

ENABLING EVIDENCE



BASED CONTINUOUS IMPROVEMENT

The Target Architecture



CONNECTING CARE SETTINGS AND IMPROVING PATIENT EXPERIENCE

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2. Our Challenge:

1. We recognise that the NHS and our wider health and care system are under real pressure.
2. The occurrence of acute, expensive to treat conditions such as obesity, diabetes, cancer and mental illness are rising rapidly.
3. We are all living longer and therefore need more care over the course of our lives than ever before.
4. Providing care for those later in life is more expensive. Recent estimates suggest that it costs five times more to treat the average 80 year old, than it does to treat a 30 year old.
5. Medical advances are constantly being made as a consequence of clinical, technological and scientific research and innovation. Yet these often life-saving advances come at a cost; providing care is now more expensive than at any time in the history of the NHS.
6. The good news is that we have a plan to meet these challenges, a plan that will harness technology and innovation to create a truly modern health and care system. A plan that will harness technology and innovation to support our mission:

...To promote Better Health for all.

...To enable health and care professionals to provide Better Care when needed.

...And to achieve Better Value in order to us to enable a sustainable health and care system.

3. The Plan - Five Year Forward View (FYFV)

This Plan outlines Our Commitments:

7. We are committed to helping reduce the demand on A&E departments as they deliver urgent and emergency care. This is our “front line”.

8. We are designing and introducing new systems for NHS 111, both for telephone and online, that will mean patients using NHS 111 at their time of need will be directed to truly personalised care:

...Care delivered at the right location (pharmacy, GP surgery or hospital).

...Care appropriate for their condition (general or specialist).

...Care prioritised for the seriousness of the patient’s condition (non-urgent or urgent).

9. We are going to give GPs the electronic capability to seek advice and guidance from a hospital specialist, without asking patients to always attend an outpatient appointment. This will help us reduce the number of unnecessary referrals that take time and attention away from patients that really need specialist help and, crucially, give patients confidence who would otherwise face a delay in diagnosis and treatment.

10. In addition, by the end of 2018, Primary and Secondary Care providers will have the capability to offer the NHS e-Referral Service to every patient. It will save time, save paper, save money and enable better care.

11. Underlying all our efforts in service integration is our work to enable each part of the health and care system to digitally “speak” to other parts of the system.

12. For GP practices to send digital information to pharmacies and hospitals seamlessly, for hospitals to send information to another Clinical Care Group that

follows patients as they move and for hospitals to send information to Local Government providers of essential social and community care.

13. This relies upon the adoption across health and care of common standards for how information is collected, formatted, analysed and communicated. We have already defined professionally endorsed “transfers of care” through the Professional Records Standards Body and the common approach to access the care record in the CareConnect Fast Healthcare Interoperability Resources (FHIR) profiles. Now is the time to move to their implementation.
14. Our technology infrastructure will integrate with, and be able to consume information from different and diverse GP surgery and hospital systems around the country through open APIs.
15. Delivering better health, better care and better value by harnessing exciting technology and innovation developments for people, professionals and health and care system leaders can only be achieved if we continue to deliver and maintain outstanding technology infrastructure.
16. People must be confident that if they use our digital services, they can do so securely, confident that they alone, along with the appropriate staff involved in their care that treat them, will have access to their confidential health information.
17. We have developed through the National Data Guardian (NDG)¹, a set of Information Governance and Transparency principles and standards that will ensure that those who collect, hold and analyse data, will be held to account for doing so to the highest possible standards of privacy protection. We are also creating an identity verification sign-on system that will ensure patient confidentiality.

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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627493/Your_data_better_security_better_choice_better_care_government_response.pdf

18. The digital solutions we are developing to gather and hold health data will enable us to do the analysis we need to develop health policy and understand how well and cost effectively we are delivering care without identifying individual patients.
19. NHS.UK will in time, provide every citizen in England and Wales with secure and safe, identity verified access to digital content, services and their individual care information. This will provide personalised health and care information guidance and condition management advice that is contextualised by place and time, and that will provide users with a life-long relationship with the whole of the NHS.

4. Enabling the Five-Year Forward View – Target Architecture:

20. The Next Steps Five Year Forward View² also outlines an approach for service transformation underpinned by three key elements.

Population Health Management:

21. Delivering personalised health, in which treatments and interventions are offered based on a data driven assessment of the personal risk and likelihood of individual responses to treatments.
22. Understanding the relevant and wider determinants of health in providing care for local populations “at place” means working with Local Government and Public Health and other relevant agencies. In this way, information taking account of the various factors relevant to a citizen and this being used to target effective preventative interventions across the whole population or sections of the population.
23. The Local Government Association has recently published the “Health in All Policies – A Manual for Local Government”³, which outlines the importance of all local organisations influencing the social determinants of health. The publication raises the importance of data and evaluation to inform the approach to population

² NHS England, Next Steps on the NHS Five Year Forward View, Mar 2017 <https://www.england.nhs.uk/publication/next-steps-on-the-nhs-five-year-forward-view/>

³ Health in All Policies – A Manual for Local Government: <https://www.local.gov.uk/sites/default/files/documents/health-all-policies-manua-ff0.pdf>

health management – for example understanding the importance that adequate housing can have on improving morbidity and mortality and therefore overlaying data and intelligence on excess winter deaths with housing that is shown to have significant heat loss can help partners make the case for stronger housing improvement programmes.

Accountable Care Systems:

24. Accountable Care Systems (ACSs) will take on collective responsibility for the total cost and quality of care for the populations they serve. This will require supportive population health management informatics.

25. As Sustainability and Transformation Partnerships deliver population-based integrated health systems, and enable new ACSs, they will need to deploy rigorous and validated population health management capabilities that; improve prevention, enhance patient activation and self-management, manage avoidable demand and reduce unwarranted variation. Technology and use of data can enable these.

Local Engagement:

26. Effective and active place-based engagement with neighbourhoods and within and across communities of shared interest is essential if we are to effect the required behaviour change that taking individual control and ownership of health and wellbeing necessitates. This requires working in partnership with community-based organisations, 3rd sector and wider groups that can also support people in these areas. Building and maintaining public and professional confidence.

27. Fundamental to delivery of these three key elements is building public and professional confidence and maintaining trust in our approach to data use. This is a clear priority for the service at all levels - be this national, regional and local. The includes the transparency of how data is to be used, by whom and for what purpose and having the robust assurance that information is safe and secure with the potential risk of re-identification being proactively managed.

28. We will ensure this through the highest standards of Information Governance controls that will be required to be consistently applied, a strengthened role of the

NDG and a vigilant approach to cyber security with these embedded upfront in taking forward the proposals in the Target Architecture. In this way, providing a coherent approach nationally whilst enabling locally led delivery.

5. Consultation and Engagement:

The Consultation Process:

29. In enabling an approach that serves these three key elements, we need the help of the Chief Clinical Officers, Chief Information Officers, Sustainability and Transformation Plan (STP) and Local Authority Leads on the front line of health and care delivery.

30. That's why, as we prepared this document – the “Target Architecture”. We have spoken with local CCIOs and CIOs, academia, professionals, those working with patient groups, industry and with local authorities in understanding their key drivers and the local approaches they wish to take to address these. We have seen best practice and we have heard your many and varied challenges and the guidance and direction you wish us to take.

31. In addition we convened in November 2016 an Interoperability and Population Health Summit that brought together varied stakeholders with the goal of establishing a cohesive strategy for interoperability and population health management across England. An initial draft was circulated in early 2017 for comment. A number of comments and responses were received and this has helped inform the subsequent development of this updated Target Architecture. The feedback included:

- being clear on the drivers, and the “use cases” that this approach enables,
- how this relates to the existing informatics landscape,
- the controls in place to ensure that information is used appropriately,
- and “what” this would mean for STPs and nationally.

What we heard:

32. To support the move to sustainable health and care systems, new models of care are changing to include the need for near real time mapped information to both better “predict and prevent” as well as “diagnose and treat”.
33. Access to GP information is necessary, but not sufficient to support the complex health informatics needs of the system. The need to access care information for the patient from across the different venues of care.
34. Data collection scope, quality and exchange is variable, place-to-place. We need stronger consistency of approach and greater consistency in how controls are applied in the use of data.
35. Any approach to use of digital, must start from the service transformation we are trying to enable where digital can facilitate as opposed to starting with the technology. It will be the service transformation that we have enabled that is the objective.
36. Localities want and need to be able to harness the richness of data captured at the point of care to be used for improving health, care and services through research and planning.
37. Localities wishing to understand and improve the health outcomes of their local populations often find it difficult to “access their own data” from the national patient data safe-haven.
38. Localities are at different speeds and maturity of implementation, so we need to enable different needs to be served.
39. Maintaining patient trust is fundamental, as we determine how we collect data about their health, and how we use their data to improve care, and that we keep their data safe as we do so.

40. There remains the need for the collection of data nationally e.g. to support rare diseases cohorts, as well as the ability to nationally benchmark and compare outcomes and performance.
41. Patients are willing to share their data “closer to home” for the purposes of providing better care for them, their families and those in their neighbourhoods and communities. They are less willing to share their data when the direct benefit for them and their local population is unclear.⁴

Thank you for your insights and assistance.

6. The Direction

42. Crucial to realising the potential for healthcare data to improve care is ensuring that the use of such data is acceptable and always in the interest of patients and professionals. A critical step is the need to implement the recommendations of the NDG, which set out new safeguards for health and care data. The proposals in this strategy are designed so that they are aligned with the NDG’s recommendations. Similarly all proposals should meet the relevant high data security standards as set out by the NDG and the recommendations of Care Quality Commission (CQC)⁵.
43. Building on this and following on from the feedback, this updated Target Architecture sets out a direction based on the following principles. It is also based and in line with data principles being developed across the Personalised Health and Care portfolio at a national level.

Patient-centric delivery:

44. This ultimately starts and ends in how we can improve the experience and outcomes of patients. And so we must put the needs of individual patients first, at all times.

⁴ <https://www.connectedhealthcities.org/>

⁵ <http://www.cqc.org.uk/publications/themed-work/safe-data-safe-care>

45. We must not create an architecture that artificially constrains citizens to a particular geography or organisation.
46. Notwithstanding our desire to deliver place-based care, access to treatment has to be a matter of individual clinical need. For example, a patient of Doncaster Royal must be able to access specialist kidney or cancer care at Leeds Teaching Hospital if they need it, when they need it. We must not let technology and the information that flows across organisations stand in the way of delivering outstanding care.
47. We have to create the means for patient information to follow the patient, wherever they need care. Common, open and consistent standards are essential.
48. We want citizens to have a relationship with what they see and experience as ‘one’ joined up NHS and Social Care system.
49. We want patients to benefit from the latest technology being put to use such as the 100,000 Genomes project, which enables patients to be provided with personalised treatment plans and ensures researchers have access to vital information to better understand conditions, such as cancer and rare diseases.

Place-based data collection and use:

50. We know that the health and wellbeing of people and their communities is a function of a wide range of individual genetic and/or lifestyle determinants. However, local socio-economic and demographic factors also matter. Factors such as poor housing conditions and uncertain employment status are equally as important as carrying the gene for a medical condition, smoking or being overweight (see figure 1).
51. Working in collaboration with other partners such as Local Government, Housing Providers and other public bodies, the NHS now has a real and important opportunity to help address these wider and place-based determinants of health and well-being.

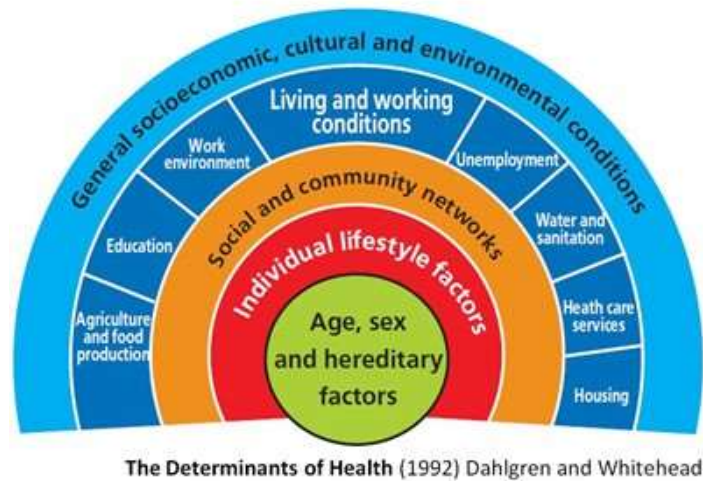


Figure 1 – Wider Determinants of Health

52. So we now need to gather and use the place-based data that will drive the improvement of place-based care. To do so effectively, we now need the ability to gather data across health and care settings and harness the potential of the use of this as information, to provide individual care to then inform how we can improve health, care and services through research and planning.

Care comes first:

53. Our primary consideration in health and care is the need to share data for individual care.

54. We must ensure that information based upon this data is available at the point of need for citizens, carers and care professionals.

55. We must respect patient confidentiality at all times and manage their data with appropriate controls and permissions.

Continuous improvement:

56. We recognise the need for information that will enable accountable and place-based, governed and managed learning health and care systems.

57. We aim to enable health and care systems to systematically learn from data, so that we can continually drive improvement in individual care, deliver to best practice, reducing unwarranted innovation, and to evaluate and learn from different practices and new care models.

58. At the Interoperability and Population Health Summit, we reaffirmed the need for, and outlined the approach to establishing “learning health and care systems.”

59. Friedman et al⁶ describing ‘*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.*’

60. Ainsworth & Buchan having also proposed a place-based approach that could kick-start learning health systems, with specific reference to the UK context⁷ to support research, improve treatment and the quality of care through health-based trials. This may use either identifiable or de-identified data, but always ensuring that required levels of consent are obtained.

61. The Interoperability and Population Health Summit defined a “5 Purpose” framework to enable this health and care system learning. Each purpose is discrete, with its own data controls with these operating in line with the NDG recommendations, but importantly these to be seen as one overall framework with a “feedback loop” from the insight gained going back into the front line provision of individual care for the patient.

⁶ Friedman, Wong & Blumenthal, Achieving a Nationwide Learning System, Science Translational Medicine, Nov 2010

⁷ Ainsworth J, Buchan I. Combining Health Data Uses to Ignite Health System Learning. Methods Inf Med. 2015;54(6):479-87.

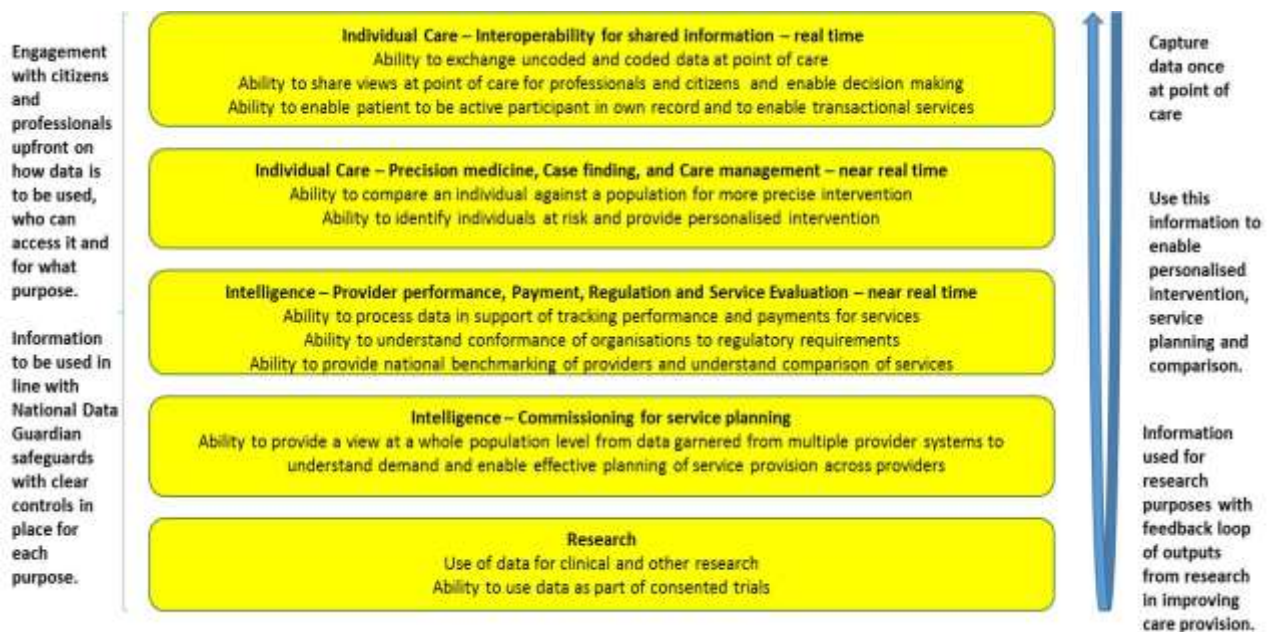


Figure 2 – Purposes of Information

62. To deliver this evidence-based continuous improvement, adaptive change and learning; we propose that we capture data once at point of care, and based upon having the appropriate controls in place, using this de-identified information to inform personalised intervention, place-based service planning and comparison, as well as for place-based treatment and care research.

63. The value of taking this approach has already been highlighted through the work of the “Understanding Patient Data” initiative. This highlights case studies of benefit, such as use of GP and Hospital data to understand trends in diabetes and putting targeted interventions in place⁸ and also in planning colorectal cancer services and enabling patients to receive tailored care programmes post diagnosis⁹.

64. In reducing the current burden on localities having to separately provide submissions in multiple formats for existing local and national purposes, we also propose that we use data collected once for defined and clear national purposes. This including - national comparison such as for benchmarking, detecting

⁸ <https://understandingpatientdata.org.uk/case-study/investigating-trends-diabetes>

⁹ <https://understandingpatientdata.org.uk/case-study/planning-services-people-living-and-beyond-cancer>

unwarranted variation, supporting rare diseases cohorts, specialised commissioning and opportunity analysis already undertaken to help us improve services across the country and make better health and care purchasing decisions.

65. Where new needs arise for national use of data, we must be clear upfront on how data is to be used and for the controls in place for this.

Scale matters:

66. We recognise that there are lessons learnt from the past in taking a single national approach, but at the same time if we are to enable a sustainable footing for health and care, we cannot have a thousand flowers blooming that will lead to greater informatics fragmentation. We need to find the right scale that maintains the trust relationship, the balance of informatics investment and ensures consistency of approach in how data is to be used, who can access it and on what basis.

67. Successful health systems around the world have achieved favourable economies of scale in establishing learning health and care systems across large population sizes (circa 2-5m population) and have been able to deliver outstanding integrated care to the smaller (circa 30-50k population) neighbourhoods and community populations that comprise them. This approach meaning that the “right interventions can be done at the right scale.”

68. We believe that larger population data enables the tracking and managing patients across the complex care pathways for which STPs are responsible and also taking account of population flows, tertiary health referral networks or ambulance networks. It informs service redesign and presents the opportunity to harness rich data for research.

69. So we anticipate that adjoining ACSs will co-operate, collaborate and establish shared platforms and informatics architecture to reduce the cost whilst leveraging scale advantages, especially where there is a high volume of patient flow along pathways.

70. ACSs and their enabling information architectures will then also be capable of supporting smaller scale integrated care hubs with accountability for their local populations, such as the ‘clinical hubs’ in primary care that will be established through the Next Steps plan at 30,000-50,000 population sizes.

71. We also acknowledge that Professor Sir John Bell is currently leading the development of a new strategy for the long-term success of UK Life Sciences. One of the emerging key themes in this work is the potential of de-identified data, collected and managed at scale, to enable world-class clinical research and real-world studies. A specific emerging proposal in discussion is the development of interoperable regional innovation hubs, to serve scaled populations of circa 3-5m. Such hubs could provide innovators with the appropriate access to the de-identified real-world data they need to develop and demonstrate the effectiveness of new technology, devices and medicines, as well as enabling the health and care system to understand the true value of these. By operating at this population size, innovation hubs could provide closer proximity to and engagement with research for patients and professionals, as well as greater flexibility to work with local or bespoke datasets.

Trust matters more and transparency in how data will be used:

72. Intrinsic to this discussion is seeking and retaining the trust and permission of the populations we serve – and the health and care professionals that deliver care. It is vital in establishing this trust that we operate within a set of consistent controls and governance and are transparent in how data is to be used. This is where adherence to the NDG’s recommendations¹⁰ is crucial both on information governance but also in respect to data security to ensure appropriate controls, processes are in place. These in effect, needing to be embedded in business as usual operation.

73. We can only establish the scale we need to support individual care across pathways, inform service redesign across defined geographies, and support research, if we seek the permission and retain trust of the populations we serve.

¹⁰ <https://www.gov.uk/government/publications/review-of-data-security-consent-and-opt-outs>; all proposals to utilise de-identified / ICO code of practice anonymised data where possible, and any use of personal confidential data to have a clear legal basis e.g. via direct consent / s251 / CAG approvals

74. Building on these controls and processes, we must also recognise the need to establish confidence in how data is used and then how trust is maintained in this. From engagement through “Citizen Juries” the concept of the “diameter of trust” has been explored and tested. This concept was discussed at our Interoperability and Population Health Summit. By focusing on the views of the public and patients, this has provided a deep understanding of how people wish to see their data being used and the benefits of doing so.

75. The work of Farr Institute¹¹ introduces the ‘diameter of trust’ concept as the way to gauge the size and characteristics of a learning, sustainable and trustworthy 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.

76. The ‘diameter of trust’ can be determined by the following elements:

- The level at which engagement with the citizen can be established and the choice citizens have on how their information is shared, ensuring that development of and investment in informatics is supported.
- The extent of patient flows within the health economy, between organisations, giving due consideration to the nature and scale of services, along a spectrum from the management of long term conditions to care for rare diseases in tertiary organisations and the scale at which for example ambulance services will need to be included.
- The scale of a data platform being of sufficient size to enable effective population analyses and avoid duplication of activity or informatics investment within the economy.
- The ability to bring data together from the wider determinants of health and care relevant for that population in near real-time (e.g. housing, education); to deliver fully neighbourhood-based initiatives and improvements.

¹¹ Combining Health Data Uses to Ignite Health System Learning J. Ainsworth; I. Buchan. *Methods Inf Med.* 2015;54(6):479-87. doi: 10.3414/ME15-01-0064. Epub 2015 Sep 17. <https://www.ncbi.nlm.nih.gov/pubmed/26395036>

77. The Interoperability and Population Health Summit discussed what scale this could reach with reference to engaging with citizens, tertiary health referral networks, or ambulance networks. The discussion recognised that the scale would need to make sense for the joining of data to drive a learning health and care system and population health management.

78. This “diameter of trust” defined from the engagement through citizen juries provides an indicative level of 2-5m population size. This being an “indicative” size as most importantly, is the need to establish a trusted ‘coalition of the willing,’ in which organisations and professionals, patients and their carers across the health and care economy come together to deliver truly integrated care services. Local leadership and readiness key to enabling these integrated care services to be delivered.

Experience elsewhere:

79. Approaches around the world define the size at which learning health systems are best organised suggest an upper-band of approximately 5 million – that is, the size of small countries like Denmark, Israel, Ireland or Scotland - that can enact laws and regulations over health data sharing without major push-back. Even with health and care systems that have larger populations, such as Catalonia in Spain (7 million) and Venice in Italy (5 million), have been more successful than their associated national initiatives (60 million, 47 million respectively).

80. This is also consistent with experience in the US, as evidenced through success in regional initiatives such as Intermountain Healthcare, Advocate HealthCare and the New York Collaborative (8 million). There are successful large health systems around the world that have established a way to operate that both achieves economies of scale across 2-5million population sizes whilst still delivering local neighbourhood-based integrated care models. One such example, which presented at an event for STP NHS leadership, is Banner Health, one of the largest non-profit health systems in the USA. Banner Health provides care for millions of citizens, but for accountable care has adopted a population health management approach through both central ‘air traffic control’ scale

initiatives and local Neighbourhoods with integrated physician and care management teams.

81. There are also examples of ACSs coming together to form new partnerships for population health management such as Stony Brook Medicine on New York Long Island that operates an Accountable care organisation (ACO) but is also working with other integrated systems across Suffolk County and established a Limited Liability Partnership and shared population health informatics platform for 1.5 million citizens in order to manage a county-wide Medicaid Delivery System Reform Incentive Payment (DSRIP) Program and for future value-based contracts.
82. There are many potential reasons for operating an informatics architecture at scale in or across STPs, including patient pathways, managing population health challenges at scale, reducing duplicative activity, leveraging scarce resources, efficiencies from cost savings, and ability to underpin a learning health and care system as well as supporting research. From experience in other countries noted above and coupled with ideal population sizes to enable research the upper bound appears to be around 2-5 million population size.
83. Whilst providing this indicative level in line with both national and international examples, we recognise that this scale can be taken even further such as initiatives through the Healthy London Partnership that is covering a 9m population. But fundamentally, size is based upon establishing local relationships and recognising the need to take collective decisions in optimising investment to ensure sustainability. It also highlights that informatics investment and scaling does not need to be tied to organisational constraints and can be done at a sustainable level by organisations coming together.
84. We also recognise that to improve outcomes for rare diseases, we also need to ensure the data is available at the required population sizes. Consequently, there will be the expectation on these local learning health and care systems supporting the ability to provide the data needed for such national registries.¹²

¹² Cf. <https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncards>

This working in collaboration with relevant patient charities that should have an active role in their development and use. The National Cancer Registry and Analysis Service being a shining example of the impact in improvement in care through these registries.¹³

85. In this context we are offering STPs what we believe is a common sense direction in taking forward their FYFV ambitions in a Target Architecture that underpins the successful digitisation and integration of health and care, and provides an approach in establishing trust, optimising informatics investment, ensuring consistency of controls and establishing a health and care system that can actively learn.

Place-based Exemplars:

86. It is proposed that this architecture is taken forward through a set of local initiatives and exemplars that grow and are supported by national bodies across health and care. This local approach to implementation will ensure that leadership, readiness and business change are fully embedded and that detailed architectural and implementation questions are considered in the light of real-world implementations. At the same time, through national co-ordination and facilitation and clear guidance, such as the standards and processes that they will follow in light of the NDG recommendations, these local initiatives will work together to form a nationally coherent approach.

87. If we succeed, we can together help create a sustainable system of health and care; a system rich with the data it needs to continuously improve its provision; a system rich with data it needs to plan and commission services more effectively and efficiently; a system rich with the data that will evaluate service provision quality in real time; a system rich with the patient data that enables precision medicines and other more targeted and effective clinical interventions; in short a learning system that delivers better health, better care and better value.

¹³ <http://www.ncras.nhs.uk/>

7. Implications

88. The implementation of the Target Architecture will mean we recommend new ways of working together, of sharing expertise and investing in informatics.
89. It will mean working in a way with technology that is sensitive to the diverse needs of local populations while observing common principles. It will provide the ability to “test” the impact of digital enablement in an agile manner through national and local collaboration.
90. It will mean that we all adopt and operate to common standards upfront. That we have common level of controls in place through our implementation Information Governance and Cyber Security. .
91. This document sets our service integration destination, provides a Target Architecture road map for reaching it and offers the practical guidance and resources you will need on the journey.

Expectations and Requirements:

92. The service landscape is already evolving where STPs and ACSs will:
- Be expected to establish new care models, and ‘evolve’ into ACSs and take on collective responsibility for the total cost and quality of care for the populations they serve. To do so they will require supportive population health management informatics.
 - Be expected to provide a more joined up approach to care co-ordination along their citizen’s care.
 - Be expected to consider how to support GPs working together in physical or virtual clinical ‘hubs’ with community nursing, mental health and clinical pharmacy teams in order to standardise the integrated care they provide across care pathways.
 - Be expected to support activity across the health and care system to raise digital maturity “at place” and provide the capability to integrate across care settings and securely exchange information.

- Be expected to pay specific attention to information sharing with key lower maturity settings such as social care. For example, a number of local areas through the New Care Models programme are working with Care Homes to ensure there are effective arrangements in place to transfer relevant information and to enable connectivity with other health and care professionals. We must work closely with both Local Government and Care Providers to support similar activity across the country in both care home and home care organisations.

The Good News - this journey has already started:

93. In response to these expectations, the Target Architecture provides a practical framework for how this can be enabled, and done so in a way that there are consistent controls in the use of data. Through its development, we have engaged on local initiatives planned and underway to both inform its development but also to show the practicality of the approach.

94. The Connected Health Cities¹⁴ programme and initiatives such as the Great North Record¹⁵ are already based on a 2m-5m scale and have demonstrated the benefit in engaging citizens to create a trusted relationship at this population size.

95. Their approach is also being applied to a practical set of local service priorities - be this

- medicines management,
- sharing of end of life preferences,
- transfers of care,
- whole system flight deck for care navigation and MDTs supporting an individual's care,
- through to management of substance misuse and reduction in avoidable deaths at a population level as part of deriving intelligence from this information.

¹⁴ <https://www.connectedhealthcities.org/>

¹⁵ <https://www.greatnorthcarerecord.org.uk/>

96. Furthermore, nearly all of STPs have explicitly expressed a requirement for an STP-wide shared care record. There are already several examples of these types of 'platforms' already in existence: for example, in Hampshire, the Hampshire Health Record (HHR) is a shared electronic care record for people living in Hampshire and registered to a Hampshire GP. The service went live in 2005, and is in routine use by over a thousand care professionals to share information in support of clinical decision making. The accompanying Hampshire Health Record Analytics solution has an associated secure data repository for analytics and research purposes that has been used to support analysis of linked clinical data to improve the targeting of care for Acute Kidney Injury and patients at risk of liver disease.
97. In the North of England, Lancashire's Local Person Record Exchange Service (LPRES) is building a similar shared care view. The platform covers all the health and care providers operating in the county, including independent providers. LPRES went live in October 2016 and is already sharing up to 4,000 documents per day and has already realised the benefits return from the initial investment outlay. The real-time exchange delivers tangible cost savings for participating organisations and is a key enabler to the new models of care emerging from the Healthier Lancashire and South Cumbria Change Programme. Similar exchanges have been, or are being, built across North England, including DataWell in Manchester, underpinning the Department of Health's Connected Health Cities programme for care pathway optimising analytics on top of integrated data.
98. Within the Fylde Coast Vanguard, patients are starting to see the benefit of the 'predict and prevent' approach. Using near real-time data analytics, care teams in Blackpool are able to reach out to patients with long-term conditions and proactively offer additional support. The impact has been fewer attendances in A&E and fewer admissions to hospital. The STP is keen to build on this success, scaling the architecture and bringing together business intelligence capabilities, knowledge experts and academic partners to create an improvement collective.
99. The connecting together of neighbouring information exchanges themselves to avoid becoming siloes has also already begun. For example, the publicised

linkage of the Health Information Exchange (HIE) managed by Barts Health NHS Trust and the HIE managed by Homerton University Hospital NHS Foundation Trust to provide a joined up information exchange including 183 GP practices, the East London Foundation Trust and three local community services in East London covering Waltham Forest, Newham, Tower Hamlets and City & Hackney CCGs. Together this is called the East London Patient Record. Out of the 89,258 patient record requests made from either Barts Health or Homerton hospitals in the region over a six month period, 30.88% (27,567) of the searches returned data from the other hospitals' linked information exchange. In the current year this has been extended to include the first group of practices from West Essex further extending the reach beyond the local STP area. In Hampshire discussions have taken place with a neighbouring health system about joining Hampshire Health Record up to other shared care records to support cross boundary patients.

100. In some areas there are many ACSs forming from groups of organisations within the STP. For example there are five ACSs forming in Hampshire. In other areas ACSs are already aligned to larger scale initiatives such as the Devolution programme in Manchester.

101. Small localities that are components of a natural health system rather than an encompassing one should consider combining digital assets to achieve greater scale and effectiveness for the IT and business processes to underpin a learning system. For example, the ten local authority districts in Greater Manchester (GM) have combined in a civic data linkage authority, GM Connect¹⁶, under local by-laws there is a 'duty to share' data for citizens' benefit, reflecting the Caldicott Principle 7¹⁷. GM NHS has pooled its resources in GM Digital Collaborative and is building a federated data integration system, Datawell, across the NHS, local authorities and academia.

¹⁶ https://www.greatermanchester-ca.gov.uk/news/article/39/pioneering_data_service_to_connect_greater_manchester_to_improved_services

¹⁷

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627493/Your_data_better_security_better_choice_better_care_government_response.pdf

102. Consequently we expect that ACSs might range in size from a single clinical hub of 30-50,000 citizens all the way up to a single ACS across the largest STP of 2.8 million citizens, and indeed ACSs could potentially span multiple STPs.

Architecture:

103. We would look towards enabling these ACSs to establish themselves as local learning health and care systems by putting in place the five different purposes outlined in Figure 2 – Purposes of Information.

104. The informatics to support ACSs would be delivered through “local platforms” operating cohesively with national platforms and using common components provided nationally.

105. The architecture is about enabling the movement of data to be available where the data is needed and the purpose and controls being clear - **be that locally for local use or nationally for national use.**

106. It will be delivered through a combination of capabilities provided at a local and a national level and so the architecture is not a local only or national only approach but **a local and national approach** (see Figure 3).

107. Importantly, these platforms would have to adhere to common governance requirements in how data is used, who can access it and for what purposes. There is a critical national role is both defining and ongoing governance in ensuring this national coherence.



Figure3 – Platforms operating cohesively

108. By taking a “platform” approach, we would enable localities to bring together different functional capabilities (from different suppliers). They would also be able to take account of existing informatics investment and tools already in place and extend or build upon what is there where it would make sense to. This would provide them with the agility to enable different functional capabilities to be introduced and tested to meet particular service priorities.
109. Platforms will allow localities to remove the complexity in gathering data from disparate sources and normalising it. This being a core underpinning activity of the platforms. It will also facilitate a move to a position where the storing of data is separate from the application functionality and so enabling innovation from a wider group of partners within their local ecosystem.
110. In not constraining these “platforms” or tying them to organisational boundaries they can be scaled for use across localities through local agreement and collaboration.
111. The platforms will also consider approaches to minimising operating costs by using technologies such as the “cloud” in line with agreed government policies providing them with scalability and extensibility of use.
112. Critically, they will be **operating cohesively** together so that information can flow between them which will provide an overall national approach and avoid information becoming siloed and geographically constrained. This will help address critical issues such as when pathways cross borders of ACSs or where they choose to demarcate their shared information architectures.
113. The platforms will operate in line with data principles being developed across the Personalised Health and Care portfolio at a national level. This includes:
- Moving to flows where data should be extracted and automated where possible
 - Providing a set of nationally mandated flows to support public accountability, with appropriate safeguards in place.

- Data shared based upon a set of fundamental standards - including use of SNOMED-CT, DM+D.
- Enabling new insights by being able to bring together data which can be linked and analysed. This includes data from care settings such as monitoring equipment, wearables and data created from the individuals themselves.

114. The platforms will be expected to use common national services, standards and governance processes to ensure national cohesion. This will include:

- Operating in line with the process, guidance, and standards as outlined in the NDG recommendations.
- Citizen's national opt-out preferences being recognised and actioned through a set of common rules being applied.
- Exposing a set of nationally published FHIR-based Open APIs based upon a common data architecture to ensure that structured information can be shared for individual care.
- Use of the National Record Locator to enable care records to be located from across organisations involved in a patient's care, so that, with patients consent, data about care that was received 'out of region' can be identified and located.
- For use of information to improve health, care and services through research and planning, the platforms will use common components such as for de-identification. This will ensure consistency in the processes followed and governance applied in how this information is handled. We intend on building upon the role of the Data Services for Commissioners (DSCROs) as established functions providing commissioning information to localities in providing a set of consistent services around de-identification in the provision of data to serve these local platforms. This will assist in ensuring that governance process and controls will be consistently applied.

115. The "platforms" providing the informatics capabilities to support the life sciences and "innovation hubs" to enable research which improves health, care and services- all within a set of clear controls and with clear citizen engagement in how their data is to be used.

116. We recognise that there will be transition steps in moving to the establishment of these local platforms, but over-time, this approach provides the opportunity for them to become a point of data aggregation and a single point of submission to national platforms and organisations - this aligns with the Five Year Forward View's Next Steps promise to ACSs that they will have a single 'one stop shop' regulatory relationship with NHS England and NHS Improvement.

Enabling seamless access to information for me as a citizen:

117. Throughout this process we have kept patients at the forefront of our considerations. To truly unleash the power of technology in health and care we need the understanding, permission and trust of the patients we serve. We also need the understanding, permission and trust of the professionals who deliver care.

118. As a citizen, the Target Architecture enables information to be available to them wherever and however they need access to it as part of their care. This is based upon an approach that does not artificially constrain citizens to a particular geography or organisation against the expectation that 'I' (as the patient) am engaging with the 'NHS and Social Care', as opposed to separate parts of it. In this approach:

- Citizens will have the ability to capture information in a secure Personal Health Record of their choice and have the ability to make this available to professionals involved in their care through a set of secure APIs. Their information will be located through the National Record Locator so that this can be used by care professionals at the point of care through the local platforms (based upon permission from the patient).
- Citizens will be able to digitally interact with care services from apps they can trust are safe and secure – e.g. be this booking appointments, accessing information or updating their care information such as for preferences or their own readings.
- Citizens will be able to access their care information through their PHR and in a meaningful way. The National Record Locator will be the location of their

care records from across local platforms and national services based upon common APIs for this to be retrieved and provided in a consolidated view.

- Citizens care information from professional systems will be managed at a local level through these local platforms so as close as possible to the source system and by retrieving this from the platforms will ensure the latest information is available to the citizens. A key role of the platforms in ensuring consistency in data quality and representation of the information captured from across local point of care systems. This can then be retrieved in an understandable and consistent manner from across the relevant platforms. Citizens can then “download” it, to be able perform any additional actions on it such as for trending or further interpretation.
- In this way, both in the sharing of and retrieval of information for the citizen is seamless and made available to them in a consolidated view through their Personal Health Record of choice.
- We will also provide the ability for citizens to know who has accessed their care information as located through the National Record Locator and on what basis.
- This approach then provides the choice for the citizens to use their digital services to interact on a local or national level in a seamless manner that suits their need. Through nhs.uk, this will provide the mechanism for the citizen to link to relevant national services as well as the more contextualised local experience where citizen provided data can be shared, with their consent, along their integrated care pathway.

119. The architecture diagram in figure 4 outlines how the local and national approach comes together as part of the overall Target Architecture.

120. Local learning health and care systems will be served by local “platforms” that can provide different capabilities that enable functionality for each of the 5 purposes of information (see figure 2) (e.g. information exchange, population health etc.) and at different scales. The “platforms” will operate together in a cohesive way by sharing information through a common and agreed set of open interfaces (Open APIs) so that information can flow across boundaries for

individual care purposes and be located through use of national capabilities such as the National Record Locator.

121. In addition, this will improve health, care and services through research and planning, by exposing modular data through appropriate controls, governance and through the use of common components e.g. for de-identification.

122. The “platforms” will not be constrained or tied to organisational boundaries but providing functionality that could be used across local learning health and care systems through local agreement and collaboration.

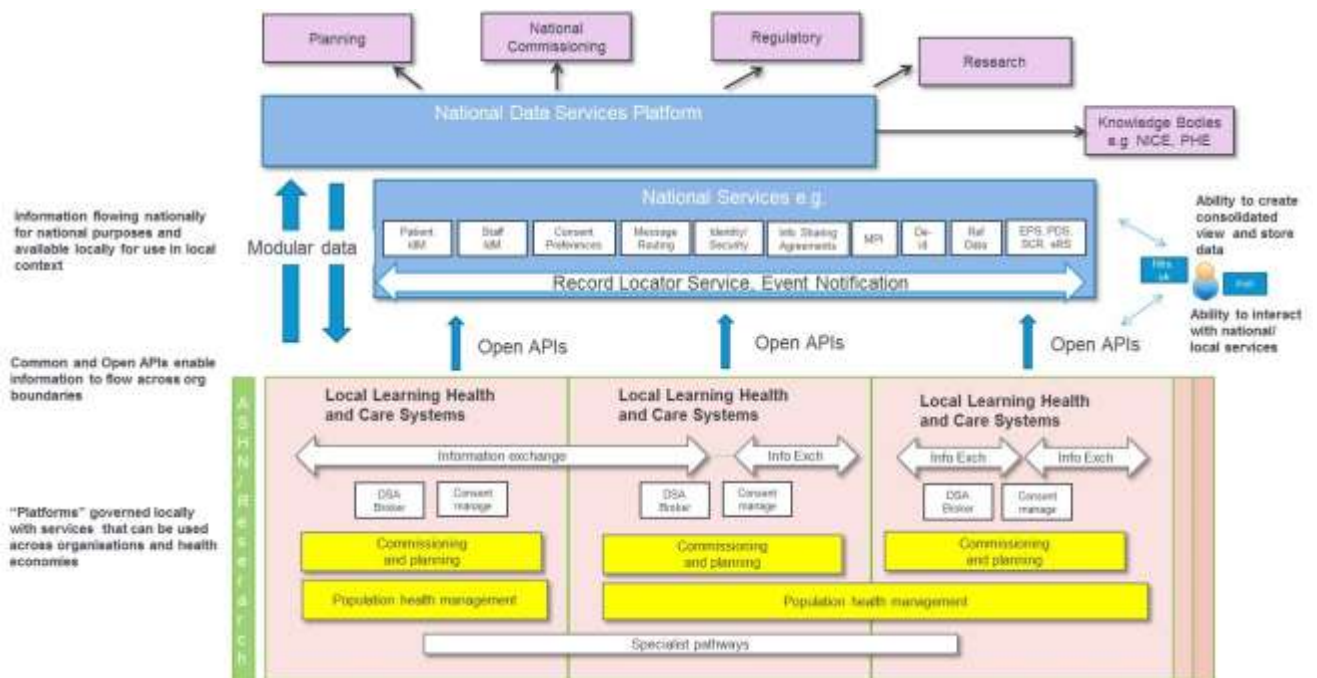


Figure 4 – Overview of the Architecture

The underpinning information governance approach:

123. The Five Purposes of Information outlined in figure 2 require different types of data:

- Personal
- Personal and confidential
- De-identified
- Aggregated

Type of Data
Non-Personal (does not come under Data Protection Act (DPA)/ General Data Protection Regulation(GDPR))
Personal
Sensitive personal - Under GDPR Special Categories of personal data (revealing health, genetic data etc.)
Confidential Subject to the Common Law Duty of Confidence (CDLC)

Levels of Data
Fully identifiable
De-identified
Aggregate

124. The obligations associated with these types of data differ. All will remain pertinent and be a consideration in the development and implementation of the Target Architecture moving forward.

Data for individual care

125. Sensitive personal and confidential data (which is fully identifiable) will almost certainly be required to achieve interoperability and to facilitate precision medicine and case finding. The NDG Review opt out will not apply. However the GDPR Right to object and the GDPR right to restrict processing will apply should a data subject wish to exercise that right and certain criteria are met.

126. The schedule conditions for processing for individual care are more straight forward requiring organisations to undertake the conditions set out in DPA and GDPR. Organisations should ensure that patients have access to information (fair processing) in privacy notices that set out the expectation for their data to be

shared with individuals that are involved in their care. It is imperative that citizens should have no surprises with electronic record sharing.

Data for intelligence

127. Data required for commissioning service learning and to inform regulation and service evaluation should predominantly require personal and confidential data which has been de-identified. If personal data is required for these purposes, it is likely that the use of a full cohort of data will not be possible as the NDG Review opt out will apply. One way to optimise the dataset available is to ensure it is anonymised in line with the Information Commissioner's Office (ICO) Code of Practice. A clear approach will be defined as part of developing new anonymisation guidance¹⁸ that outlines the standard for de-identification and the standard controls that need to be in place so that data is anonymised in line with ICO code of practice. This work will be progressed in light of the GDPR.

Data for Research

128. The use of data for clinical and other research will likely require a range of data spanning all types and levels of data. The information sharing considerations for each circumstance will potentially be different. It is anticipated that standards and guidance will be developed to ensure and explain how data can be anonymised when being used for research in line with ICO guidance. Where personal confidential data is required, considerations of the Common law duty of Confidentiality (CLDC) and the NDG opt out will need to be worked through. Even if opt outs do apply, individuals can explicitly consent to opt in to some data sharing for research. Developing a process to facilitate and curate opt in options will be required.

129. A Fair Processing Framework will also be developed to enable a consistent and appropriate approach to fair processing across the system, supported by a communication process to ensure that expectations across the system are

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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627493/Your_data_better_security_better_choice_better_care_government_response.pdf

managed. The Fair Processing Framework will inform citizens of their opportunity to opt out, how they can initiate that choice and what it will mean.

130. The details will be worked through prior to implementation including establishing a “Privacy by Design” approach with the place-based exemplars completion of Privacy Impact Assessments and done in conjunction with NDG and national bodies such as NHS Digital so that the end to end process is clear, risks are identified and mitigated and compliance assured.

8. Next steps

At a National level

<ul style="list-style-type: none">• We will define a consistent information governance framework and approach to enable the five high level purposes of information outlined within the Target Architecture to be enacted in conjunction with the NDG and Information Governance Alliance. This will include guidance pre-GDPR and what this means when GDPR becomes active. This will also clarify the associated data controllership models.• We will demonstrate these through a set of test sites working with the DSCROs.
<ul style="list-style-type: none">• We will establish and launch a set of “place-based exemplars” with leading localities to demonstrate the delivery of the five purposes of the Target Architecture. Importantly these will be driven by the demonstration of mature local leadership and clear understanding of how their approach will enable their service transformation priorities.
<ul style="list-style-type: none">• We will define in conjunction with the wider service such as INTEROPen a set of nationally published FHIR based Open APIs that would expect the local platforms to expose when sharing information for individual care across boundaries. Work has already commenced on the “Care Connect” FHIR resources and we would be expecting each of the local platforms expose these.
<ul style="list-style-type: none">• We will develop an underpinning data architecture, with common meta and reference data. We will expect local platforms to use a set of modular data specifications and associated terminology as they move to automated

extractions.

- At a national level, we will deliver a set of underpinning national capabilities/services to be used by these local platforms that have been called out by the service. These will include:
 - A National Record Locator Service to enable the location of patient records anywhere in the country
 - Nationally available patient preferences about how their data is to be handled,
 - Nationally available Flag settings (e.g. Child Protection Information Sharing);
 - 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.
 - The core set of information that patients have consented to be to available nationally for viewing by professionals through the Summary Care Record - particularly for use in lower digitally mature settings where not yet covered by shared care records e.g. community pharmacy, care homes or settings where only a summary set of information is needed.
 - The GP Connect APIs to enable access to structured information from the GP systems
 - GP Data extract to be used for local and national purposes.
 - Master Demographics Service - to enable the unique identification of a patient to link them to their care records and data items.
 - Messaging and Routing – ability to enable the routing of messages.
 - Simplified access – approaches to enable mobile access to national applications, and address some of the usability barriers of access via N3 through the use of physical smartcards while still ensuring appropriate levels of controls are in place.

- We will commit that all national applications are designed by default with Open APIs and have access to structured information.

- We will deliver the Data Services Platform providing the ability to receive and analyse data for national purposes.
- In addition, we will ensure that it is responsive in enabling national data to be accessed by localities.
- It will also provide a set of capabilities (such as de-identification) that can be used by the local platforms to ensure consistency.

- We will work with existing constructs such as the DSCROs on defining a consistent approach for de-identification. We will undertake a small number of

early implementations to show this working in reality in conjunction with localities and NHS Digital to formulate the associated capabilities, governance and processes that need to be in place. The delivery of a federated de-identification is already in plans for the Data Services Platform.

- We will form multi-disciplinary teams working in conjunction with localities to test how best to deliver the capabilities to enable an ecosystem of digital services.
- We will provide a nationally coordinated but locally tailored and flexible framework of accredited supporting capabilities that can be used to progress local plans.
- We will co-create associated “blueprints”, “design guides” and “tools”; and outline standards, patterns, and service standards to support the development and implementation of these local platforms in conjunction with national delivery.

For STPs, they should consider to undertake the following:

Governance - in relation to their service transformation priorities

- Complete Privacy Impact assessments
- Identifying the specific purposes for which they need to bring together patient data and consider what scale this needs to operate at for each purpose
- Consider the opportunity for establishing scale informatics architectures, up to an upper limit of 2-5 million citizens, in light of their population size and patient flow, to support appropriate care and research requirements, whilst achieving economies of scale. They should consider Academic Health Science Network (AHSN) footprints.
- Consult with care professionals and the public on ratifying their approach to scale informatics approaches to establish a local accepted mandate
- Establish a legal basis for the aggregation and dissemination of data for each purpose that they identify, and that there are different legal, regulatory, policy, strategy, guidelines and operational practice for different types of information used for different purpose
- Establish clear governance processes and arrangements for each type of data and purpose for which it is used, from individual care through to service design

and research

- Establish organisation ownership for data controller arrangements for aggregated and disseminated data
- Establish robust risk management approaches to managing and disseminating data, which adheres to nationally defined standards and best practice
- Work with local government, voluntary organisations, public health and the public to establish how to start utilising a wider set of knowledge around social determinants of health such as housing, leisure, transport and mapping of community assets. This work will also, directly include linkages across health and care such as including care homes as part of their local plans.
- Create an explicitly governed approach for how data quality and data provenance will be improved to a level needed to serve the five purposes outlined in the Target Architecture.

Process

- STPs to create strategies and investment plans for population health informatics required to support the establishment of ACSs with their new care models and ability to operate accountable performance contracts.
- These plans will focus as much on the ecosystem and capability needed to be put in place, with leadership and culture change being as important as the technology and informatics.
- Deploy rigorous and validated population health management informatics capabilities that improve prevention, enhance patient activation and supported self- management for long term conditions, manage avoidable demand, and reduce unwarranted variation in line with the RightCare programme
- Local health and care systems also need to engage with their citizens with a clear narrative and value proposition for sharing data for purposes other than individual care. Underpinning the public engagement will be a set of accessible information that forms part of an overall fair processing strategy.
- Look for the opportunity to make available with citizen consent, the cleansed, rich, anonymised, linked data for the purposes of research
- Establish with local Universities and Academic Health Science centres how anonymised care data can be utilised in research platforms, and how results of research are more rapidly prototyped and diffused back through the information

architectures established in the health and care system.

Requirements

- STPs without shared care records need to establish one
- Where shared care records exist but the coverage of an STP is not complete, the STP should look in preference at extending the coverage of existing successful shared record programmes
- Where there is more than one shared care record in place across a region, the STP(s), where it is appropriate to do so, should look at connecting them together.
- Where there are too many existing shared care record services in place across an area, the STP, where it is appropriate to do so, should look to consolidate over time as vendor contracts expire and as the most successful services shine through
- Where there are good purposes and it makes sense to do, such as in the case of having patient pathways that regularly span across different STP regions, neighbouring STPs should look at the merits of connecting their shared care records to each other
- It will be expected that all existing shared care record services will be connected to the National Record Locator Service and will need to adhere to these standards
- Where there are good purposes and it makes sense within a larger region like London, or even within a large STP, consideration could be made of the merits of establishing regional Record Locator Services or selecting dominant health information exchanges as master nodes. In such a situation these regional Record Locator Services will need to be linked to the National Record Locator Service.
- For Improving health, care and services through research and planning, person-level data must be anonymised in accordance with the ICO code of practice by complying with nationally provided standards and guidance and released to controlled environments for secondary uses purposes.
- In strict accordance with national controls and processes that will be defined following on from the NDG recommendations, commissioners should look to use anonymised data from individual care provision in their business intelligence tools. This to ensure local integrated care systems are working off of a single

source of truth and not arguing about differences in cuts of data.

- Extractions of data should be implemented in line with nationally defined modular data standards and data architecture.

9. Conclusion

131. The opportunity for informatics and technology to revolutionise the health and care system is well documented. The opportunity ahead of us is how to practically exploit these advances to both create short term sustainability, whilst enabling a learning health and care system that can set us up for the long term.

132. This Target Architecture outlines a strategic approach for the informatics architectures that will be required to execute key strategies and plans such as the Next Steps on the NHS Five Year Forward View, Life Sciences Industrial Strategy and the Accelerated Access Review.

133. This Target Architecture sets out some of the key principles and design decisions to support the range of identified information purposes. In addition, it outlines areas to be worked through as part of its next steps with these done through real-world local projects. The prize is clear, for both the health and care system and for the research community, which is to harness the power of information to leverage the maximum utility for citizens, patients, carers, their families and the care professionals that work in our system.

134. This Target Architecture argues the case for consolidation and sets out the strategic approach of shared care records and connecting them together. It states the case for establishing intelligence capabilities that are capable of supporting ACSs deliver on population health management. It also supports them in taking accountability for the populations they serve, for connecting citizens and their technologies to the mainstream of health and care and ensuring they are themselves an integral part of the care team. All of these are required to operate within a consistent set of controls and governance that will be nationally

facilitated. It challenges the localities and the market to consider the opportunity to scale their informatics approaches in line with maintaining the trust of citizens that we serve to reach population sizes that can underpin learning health and care systems, ensure sustainability and deliver rich and world leading research.

135. This document is a “national framework” for addressing the plans outlined for the service. The subsequent implementation of its next steps are to be taken forward through the local exemplars and supporting national capabilities. It outlines:

- key information governance considerations,
- capabilities at a local and national level,
- the governance for how the local learning health and care systems operate cohesively,
- the underpinning standards (e.g. Open APIs) required from these “local platforms”
- the need for deployment of common functionality such as “de-identification”
- and the use of common governance and reference data across these to ensure consistency in approach.

136. There is much to be done and much to be worked through, but this will only be achieved through productive collaboration. Collaborations of national bodies with Sustainability and Transformation Partnerships, collaborations of the public sector working with the private sector and informatics vendors, and collaborations of vendors working together and to agreed standards.

Annex A - Use cases enabled through the Target Architecture

Purpose 1: Individual Care – Interoperability for shared information

4.1 The basic level needed for fully interoperable information exchange in real-time to be able to bring together the longitudinal record for the patient to support direct patient care. For example:

“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 list of medications prescribed for this patient by their GP against those currently in my hospital system”

“As an emergency care physician, I want to be able to access all the information about a patient I can, regardless of where they have been seen in the country to provide emergency care to my sickest patients”

“As part of an integrated care team, we want to be able to view from our own information systems a single aggregated view of all the interactions a patient has in our health and care system and the information we require to make better care decisions”

Purpose 2: Individual Care – Precision medicine, Case finding, and Care management

4.2 Data about the citizen is brought together and mapped into a format allowing analysis and rules to be applied to generate information and insights in near real time for a patient or a group of patients with comparison to information held about a wider population to enable a more precise intervention for defined groups of individuals (case finding). For example:

“As a Local Authority I want to understand who is at risk of an increasing social care need, so that I can review their care package and consider opportunities for preventative support at home.”

“Before discharging this patient after his heart operation, I want to understand the outcomes for patients who had similar characteristics that transitioned to different care environments so that I can ensure optimal and cost-effective recovery”

“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 community nurse supporting three clinical hubs, I want to be able to review progress for all the patients I have responsibility for that they are meeting all the quality metrics and outcomes we agreed in our Accountable Care System.”

“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.”

“As part of an integrated care team, we 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.”

Purpose 3: Intelligence – Provider performance, Payment, Regulation and Service Evaluation

- 4.3 Information which has been anonymised or is provided in aggregate views sometimes linked with wider information sources such as patient reported outcomes measures. Such information being required by health and care provider organisations individually or together in ACSs, for activities such as tracking their performance against quality metrics, tracking financial performance on contracts, benchmarking and national comparison. Also required by commissioners and regulators – local or nation – for tracking contracts and performance. For example:

“As a provider, I want to understand how my referral to treatment times compares with similar organisations”

“As a partner care provider organisation in an Accountable Care System, I want to know whether we are performing to the ACS standards agreed and where I need to focus our effort”

“As a partner care provider organisation in an Accountable Care System, I want to understand performance and utilisation across the network to evolve our care models or shift activity in the system”

“As a commissioner, I want to ensure that I am paying for the services being provided – either to a single provider or multiple care providers”

“As a regulator, I want to be able to compare organisations who are providing cancer services with their peers”

“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 entire populations 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.”

Purpose 4: Intelligence – Commissioning for Service Planning

- 4.4 Information which has been linked, with appropriate legal basis to other information sources and suitably anonymised for service planning and commissioning. For example:

“As a commissioner I need to understand whether a new preventative falls service providing support to people at home has helped to reduce the impact of individuals accessing hospital and other secondary care settings by

comparing one cohort of individuals who had receiving the service, with another similar cohort of individuals who had not received the service.”

“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.”

Purpose 5: Research

- 4.5 Information can be linked with wider information sources, with appropriate legal basis, for research purposes. For example;

“As a patient who has recently had a cancer, I would like my data to be used to improve the cancer care”

“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”