Crowdsourcing Request: Use Case Documentation

Open Health & Care Data Architecture

NHS Transformation Directorate | EY

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The Ask & Approach | Open Health & Care Data Architecture

The Vision of Open Health & Care Data Architecture

NHS Transformation Directorate (NHS/TD) have five missions, which are focused on making things better for patients and staff. These are:

- Reducing the burden on clinicians and staff, so they can focus on patients
- Giving people the tools to access information and services directly
- Ensuring clinical information can be safely accessed, wherever it is needed
- Improving patient safety across the NHS
- Improving NHS productivity with digital technology

To support these missions, NHS/TD are exploring and progressing an **Open Health and Care Data Architecture** across all care settings - including social care - to achieve vertical integration in health and care at an ICS, Region, National level. This in turn enables a patient centric longitudinal care record / plan which one day can follow a patient from birth to death, across English geographies and all care settings. For this to succeed **patient data should be made more accessible** from and to all IT systems, in an agreed consistent format, frequency and quality. There is also a need to focus on **health and care reform** in order to encourage processes that reflect the principles of open health and care data. To make this happen, we therefore need to answer the following:

1) **What are the tools and techniques required in order to achieve these missions?**
2) **How can the NHS best organise itself to be a more effective body in the journey to achieving these missions?**
3) **What are the care pathway categories that we can draw on to support the case?**

Adopting a Use Case Approach

To answer these questions, we must first understand the real-world scenarios that these missions are trying to address. We therefore recommend undertaking a structured process to bring clarity and granularity between them. **Through selected and agreed 'use cases' we can focus all workstreams that are working towards these missions onto one aligned direction.**

Indicative Categories to Assess & Analyse the Use Cases

1	2	3
Care Efficiency	**Care Effectiveness**	**Research & Planning**
Ensure access to all essential information to deliver high quality care allowing improved management of NHS time and resources	Improve quality of care processes through holistic patient records to ensure better patient and care outcome	Develop a richer and more longitudinal national data set to inform innovation and population health management

The Ask & Approach | The Need for Use Case Documentation

The Approach: Use Case Documentation to Set the Foundation for Transformation Direction

There is a need to crowdsource use cases to assist with all workstreams within the NHS that are working towards missions of data sharing, interoperability and open architecture. This encourages a need for an assessment of all levers and incentives in light of the objectives and benefits derived from the identified care pathways that underpin components of the health and care system in this country. Further, we are also able to perform a more directed and guided impact assessment on the chosen lever(s) as well as utilise the documented use cases to align programmes to a common goal.

Our proposed approach ensures clear alignment and ownership amongst stakeholders, which we believe is essential when supporting efforts towards transformation. To support this process, and to support the appraisal of levers (ISNs, CQC, legislation etc.), a library of consolidated use cases provide the set of problems that can underpin the entire process and solidify the blueprint upon which the transformation efforts will be driven by.

1 **Use Case Documentation & Review: structured, evidence-based, mechanism for addressing available levers to achieve the mission**

- **Central ask of the stakeholders is to reach a consensus on the <u>use cases, problem scope and statement</u>**
- Identify the levers available to resolve the problem statement, understanding all associated implications, in order to demonstrate incremental benefit of any single lever over another, and ensure alignment with centrally derived use cases
- Understand the central KPIs / methods of measure to ensure quantifiable incrementality

2 **Use the outcomes of the Strategic Options Review to formalise and align transformation workstreams**

- Common alignment of problem statement and priorities that will underpin all programmes that require use case enabled direction
- Increased stakeholder engagement and ownership throughout all transformation programmes, centred around mutually derived use cases
- Stronger support for all transformation streams inc. enterprise architecture, business capabilities, governance, standards adoption, and more
- One vision approach to achieving Transformation Directorate and National priorities

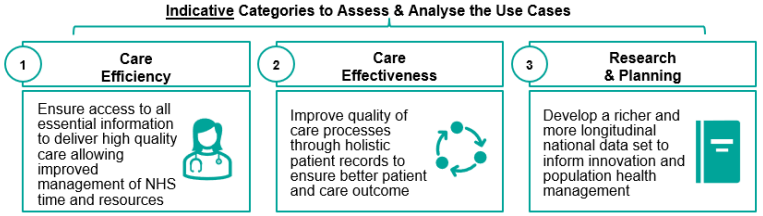
To drive this process, there is a need to consolidate and agree on the underlying use cases that are the drivers for digital transformation.

The Why | Use cases must be addressed by considering the needs / concerns of various stakeholders, as well as analysing and agreeing on the current state situation

AREA	SITUATION	CONCERNS
Patient Landscape	• Must capture patient information from EPRs, PACs, PASs and more. • Patient view to be captured across all care settings.	Less than full buy-in from UK citizens to nationally accessible record sets • Distrust over purposes for which data will be used, data security and data monetisation / commercial exploitation • Possibility of control of data being lost to commercial companies (AWS, MS Azure) • May drive patients opting out of data sharing
Standards Landscape	• Range of published standards, does not cover all areas of health • Status of aligning to international standardisation efforts	• Currently recommended rather than mandatory, so no common standard if a standard is adopted at all. Multiple standards currently in use across the ICS landscape. • Is the way forward vision to work towards national standardisation or global alignment?
Supplier / Market Landscape	• No obvious system that covers all care settings • Coverage of systems in England is mixed • Huge range of progress globally, as demonstrated by Horizon Scan	• Any move to mandate compliance with data standards for existing suppliers will almost certainly represent contractual change, could trigger termination for convenience clauses • Supplier technology landscape is massively fragmented (ICS controlled) and materially locked in for 10 years+ • UK market may not be big enough for global providers not to walk away • Transitioning from one EPR to another is very complicated and very expensive
Benefits Landscape	• Multiple sources of benefit, including, but not limited to: • Better patient outcomes Operational efficiency • Benchmarking to drive operational improvement and cost effectiveness (e.g., prescribing) • R&D, including monetising data	• Material limitations to what can be achieved via APIs alone • No national repository • Analogue records • Data quality, completeness and compatibility • Data is not consistently available at patient level outside of the Data Controller • Limited national record set - involves 1,000+ NHSD staff manually cleansing data • NHSD Data Controller rights on enhanced national data set (i.e., would their right to share the data to extract the benefit still be valid…further legislation?)? • Significant process and technology costs

The Why | Example Illustration of the Problem[1]: Open Health & Care Data Architecture, Safe Cross-Organisation Care Delivery

Taking the case of safe cross-organisation care delivery, we can demonstrate the gaps that need to be satisfied by an Open Health and Care Data Architecture. We can then understand how this formulates the business case for certain levers to achieve this vision, as well as the identification of alternative routes in order to attempt to demonstrate incremental benefit from a specifically chosen route.



Arrival at ED

Jim is on multiple medicines regimen after developing Parkinson's Diseases. Comes into ED with chest pains.

With mental health problems and an intravenous drug user, Mark is on a methadone programme keeping him off street drugs. Also walks into the ED with a severely red and swollen leg.

Doctors deem low priority, both wait three hours to be seen.. LPRES used to confirm GP's prescribed history.

During the Wait

Jim has missed two doses of Parkinson's medicines, although felt well. LPRES did not show regular medicines for Mark but he mentioned his methadone prescription. Exact dose unknown so a 'when required' 10mg was prescribed.

Jim diagnosed with community acquired pneumonia. Admitted with antibiotics, steroids and oxygen. Also found to be tachycardic, so started on bisoprolol. Mark diagnosed with severe cellulitis and admitted for intravenous therapy.

Two Days Later

Jim's tremors developed into bad shakes. Jim's missed and delayed Parkinson's medicines triggered a deterioration in his symptoms. Medicines were reconciled the following day by ward pharmacist, taking 25 minutes to process. Remained in hospital for a further two weeks.

Mark developed strange behaviours, and a psychiatric referral was made. Ward pharmacist confirmed 30mg methadone dose the following day, taking 30 minutes to process. Mark had taken 50mg up to this point.

Outcome

Jim was moved to a rehabilitation unit for a month. Subsequently Jim was discharged and moved to a Care Home where he was looked after for the last 6 months of his life. Biosprolol was not continued when he moved to the Care Home.

Mark was seen by the psychiatric team the following day. They confirmed that he'd not been prescribed his regular clozapine prescription; he had forgotten to mention that he takes this to control his schizophrenia symptoms. This is not prescribed by his GP and didn't show on LPRES. Transferred to a mental health facility, away from family.

What gaps would be satisfied by Open Health and Care Data Architecture?

1. Prescribed critical medicines will be immediately known as soon as a patient transitions between care settings, allowing clinicians to prioritise and act in a way that does not jeopardise the critical course of treatment.

2. Full and complete information around prescribed medications, including dosage, will be immediately available and provides clinicians with the holistic patient view required to provide care effectively and efficiently.

3. Relevant referrals and information exchange between care settings can occur, enabling stronger vertical integration across care settings and allows for the smooth continuation of the care pathway.

1 – Taken from Lancashire and South Cumbria "Tale of Two Patients: or how the Unified Medicines Record with Referrals revolutionised practices"

The How | What We Need From You

We now need to continue building out the library of use cases that can support the present and future programmes that are working towards digital transformation.

Identifying Use Cases

- We need a strong set of use cases to form the foundations for analysis. Direct care and improvement of patient outcomes underpin all that we do so we want to ensure that this is brought out from each and every use case submitted as part of this process. We want to also highlight specific transactions, data points and system required at each step of this pathway; for this, we want to ensure that we capture points that specific to a particular care pathway as well as any universal requirements.

- We presented some indicative categories to assess and analyse these use cases earlier in this document. These categories need to be defined and refined by the use cases themselves. We therefore need to consider examples of specific care pathways that can highlight the categories that we are seeking, much like the illustration on the previous page.

Formats & Templates

- We appreciate any information that comes through to be aligned to a certain template in order to easily compare and contrast documentation. Guidelines / Best practices for this information capture will be shared.

Timelines

- Submissions will be open from **Thursday 28th April 2022.**

Submission

- Upon formulating the material, please submit all relevant document to frontline.digitisation@nhs.net. Submissions will be collated and organised before placed in a central repository for wider viewing.

The How | Communication Plan

Stakeholders groups and audience that will also be engaged in this initiative, but not limited to are; ***TechUK, Digital Health Networks (DHN), Care Software Providers Association (CASPA), Social Care Working group, CIO Touchpoint, NHS Confederation ICS network***

Information and updates related to the crowdsourcing activity will be distributed and updated via NHS Transformation Directorate Social Media i.e., Twitter (@NHSTransform), Transformation Website

Please contact the Frontline Digitisation team if you have any questions in this process frontline.digitisation@nhs.net

Connect with us

NHSX is now part of the NHS Transformation Directorate. We are in the process of transitioning our communications channels.

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