

# Priority Issues in Information Governance

IG Taskforce Consultation Paper CP-01  
February 2014



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**Prepared by: Information Governance Taskforce**

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## Executive Summary

The 2012 Act created significant challenges in the use of data, most notably for commissioners. It requires new data systems to be developed, and new approaches to the use of data. Although the Health & Social Care Information Centre (HSCIC) is designed to collect personal confidential data (PCD) and disseminate data, to act as an "honest broker" providing data cleansing, linkage, and de-identification services to NHS and other organisations, it is a newly established body and will require time to develop capacity and capability.

To support the needs of commissioning at an operational level, HSCIC has to provide not only the provision of national standard data sets, but also to provide operational level data with all the complexities and the need for local flexibility and responsiveness that is part and parcel of delivering for localised services. Over time, it will develop the necessary capabilities and capacity to meet many of these data needs; however, these are not fully in place at present.

The key question is whether the HSCIC should focus its efforts, at least initially; on national collections of standardised data sets and not seek to try and also support local operational data requirements. A policy decision is required to help direct and support HSCIC to prioritise on the scope and purpose of its emerging data services for commissioning.

This document identifies the priority information governance issues for NHS England and sets out a summary of the actions taken to date to address the issues, our vision in terms of the end state, and consideration of the key issues and options for developing solutions. It clarifies where we think the law needs to be changed and why and explores some of the alternatives. The key end state proposals are:

- **Invoice validation**
  - a. HSCIC providing Data Services for Commissioners (DSC) for those elements needing PCD and provision of weakly pseudonymised outputs to Accredited Safe Havens (ASH) arrangements
  - OR
  - b. HSCIC providing full pseudonymisation service BUT probably only suitable for longer term as need to demonstrate efficacy of HSCIC DSC to commissioners.

Both end state options can be delivered within the current legal framework in terms of primary legislation. However, option a) is a likely interim step for option b); also Accredited Safe Havens for health will need either new regulations under Section 251 or at the very least continuing support under regulation 5 of the existing regulations until using fully pseudonymised data has been demonstrated to provide a feasible and acceptable solution for commissioners.

- **Risk Stratification**
  - For risk stratification tools using health data it is proposed that a new regulation under the Section 251 of NHS Act 2006 be created to permit the transfer of PCD to the tools that meet the ASH standards or operate as an effective closed system

- It is proposed that for risk stratification tools using both health and social care data that primary legislation be developed to permit the disclosure and use of personal confidential health and social care data for risk stratification.
- HSCIC is not a suitable end-state as it would require the HSCIC to have capacity and capability to provide linked pseudonymised extracts for a variety of risk stratification tools on a routine timely basis. To do this efficiently would require the HSCIC to control the data standards for proprietary tools which may prevent innovation, where local variation is being encouraged to allow and test innovation. An alternative is that HSCIC could develop an in-house tool set or operate third party tools under licence, which would mean that the HSCIC would be in direct competition with existing risk stratification suppliers. This would mean the need for HSCIC to develop an analysis service as a state monopoly, and is outwith its intended role as an honest broker for data services.
- **Registries for individuals with learning disabilities and autistic spectrum disorders**
  - Clinical Commissioning Groups (CCGs) and NHS England have a requirement under the Mandate and the Transforming Care report to create registries for people with LDs and autisms,
  - HSCIC would be required to collect and anonymise data for analysis, which is possible within current legal framework
  - We propose a change in the law so that commissioners can appoint an appropriate independent healthcare professional to visit care homes to observe the quality of care being provided and to compare their observations with what is written in both corporate and health and care records.
- **Case management for specialised commissioning**
  - Case managers need to have access to PCD in order to meet the functions for directly commissioned specialized services.
  - Consent for these patients is not always practicable due to impaired capacity or a lack of competency, and may be problematic if consent is to be sought from conflicted providers
  - We propose a change in the law to permit case manager access to PCD within a controlled environment that are outwith the HSCIC
- **Year of care** – this is in an early stage of development, but has been included as it sets out some of the issues we are seeking to address.
  - Potential end state is to have a controlled environment outwith HSCIC that enables risk stratification process to identify potential cohorts suitable for inclusion and ability to track and monitor patient activity and costs.

In summary, NHS England has identified a set of high priority information governance issues that we have been working over the past nine months to put in place short term solutions. For the next stage of solutions we need Department of Health support and policy input, to implement, longer term solutions and development of exit strategies that are necessary to maintain Section 251 support in the interim. We fully endorse and support the role of the HSCIC as an honest broker for nationally collected, standardised commissioning data sets, and the provision of a national pseudonymisation service for that data. In addition we would like to make a case for the development of controlled environments (ASH) to allow commissioners flexibility to use locally derived data set to support bespoke local commissioning decisions. Consideration also needs to be given to the business need to integrate health and social care data more effectively, so that new local models of health and wellbeing can be established within a robust legal framework.

This is a consultation paper. Readers are invited to comment on the areas covered in this document, and in particular the questions posed at the conclusion of the paper (see page 22).

## Background

The Health and Social Care Act 2012 established the Health & Social Care Information Centre (HSCIC) with powers to collect, link, and otherwise process personal confidential information (PCD) for purposes other than direct care. Other organisations in the health and social care system require an alternative legal basis to collect or link PCD such as through other statutory provisions or through consent or to use anonymised or de-identified data. Examples of such bases are support under the Section 251 regulations<sup>1</sup> and the consent of the patient.

In the past, Primary Care Trusts relied heavily on PCD for a wide range of commissioning functions. Typically, commissioners would access PCD from both from the Secondary Uses Service (SUS) and from their local providers in the form of commissioning datasets that were defined locally. This was with support under the Section 251 and General Medical Services (GMS) regulations or other statutory provisions. Having obtained the data for certain purposes, they were then able to use it in de-identified form for other purposes.

## Issue

The 2012 Act created significant challenges in the use of data, most notably for commissioners. It requires new data systems to be developed, and new approaches to the use of data.

Although the HSCIC is designed to collect PCD and disseminate data, to act as an "honest broker" providing data cleansing, linkage, and de-identification services to NHS and other organisation, it is a newly established body. Over time, it will develop the necessary capabilities and capacity to meet many of these data needs; however, these are not fully in place at present. There is also the question of whether the HSCIC should focus its efforts, at least initially, on national, standardisable collections of data and not seek to try and also support local data requirements. Specialised commissioning data requirements are standardisable, but to date have not generally been the focus of Information Standards. It will therefore take time for these standards to be developed.

Policy decisions need to be taken about the prioritisation of what the HSCIC should be commissioned to support and whether this should include supporting local data requirements, or whether it should be asked to focus on national standardisable collections. If the latter, then consideration needs to be given as to how local data requirements can best be met either within the current legal framework or if this is not feasible, to create a lawful means by which these data requirements can be met. These decisions need to be considered jointly by the Department of Health and NHS England in conjunction with the HSCIC as to what they feel it is feasible for them to deliver within a reasonable timescale.

As the lead commissioner of the HSCIC, NHS England has established a programme board to oversee the necessary changes in terms of interim arrangements to support the

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<sup>1</sup> The Health Service (Control of patient information) regulations 2002 [SI2002/1438]



commissioning system and to consider the longer term, and an operational task force to deliver those changes. Earlier this year, NHS England secured Section 251 support for commissioners to use PCD while they develop their capacity to use pseudonymous data within an Accredited Safe Haven environment. However, this initial support excluded three commissioning functions (viz., invoice validation, risk stratification and case management), which have consequently caused particular problems.

We have since obtained temporary Section 251 support for invoice validation for CCGs, risk stratification and the establishment of registers and an enhanced quality assurance programme for patients with learning disabilities or autistic spectrum disorders. An application is also in development to support specialised mental health case management. This paper sets out in turn our approach to dealing with each of these issues going forward (i.e. the exit strategy from continuing to need support under the Section 251 class support mechanism (regulation 5)).

Additionally, consideration needs to be given to how all the different commissioning data requirements may be met and brought together where the same end-state solutions are identified

## Invoice Validation

Because commissioners have been neither general nor specific statutory powers to process PCD under the 2012 Act, they have been unable the monthly invoice reconciliation process since April 2013. As a result, there have been inaccuracies and mis-apportionment of costs between CCGs and NHS England. The changes to the definition of specialised commissioning and commissioners and providers being clear about these changes, have contributed to these issues, alongside the limitations on access to data. Commissioners have been unable to understand their total financial trading position and have been incapable of managing provider costs. As a result, CCGs and NHS England are finding it difficult to satisfy their statutory duties for fiscal probity and to demonstrate scrutiny for public expenditure. Finally, healthcare providers have experienced problems where commissioners have not paid invoices in cases of dispute that might previously have been resolved using PCD.

**Table 1: Invoice Validation**

Short term solutions	NHS England received s251 support on 22 November 2013 for CCG invoice validation (valid until 31 October 2014)
Scale and operational impact of issue	<p><b>CCG invoice validation</b></p> <p>Approximately 50-60% of CCG invoice validation can be done using nationally collected SUS data.</p> <p>The remaining invoices require to be checked against supporting data prior to payment. These are non-contracted activity, and correct commissioner needs to be confirmed or the data is not collected by SUS (drugs and devices) or other providers where submission data is not suitable for SUS collection e.g. Any Qualified Provider (AQP).</p>

	<p><b>Specialised Commissioning data</b>  Approximately 60% of data does not conform with SUS and needs to be collected separately e.g. high cost drugs and devices, transplants and specialist procedures without a national data standards</p> <p><b>Operational Impacts</b>  The delay in gaining S251 support for this activity has a number of critical operational impacts:</p> <ul style="list-style-type: none"> <li>• Back log of unpaid invoices – this has significant impact on SME providers</li> <li>• We have not been able to finalise and provide robust financial trading position for CCGs and NHS England.</li> <li>• The lack of clarity of the financial position means that we are carrying that uncertainty (activity and finance) into the planning process, and thus creating inaccurate forecasts and plans for financial year 2014/15, which will make delivery of cost reductions very difficult.</li> </ul>
<p>Progress towards implementation</p>	<p>NHS England is establishing the controls necessary to satisfy the conditions that were set out by the Confidentiality Advisory Group, (CAG) including the establishment of <i>controlled environments for finance</i> (CEfF) within CCGs or CSUs or with the HSCIC's Data Services for Commissioners Regional Offices (DSCROs) undertaking some initial analysis of identifiers before passing weakly pseudonymised data to an Accredited Safe Haven (within a CSU or CCG) to undertake the relevant analyses and follow-up queries with the provider</p> <p>By early February 2013, we anticipate that most CSUs will be in a position to commence invoice validation within a CEfF (10 confirmed as of 06 Feb 2014)</p> <p>We are now working on further applications for s251 support to enable</p> <ul style="list-style-type: none"> <li>• NHS England to use PCD to validate invoices relating to its directly commissioned services; and</li> <li>• Commercial third party data processors to provide invoice validation services to CCGs</li> </ul> <p>Guidance to support the implementation of the Section 251 arrangements was issued in early December and further guidance will be produced to support migration to the end state.</p>
<p>End-state vision</p>	<p>The HSCIC providing data services for commissioners that support invoice validation by undertaking those stages of invoice validation that require access to PCD and providing weakly pseudonymised outputs to ASHs with the NHS Number OR local patient identity</p>

number for further processing and follow up with the provider by the relevant CCG, CSU or Area Team.

Although it should be feasible for the whole invoice validation process to be conducted using fully pseudonymised data by commissioners, it will require major changes to national HSCIC and Integrated Single Finance Environment (ISFE) (Shared Business Services) systems as well as changes to each individual provider system. The proposed end state above is a necessary interim step which will enable commissioners to have assurance that the HSCIC invoice validation processing is working effectively before moving to fully pseudonymised data, given the changes to the definition of specialised commissioning and organisational changes.

The end state can be delivered within the current legal framework in terms of primary legislation. However, Accredited Safe Havens for health will need either new regulations under s251 or at the very least continuing support under regulation 5 of the existing regulations until using fully pseudonymised data has been demonstrated to provide a feasible and acceptable solution for commissioners.

#### **End-state assumptions**

- Adoption of a national data standard for invoice validation that is used by all healthcare providers
- HSCIC to provide a national pseudonymisation service that can collect all invoice validation information, match PCD with commissioner code, validate and provide a pseudonymised feed back to the commissioning organisation to verify activity and payment

#### **Potential issues:**

- Where there are local data requirements (i.e. a particular commissioner requires specific data items that are not entirely conformant with the relevant information standard(s) then this will require the current DSCRO arrangements to continue for the processing of identifiable data. However, in due course it should be possible for these additional data items (outwith the information standard) to be sent directly from the provider to the ASH. The current approval requires that all data flows through the HSCIC (DSCROs).
- *Fair processing* so that patients understand how their data are used for commissioning including invoice validation.

#### **Alternatives**

If the HSCIC were to be unable to provide some or all of the above data services for commissioners, then the alternative NHS England would be looking to establish would be a limited number of Controlled Environments for Finance within the CSUs or within NHS

	England to process PCD. This would require a change in law either through primary legislation or new regulations under S251 to support this.
Implementation	<ul style="list-style-type: none"> <li>• We have documented the business needs for invoice validation and mapped out the current data flows</li> <li>• NHS England is working with the HSCIC to develop a register of CEfFs and the associated data flows. Work will be undertaken to develop a national data standard for invoice validation</li> <li>• A statement of compliance has been signed off by Caldicott Guardians and we have established an auditing system for statements of compliance</li> <li>• We are developing a <i>fair processing</i> strategy which will be aligned with the overall target end-state and fair processing materials will be developed for commissioning including invoice validation.</li> <li>• Further guidance to support implementation and migrate to desired end state will be developed</li> </ul>
Communications	<p>Monthly IG Bulletin published by the IG Taskforce  FAQs published weekly  Query mailbox  Commissioning Assembly subgroup on data, involving NHS England and CCG representatives  Publication of <i>Who Pays</i> Draft Information Governance Guidance for CCGs  Dedicated web page(s)</p>

## Risk Stratification

Risk stratification tools can help determine which people in a population are at high risk of experiencing *Triple Fail* outcomes, such as unplanned hospital admissions, that are simultaneously (1) undesirable for patients; (2) costly to the health service; and (3) potential markers of low-quality care. Also known as predictive risk models, these tools are used widely in the NHS both for:

- analysing the health of a population for planning purposes (“risk stratification for commissioning”); and
- targeting additional preventive care interventions – such as the support of a community matron, a virtual ward or another multidisciplinary team – to patients at high risk of a *triple fail* event (“risk stratification for case finding”).

Risk stratification is a form of profiling and is classified as a secondary use of data as not all patients will receive an intervention. In principle, therefore it should be undertaken using pseudonymised data. In reality, many CCGs wish to use risk stratification tools not only to develop and commission packages of care for small cohorts of specific patients, but also to select which patients should be offered these packages of care and to guide the care process. There are therefore two elements: risk stratification for commissioning and risk

stratification for case finding. Both elements are achieved through the same risk stratification tools. NHS England has been given a mandate to commission GPs to undertake risk stratification<sup>2</sup> so that the predictive tools can be used both by commissioners (who can view anonymised data) and by clinicians with direct responsibility for patients (who can view identifiable data). The Section 251 support granted to NHS England in April 2013 for Accredited Safe Havens excluded the use of PCD for risk stratification.

The work to date on risk stratification has been focused on health related uses. Many CCGs and local authorities would also like to include social care data, either as part their role as integrated care pioneers, to enable them to undertake local reviews as part of Quality, Innovation, Productivity and Prevention (QIPP) plans, or simply to better manage care in the community. The short term solution in place does not include social care data as the scope of Section 251 and its supporting regulations only applies to patient health data. Additionally, the only basis for processing of sensitive personal data from social care under Schedule 3 of the Data Protection Act (DPA), for this purpose is the explicit consent of the data subjects. NHS England will work with the Department of Health and Integrated Care Pioneer sites to establish the medium and longer term requirements to address the information governance issues.

**Table 2: Risk Stratification**

Short term solutions	NHS England has submitted an overarching request for s251 support specifically for the purpose of risk stratification, together with individual applications for each individual existing data processor (i.e., each CSU and each commercial third party supplier)
Scale and operational impact of issue	All CCGs were incentivised to conduct risk stratification through a national Directed Enhanced Service (DES). For majority of CCGs and practices, they started financial year 2013/14 with the intention of building on locally agreed risk stratification programmes supported by multi-disciplinary teams to manage at risk patients.  The delay in getting S251 support has meant that the vast majority of risk stratification programmes stopped. Some CCGs reverted back using GP clinical review of potential risk cohorts within a practice. The delay also has had a significant impact to developing working practices and evidence for integrating care. The application and ability to fully utilise the Better Care Funds has also created problems on the ground.
Progress towards implementation	NHS England received S251 support on 23 January 2014 (valid until 23 July 2014) a number of conditions need to be met as part of the approval.
End-state vision	Risk stratification conducted both within the HSCIC and within <i>controlled environments</i> that are outwith the HSCIC. The rationale for this is that there are a number of risk stratification tools available

<sup>2</sup> Insert ref from Mandate 9.2?

in the market with differing strengths and these are subject to intellectual property restrictions. Whilst some of these tools are available to be held under licence by the HSCIC (e.g. Adjusted Clinical Groups [ACG]) other are not. Competition rules mean that it is unlikely to be feasible for the HSCIC to be able to hold and run these tools. There is also a question about whether the HSCIC is likely to have the capacity to hold and run these tools in house.

In information governance terms, these tools use either weakly pseudonymised data (i.e., they can use just NHS number with age and deprivation score) or pseudonymise the data on landing within their systems. Whilst a legal basis for disclosure is needed for the transfer of PCD to the risk stratification tool providers, the other information governance risks to these data are low and can be managed.

The long term strategy could be to require these tools to use fully pseudonymised data provided by the HSCIC but that would require the HSCIC to have the capacity to provide linked pseudonymised extracts for at least 22 particular data sets (the number of risk stratification (RS) tools in the current market) for a variety of different geographical catchments on a monthly basis.

A clear specification for the requirement to use pseudonymised data would need to be developed in consultation with the RS tool suppliers and the RS tool providers given an appropriate time period in which to prepare and test the required changes to their systems and to ensure the changes did not impact significantly on the utility of the tool.

In conclusion, whilst the HSCIC could provide a risk stratification service for those tools available under licence, it would need to compete for business with other RS suppliers on an equally competitive basis.

It is proposed that for RS tools using both health and social care data that primary legislation be developed to permit the disclosure and use of personal confidential health and social care data for risk stratification. This could include the requirement to provide information to individuals about this form of profiling and their right to opt out of having their data processed in this way.

For RS tools using just health data that it is proposed that a new regulation under the section 251 of the NHS Act 2006 be created to permit the transfer of PCD to the tools that meet the ASH standards for weakly pseudonymised data or operate an effective closed system (i.e. the data are pseudonymised on landing). Alternatively that the current Section 251 approval under regulation 5 be extended indefinitely and is amended to enable new risk stratification tool providers to be added to the approval provided they meet the Controlled Environment/ASH or pseudonymisation

	<p>standards set by the HSCIC.</p> <p>Systems and structures need to be put in place at the HSCIC to support and verify these controlled environments. If HSCIC nationally were to develop risk stratification tool provision then their conflict of interest as a competitor and accreditation role for risk stratification tool suppliers would need to be managed carefully.</p> <p>We are developing a <i>fair processing</i> strategy which will be aligned with the overall target end-state and fair processing materials will be developed specifically to explain risk stratification.</p>
Implementation	<p>We have documented the business needs of CCGs, CSUs, and NHS England for risk stratification and have mapped out the current data flows</p> <p>We have set out the operating model and a service-level agreement (SLA) between NHS England and HSCIC for the data service for commissioners that will satisfy these operational business requirements in terms of providing SUS data to RS suppliers.</p> <p>NHS England is working with the HSCIC to develop a register of <i>controlled environments</i></p> <p>A statement of compliance has been signed off by Caldicott Guardians and we have established an auditing system for statements of compliance from CCGs and their appointed risk stratification suppliers</p>
Communications	<p>Preliminary guidance on risk stratification published in June 2013, which will be revised in line with the s251 support.</p> <p>Monthly updates published in the information governance bulletin (IG Bulletin)</p> <p>FAQs published weekly</p> <p>Query mailbox established</p> <p>Commissioning Assembly sub group on data, as above</p> <p>Dedicated web page(s)</p>

## Registries for people with Learning Disabilities and Autistic Spectrum disorders

In response to the shocking abuse that occurred at Winterbourne View, NHS England and the Local Government Association have established a programme to help local areas transform health and care services for people with learning disabilities or autistic spectrum disorders. There is a requirement under the Mandate and the Transforming Care report<sup>3</sup>

<sup>3</sup> *Transforming Care: a national response to Winterbourne View Hospital*, Department of Health, London, December 2012

for NHS England to ensure that CCGs work with local authorities to ensure safe and effective care for people with learning disabilities and autistic spectrum disorders. Registers are a first step in assuring the quality of care being provided by ensuring the population affected is known. There is a need to consider the extent of the PCD necessary to support this and for the legal basis to establish registers.

Commissioners require access to some PCD for these registers but it may also be helpful for more extensive information to be obtained to support the quality assurance of their care. Whilst ordinarily, registries could seek consent for the disclosure and use of PCD, consideration needs to be given to the extent that individuals may or may have capacity to give informed consent for the inclusion of their PCD on such registers. This situation is compounded by providers' potential conflict of interest when asked to obtain consent from these patients or their representatives under Mental Capacity Act provisions, where some may be seeking to hide poor practice. There is a strong public interest in protecting this vulnerable patient group, possibly even at times against the wishes of an individual where there are concerns about a providers overall ability to care for this population. Measures can be put in place to respect individual's wishes (e.g. through objections) where the individual has capacity.

**Table 3: Registries for individuals with learning disabilities or autistic spectrum disorders**

Short term solutions	Section 251 support for an enhanced quality assurance process including a one-off triangulation exercise for the registers to try to ensure all the relevant individuals have been included on the registers.
Progress towards implementation	We have obtained s251 support for this "one-off" triangulation exercise to try to capture the details of all the relevant patients and the quality assurance process is underway. We have since clarified that these registries were not previously established by PCTs so a further application needs to be made for their establishment.
End-state vision	<p>This application was for a one-off process for this year. Going forward CCGs and local authorities should work together to maintain the registers. It is also anticipated that the HSCIC will collect the relevant data for the enhanced quality assurance programme and provide anonymised data for the relevant teams within NHS England and the Department of Health to analyse the data for the enhanced quality assurance programme.</p> <p>Data analysis by itself will not prevent another Winterbourne View scandal.</p> <p>We propose a change in the law so that commissioners can appoint an appropriate independent healthcare professional to visit care homes to observe the quality of care being provided and to compare their observations with what is written in both corporate and health and care records.</p> <p>As indicated above commissioners have the vires to collect the</p>



	minimum data necessary for the registers themselves.
Implementation	The HSCIC to be commissioned and empowered to collect the data necessary for the enhanced quality assurance process going forward and to provide pseudonymised data to commissioners for analysis. A process for the re-identification of individuals or particular care homes where there is cause for concern needs to be developed and agreed.
Communications	We are issuing advice and communicating through various channels as above, including the IG Bulletin

## Case management of specialised services

NHS England is responsible for commissioning over £12 billion of specialised services. The Health and Social Care Act 2012 recognises that specialised services are generally high cost and low volume procedures. The complex nature of highly specialised care packages requires assessment and selection based on the needs of individuals and assurances that the care provided meets standards and is appropriate for the condition and stage of the pathway. This inevitably means that part of the necessary commissioning activity involves case-managing individual patients, for example in relation to secure mental health and neuro-rehabilitation services.

The 2012 Act sets out the four drivers for requiring NHS England to directly commission a service:

- (a) the number of individuals who require the provision of the service or facility;
- (b) the cost of providing the service or facility;
- (c) the number of persons able to provide the service or facility;
- (d) the financial implications for clinical commissioning groups if they were required to arrange for the provision of the service or facility.

However the Act does not set out the requirement for case management in order to meet the functions for directly commissioned specialised services. In order to assure the quality of care being provided for individuals, commissioners may need access to PCD including for persons with impaired capacity or a lack of competency<sup>4</sup> to provide valid consent such as some of those individuals requiring specialised mental health (secure mental health services and Child and Adolescent Mental Health Services [CAMHS]).

Case management is in an impossible situation. First, case management could be regarded as direct care in which case commissioners have a problem as they do not have the vires to provide direct care. Alternatively, case management could be regarded as commissioning and therefore as “indirect care” in which case there is no basis for implying consent for the disclosure and use of PCD by the case managers. We propose that a change in the law is required to address this Catch 22.

<sup>4</sup> Capacity for adults, competency for children who will attain competency

Whilst the case managers themselves could seek consent from the individuals they are supporting where they have direct contact with them, this only occurs after PCD has been disclosed to them. Alternatively, the providers could be required to seek the consent of the individuals to the disclosure but a conflict of interest arises where the provider may have an interest in retaining responsibility for the care of the individual but may not be best placed to meet their needs. Additionally, there may also be issues of capacity to give consent and in relation to specialised mental health, in some instances this will be further complicated by the individual having fluctuating capacity arising from their mental health issues or where withholding consent is used to sabotage their care and treatment.

**Table 4: Case Management of specialised services**

Short term solutions	Seek Section 251 support for specialised commissioning purposes that will cover use of PCD for case management and invoice validation activities
Progress towards implementation	<p>Work is underway to identify further specialised and direct commissioning activity requiring access to PCD. Once this has been completed, we will reconvene discussion with DH colleagues to work through the legal basis for these activities once the s251 support has been implemented for CCG commissioned activity for invoice validation.</p> <p>An application for Specialised mental health services has been submitted to CAG for consideration. Further work is needed to identify the requirements in relation to other specialised services and for direct commissioning (primary care, ophthalmology, dentistry and pharmacy).</p>
End-state vision	<p>We propose a change in the law to permit case managers to access to PCD to support specialised mental health commissioning and other specialised commissioning for vulnerable patient groups, a high proportion of whom will lack the capacity to give consent.</p> <p>Case management of specialised patients conducted within controlled environments that are outwith the HSCIC</p> <p>To ensure the controlled environment systems for case management can support case managers in their work, facilitate the transfer of patients between providers and Area Teams and generate pseudonymous data for invoice validation and other commissioning purposes.</p> <p>Systems and structures need to be put in place at the HSCIC to support and verify these controlled environments.</p> <p>We are developing a <i>fair processing</i> strategy which will be aligned with the overall target end-state</p>
Implementation	We have included an amendment to the standard contract requiring providers to obtain patient consent for the use of data

	where this is appropriate
Communications	We are issuing advice and communicating through various channels as above, including the IG bulletin

### **Development of Year of Care and monitoring of integrated care models for long term conditions**

The aim of this programme is to have a national 'Year of Care Funding Model', which facilitates the delivery of integrated health and social care for people with long term conditions (LTC), based on need rather than disease. The financial model will be an annual risk adjusted capitation budget which is based on these levels of need.

The model aims to improve outcomes and deliver a more effective use of resources by focussing providers on moving away from episodic, activity driven funding flows and towards person centred care, irrespective of organisational boundaries.

Implementation of the funding model will require variation to commissioning, contracts and service delivery to include greater capacity to provide the alternative LTC services closer to home with providers focussing on delivering a year's worth of care jointly. Accountability for the person with LTC, the outcomes and the use of resources across the continuum of that care will lie with all providers. This shift will be supported through strong risk sharing arrangements between commissioners and providers.

PCD will be required in order to properly track patients and monitor their specific outcomes, for analysis and to accurately determine an appropriate tariff.

Work is ongoing to clarify the requirements and options for this but we have included our current thinking below.

### **Table 5: Year of Care and monitoring of integrated care models for long term conditions**

Short term solutions	Seek Section 251 support for year of care and monitoring of LTC services
Progress towards implementation	We agreed with colleagues to review the need to submit a specific s251 application to support the early implementer sites. Further development is required to understand the specific requirements for early implementer sites, as they are likely to require a combination of risk stratification and invoice validation and potentially the inclusion of social care data. This requirement is outwith the scope of S251 regulations so consideration will need to be given to the legal basis for disclosure and the use of social care data for this purpose.

End-state vision	<p>A controlled environment that enable the risk stratification to identify potential cohorts suitable for inclusion and ability to track and monitor patient activity either through nationally collected information (Secondary Uses Services) or specific invoices that will be validated within CEfFs that are outwith the HSCIC.</p> <p>Systems and structures in place at the HSCIC to support Year of Care controlled environments.</p> <p><i>Fair processing</i> so that patients understand how their data are used</p>
Implementation	<p>We are working with the early implementer sites and NHS IQ to understand their specific requirements.</p>
Communications	<p>We are issuing advice and communicating through various channels as above, including the IG Bulletin</p>

## Abbreviations used in this paper

ACG	Adjusted Clinical Groups
AQP	Any Qualified Provider
CAG	Confidentiality Advisory Group
CAMHS	Child and adolescent mental health services
CCG	Clinical Commissioning Group
CEff	Controlled Environment for Finance
CSU	Commissioning Support Unit
DES	Directed Enhanced Service
DSC	Data Services for Commissioners
DSCRO	Data Services for Commissioners Regional Offices
FAQ	Frequently Asked Questions
GMS	General Medical Services
HSCIC	Health & Social Care Information Centre
ISFE	Integrated Single Finance Environment
LTC	Long Term Condition(s)
PCD	personal confidential data
QIPP	Quality, Innovation, Productivity and Prevention
s251	Section 251 (of the Health and Social Care Act)
SLA	Service Level Agreement
SUS	Secondary Uses Service

## **Consultation Process**

The IG Taskforce invites comments on this Consultation Paper and, in particular, responses to the following questions:

CP-01-Q1: Is the overall approach to information requirements for integrated care outline in this paper correct?

CP-01-Q2: Are there significant omissions/issues with the approach set out in this paper?

CP-01-Q3: Have all alternative options been satisfactorily covered? If not, what other options should be considered?

Comments should be sent by electronic submission using the form on the IG Taskforce website at: [insert webform link](#).

Comments should reach us by 30 April 2014.

Following this consultation it is our intention to publish feedback and a Best Practice guide. We may publish consultation responses, in whole or in part, as part of this process unless the respondent requests otherwise. (Responses will normally be anonymised, however.)

## **For further information**

Follow us on twitter @IGTaskforce for regular updates on this consultation and the work of the NHE England IG Taskforce.