham Sumner	Client Executive	IBM (UK) Ltd
Ian Lowry	Programme Manager	NHS Digital
Ian Townend	Lead Enterprise Business Architect	NHS England
Inderjit Singh	Head of Architecture	NHS England
James Mucklow	Digital Healthcare Expert	PA Consulting Group
Jane Barnacle	Regional director for patients and information	NHS England - London
Jeremy Thorp	Director of Business Architecture	NHS Digital
Jim Murry	Chief Information Officer	Stony Brook Medicine
Jitin Asnaani	Executive Director	CommonWell Health Alliance
Joe McDonald	Chief Clinical Information Officer	Northumberland, Tyne & Wear NHS Mental

		Health Trust. CCIO Community Chair.
Johan Nolan	Enterprise Architect	eHealth Scottish Government
John Doyle	Lead Technology Strategist	Microsoft
Joseph Waller	Spine architect	NHS Digital
Juliet Bauer	Director of Digital Experience	NHS England
Lenore Ogilvy	Transformation Consultant	ConBrio Associates
Lisa Franklin	Director of Information & Technology	Southern Health NHS Foundation Trust
Luke Readman	Chief Information Officer	Waltham Forest Newham and Tower Hamlets CCGs
Mark Golledge	Programme Manager – Health and Care Informatics	Local Government Association
Michael Trevett	Deputy Director (Security)	NHS Digital
Mike Broomhead	Healthcare & Life Sciences Industry Architect & CTO	IBM (UK) Ltd
Mike Part	Chief Information Officer	NHS England London Region
Niall Sinnott	Asst. National Director	Health Service Executive
Paul Campbell	eHealth Lead	NHS Scotland and the Scottish Government
Paul Docherty	Applications Architecture Manager	NHS Greater Glasgow and Clyde
Paul Fleming	Head of Digital Technology	NHS England - Midlands & East of England
Paul Henderson	Analytics Director	KPMG UK
Paul Rice	Head of Technology Strategy	NHS England
Paul Thomas	Healthcare Chief Technology Officer	Microsoft
Peter Sinden	Chief Information Officer	NHS Improvement
Phil Sinclair	Partner	Philips Healthcare Transformation Services
Phil Stradling	Lead Enterprise Business Architect	NHS England
Prof Iain Buchan	Professor of Public Health Informatics and Director	University of Manchester
Prof John Ainsworth	Professor of Health Informatics	University of Manchester
Rachel Dunscombe	Chief Information Officer	Salford Royal Foundation Trust
Rana Bhattacharya	Chief Architect	Nationwide Building Society
Richard Jefferson	Enterprise Architecture Board (EAB) Chair	NHS Digital
Stephen Docherty	Chief Information Officer	South London and Maudsley
William Smart	Chief Information Officer for Health and Social Care	NHS England