SCIMP Special Interest Group May 2019

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# What is the NHS Scotland NATIONALDIGITAL PLATFORM, and how can it replace the “GP-Record” as the “go-to” source of truth?

## 1 What do we mean by the GP Record?

We all talk about the GP Record and might incorrectly assume that it is obvious that everyone knows what we are talking about. Although it originally developed for GPs the primary purpose to note their consultations and provide a record that allows patient care to be delivered, a host of medical and legal developments have influenced how the records are used and there are secondary purposes of this record including research.

### 1.1 A functional definition of the GP Record:

GP records are considered to be the most comprehensive and reliable longitudinal healthcare record in Scotland. And are, therefore, the records that are used for:

* Vaccination records
* Medication records
* Drug adverse reaction records
* Insurance reports
* GDPR Subject Access Requests

### 1.2 How did the GP Record come to be the “go-to” record for these functions?

The paradigm is currently that it is the GP record, rather than multiple hospital records, that is the “go-to” record for the above functions. But Why? The answer is historical – GP records are curated and have continuity over the life-course of the patient, information from them is shared with specialities and between primary care doctors, most contacts are structured/coded which makes them more useful. They are of reasonable quality. They have multiple contributors and they are population wide – almost everyone has one. In addition, there is nothing generally equivalent from secondary care, though some services for long-term conditions also manage a similar record.

## 2 What are the benefits of having a single medical record?

Having a single medical record to act as a single source of truth would be very useful. An exemplar example is in the case of adverse drug reactions. Currently each admission to hospital involves a clerking in of the patient, although the hospital record might then contain multiple different representations of allergies that are not necessarily congruous with the one in the GP record and potentially another one in pharmacy records. This gives much scope for confusion. If there has been a spurious recording of an allergy this can become perpetuated across records. Even when senior clinicians take the time to unravel the precise effect of the drug and whether it was a true allergy and test the patients (e.g. by an IV injection of penicillin in controlled circumstances into a patient who has the label of penicillin allergic and it is tolerated) such an “allergic to X” label cannot be easily overwritten in the records because; even if the falsehood of this allergy is carefully recorded with full context in one instance of the record, multiple other instances of the record will persist and be conflicting. This confuses the clinician and the patient is denied a potentially useful drug.

A single medication record across primary and secondary care is promoted as a way of avoiding duplication, interactions would be picked up, quality improvement work could be done. There may be some medication prescribing that would fall into separate sections of this record such as some inpatient prescribing or highly confidential prescribing such as PrEP (Pre- exposure prophylaxis for HIV protection). Role based access would allow some degree of control over who could view or modify these separate sections of the record, e.g. for inpatients or only with consent (for PrEP).

## 3 Currently the “GP Record” is in the middle

Currently the GP record facilitates the exchange of information between multiple other entities. However, even the lay perception that there is one self-contained “GP Record” is a misunderstanding. The “GP Record” is made up of multiple IT systems that interoperate to a greater or lesser extent. These all communicate with other entities as shown in Figure 1 below.

Figure 1. The “GP Record” in the middle

The **“GP Record”**

VISION/EMIS/(Microtest)

DOCMAN, SCIStore, SCIGateway, Lab ordercomms,

Office spreadsheets,

Shadow or “feral” IT systems

**Secondary Care**

Inpatients (discharge summaries

Outpatients (letters)

**OOH**

Emergency Care Summary

Key Information Summary

**Patient Portal**

Pharmacy

**Screening systems**

SCCRS (Cervical), BOSS(bowel), breast,

anuerysm

### 3.1 The “GP Record” is not just one thing

The systems within the GP record only interoperate to a limited extent. They are largely siloed, and there is no standard quality. There are also lots of office spreadsheets and bespoke access databases which have evolved as workarounds for specific bits of functionality that GPIT lacks. E.g. Disease Modifying Anti-Rheumatoid Drugs (DMARDs) variable time blood test recalls (after 2 weeks, after 6 weeks unless…)

## 4 Policy Review

The Health and Sport committee of the Scottish Parliament looked at Technology and Innovation in Health and Social Care and the conclusion of their report observed that:

* “We did not expect to hear of a culture where innovation is not encouraged and heavily outdated IT systems still cause major barriers”
* “It is no longer acceptable in this age that our health service is still using multiple incompatible systems”

### 4.1 Current Problems in GPIT

There are many current problems with GPIT which may only be partially addressed by the GPIT reprovisioning processes

* Siloed care, GPs want choice but there are too few suppliers. It is not always technical considerations but also human and legal factors that have led to the siloed situation.
* Suppliers having a monopoly potentially contributes to be slow in adopting innovation due to the lack of competition.
* Good companies also get taken over, bad companies go bust. Vendor lock-in is dangerous in this territory.
* Providers are very slow to change. Getting new functionality requested and added “once for Scotland” involved negotiating with 2 (potentially 3 in future) companies over cost (high) and timescales (long) and what can be delivered. Then when new functionality is delivered it isn’t how the user really wanted it to be. This is in part due to a lack of fast iterative development cycles where the user can review prototypes and comment and the developer then updates them accordingly – such as an Agile product development cycle.
* It is very challenging to hold vendors to account in the current climate as we are so reliant on them. There is no broad marketplace – we cannot simply change supplier if one isn’t working because we don’t like them due to the need to conduct business as usual. GP reprovisioning may mitigate this to some extent with financial penalties for vendors who do not deliver changes as required – however, vendor lock-in will remain a problem.

If there was only one supplier you might think that this would solve interoperability concerns. Perhaps, but other problems might be associated- for example that company leaving the market. Innovation is also thought to occur when there is product market competition. Potentially, vendors would become lazy with a monopoly and could be slow to develop new functionality. In our current GPIT reprovisioning, the success of appointing three suppliers onto a framework contract is perhaps giving an “illusion” of choice. Each of them will build a system, but, given the number of other IT systems that their software will be required to integrate with, problems would seem inevitable.

There is also currently concern that there is a huge lag time between need for new tech and delivery of tech.

### 4.2 Frustrations in GP in slow adoption of technology

Why can’t we have new technologies quickly incorporated into our workflows.

* Videos of consultations added to the records.
* Send patients notifications of that referrals and labs have actually been done and returned (tracking appts and tracking labs).

### 4.3 The Digital Health and Social Care Strategy April 2018

* “…the best way forward for data sharing is through a single platform”

Domain E of the strategy described a national digital platform based on the Apperta definition of an open platform. There was a unanimous vote at the Clinical change leaders group (CCLG) to adopt this.

## 5. So what is the national digital platform (NDP)?

The NDP allows applications to run on a services platform that will include an integration layer to communicate with existing systems and data sources. See Figure 2.

Figure 2: NDP Structure.

New Applications

Information platform

Existing systems and data sources

### 5.1 The NDP will be developed with four initial platform services:

1. CDR clinical data repository – currently built on EtherCis to an Open Standard, using OpenEHR (see appendix about OpenEHR).
2. Authentication – Azure Active Directory, initially to all NHS Scotland staff and then in time all to health and social care workers – to link into Office 365, for staff entry system. Also uses Digital Identity Scotland – citizens’ authentication, across all government services, offers of choice of methods to register (the mygov.scot account was previously for local authorities).
3. EMPI -Enterprise Master Patient Index (successor to CHI) - Nextgate queries multiple patient records, provides service of record locator.
4. Service Directory – for multiple applications – e.g. hospitals, GP surgeries, outpatient services, no. of ECG machines, clinic rooms, resource management – places and dates available for work planning

### 5.2 The NDP will be built on open standards

* HL7 FHIR depends on which implementation e.g. versions of source/target systems for Care Connect/GP Connect, need to be specified
* SNOMED CT – needs expertise. There are broader questions as to whether NHS Scotland should support both SNOMED CT and ICD10/11 given the specialist skills required and limited resource. Can we just use SNOMED CT and possibly deprecate ICD 10?
* OpenEHR – see appendix
* IHE-XDS – document metadata – for images e.g. label image as from gastro and name of patient, and allows record look up service, works well with OpenEHR.
Templates from Apperta are being labelled with XDS so that they work well.

### 5.3 Standards need management

Digital Health and Care Scotland is working on selecting standards (IT standards – not clinical quality standards) with governance, starting by looking at how NWIS in Wales have approached standards selection. There would be advantage in having efforts to ensure that the standards selection process and standards governance and maintenance are aligned across UK countries.

### 5.4 Advantages of NDP/OpenEHR

* Separating the data from the modelling and rendering of the template means that different bespoke views of the same data can be created easily for specific situations. The data is just reused and repositioned. E.g. one view for primary care and one view for secondary care etc. The data is all held in one place it is just that different bits of it are pulled to assemble a view for different situations. Even more granularly, a consultant gastroenterologist can have a different view to a respiratory physician. And that respiratory physician can have lung cancer clinic view and an asthma clinic view, if required. Both for the same patient with the same data as a result of using different templates. These views are produced by the applications. There can be many applications – run by different companies; they do not need to be managed as “Once for Scotland” because the underlying infrastructure already is Once for Scotland.
* Still need to maintain role-based access – e.g. governance maintaining “virtual” silos. Anaesthetists don’t want GPs adding a BP in the middle of clinic.
Or professional governance – instead of setting up systems to accommodate 40-50 different professional roles, it might be possible to group these into only 3 levels of access. – and other professional governance (legal regulations.)
* Federated data- so data is not necessarily kept in one data store but multiple data stores across the country and can be accessed by someone according to their role-based access from anywhere.
* Local developers get into market, software houses. Boards run smaller procurement because data is managed by models. i.e. 80% of a new system is already there – 20% to pay developer to develop the view to standards – can’t afford to allow a clinician to demand a new bespoke system.
* Quick wins – suppliers currently own some data – accessing data charge, storing data charge, extracting data charge. These charges won’t be accrued when the data is within a national clinical data repository.
* Solves problematic rumours/ data corruption when data extracted/ moved across systems because the archetypes anchor the data.

### 5.5 NDP in the Middle!

Figure 3: NDP in the Middle - Our Brave new World:

NDP

**Secondary Care**

Inpatients (discharge summaries

Outpatients (letters)

**OOH**

Emergency Care Summary

Key Information Summary

**Patient Portal**

Pharmacy

GP Record VISION/EMIS

(Microtest)

**Screening systems**

SCCRS (Cervical), BOSS(bowel), breast,

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### 5.6 Managing expectations

Need to manage expectations around NDP because people are thinking that it will be a solution to everything. NDP can’t deliver what re-provisioning is designed to deliver in the timescale. There is also a need for a Scottish Technical Design Authority to decide which specifications and standards and technologies. Starting to work up (digital strategy domain F standards assurance.) Previously had failed attempts at this.

## 6 Implementing the NDP

It is a question of thinking about what actually needs to be in a GP system. For example, housing status is important to know for many social care and sometimes GP purposes. It can be taken out of the GP record, stored in the NDP, then the NDP is queried by applications (e.g. web-based or integrated to health care record can find the information from the NDP). take all the below out of the “GP record” and put them on the platform – GP can still view – patient can also view. One result of this is that in the next GPIT reprovisioning may become less complex.

### 6.1 Possible things to start putting on the platform instead of the ‘GP record’

DNACPR

Immunisations

Medications

Adverse drug reactions

Child Health

Child Protection

Housing

Scheduling

Registers – Abdominal Aortic Aneurysm screening results, Pacemakers and implants etc.

Licences (driving, HGV, shotgun)

Key Safe access codes

Labs

Referrals/ communications

Dentistry

Optometry

### 6.2 Starting the NDP up with the RESPECT DNACPR form

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) CPR conversation, contains much more than a straight documentation of DNA CPR status. NDS has been negotiating with Forth Valley in Acute, and GPs, to put in one central place with access under appropriate rules – not requiring a separate login. Don’t make it more difficult/don’t make things worse. The scenario of “I lost the form” shouldn’t happen, DNACPR that hasn’t been discussed with relatives – ambulance drivers will be able to view.

Prototype was reviewed - more work is being needed to be done e.g. purple dates are in the American format, unsure whether religion and housing will be part of NDP or somewhere else rather than RESPECT, contacts – repopulate somewhere. The idea is to have several views – patient portal view, GP view, secondary care view, emergency view e.g. for back of ambulance. Legacy for print view for record, can print off. Or send email. Probably not to put onto the current Key Information Summary – transition from KIS to RESPECT.

### 6.3 How do we transform EMIS - VISION - Microtest environment to the NDP?

They would have to come in as an application - lots of work to do. The vendors who tendered in reprovisioning have been asked the following questions:

1. Is your solution capable of integrating with OpenEHR?

2. Can your solution authenticate users using an external authentication solution such as Azure active Directory which has now been procured for NHS?

3. Can your solution accommodate Patients Facing Services using external authentication such as the Scottish My Account and National Patient Portal?

Responses were of variable quality.

### 6.4 Going Forward

* Confidence issue – concepts and theories coming together
* People worried about the systems falling over and ending up in the daily record.
* Untried organisation – how will they cope with the potentially huge demand for applications
* Get clinicians involved in modelling own work – e.g. a new head and neck record, can have contributed to International ENT archetype – put this in their PDP.
* Questions still remain:
	+ what if the big players won’t allow patient-data models to be made available?
	+ what is the timeline?

## Appendix

Slides from Alistair Hann

## A1. What is OpenEHR and how it works

OpenEHR is a set of specifications for building health records.

Paradigm changing –yet many vendors have little understanding of this.

**Reference** **model** – This defines how the rest of the specification can be built, putting the concepts and ideas into real world things, for example which data types can we use, or when build our models will be in cm and kg… etc.

**Archetypes** – next layer – clinical content, Apgar, diagnosis, labs, pain… - health care professionals are interested in this layer – maximal list of all the attributes of the data you might possibly want to record… e.g. systolic, diastolic, lying standing, Korotkoff sound…, start time, setting, metadata

**Template** – BP intraoperative or contextual use case from the archetype, can use bits from multiple archetypes – e.g. for diabetes check-up template has glucose from labs archetype and BP from BP archetype.

Several consequences of this:

1. Out of this three-layer model – developer can build applications, clinicians want XYZ for my use case.
2. Content is independent of database, new template and new archetypes will keep moving data in and out of database and not fall over.
3. Can query templates, or directly query archetypes, i.e. find everyone who had that BP between weeks X and Y.
4. Separates Content from Data Model, which is internationally published.
5. These Data Models are publicly “owned” as they are publicly available.
6. Data Models are uploaded to each Central Data Repository so that each one structures data in the same way, by “registering” them with the CDR.
7. Can do Clinical Decision Support on top of queries – alerting and risk scoring e.g. because of these variables the answer is “10”.
8. Clinical processes, pathways – task management, informing next step in score – because the answer is “10” – you should do A, B, C.
9. 7 and 8 overlap.

**Interoperability:**

Two metaphors for data exchange between different systems:

1. Messaging model:

e.g. using FHIR is as if between two different spreadsheets: the systems must use metadata for the position of each cell and then return information – so rapidly increasing scale and complexity with more connections to more different systems. (Metcalfe’s law states that a network's impact is the square of the number of nodes in the network)

1. Architecture model:

Systems currently store data as if using different languages, so FHIR is like a set of phrase books, and different translations need different (local) phrase books.

If systems use OpenEHR as if a common language, communications between them are simple, more like between two spreadsheets with the cells in the same positions.