

NHS Data: 'State of Play' – a discussion paper

Executive Summary

It has been appreciated for a long time that the collection, storage and flow of NHS data is complicated, principally because it has evolved in a piecemeal fashion in response to specific pressures and expectations rather than systems having being designed from scratch. Very rarely has consideration been given to how these developments might improve the delivery of direct clinical care.

As a group of clinicians with extensive experience of NHS data systems we felt it important to make an attempt to draw together some of the key issues we all face.

One of the principal concerns is the lack of ownership of what is an extensive and complicated problem for which there appears to be no overarching plan that primarily focuses on improving the delivery of direct clinical care, and in so doing improve the accuracy and thus the utility of information currently gathered for quality assurance, demand and capacity estimation or commissioning purposes.

If changes are made to reduce the duplication of data collection, analysis and interpretation and the NHS begins to work based on a single version of the truth we feel significant improvements can be brought about, but to do so the full end to end complexity of the current picture needs to be appreciated.

A key driver for this must be to bring about an improvement in the availability of clinically relevant information to frontline staff and an improvement in patient care by the appropriate sharing of linked health information.

Another very important consequence of the current complexity and confusion is that it has caused managers and clinicians at all levels to disengage and develop further isolated standalone data collections rather than to actively try to improve national data collection and flow.

In this paper we go on to suggest that the initial focus for improvements in NHS data collection, flow and utility should be to:

1. establish clarity of ownership and responsibility for the end to end process
2. concentrate on providing linked data to front line clinical teams
3. develop greater standardisation in the way routine data is collected and reported
4. ensure that NHS data is held and used in the NHS to produce one version of the truth

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1. Introduction

This document has been written by clinicians who have extensive experience concerning the collection and use of data in the NHS plus an appreciation of the confusion concerning ownership, governance and access to data created by the convoluted series of unconnected systems currently in use.

The document is intended to provide an instructive overview based on our experience and to suggest a ways to support the development of a unified approach to data collection and flow in the NHS.

The authors are aware that many authoritative documents exist concerning the difficulties of data management within the NHS but these have rarely, if ever, dealt with the detail of some of the issues and to represent the true complexities which exist, and must be resolved if the NHS is to realise its information utilisation potential.

2. Background

It has long been appreciated that the collection, storage and flow of NHS data is complicated, principally because systems have evolved in piecemeal fashion in response to specific pressures and expectations rather than an integrated system being designed from scratch.

This means that systems have been developed in relative isolation and in the absence of an overall vision of the wider health system or an appreciation of the need for systems to interconnect.

It was interesting to confirm with the first NHS Information Officer, Mr Roy Dudley-Southern MBE, appointed to the NHS in 1971 that it 'was for ever thus'.

Very rarely has consideration been given to how these disparate developments might improve the delivery of direct clinical care. The result is that we have an extremely convoluted picture with confusion concerning ownership, governance and access to NHS data.

For clinicians, the lack of real progress has been deeply frustrating and seems to have been contributed to at a national level in recent years by such things such as:

- Lack of a comprehensive plan for informatics and lack of informed, consistent leadership
- Politically driven change rather than responding to clinical or service requirements
- Increased pressure to respond to political crises and targets
- Diversion of attention and resource to the latest 'quick fix' policy
- Fragmentation of the NHS with the increased influence of what can only be described as opposing factions and agenda
- The loss of corporate memory as key staff are lost
- Positive change and innovation findings not captured, disseminated or widely applied
- Lack of capital funding

The lack of clarity in the NHS data landscape may, in part, be the reason why many aspects of data collection, flow, analysis and interpretation are duplicated (sometimes many times) in the NHS.

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A very important consequence of this complexity is that managers and clinicians at all levels feel a sense of hopelessness regarding the potential to improve matters and thus minimise interest in resolving the known issues. As a result, the NHS has had to rely on non-clinical staff who may not appreciate the organisational and clinical consequences of their actions, to interpret data and produce outputs that do not meet the requirements and which are not standardised within and across organisations. This also gives rise to different 'versions of the truth' which have in turn resulted in conflicting interpretation and contributed to organisational indecision.

Current NHS policy appears to be undecided about the balance between a desire for minimal data collection and analysis for costing and pricing – as implied by the introduction of Blended Payment methodologies (as yet not well understood, or proven) – or ever greater detail and granularity, despite the administrative load this entails, to support programmes such as the National Clinical Improvement Programme (NCIP), Lord Carter reforms, Get It Right First Time (GIRFT) and replacing Reference Costs with PLICS derive tariffs. And failing to make use of this highly detailed data to better understand where and why the demand for services exists and how best to commission services to meet it.

It is not clear which philosophy will prevail but the lack of clarity has given rise to opportunistic, uncoordinated and potentially destructive activity in several areas (see appendices) which threaten the collective ability of the NHS to understand what it does and to allow international benchmarking.

3. Who holds patient level NHS Data?

The true extent of all NHS data depositories is not widely appreciated. Data is held by many other bodies than NHS Digital with many more principle stakeholders in this arena, which include:

- NHS Digital
- Public Health England (PHE)
- Commissioning Support Units (CSU)
- Data Services for Commissioners Regional Offices (DSCRO)
- Business Services Authority (BSA)
- Community Interest Companies (CIC)
- NHS England
- NHS Improvement
- National Casemix Office (NCO)
- National Audits organised by the Healthcare Quality Improvement Partnership (HQIP)
- Clinical Registries run by professional Associations and Colleges
- Clinical Registries run by universities and research establishments
- Clinical Registries run by charities
- Clinical Registries run by commercial companies
- Clinical data held on GP and community service systems
- Multiple local systems in hospitals

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4. Organisational Change

The NHS Long Term Plan ambition to manage the NHS at a whole system level means that now is the time for the NHS to recognise the full end to end complexity of the entire data picture and take the necessary steps to rationalise it.

In an effort to develop the NHS there are currently organisational changes taking place within all key NHS organisations in response to the Long-Term Plan and other initiatives. At the same time profoundly impactful policy changes are being developed and announced with little if any evaluation concerning the likely impact (see appendices: EBI, ECDS, SDEC). What little analysis has been undertaken has in each case identified inaccuracies and misleading statements.

Progress will depend upon making changes but the environment for innovators in the NHS is currently not a friendly one. Whether you are a clinical team aiming to change practice with the support of provider IT or a software company, your efforts are likely to be ignored by the NHS at large. There is no process for success in one part of the NHS to be readily adopted elsewhere. Only those larger companies with the available resources to commit to satisfying the current massively bureaucratic processes and who can commit to expensive marketing are likely to prosper.

The situation is highly reminiscent of the mid-2000s when NHS providers were constantly being told that National Programme for IT (NPfIT) would satisfy all their requirements. This included EPR, tele-medicine and videoconferencing. At that time many software companies catering to the NHS went out of business because they could not get their products used in the NHS as it was believed NPfIT would provide, if you simply waited long enough. Arguments to the contrary were ignored at that time. Six years later and with the loss of several billion GBP, that misguided belief was revealed for what it was.

5. What is needed now?

Resolution of the issues we describe demands above all else clarity of ownership of the problem. An appropriate body, which may prove to be NHS X, needs to be given the responsibility and funding to address these within a reasonable time frame. As part of this process such a body must embrace the full detail and end to end complexity of the entire picture if the necessary remedial steps are to be developed. Any solution of value will take far more than the term of one government to achieve.

A novel approach to system improvement and one that is likely to attract the interest and support of clinical and managers might be to establish and agree what the expected outputs from the NHS data systems should be. Broadly these might be considered to be:

- Operational patient identifiable information to support patient care delivery across all settings
- Tactical informational to allow commissioning, cost and service activity to be appreciated
- Strategic information to allow service review, organisation and improvement.
- Research data to allow some fundamental issues to be illuminated

At some levels there appears to be an emerging view that the simple addition of health apps and the results from Big Data analysis using machine learning or artificial intelligence will be all that is necessary. Whilst these will undoubtedly help in a few selected places, the bigger challenge is how

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to rationalise and simplify the amalgam of data collections and to minimise the administrative burden while deriving the maximum operational, tactical and strategic benefit from doing so.

A recent review by the BMA (<https://www.bma.org.uk/collective-voice/policy-and-research/nhs-structure-and-delivery/technology-infrastructure-and-data-supporting-nhs-staff>), focussed on front-line clinical systems and made the following recommendations:

- *Prioritising the digitisation of all patient records swiftly and safely*
- *Digitising both primary and secondary care settings at the same time to enable system developers to build interoperability into all systems*
- *Ensuring enough new, ring-fenced resources are allocated for digital transformation to enable implementation of upgraded and new IT systems*
- *Developing national minimum IT standards / principles, e.g. interoperability, efficiency, improvements in care etc, in collaboration with staff representative bodies and experts to ensure consistency of approach across local areas when procuring new technology*
- *Making digital health care a requirement of medical training and education for existing and future doctors working in the NHS*
- *Balancing the encouragement of a culture where innovation can flourish, appropriate evaluation and sharing of the outcomes.*

To derive maximum operational benefit data flows need to be as close to real-time as possible but to allow delays for data quality assurance where necessary and to allow the necessary data linkages to highlight clinically important events at individual patient level. The information governance framework to allow this already exists but the rules are often misunderstood or misrepresented, thus reducing or removing the potential benefits of such developments.

With these aims in mind a single encompassing plan could be devised to instigate the necessary incremental changes and to allow iterative improvements to be seen towards the development of a unified NHS data flow system to deliver a single 'version of the truth' from NHS data irrespective of setting or intended purpose.

A further step would be to concentrate on the clinical and operational utilisation of information to improve clinical care. This will include agreeing interim measures and protocols for universal interoperability and system linkage. The majority of tactical and strategic data can be derived from appropriately designed clinical systems without the need for collection systems divorced from direct clinical care.

Early statements from NHS X stating the need for uniform application of standards across IT developments are of themselves logical and undoubtedly required, the problem will be the execution and the utility of the results. NHS X and partner organisations will need to learn from the lessons of previous IT programmes in the NHS to deliver programmes that are focused on supporting clinicians and managers to release time for care rather than adding to the burden of delivering care.

Additionally, standards need to be described for how provider trusts should enter data prior to its centralisation. The current variations described in the appendices make dependable analysis extremely difficult if not impossible.

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Experience suggests the best way forward is to develop operational clinical systems which support integrate care delivery across all care settings which are simple to use and require data to be entered only once and for that system to be used to extract the tactical and strategic information required by the NHS.

A benefit vs burden approach should be at the forefront of thinking as policies and programmes are developed and implemented. These include, but are not limited to:

- Community Services Data Set (CSDS) - see appendix 1
 - National Wound Care Strategy (NWCS) <https://www.ahsnetwork.com/about-academic-health-science-networks/national-programmes-priorities/national-wound-care-strategy-programme/> - see appendix 2
 - SNOMED CT terminology introduction - see appendix 4f
 - Clinical Registries review by NHS England - see appendix 7
 - Evidence Based Interventions Programme (EBI) - see appendix 8
 - Emergency Care Data Set (ECDS) - see appendix 9
 - Same Day Emergency Care (SDEC) – see appendix 10
 - PLICS based Reference Costing – see appendix 11
 - Get It Right First Time (GIRFT) - see appendix 12
 - National Clinical Improvement Programme (NCIP) - see appendix 12a
 - <https://gettingitrightfirsttime.co.uk/associated-projects/ncip/>
- Plus:
- Blended Payment approach <https://improvement.nhs.uk/resources/201920-payment-reform-proposals/>
 - Model Hospital <https://improvement.nhs.uk/resources/model-hospital/>

6. Who should have access to patient identifiable NHS Data?

Access to patient identifiable data (PID) is an important concern for many and should be based on clinical need. Such access needs to be audited and monitored in such a way as to ensure only appropriate access is actioned. This is already the case in every NHS Provider Trust currently with regard to access to their Patient Administration System (PAS). The development of a single NHS staff identifier by NHS Digital could make the task of arranging access to linked, real-time data a safe reality. It would also help track what care is provided and by whom. The creation of a single identifier is not technically difficult and should be expedited.

Data acquisition and linkage requires individual organisations to cooperate in the interest of patients. It is widely known that patients already expect their clinicians to have access to this information. The frequent and unnecessary requirement for them to repeat their medical history or to repeat blood tests and other investigations continues to confuse and irritate everyone involved and has led to the development of a commercial offering (Patients Know Best - PKB), which allows the patient to control access to their information across different institutions and settings.

Legitimate concern exists concerning nonclinical access to information particularly at a collective 'Big Data' level by researchers, pharmaceutical and insurance companies as well as non-health governmental departments (Immigration, HMRC etc). Access to identifiable patient level data by such bodies should be absolutely denied.

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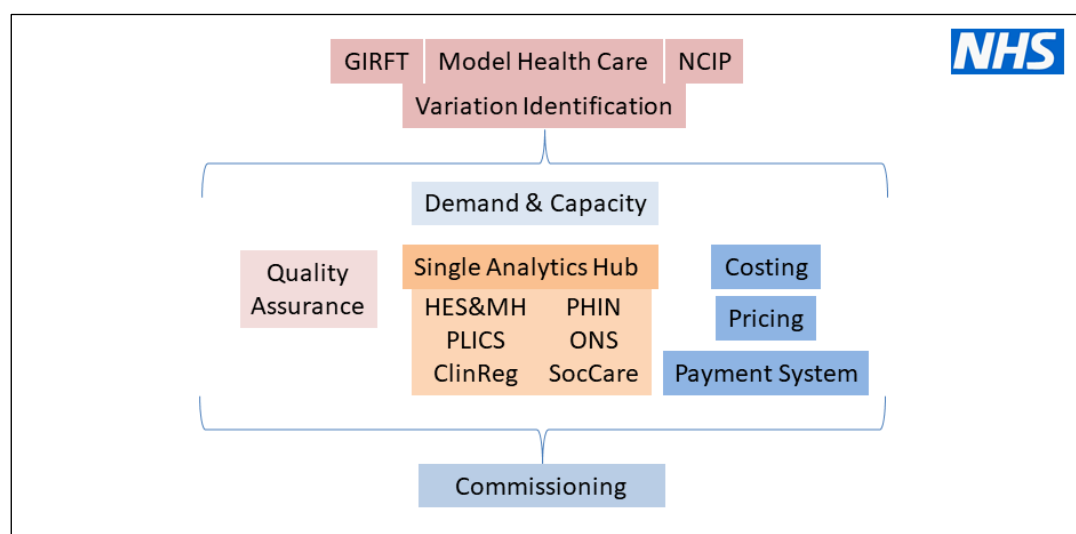
The sale of data beyond the health and research community within the UK is unsupportable.

Access to collective data for purposes including research and population studies should be performed only under extended 'safe haven' arrangements and be considered on a case-by-case basis by a designated responsible organisation. There should be no requirement for access other than that already described to successfully undertake such work.

The development of metrics and access to dashboards derived from linked near real-time data should be restricted to healthcare providing institutions and those responsible for the commissioning, delivery and organisation of services within the NHS. Such access requires only the use of (pseudo) anonymised data but enhanced security access should be put in place to allow access to individual records at a senior level to consider care provision exceptions (Effective Use of Resources Policies for example). Such access would be strictly audited and reviewed as happens in most trusts already.

Crucially, the use of data in this way could produce reliable metrics to quality assure the care provided by teams and individuals in all sectors, NHS or private care, and has already been proven to be far more effective and less costly in establishing outlier practice than the fundamentally flawed Appraisal and Revalidation processes run by the GMC.

The identification of variation in access to services would also result from these metrics, especially if undertaken in a single analysis hub with the results being widely available.



GIRFT – Get it Right First Time

HES & MH – Hospital Episode Statistics (for secondary care) & Mental Health

ClinReg – Clinical Registries

ONS – Office of National Statistics (Mortality Database)

NCIP – National Clinical Improvement Programme

PHIN – Private Health Information Network

PLICS – Patient Level Information Costing Systems

SocCare – Social Care

By centralising the data flows it would allow a wide range of linkages to be made, including data sources not viewed as traditionally of NHS interest, such as the ONS mortality database and the Private Healthcare Information Network (PHIN), in the latter instance this should cover NHS activity done and private practice activity to establish common metrics and outlier identification.

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As detailed in appendix 7 the provision of NHS data back from Clinical Registries is urgently required.

Similar, but more geographically limited work undertaken in several sustainability and transformation partnerships (STP) are an indication of what could be done at a national level, but done once, with no duplication, thus creating significant savings by reducing the replication of effort and infrastructure investment.

The baseline NHS functions of costing, pricing and tariff or payment system development would also flow from this process, giving rise to a better understanding about demand and capacity variation, and the reasons for it, as well as allowing the better planning of services. It would also allow greater understanding of the consequences and costs of proposed change. In other words, more accurate and evidence based commissioning would be possible, which is currently undertaken in a relative information vacuum.

It is our hope that this document may be of some use in highlighting issues which have been generally ignored and stimulate an informed debate as to the way forward.

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Appendices: Specific sections of the NHS system

1. Community Services Data Set (CSDS)

Currently there are no community clinical systems comparable with the major GP software packages which offer to community staff the type of clinical functionality GPs are used to. Community staff are either using hardcopy or partial electronic systems, usually based on variants of the GP systems.

The development of the Community Services Data Set (CSDS) was intended to establish a mandated flow of information concerning community services from October 2017. Initially this system was intended to cover paediatric requirements only but has morphed without significant redesign into covering all community activity.

NHS England defined the currencies for each of the five areas:

- Children and Young People with Disabilities
- Last year of Life
- Frailty
- Long Term Conditions
- Single Episodes of Care

It fails to produce data that is comprehensive, analysable and clinically meaningful. The existing collection is reliant on systems that are not clinical but are an additional administrative load on already hard pressed services while providing no useful products back to clinical teams.

2. National Wound Care Strategy (NWCS) and the CSDS

However the largest component of community care is the nursing care for wounds which has been highlighted by the work of the National Wound Care Strategy (NWCS). The forthcoming Strategy will call for the creation of an integrated, mobile clinical system to allow the coordinated care of patients in the community with wounds and the incorporation of all other forms of community clinical record keeping requirements is the preferred option. Such an approach would require an unprecedented coordination of existing systems, especially GP systems and Supply and Distribution data sources.

3. Primary Care NHS data issues

The vast majority of primary care practices use an electronic clinical record rather than the 'Lloyd George' hard copy design used in the past. There are three major software providers (referred to by NHS Digital as Principal Clinical Systems) each with differing market shares:

- EMIS Web (from EMIS) – approx. 46% coverage
- Vision (from INPS) – approx. 32% coverage
- SystemOne (from TPP) – approx. 29% coverage

A fourth Principal Clinical System, Evolution (from Microtest) appears to have a very small market share but is still enjoys PCS designation by the NHS.

These companies are well established in the primary care arena but their relationship with clinicians and the NHS is fraught. Each company has a vested interest in the provision of systems but appear

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not to be competing with each other effectively as they are not engaging with the clinical teams to develop their systems and providing greater functionality. Nor is there collaboration with other software providers or the NHS at large with key issues such as system integration. This inaction culminated in a well-publicised admonishment by Matt Hancock as health minister in January of 2019. No discernible effect has been observed since that time.

Information from NHS Digital suggests that there are currently 42 outstanding requests by software companies for collaboration with just one of these companies, but only one of these has been processed in the last 12 months.

The number of small business innovators lined up and requesting integration and collaboration is growing but they are frustrated not only by the three company's bureaucratic response but also by GP IT Futures frameworks developed by NHS Digital which is labyrinthine in its complexity and expense. A recent letter from a group calling itself SupplierX claimed to represent the views of small business software providers to the NHS and suggested that the actions of the Principal Clinical System companies and NHS Digital are intended to exclude innovation and small-business involvement in this arena.

a. Coding

Historically GP systems used Read codes but there has been a move to slowly adopt SNOMED CT. This move was explained by the NHS England policy announcement that all provider systems should move to use SNOMED CT by April 2020. Thus a freer flow of coded information to and from secondary care providers would have been possible. As explained elsewhere in this document, there are several barriers to this happening in secondary care and the deadline will undoubtedly be missed in primary care.

b. Access

Concerning the flow and visibility of GP data, issues exist concerning the ownership of all primary care data as the current arrangements place the information governance responsibilities with each individual practice. As a consequence data does not flow and is not centralised or available for analysis other than as part of a few small scale examples as agreement with each practice is difficult to obtain and rarely granted. Even requests to allow emergency departments to simply view primary care information to help deliver direct clinical care have typically been rejected, either by individual practices or local medical committees (LMC), because of the high levels of GP practice anxiety concerning the risk of data breaches and the fact individual practices feel they could not survive the financial penalties imposed.

A process is used in England by NHS Digital to centralise data from all four system providers as part of the GP Extract Service (GPES) is mandated to be used each year to assess the Quality and Outcomes Framework (QOF) for each practice and to update the patient opt-out scheme which is used as part of the HES processing prior to it being available for release via the Data Access Request Service (DARS). The cost of the GPES is passed on to the individual or group making the request. Each request is individual, time limited and not repeated.

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c. Referrals

Currently elective referral of patients into secondary care is mandated by NHS England to be via the electronic referral system (eRS) produced by NHS Digital, which is linked with each of the GP systems. Pressure has not been applied by NHS England to GPs to make this happen (which contractually is not possible) but rather on secondary providers who have been told they will not be paid for any outpatient activity processed other than by eRS.

A number of issues affect the eRS utility. It has no effective referral management functionality and the lack of an ability to check the referrals means the semi-automated Choose and Book methodology frequently places patients into the wrong clinic. Whilst eRS has the ability to use predesigned proforma to aid referral placement this functionality is not available. Additionally the attachment of images to referrals is so time-consuming that small pilots using this function have typically failed. It is therefore extremely difficult to see how the rise in non-face-to-face appointments outlined in the NHS Long Term Plan can be achieved using this system in isolation.

A number of small software companies have produced alternatives to augment eRS which require the use of an application program interface (API) to allow integration of other systems with eRS and allow provider to be paid. The eRS API was due to be delivered by NHS Digital at the end of Q2 in 2018/19 but has not been. A non-operational beta version of the API has been inspected by a small number of companies but was found to be using outmoded technology and required the use of a security card system to verify the identification of the referrer. Such systems are no longer in widespread use in the NHS.

The majority of providers refuse to consider the use of any system of referral that does not generate an eRS identification number which is required if they are to be paid for the activity. There appears no prospect of this being possible using systems other than eRS in the foreseeable future.

4. Secondary Care and Mental Health NHS Data issues

There are a number of fundamental issues which adversely impact on the quality of the data currently being held in a number of national datasets. Understanding the strengths and weaknesses of these is key if improvements to it are to be made and appropriate analysis and understanding of the results is to be achieved.

These issues include:

a. Standardised approach to use of Treatment Function

Typically when a patient is admitted as a day case or for a longer stay, it is the ward clerk that enters details into the patient administration system (PAS) including the consultant name and specialty under which that patient has been admitted.

We have found that there are profound inaccuracies in this part of the process. In part this is due to the significant variance nationwide in the recording of both the relevant treatment function code (TFC – aka subspecialty) and the recording of when a finished consultant episode (FCE) starts and ends.

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National guidance is not prescriptive regarding one approach over another. For example, some providers may have a patient in critical care who undergoes surgery and there is no change in TFC on the system and the surgical care is “allocated” to the critical care episode, when in fact it has been undertaken by say a thoracic surgeon. At another Provider, each time a patient moves between clinical areas and or teams a new TFC is recorded, resulting in the patient having a multi-episode Spell where the activity undertaken within each FCE would be allocated to each TFC.

b. Definition of a dominant Spell Treatment Function Code

There remains a non-uniform method by which providers allocate the TFC for a Spell. In some it is allocated based on which speciality has the longest FCE-based length of stay while others allocate it based on the admitting specialty alone. Another method in use is based on the FCE involving the greatest resource use within the Spell. This list is not exhaustive but illustrates that any analysis of specialty based activity at Spell level is unreliable, especially for patients with complex needs. The adoption of a single methodology is an obvious requirement.

c. Insufficient Treatment Function Codes

In addition, the current coding system allows for only one TFC to be allocated per FCE, so if a patient is undergoing a complex procedure involving many surgical specialties, the TFC would only be able to reflect the most significant of these, which is usually attributed to the lead clinician. The contribution of other teams may not be specifically identifiable. A solution for this issue which could be used without altering the existing systems is being discussed with NHS Digital by the lead author.

Data quality and hence data analysis is also hampered by an inadequate number of Treatment Function Codes (TFC) being available to allow the current spread of sub-specialty work to be accurately reflected. Even if the correct TFC is applied to an FCE the current TFC list limitation makes clinical metric design, such as is required for a number of national programmes, including the Get It right First Time Programme, insufficiently granular to be able to confidently benchmark between providers.

d. Mandated national data collections and subsequent data access

With regard to critical care, it should be noted there are mandated collections for neonates, children and adults but only adult activity is felt to be reflected in SUS or HES by way of the mandated Augmented Care Pathway collection. Neonatal data is available from BadgerNet, a private commercial company. Paediatric critical care data is effectively only available from the PICaNet registry, held by a university, while additional adult data is available from the ICNARC registry, held by a limited company.

e. Current coding systems

Following discharge patient notes are typically required to be formally coded in the coding department for the data to be uploaded into the NHS Digital secondary uses service (SUS) within 6 weeks.

The current coding systems in use in secondary care are ICD-10 (introduced in 1996) and OPCS-4.8.

The ICD-10 has in excess of 16,000 codes and OPCS-4 has in excess of 9,000 codes with associated date fields. The number of ICD-10 and OPCS – 4 codes that SUS can accept is unlimited but many

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Provider PAS are restricted in the number they can record. The result is that the provision of data from SUS by NHS Digital to clinicians, commissioners, researchers, policy makers and the like is often limited to 21 of both ICD and OPCS codes per FCE. For many specialities this severely limits the utility of the data.

It is anticipated that ICD-11 will become the NHS standard after 2022 (this would be a decision made by the Department of Health and Social Care) while OPCS-4.9 is due to come into use in April 2020 as part of its regular three-year review cycle. There are suggestions from several parts of the NHS that the cycle of coding improvement needs to be shorter and more responsive to clinical developments.

It should be noted that ICD-11 can only be used electronically and to introduce it would require all PAS software to be updated or replaced.

f. SNOMED – CT (Clinical Terms)

A commonly held belief is that SNOMED-CT will become the dominant coding system within the NHS as it was previously advocated by NHS England for use across the NHS by 2020. This is unlikely to happen for a variety reasons.

Foremost of these is that SNOMED-CT, as a terminology rather than a classification system, can only be applied electronically as it is too large (over 1.5 million terms) to be delivered via coding books as is the case of ICD-10. Only a few of the EPR systems in use in secondary care can accommodate it. Also there are no plans for a flow of such data into NHS Digital to be established, beyond those data sets – such as the Emergency Care Data set (ECDS) - that already partially utilise it (see below).

It is also impractical to suggest that clinicians should code directly using SNOMED-CT as it would take too long. The only practical way is for clinical terms typed or dictated into an EPR be used by the system to provide applicable codes from which the clinician would be invited to choose the best representative.

Having said this, there are a small number of trusts coding in SNOMED CT within their EPR. These typically have to then map these codes to ICD and OPCS to allow the use of HRG Grouper software (see below) and to allow the mandated flow of data to NHS Digital.

The current use in Emergency Departments from November 2018 of the emergency care dataset (ECDS) purportedly uses SNOMED-CT codes as the coding bedrock, but this is in fact not the case. A very small number of selected codes have been extracted for use within this system, which are the only codes available to be chosen at the point of data entry. Access to the whole of SNOMED-CT is not available so this is not an example of a true SNOMED-CT application.

[<https://digital.nhs.uk/ECDS>]

In addition, whereas the use of ICD-10 is widespread internationally, SNOMED-CT is not, therefore if we moved to exclusively use SNOMED-CT we would lose the ability to benchmark against international data, contribute to international research etc.

While cross mapping between ICD and SNOMED-CT does exist the profound structural differences between the systems makes such mapping imprecise, which is particularly important to those trusts implementing the use of SNOMED CT in their EPR systems

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Increasingly, primary care is moving from the Read coding system, which is also only usable electronically, to the more comprehensive SNOMED-CT, but this transition is slow and patchy across the UK. According to the NHS Digital site this went live in April 2018 – see:

<https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct/snomed-ct-implementation-in-primary-care>

with dual coding continuing until April 2020 (dual coding meaning that both SNOMED-CT and Read Codes will be held in the clinical system during the transition between 1 April 2018 and 31 March 2020). Feedback from GP practices tells a different story, where considerable difficulties are being encountered.

The community service dataset (CSDS) is currently text based and not coded at all. SNOMED-CT is one of the options in the data set spec for CSDS – see:

<https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1069-community-services-data-set>.

A decision about this has not yet been made. [<https://www.digital.nhs.uk/Community-Services-Data-Set>]

g. Coders in secondary care

Coders are trained by one of the 116 accredited coding trainers listed with the Terminology and Classifications Delivery Service at NHS Digital, which represents a very limited training capacity for any new or expanded service. This is of particular relevance concerning the likely introduction of ICD-11 in 2022.

Coders typically utilise either hard copy notes or information within electronic patient records (EPR) or in some instances information held in a variety of other electronic data collection systems within their organisation, although they may not have access to all of them. This may include a number of the national registries where significantly more detailed information is often held concerning patient care than is available in the other clinical records, but these registries may not be accessible to coders either. Access levels to these other sources of clinical data are variable between providers.

It should be emphasised that the coders can only code definitive diagnoses or procedures recorded in clinical records. For example, a patient with chest pain with a 'possible', 'likely' or 'query' heart attack would be coded as chest pain but with 'probable' or 'treat as' in the record would be coded as a heart attack – so subtleties in the language make significant changes to coding. Coders cannot interpret test results e.g. BP 150/90 would not be coded as high blood pressure, and they cannot infer what else might normally be recorded but is not, nor can they fail to code what is clearly recorded. A similar situation exists with Body Mass Index, which may be recorded but unless it is interpreted in the record defining degrees of obesity, this condition will not be coded.

h. Admitted, Day Case or Outpatient Procedure

There remains considerable confusion in the way that day case activity is defined and data collected by providers nationally. What is a day case in one organisation can be coded as an outpatient

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procedure in another or even a short stay admission. Historic service organisational practices, often based on what creates optimal remuneration are not uncommonly the basis for the ways in which this activity is recorded. The lack of clear national guidance on this issue makes the interpretation of activity levels in different specialties difficult to define and meaningfully compare.

Following the attendance or non-attendance of patients to outpatients the clerk for that clinic is supposed to complete the record for each appointment with regard to the date and time of attendance and the outcome, such as a further appointment or discharge. In the case of outpatient clinics it is often the clinic clerk (and not the clinical coders) that enters any relevant procedure codes onto the system. This is typically based on a set tick-list of limited procedures which the clinician will complete. Many procedures (in fact around 2000) will attract an outpatient procedure tariff. However, unlike admitted patient care, the coding of outpatient procedures is not mandatory and is therefore patchy across providers and tends to focus on about 16 procedures which are believed by many to be the remunerated codes. It is common for clinicians to be asked to concentrate on recording only these.

No other form of coding takes place routinely across the NHS, including the presenting diagnosis i.e. diagnosis coding in outpatient clinics. To begin doing this would be a massive undertaking from the point of view of training and cost. The only practical way forward is to code directly from any electronic source pertaining to that appointment using an electronic system based on either SNOMED-CT or more likely are ICD-11.

Therefore in future the role of clinical coders may move away from manually coding every record into a role of auditing the codes assigned based on electronic system mapping.

i. Trust and Site code allocation

Before any FCE record is exported from the care Provider to NHS Digital a 3 digit alphanumeric code is attached to each record which represents the Provider Trust while a 5 digit alphanumeric code is also attached to each record which represents the Site on which the care has been provided. These codes frequently change as trusts merge or reorganise and are therefore not simply analysable over long periods of time.

It has been found that on occasion they are not consistently applied by hospital systems even within a single financial year which means identifying the full range of activity undertaken on a given Site or within a given Trust can be difficult.

Also codes can be attributed to the employing Provider of the staff undertaking clinical work on a completely different Site because of contractual arrangements, making any analysis of where a patient is actually treated in relation to their residence impossible.

Analysis of the Site and Trust codes indicate that some trusts have over 50 different Sites attributed to their 3 digit Trust code which means analysing activity based on the Trust alone will be inappropriate if a geographical appreciation of activity is to be part of the analysis. Site codes are preferable but over a long period of time it is often more appropriate to use the postcode of each Site as the basis of analysis. Although postcodes can also change over time, old postcodes are maintained longitudinally by the Post Office.

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5. Secondary care data flow to NHS Digital

On a monthly basis each Provider trust is mandated to provide data to NHS Digital. A rapid process of amalgamation allows the generation of monthly secondary uses service (SUS) data which is used by commissioners as a means of understanding activity at Provider level and to pay for it.

A few validation steps are applied to data received from providers into NHS Digital. The basic tests used in the Data Quality Maturity Index (DQMI) each month do not test the appropriateness of the submitted data just the fact the field has something in it. <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/data-quality>

Following the end of the financial year a full year of data is cleaned and checked within NHS Digital and released around September of the following financial year as a definitive record of the preceding year's activity – known as Hospital Episode Statistics (HES) online. This process is slow and the limited data available freely online means it is of limited utility in understanding a patient's pathway in the healthcare system.

NHS Digital is expanding the scope of data linkage of this data to other datasets e.g. the Diagnostic Imaging Dataset but getting access to this data is cumbersome and can be costly. In addition, there is lack of data linkage with other datasets held by NHS Digital, including the ONS mortality database, mental health record, community care record and primary care data.

6. Healthcare Resource Group (HRG) design

It can be appreciated that with the large number of codes available, to gain an understanding of all activity within the NHS can be bewilderingly complicated. In an effort to simplify this some countries use diagnosis related groups (DRG) to group activity into a manageably small number of subunits. This is very helpful for healthcare commissioners and analysts but the DRGs each contain a wide variety of disease severities and complexities.

In an effort to better reflect these complexities in the NHS, healthcare resource groups (HRGs) were created in the 1990's in an effort to create groups which clinical advisers felt reflected iso-resource groups of patients and activity, in other words groups of patients which would each consume about the same amount of NHS resource to treat.

a. Healthcare Resource Group (HRG) design

Within the National Casemix Office (NCO) there are 34 clinical Expert Working Groups (EWG) which use their clinical experience and coding expertise to best describe HRGs for their specialist area which are consistent and meaningful. These are modified over time to reflect changes in clinical practice.

Members of the EWGs are put forward by the professional colleges and associations. They are unpaid and are reviewed every 3 years by the NCO. The chairs of each EWG are chosen by the members and a single lead chair is voted for by all members to represent them to NHS Digital, Improvement and England and to chair the Casemix Advisory Board (CAB), which meets 4 times per year and has a long list of additional contributors including the HFMA, the Terminology and Classifications Delivery Service and providers. In addition there is an EWG Chair's Forum once a year, usually in December.

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Many EWG members have fulfilled this role for years and have a close working relationship with the NCO and their clinical colleagues. It should be appreciated that the NCO and EWGs have access to pseudonimised HES data and to Reference Costs but have to request access to any SUS data, which is a labourious and slow process. They have as yet no access to PLICS data and no access to other data sources as a matter of routine.

b. Healthcare Resource Group (HRG) allocation

Once an FCE has been coded, providers use HRG Grouper software to process their records and generate an HRG for each FCE. The software that undertakes this is provided by the NCO as part of its contract with NHS England.

[\[https://digital.nhs.uk/binaries/content/assets/legacy/pdf/d/a/the_science_of_casemix_v1_1_april_2015.pdf\]](https://digital.nhs.uk/binaries/content/assets/legacy/pdf/d/a/the_science_of_casemix_v1_1_april_2015.pdf)

There are two sets of HRG Groupers which are updated on an annual basis: The Costing Groupers are to be used by providers during their Reference Costs (and PLICS, see below) collection and the Payment Groupers should be used to derive HRGs as part of the National Prices.

It is apparent that a number of Provider organisations do not use the most up-to-date Grouper software e.g. using the Payment 2016/17 Grouper in the 2017/18 financial year (instead of the Payment 2017/18 Grouper) and as a consequence the HRGs produced are inaccurate – as the design is updated on an annual basis, to retain clinical relevance.

It has also been found that local analysts frequently export data from Provider PAS and clean that data themselves prior to analysis for internal use. As a consequence these analyses cannot match that produced from Hospital Episodes Statistics (HES) data which has itself been cleaned, but using different methodologies employed by providers.

In addition, centrally cleaned HES data at NHS Digital coming from Provider PAS needs to be put through the appropriate HRG Grouper software because of the problem identified of out of date Grouper software being used by providers locally. Currently the centralised re-running of the Grouper does not happen except in SUS, which allows a price to be attached to the recorded activity.

An increase in the average number of diagnoses linked with FCEs has been noted in recent years. This is mainly due to the importance placed on the recording of co-existing disorders in both standardised mortality ratios (SMR) and on the revised HRG construction in HRG4+ which associate more complex casemix with higher tariffs. However it should be noted that the coding rules require that the disorders are confirmed in the medical record so this change reflects an increase in coding of what was already there.

7. Clinical Registries

There are currently over 100 such collections in the NHS. Several attempts have been made by NHS England to review these in recent years. Another review is currently underway of the 16 or so which are relevant to specialised commissioning but there is no published timetable for the release of any conclusions or plan.

This is a complex issue because of the myriad of circumstances which apply and which appear to be almost unique to each data collection.

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Only a small number (3 at the last count) have some form of regular data flow into NHS Digital and thus available to support the commissioning of specialised services.

The wealth of information these registries contain is largely inaccessible because of the way they were set up and funded. Ownership and governance arrangements are very variable and the NHS has claim to the data of very few and even fewer are available in a timely fashion. This is particularly the case when NHS clinical data is held by specialty Associations, HQIP, PHE, Universities and commercial software companies, which is the norm for most registries. The number owned, held and accessible by the NHS is very low (fewer than 12 at the last count).

Similarly, access to data concerning drugs and devices usage in the NHS is extremely difficult or impossible to achieve and yet several GIRFT and Carter Reform work streams would wish to depend on this data to develop a deeper understanding of the variation in the delivery of services.

Resolution of the current impasse is urgently needed if many of the more advanced NCIP, GIRFT and Quality Surveillance metrics are to become embedded and made fully functional and effective and if commissioning at any level is to be appropriately informed.

It is apparent from recent communications that the leaders in NHS X and NHS E&I feel that all information generated by the NHS concerning patients and activity should be held within and by the NHS and be accessible without undue obstruction and in a timely fashion.

Should NHS policy adopt these requirements, the current arrangements for most clinical registries would mean they could not continue in their current form as the majority of them are held outside the NHS. Because these collections have historically not been seen (incorrectly) as of operational or commissioning importance the information governance rules applied by them do not allow access by the NHS to information in a timely fashion. This is of particular relevance to specialised services commissioning, the production of NHS Quality Dashboards, the NCIP and GIRFT work streams.

Currently access to data from most registries is fraught with problems, expense and delays.

In addition, many registries were created and are run by a small number of people who hold all of the operational knowledge of how they work. Loss or retirement of these people is a risk to the sustainability of these registries on which many Quality Assurance processes depend. The fact each of these teams are small means there is significant replication of roles and associated expense across the clinical registries and an obvious opportunity for shared learning and economies of scale should they be joined in some form of collective or federation.

However, it should also be appreciated that the very reason the registries were created in the first place was because routine NHS data sources were not granular enough to fulfil the desired purpose. The clinical design and interpretation elements of each registry is what makes them valuable, relevant and respected within clinical communities and is something that any changes to the way the registries are run in future must be retained.

In the particular area of trauma care, repair, recovery and rehabilitation registries there is a selection of existing data collections which arguably should fall under the NHS data banner as a single group as their interlinkage would offer significant advantages and cost savings to the NHS.

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For these and other reasons it appears timely to consider the organisational constructs under which these registries currently work and to develop a proposal to bring them wholesale under the NHS information governance umbrella and to make them accessible and linkable to other data collections.

Such a move would undoubtedly be complicated and could not be achieved in a short timeframe but has been significantly facilitated by the acceptance by NHS Digital of the safety and appropriateness of cloud-based storage technology.

Other specific benefits to consider include:

- Cheaper project management – a senior PM with assistants overseeing several databases would be able to do the same job cheaper (and arguably better) than a PM per database.
- Greater resilience – if something unforeseen happens to the single member of clinical or project management staff it could easily put back planned work streams for months or years.
- Easier replication – the creation, re-design or re-procurement of a registry would be far faster and cheaper than is currently the case.
- The ability to retain the clinical ownership and contribution to each collection while improving the collective utility of all registries.

Each of the identified registry leaders should be approached for their thoughts on this proposal with an invitation to their governance boards to discuss the longer term strategy of their clinical registry in light of NHS requirements.

Appendices: Specific current programmes in the NHS:

8. Evidence Based Interventions Programme (EBI)

The reappearance of the list of 'Interventions of Lower Clinical Value' originally published by Right Care in 2010 was announced in mid-2018.

<https://www.england.nhs.uk/evidence-based-interventions/>

"The aim of the Evidence-Based Interventions programme is to prevent avoidable harm to patients, to avoid unnecessary operations, and to free up clinical time by only offering interventions on the NHS that are evidence-based and appropriate..."

The programme focuses on 17 interventions which allegedly fall into this category. Four are identified as ones which should not be routinely offered to patients unless there are exceptional circumstances and 13 interventions that should only be offered to patients when certain clinical criteria are met.

<https://www.england.nhs.uk/wp-content/uploads/2018/11/ebi-statutory-guidance-v2.pdf> This guidance for CCGs document includes in the last four or so pages include details of how to identify patients which fall into one of the 17 categories specified by using ICD 10 / OPCS codes and age.

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This policy has the potential to affect activity and HRGs across specific HRG subchapters, such as orthopaedics and gynaecology. As the code has been written without any consideration of the impact on the EWG designed HRGs, this may render some of the current HRGs obsolete as commissioners will not fund these services irrespective of what the HRG actually is, and providers will not be able to sustain some services.

The lack of consideration of the HRG design and other policies such as Best Practice Tariffs and Specialised Commissioning could result in anomalous commissioning decisions being made on the basis of binary decision-making. As the definition of a child in the EBI instructions is up to 17 years old, rather than the 18 years as used in the HRG design this will see a mismatch in some activity as services that shouldn't be commissioned for adults has the potential to include child activity from an HRG design perspective. Each of the 17 interventions outlined requires a careful clinical review of the criterion that has been implemented in SUS and used to flag a patient for special commissioning attention, and also how that activity links to the HRG design.

While the results of this Phase 1 implementation are unknown, a Phase 2 EBI has been announced which is intended to go out for consultation in February 2020. This lists a further 35 investigation and procedures. Many of these are not recorded in NHS data systems which might allow the differentiation of acceptable or unacceptable usage. This leaves the evaluation of the whole EBI initiative in significant doubt.

9. Emergency Care Data Set (ECDS)

This initiative replaces the A&E CDS (010).

<https://www.england.nhs.uk/ourwork/tsd/ec-data-set/>

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/emergency-care-data-set-ecds>

The justification for this change is quoted as "ECDS Type 011 is better equipped to keep pace with the increasing complexity of delivering emergency care than its predecessor. This means that the improved quality of data collected in emergency departments provides better support to healthcare planning and better-informed decision making on improvements to services.

This improved data helps improve understanding of:

- the complexity and acuity of attending patients
- the causes of rising demand
- the value added by emergency departments"

The initial intention was to restrict the use of the ECDS to Emergency Medicine departments, Minor Injuries Units and Walk in Centres (which will be transformed into Urgent Treatment Centres). However, it will affect the VB* HRGs currently generated from the A&E dataset only, with little impact across other EWG subchapters but introduces a small subset of selected codes from SNOMED-CT as the preferred terminology for patient data, including a SNOMED-CT translation of current Investigation and Treatment Codes (specific to A&E only).

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10. Same Day Emergency Care (SDEC)

An extension of the ECDS is planned into other areas of urgent care even though ECDS is not fully in place or formally evaluated.

<https://improvement.nhs.uk/resources/same-day-emergency-care/>

The recording of SDEC activity in the ECDS dataset is outlined in the Long Term Plan:

NHS Long Term Plan:

<https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

[1.30]...“Every acute hospital with a type 1 A&E department will move to a comprehensive model of Same Day Emergency Care. This will increase the proportion of acute admissions discharged on the day of attendance from a fifth to a third...The SDEC model should be embedded in every hospital, in both medical and surgical specialties during 2019/20.”

The ambitions from the NHS Long Term Plan note that all hospitals with a 24 hour ED (type 1) will provide:

All hospitals with a major A&E department will:

- Provide SDEC services at least 12 hours a day, 7 days a week by the end of 2019/20
- Provide an acute frailty service for at least 70 hours a week. They will work towards achieving clinical frailty assessment within 30 minutes of arrival
- Aim to record 100% of patient activity in A&E, UTCs and SDEC via ECDS by March 2020.

Depending on the definition of SDEC patients, there is the possibility that all patients that are or should be treated in an SDEC unit (whether centralised or spread across provider sites) will be recorded using a type 5 attendance classification in the ECDS, and the SNOMED-CT confirmed diagnosis list from the ECDS. This will see activity shift from outpatient and admitted patient care datasets, if providers are currently recording these patients on those systems. It may also see patients being reported as SDEC where they are currently not captured in any national data flow.

This planned change has the potential to affect activity and HRGs across all HRG subchapters, shifting activity out of the EWG designed HRGs into a different dataset which is not captured using ICD-10 or OPCS codes for diagnoses or procedures.

It also introduces SNOMED-CT as the preferred terminology for patient data from October 2019 (mid-financial year). This will affect historic data analysis and also has the potential to render some HRGs obsolete as a result of a change in the way data are captured. There will also be a shift in child activity as the SDEC definition of a child is up to 17 years old, whilst the NHS Data Dictionary standard defines a child as 18 and under. There will therefore be an impact on child-specific HRGs where the patients in those HRGs are 18 years old.

With regards to costing NHS activity, the move to PLICS from 2018/19 will render comparison with previous years' Reference Costs data difficult. This will be compounded if a large amount of activity is reported as SDEC from October 2019 when previously it was reported as SPC / OP as there are no

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Casemix classifications for SDEC activity as yet, whilst the PLICS data will identify the costs of these patients at patient level, there is no mechanism to group them to an HRG, nor any mechanism to understand where the patients would have grouped to in HRG terms had they not been reported as SDEC patients within the ECDS data set. (Data items are not comparable for all fields; whilst there is a mapping from SNOMED-CT to ICD-10, (and incidentally from SNOMED-CT to OPCS) is it unclear whether the procedures currently captured using OPCS codes can actually be captured in the ECDS in any field, as the current ECDS does not include a procedure field).

The latest information suggests that significant concern regarding the utility of the ECDS has delayed its application to SDEC activity recording. Announcements regarding policy change are awaited.

11. Patient Level Information and Costing Systems (PLICS)

It is intended that detailed costing information from PLICS regarding each FCE will flow into NHS Digital from September 2019 from all acute provider trusts. This was mandated in a letter to providers in February 2018.

The dataset is more extensive than previously collected and is intended to provide significant granularity concerning the use of funds in the NHS at individual patient level. It should allow the full patient pathway in secondary providers to be detailed in financial terms. This could have significant utility in considering the use of high cost devices and other consumables as well as helping to see any variation of costs across the NHS. Such information has previously been unavailable except as outputs from a 2 clinical registries: Specialised Rehabilitation and Burn Care.

However, there are significant concerns about the ability of acute Provider trusts to reliably deliver this level of data by the expected date as most of them have a very short timeframe to achieve what early adopters of the approach have taken 3-5 years to achieve.

There are also doubts about the ability of the NHS to analyse and synthesise such huge volumes of data.

In addition, the current Reference Cost collection, which has been undertaken for over 20 years and is a well understood and defined process is due to be stopped for all acute trusts. The last return was made in 2018. There are acknowledged issues with the quality of the process undertaken in many providers but ceasing this and replacing with a PLICS collection with limited, if any, dual running will hinder long-term time-series analysis. Also, although PLICS may be far more granular, there has been very little assessment of the robustness of data submitted. There is therefore the potential for a misinterpretation of 'more granular = better quality' from the outset when in fact, especially in the early years of collection, it is likely the opposite will be true.

A recent report from the Health Finance Medical Association (HFMA) has highlighted the difficulties their members have experienced attempting to follow the PLICS guidance running up to the first formal submission in August 2019.

12. Get It Right First Time (GIRFT)

The Clinical Lead of the Coding and Informatics GIRFT work stream and the Lead Clinical Chair of the National Casemix Office's Expert Working Groups have undertaken a review of already published

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GIRFT reports looking at any recommendations which pertain to Informatics. What have emerged are several common themes which can broadly be listed as follows:

- need to improve coding
- need to involve clinicians in the coding process
- clinicians should have access to and review their own data
- change NHS treating specialty codes
- change diagnostic (ICD) and procedure (OPCS) codes
- change coding guidance and practice
- need to make data entry into existing registries mandatory
- create new registries and mandate their use
- develop and mandate the collection of PROMS
- link datasets to understand the pathways of care

It is already apparent that some of the recommendations were based on a misunderstanding of where the source of data completeness and quality problems may lie. The brief overview of the principles of data collection and flow within NHS secondary care as provided in this document is intended to assist GIRFT clinical leads in these discussions.

A heightened understanding of these processes is vitally important when considering any secondary care services, but will be essential during the consideration of primary or community care provision where the lack of alignment, linkage and interoperability between data systems, and the principles on which the data collections are based, will make these work streams all the more challenging.

In recognition of the need to sense check current and future recommendations in GIRFT reports, it has been agreed that a memorandum of understanding (MoU) will be constructed between GIRFT and the National Casemix Office (NCO) to ensure that the NCO staff and clinical chairs of the Expert Working Groups (EWG) are given early sight of draft metrics and reports and invited to comment. The guidance and recommendations of how this will work will be encapsulated within the MoU which is an advanced state.

To date, the GIRFT programme has followed the line established with the original 2012 elective orthopaedic process: Identify a clinical service and related activities which allows the development of reproducible metrics from established data sources, which are then used to compare and contrast provision in different parts of the country. The focus has quite reasonably been on identifying the low hanging fruit of benefits, usually less than half a dozen items for each specialty with the intention of implementing these over a number of cycles using the same metrics.

An issue which has emerged as the scope of the GIRFT programme is widened, most recently to improve include community wound management, general practice and mental health is that the significant complexities of these areas highlight the limitations of the available data flow, access and timely accurate analysis and interpretation.

Resolving this would not only improve the GIRFT processes themselves but also allow greater insights to the organisation of services, their infrastructure requirements and illuminate costs and more appropriate tariff constructs while fundamentally feeding into the commissioning cycle.

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The cycle of commissioning as originally described has never, or rarely, been completed, largely because of the lack of timely detailed information agreed by all parties as accurately representing what is being commissioned, along with associated costs to a level of detail which allows rational decisions to be made.

Resolution of the current impasse with regard to NHS data sources, flow, ownership and access could revolutionise healthcare commissioning as originally intended.

<https://www.england.nhs.uk/participation/resources/commissioning-engagement-cycle/>

a. National Clinical Improvement Programme (NCIP)

A DHSC funded programme delivered under the GIRFT banner aims to provide consultant level information back to surgical consultants. <https://gettingitrightfirsttime.co.uk/ncip/>

“The programme involves creating a secure online portal to provide consultant surgeons with their individual-level activity and metrics across their practice.The portal is being delivered through the GIRFT programme and our ambition is to provide a unique service – a single point of access to existing information from Hospital Episode Statistics (HES), audit and registry, and private sector. It is anticipated that consultants will use the portal to support their personal development and learning. Individual consultant-level data will not be available for external publication.”

To fulfil this ambition requires consultant identified activity to be centralised and where necessary linked to provide the necessary detail. Where this involves private sector data an extract from the Private Healthcare Information Network (PHIN) is expected. <https://www.phin.org.uk/>

Access to audit and registry data is far more complicated, as referred to above.

In recognition of the limited accuracy and range of data available in HES regarding theatre activity, an additional programme has been initiated with NHS Digital to access Provider level theatre systems. This is also a far from simple endeavour. <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/mandatory-requests-from-nhs-improvement/ncip---theatre-dataset-requirements-specification>