

**Ref:** care.data/Programme Board/Paper 09

**Title:** care.data Planning Principles and FAQs

**Author:** Eve Roodhouse

**Programme Board Sponsor:** Eve Roodhouse, Programme Director

**Purpose:** The high level planning principles and assumptions being adopted for the first phase of the programme are presented for review and approval by the programme board. The document will help to inform communications and engagement and set the framework for the programme plan.

**Background:** In February 2014, the decision was taken to delay the start of the extraction of primary care data from general practice following concerns raised by key stakeholders, in the media and across social media. Since then the programme has been listening to the views of patients, the public, GPs and stakeholders on how best to build trust and confidence in the programme. The planning principles reflect what the programme team has heard and, once approved will provide a framework within which to move forward with detailing planning and delivery.

**Key Points:** The planning principles document sets out a high level plan for the first phase of the programme (focused on the delivery of a primary-secondary care linked dataset). It sets out the pre-requisites and success criteria for each milestone in the pathfinder stage.

**Desired outcome(s):** For information as baselined version following updates - programme board approved this document at meeting on 16 July 2014.

**Circulation:** Programme Board attendees and Advisory Group

# Care.data Programme: Planning Principles and associated Frequently Asked Questions

11 July 2014 (v1.2)

## Purpose

1. The purpose of this briefing note is to set out the definitive position in relation to the planning assumptions being adopted by the programme in relation to the first phase of the programme, with particular emphasis on delivery relating to a number of 'pathfinder' GP practices. It also provides responses to a number of associated Frequently Asked Questions (or FAQs). This note will inform communications and engagement and also set the framework for the programme plan as we begin to select and work with the pathfinder practices.
2. The programme has developed a number of high level planning principles through discussion with stakeholders, including the care.data Advisory Group. They are intended to address the concerns raised and have been tested with the Advisory Group and formally agreed by the Programme Board and the Senior Responsible Owner on 25 June 2014. The programme team has now formally adopted these planning principles.
3. The first phase of the programme is defined as the delivery of a dataset which links data from GP systems with Hospital Episode Statistics (HES) to support clinicians, commissioners, researchers, charities and patients, to improve quality, safety and effectiveness of local care services.

## Planning Principles

4. The planning principles are set out in the table below. High level milestones, including dependencies, are described in Annex A1 and A2 these now be base-lined and reflected in all reporting to the Programme Board.

Ref	Description
1	The programme will take a phased approach to implementation and will work with between 100 and 500 GP practices (pathfinders) to test, evaluate and refine all aspects of the data extraction process ahead of any further (national) rollout. The objectives for and approach to the selection of the pathfinder practices, as well as the criteria to assess the success of the pathfinder stage, will be developed in partnership with key stakeholders, and signed off by the Programme Board.
2	Dame Fiona Caldicott and IIGOP will provide independent advice on the pathfinder stage to inform the development of the pathfinder stage and decisions about further rollout. Any advice will be shared with the Advisory Group and Programme Board.

Ref	Description
3	The decision to proceed to data extraction from the pathfinder practices will be taken by the Programme Board. This will be based on all the dependencies as described in the programme plan being met. These dependencies are shown (in draft form as they are in development and for agreement) in Annex A3.
4	A package of resource materials and tools for the public, GPs and their staff will be co-produced with pathfinder practices and wider stakeholders. This will include straightforward descriptions and mechanisms for supporting the objections process for professionals and the public which must be agreed with the Secretary of State as previously requested by him. They will be properly evaluated and refined with the involvement of GPs, their practice staff and patients. This will not include a change to the clinical codes which have been used to capture objections in primary care to date to ensure that any objections recorded between autumn 2013 and the start of the pathfinder stage can be properly observed.
5	The rules around access to identifiable data or data which is potentially identifiable will be clearly articulated before data extraction from pathfinder practices commences and implemented before any data collected as part of the programme is made available to organisations outside of the HSCIC. This includes changes to primary legislation having received Royal Assent and associated Regulations having commenced before data is disseminated.
6	The HSCIC intends to deliver a secure data facility service to support strengthened controls around data access. A roadmap for the development and delivery of such a service should be in place before data is extracted from pathfinder practices. Access to data collected from pathfinder practices will only be available on HSCIC premises and only to analysts who will work within an early version of the secure data facility.
7	The Code of Practice for Confidentiality will be published by the HSCIC before data is extracted from pathfinder practices.
8	The HSCIC will deliver fair processing pages on their website for members of the public to support pathfinder practices, and therefore in advance of data being extracted. The fair processing pages will set out the data to be extracted, how it will be processed and who will have access to it. The fair processing pages will cover all data collected under the programme in the future.
9	The programme team will work to ensure that data to be extracted from pathfinder practices is available to analysts from research organisations, charities and others, in line with planning assumption (6) above. The constraints around access should be aligned to rules referred to in planning principle (5) rather than by organisation type. The programme team will also work with stakeholders to reach agreement on the inclusion of additional non contentious codes in the primary care extract, this will include musculoskeletal data. A roadmap for the development of the primary care dataset will be published in advance of data being extracted from pathfinder practices.
10	The HSCIC and NHS England will put in place a formal agreement to set out respective roles as Joint Data Controllers for the data to be extracted. This will be in place in advance of data being extracted from pathfinder practices.
11	In order to ensure that the programme is on a firm foundation, the business case

Ref	Description
	(Strategic Outline Case or equivalent agile methodology) for the overall programme should be developed and agreed (as a minimum) with the Programme Board before data is collected from pathfinder practices.
12	The pathfinder stage will be evaluated against agreed success criteria by the Programme Board. The Programme Board will rely on the advice of the pathfinders themselves, the Advisory Group and the Independent Information Governance Oversight Panel (IIGOP) (see principle (2) above) to assess success. There are no artificial deadlines for national rollout – the programme will proceed only when the Programme Board is sure that the process is right.

### Frequently Asked Questions (FAQs)

5. A set of Frequently Asked Questions have been developed to reflect the planning principles and these are included in draft form at Annex B. They are intended for use with key stakeholders including the public and will be updated on an ongoing basis.

### Next Steps

6. Delivery plan to be base-lined and communicated effectively to all stakeholders including the Advisory Group. Key milestones to be reflected in Board highlight reports.
7. Frequently Asked Questions to be further developed with the support of Advisor Group members and made available for use.

## Annex A1: Key Milestones and Dependencies

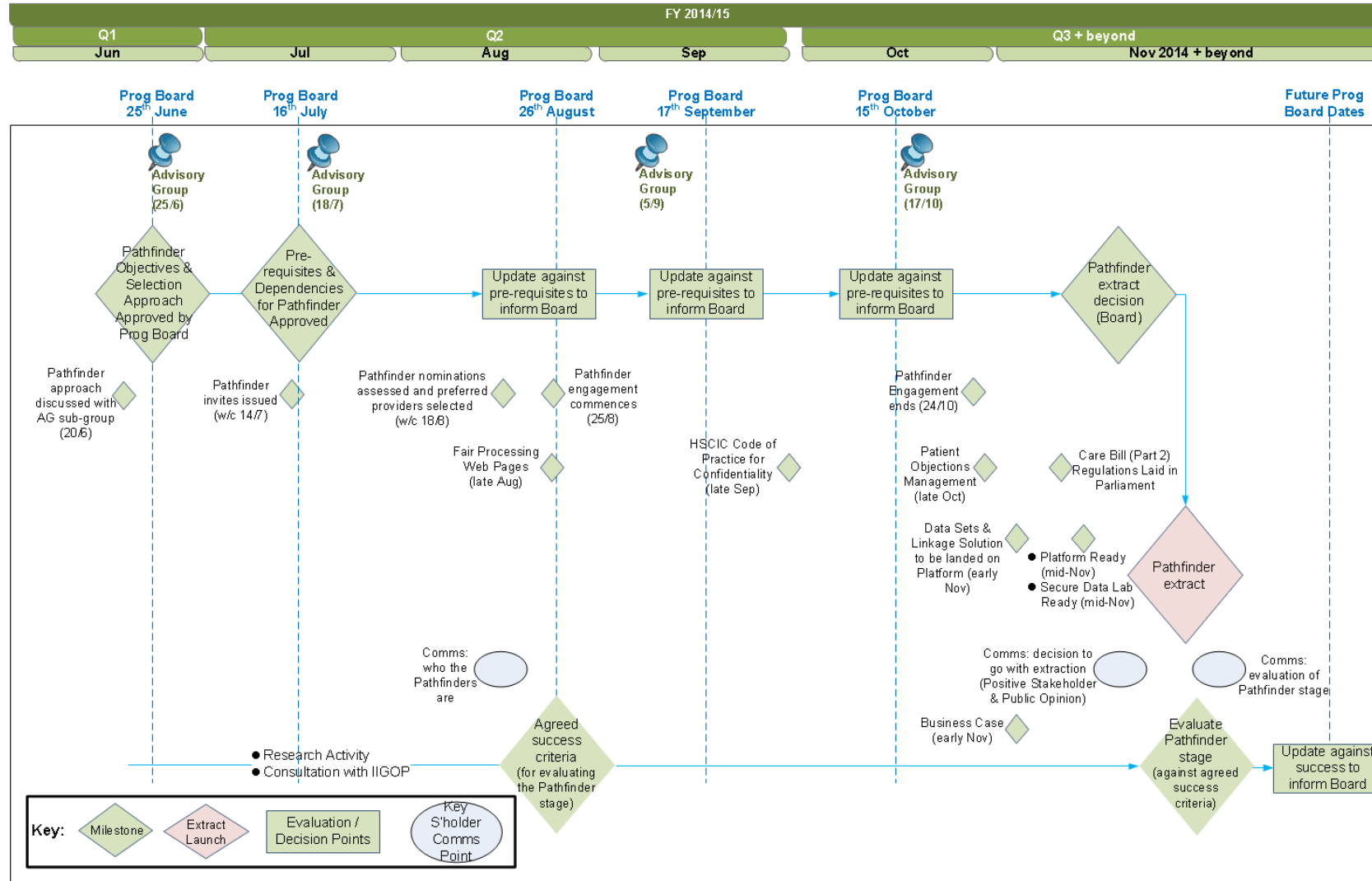
Ref	Title	Description	Dependencies	Lead	Milestone Date
1	<i>Strategic Capability Platform Phase 1 approved</i>	<i>Brief for phase 1 of Strategic Capability Platform (SCP) (infrastructure uplift in the HSCIC to enable appropriate data platform for care.data) approved by the SCP Project Board – to enable procurement, development and delivery to commence. This phase 1 development is via separate business justification. (This is now approved by SCP Project Board and by HSCIC Portfolio Board).</i>	<i>SCP Project Board and HSCIC Portfolio Board approval (HSCIC governance).</i>	<i>Care.data Programme Team (Capability Platform and Operating Model workstream)</i>	<i>Completed (Approved May 2014)</i>
2	<i>Marketing and research funding approved</i>	<i>Department of Health approval for the marketing spend</i>	<i>Cabinet Office approvals body (ERG).</i>	<i>Care.data Programme Team (Phased Extension workstream)</i>	<i>Completed (Approved early June 2014)</i>
3	<i>Commencement Order of CAG Elements of Care Bill</i>	<i>Commencement of Order of Confidentiality Advisory Group (CAG) elements of Care Bill &amp; associated elements (i.e. receives Royal Assent).</i>	<i>Department of Health (outside of care.data).</i>	<i>Department of Health</i>	<i>Completed (Received Royal Assent late May 2014)</i>
4	<i>Marketing, research and stakeholder events launched</i>	<i>Funded marketing supported by regional stakeholder events. Research activity commenced to support engagement campaign.</i>	<i>Approval of funding (dependency on milestone 2 above).</i>	<i>Care.data Programme Team (Phased Extension workstream)</i>	<i>Completed</i>
5	<i>Pathfinder objectives and selection approach agreed</i>	<i>Objectives, the approach to GP pathfinder practice selection (including the criteria) to be agreed and approved by Programme Board with a clear plan of delivery (selection).</i>	<i>Approval by Programme Board. Advisory Group consultation (anticipated sub-group in June). IIGOP consultation. GP consultation.</i>	<i>Care.data Programme Team (cross-programme)</i>	<i>Completed (Board approval secured 25 June)</i>

Ref	Title	Description	Dependencies	Lead	Milestone Date
6	Pathfinder practices selected	GP practices selected and fully engaged with appropriate communication and delivery plans available.	<i>(dependency on milestone 5 (approach) above)</i>	Care.data Programme Team (cross-programme)	August 2014
7	Pathfinder stage success criteria agreed	Agreement and documentation of the success criteria to be met (baselined for measure where appropriate) to enable the success of the forthcoming pathfinder stage to be evaluated.	Pathfinder stage success criteria approved Programme Board. IIGOP consultation and agreement. Advisory Group consultation. Will be informed by research work (for engagement effectiveness elements of evaluation).	Care.data Programme Team	End Aug 2014
8	Decision made to proceed to pathfinder launch	The decision to proceed (to launch) to data extraction from the pathfinder practices will be made by the Programme Board and will be based upon a number of dependencies being met. <b>These dependencies are shown (in draft form as they are in development and for agreement) in Annex A2.</b>	<b>See Annex A3</b>  Programme Board decision on go-ahead and communicated with plan to implementation.	Care.data Programme Team (cross-programme)	Date tbc  (when Board deems dependencies are met)
9	Primary Care pathfinder data extract launch	Data extract commenced for pathfinder GP practices with linkage to HES.	As per date confirmed following Board decision <i>(see milestone 8 above)</i> .		Date tbc
10	Assurance of pathfinder stage complete	IIGOP assurance complete and recommendations made to Programme Board.	Agreed success criteria agreed see Annex A4. <i>(dependency on milestone 7 above)</i> .	tbc (Programme Director currently owns)	Date tbc
11	Decision and definition in	Following the pathfinder stage, decisions and further definition will follow regarding	Recommendations as made to the programme	tbc (Programme Director)	Date tbc

Ref	Title	Description	Dependencies	Lead	Milestone Date
	relation to future implementation stages	next steps and future stages (including potentially to national rollout, if deemed successful)	Board to enable them to make informed decisions re future <i>(dependency on milestone 10 above).</i>	currently owns)	

# Annex A2: Care.data Pathfinder Success Evaluation Summary

## care.data Summary of Pathfinder Activity - Draft







## Annex A3 – Pre-requisites and Dependencies to inform the Pathfinders ‘launch’ decision

*(Draft – in development and for agreement)*

Ref	Responsible Area	Proposed Pre-requisite and Dependency for Pathfinder stage launch	Informed by:
<b>Pathfinders to Influence:</b>			
1	Stakeholder Engagement	<p>Stakeholders have been informed and engaged with in advance of Pathfinders going live:</p> <ol style="list-style-type: none"> <li>1. <b>Stakeholders have received appropriate briefings and been appropriately engaged in the development of the Pathfinder stage</b> (national groups, Healthwatch, vulnerable groups, Clinical groups, GP practices etc.)</li> <li>2. <b>Pathfinder GP Practices are confident that their patients are sufficiently informed about the intention to extract data and their right to object</b> in their local area.</li> <li>3. <b>Pathfinders (100-500 GP practices) &amp; Programme Partners (HSCIC service providers, GP systems providers) have defined roles and understand those roles.</b> In addition they have been sufficiently supported to commence, have received appropriate communications material for their patients, have had an opportunity to participate in the development of key pathfinder proposals, and are willing to commence.</li> <li>4. <b>Staff/Internal NHS England and HSCIC are appropriately briefed</b> to support the care.data Programme’s Pathfinder roll-out.</li> </ol>	
2	Engagement / Commissioning / Technical	<b>Pathfinders Champion Support network is operational</b> - to support full technical, commissioning, and engagement queries during the Pathfinder stage.	
3	Data Access / Commissioning	<p><b>Fair Processing is in place and appropriate and has been developed to support Pathfinder stage:</b></p> <p>Pathfinder GP practices have been supplied with, and been included in the development of, the legal and public information that they require to make patients aware of care.data and how their data might be used.</p>	ICO advice Research

Ref	Responsible Area	Proposed Pre-requisite and Dependency for Pathfinder stage launch	Informed by:
		Pathfinders have access to materials/products to use with their patients e.g. web pages / communications toolkit etc.	
5	Pathfinders	<b>Pathfinder GP practices have confirmed they are ready to launch.</b>	
<b>Programme to ensure:</b>			
6	Data Access & Application	<p><b>Arrangements in place to ensure primary care data linked to Hospital Episode Statistics can be accessed by nominated partners.</b></p> <p><b>Delivered Data will only be available to nominated pathfinder partners.</b> During the Pathfinder stage these partners are expected to be a small controlled group of:</p> <ol style="list-style-type: none"> <li>1. NHS England Analysts,</li> <li>2. HSCIC Analysts,</li> <li>3. CQC/Public Health England nominated representatives, and</li> <li>4. The pathfinders CCGs, GPs and GP surgeries themselves.</li> </ol> <p>Pathfinder partners are expected to expand if the programme team secures the support of the GPES Independent Advisory Group to expand access to researchers etc. (see planning principle 9).</p>	
7	Data Security	<p><b>Secure Data Facility Access has been created for the agreed specific sub-set of users to support Pathfinders only.</b> The subset of users is: NHS England Analysts, HSCIC Analysts, CQC/Public Health England nominated pathfinders representatives, and the pathfinders themselves. (i.e. this specific sub-set only of users).</p> <p>Secure data facility Access is NOT to be available to general or external users beyond the named communities above.</p>	

Ref	Responsible Area	Proposed Pre-requisite and Dependency for Pathfinder stage launch	Informed by:
8	Policy	<b>Care Bill (Part 1) Regulations have been laid in Parliament.</b>	Parliament / DH
9	Commissioning	<b>The commissioned data set specification is agreed and commissioned to HSCIC.</b> Pathfinder stage is based on September 2012 agreed specification only (i.e. no further expansion of data sets).	
10	Commissioning	<b>Formal Agreement in place between NHS England and HSCIC to formalise Joint Data Controller Agreements.</b> These agreements are signed by named accountable officers in HSCIC and NHS England.	
11	Policy	<b>NHS England Privacy Impact Assessment has been revisited and refreshed</b> to re-state that data is worth collecting, and worth impacting patients' confidentiality before going ahead.	
12	Policy	<b>Primary Care Directions have been revisited and (if necessary) re-issued</b> by NHS England to the HSCIC.	Code Of Practice in place  Care Bill part 1 in place.
13	Data Access	<b>HSCIC Code Of Practice must be agreed and in place.</b>	
14	Engagement / Commissioning / Technical	<b>Contact Support Centre is operational to support GPs and Patients</b> both generally, and those specifically involved in the Pathfinder phase.	

Ref	Responsible Area	Proposed Pre-requisite and Dependency for Pathfinder stage launch	Informed by:
15	Technical Platform/Access	<ol style="list-style-type: none"> <li>1. <b>Strategic Capability Platform – Phase 1, Drop 1 has been implemented</b> and completed Volume &amp; Performance (V&amp;P)</li> <li>2. <b>GPES Certification testing of care.data extract has been completed</b> with each GP system supplier, is working and has been tested</li> <li>3. <b>GPES Transition Project elements are complete</b> i.e. Q-Divert,DTS mail box, DDS, QRA responder, and have completed acceptance and V&amp;P testing</li> <li>4. <b>SAS Data Linkage processing module is implemented</b> and has successfully completed acceptance testing.</li> </ol>	
16	Data Sets	<b>GP Data set has received SCCI approval.</b>	
17	Data Access & Applications	<b>Access to primary care data linked to Hospital Episode Statistics is available.</b>	
18	Programme Controls	<b>Approved (by Programme Board) Business Case to be in place.</b>	
19	Programme Controls	<b>Governance bodies involved in the sign off of the success criteria are ready to meet in a timely matter to sign off the criteria as having been met</b> prior to any launch decision.	

## Annex A4 – Post-Launch Pathfinders Success Criteria to support the decision to progress to future roll-out.

*(Draft – in development and for agreement)*

Ref	Responsible Area	Proposed Post Launch Success Criteria for Pathfinders stage	Informed by:
<b>Pathfinders to Influence:</b>			
1	Stakeholder Engagement	<p>Stakeholders have been effectively informed and engaged with during Pathfinders stage:</p> <ol style="list-style-type: none"> <li><b>Stakeholders have received appropriate briefings and been appropriately engaged in the development of the Pathfinder stage</b> (national groups, Healthwatch, vulnerable groups, clinical groups, GP practices etc.)</li> <li><b>Pathfinder GP Practices are confident that their patients were sufficiently informed about the intention to extract data and their right to object</b> in their local area.</li> <li><b>Pathfinders (100-500 GP practices) &amp; Programme Partners (HSCIC service providers, GP systems providers) roles were clear GP Practices able to operate within this role.</b> Appropriate GP Surgery support and communications material for their patients was tested successfully. In addition, required amendments to support future GP extractions have been either implemented or a plan to address put in place to improve engagement to support for future roll-outs.</li> <li><b>Staff/Internal NHS England and HSCIC are appropriately briefed</b> to support care.data future roll-outs.</li> </ol>	
2	Engagement / Commissioning / Technical	<p><b>Pathfinders Champion Support network was successful</b> - at supporting full technical, commissioning, and engagement queries throughout the Pathfinder stage.</p> <p><b>Appropriate expansion plans have been put in place</b> to deliver and train the next phase of Champions to support future roll-out.</p>	
3	Data Access /	<b>Fair Processing in place and operational:</b>	ICO advice

Ref	Responsible Area	Proposed Post Launch Success Criteria for Pathfinders stage	Informed by:
	Commissioning	Pathfinders fair processing materials/products have been tested successfully with GPs during the Pathfinders stage e.g. web pages / communications toolkit etc. An action plan exists to address any Fair Processing enhancements during future roll-outs.	Research
4	Policy/Engagement	<b>The Patient objections process has been tested with pathfinders</b> and an action plan to address any future enhancements has been drawn up.	
5	Pathfinders	<b>Pathfinder GP practices have agreed that the Pathfinder stage has completed successfully.</b>	
<b>Programme to direct:</b>			
6	Data Security	<b>Secure Data Facility has successfully provided secure access to each representative group in the Pathfinder stage.</b>  A plan is in place to extend Secure Data Facility Access to appropriate groups for future roll-out phases.	
7	Engagement / Commissioning / Technical	<b>Contact Support Centre has successfully supported GPs and Patients during the Pathfinder stage</b> , and a plan is in place to support future care.data roll-outs.	
8	Technical Platform	<b>Strategic Capability Platform has successfully supported the Pathfinders stage.</b> <ol style="list-style-type: none"> <li>1. <b>Strategic Capability Platform – Phase 1, Drop 1</b> platform successfully supported Pathfinders stage or an enhancement plan is in place prior to next stage roll-out</li> <li>2. <b>GPES Certification tests or GP systems effectively supported the Pathfinders</b> or an enhancement plan is in place prior to next stage roll-out.</li> <li>3. <b>GPES Transition Project elements successfully supported Pathfinders</b> or an enhancement plan is in place prior to next stage roll-out.</li> <li>4. <b>SAS Data Linkage processing module successfully accepted data and supported Pathfinders</b> or an enhancement plan is in place prior to next stage roll-out.</li> </ol>	

Ref	Responsible Area	Proposed Post Launch Success Criteria for Pathfinders stage	Informed by:
9	Data Sets	<b>Pseudonymised linked data tables for primary care and HES worked effectively during the Pathfinders stage</b> and supported the concept of data privacy for individuals.	



## **Annex B: Frequently Asked Questions (FAQs)**

**NB: These FAQs will be further developed with the support of members of the Advisory Group as agreed on 25 June 2014.**

### **1. Why are you going to collect data from GP practices?**

Every patient should expect the highest quality care. One of the most powerful ways in which the NHS can be sure it is providing patients with the best possible care is by analysing detailed, high quality information about illnesses, treatments, and health outcomes.

Sharing information about a patient's care when they visit the GP helps us to understand their health needs and how well they are being treated. If we link this information together with everyone else's health information, from both GP records and hospital records, we will have a more rounded picture of what is happening in our health and care services across the country.

This means we can see where things are working well but also see where there may be problems that need to be addressed. Using patient information to identify gaps in this way – whilst protecting everyone's personal confidential data – is the purpose of care.data.

The NHS in England already has some of the best information and data systems in the world and our hospital episode statistics (HES) system has been collecting information about every hospital admission, nationwide, since the 1980s. However, we are currently missing information for most of the care provided outside of hospital which means there is a gap in our knowledge. For example, we would like to know the average time taken – in every area of the country - between someone seeing their GP with bowel symptoms, to being diagnosed with colon cancer at the hospital. In order to know this, we need to link GP and hospital data.

The care.data programme will mean that for the first time, the NHS will find out about the quality of care being provided in all GP practices, and how well GP practices and hospitals are working together to provide joined-up care for patients. By studying this information in formats that identify conditions but not people, analysts can check that patients are receiving safe care in every NHS setting. Analysis of this type of data can help identify where a hospital is providing unacceptable care. Other uses of the data include identifying where the NHS needs to invest more in different diseases and in different parts of the country, illustrating examples of excellent care that should be rolled-out across the NHS, planning new services, and researching new treatments. Without this joined-up information it is impossible to commission joined-up care or to address variations in the quality, efficiency and equity of health and care provision.

### **2. When will data be collected from GP systems for care.data?**

In light of what we have been hearing from patients, the public, GPs and stakeholders we are proposing to phase the implementation of care.data and work with between 100 and 500 GP practices. Those GP practices who participate in this first stage (known as pathfinder practices) will be involved in testing all aspects of the data extraction so they can be refined before any decision is made on widening participation. Additionally, any decision on

widening participation (Programme Board decision) will be informed through independent evaluation of the success of the pathfinder stage using agreed success criteria.

### **3. How will pathfinder practices be selected?**

A proposal for how pathfinder practices will be selected (the objectives and the approach to selection) is under development and will be refined in partnership with clinical colleagues, patient groups and other key stakeholders. This approach will also be informed by the Independent Information Governance Oversight Panel (IIGOP), chaired by Dame Fiona Caldicott. More information will be available throughout June.

### **4. Who will decide to go ahead with data extraction?**

The care.data Programme Board will make the decision about proceeding with data extraction at pathfinder practices. This will be based on all the dependencies as described in the programme plan being met to their satisfaction where engagement activity outcomes will be informed by supporting research activities. Following the pathfinder data extraction implementation, there will be an independent evaluation of the success of this pathfinder stage to inform Programme Board decisions as regards any further rollout stages. This evaluation will be provided by the IIGOP. There are no artificial deadlines for national rollout – we will proceed only when we are sure the process is right.

### **5. How frequently will data be extracted?**

Data will be collected on a monthly basis where information about a patient is recorded on a General Practice electronic patient record within the previous four months.

### **6. Who will have access to my data?**

There will be complete transparency of all those permitted to this data by the Health and Social Care Information Centre (HSCIC) and for what purpose. In this way patients will know how their data has been used for the improvement of services. Access to data will be strictly controlled by the HSCIC in accordance with the law. Initially, data will be used to support commissioning. Further down the line, data may be used to support those looking at public health issues such as outbreaks of diseases or with those researching new treatments. New legislation is currently being considered by Parliament which will prevent the HSCIC from sharing information that may identify you unless the purpose is for the provision of health and social care services or for the promotion of health. The uses of data will be subject to robust independent scrutiny and no uses will be permitted that are not for the benefit of patients.

### **7. What data will be extracted?**

When we are collecting data from the GP practice we will collect the patient's NHS number, date of birth, gender, and postcode. We also collect information about referrals, prescriptions or health information such as diagnoses. These diagnoses relate to health conditions such as diabetes, heart disease, stroke, cancers (including bowel, breast, and cervical), chronic liver disease, chronic kidney disease, asthma, damage to the retina of the eye, high blood pressure and dementia.

GPs record this information in the form of codes (for example, code C10E for diabetes). We will collect the coded information. We will not collect information that GPs record as written notes, such as details of any conversations that they have had with the patient. Further information is available at: <http://www.hscic.gov.uk/article/3915/What-we-will-collect-from-GP-records-under-caredata>

## **8. What does opt-out mean?**

The patient has the right to opt out of information that identifies them from being used for reasons other than their direct care and to have their wishes respected. If the patient does not want information that identifies them to leave their GP practice for any reason other than providing their direct care they need to ask their GP practice to record their decision to opt out in their medical record. This action will stop information being shared by their GP practice unless it is being used to support their direct care. If the patient does not want information that identifies them that goes beyond their direct care to leave the Health and Social care Information Centre (HSCIC) then they will ask their GP to record their decision to opt out in their medical record.

If the patient has already decided to opt out of information leaving their GP practice, their GP will automatically assume that they would not want information that identifies them and that comes to HSCIC (for example, from hospital) to be released by the HSCIC and will record this.

If the patient has asked their GP practice to record an objection to information that identifies them from being shared by the HSCIC, then we will collect information from the GP practice that they have recorded this objection, the date of the objection, and the NHS number. We need the NHS number so that we can prevent any other information we hold that identifies the patient from being shared.

No other information about the patient and their care will be collected from the GP practice in relation to care.data.

## **9. Are there any risks to my data?**

The Health and Social Care Information Centre (HSCIC) takes the safety and security of patient data very seriously. The HSCIC carried out a Cyber Security Review in October 2013 to enhance the preparedness and capabilities of the organisations to new and emerging cyber security threats.

When the HSCIC releases pseudonymous information it does not include information that allows the patient to be directly identified from the data. However, there is a risk that individuals might be identified, for example, it might be possible to identify someone with a rare disease in a particular area which is why this type of information will never be published. As a result, this type of information will only be released to organisations for approved purposes, and there must be a legal contract in place with penalties for any misuse of the information.

## **10. How will I know how who has access to it and how it is being used?**

The Health and Social Care Information Centre (HSCIC) is developing web pages to support pathfinder practices in advance of data being collected that will set out what data is to be

collected, how it will be processed and who will have access to it. It will also carry information data extractions in the future.

The HSCIC is committed to transparency and being open with citizens about who has access to their data and why. The HSCIC published a register on 3 April 2014 of the instances where the HSCIC provided data under a data sharing agreement. The register covers data releases approved by the HSCIC from the point it was established on April 1 2013 to December 31 2013. The register lists each organisation, the type of data released, the legal basis for release and the purpose for which the data was provided. This register will be updated on a quarterly basis and in the future will include details on releases of data under care.data where there is a data sharing contract. The register is intended to encourage public scrutiny of HSCIC decisions. The register is available via the HSCIC website at: [www.hscic.gov.uk/dataregister](http://www.hscic.gov.uk/dataregister).

### **11. Will the private sector be allowed access to the data?**

The NHS works with a range of private and not-for-profit organisations which provide services which help them improve patient care in a variety of ways, both directly and indirectly. Access to good quality data is essential for many of these services to operate effectively. New legislation is currently being considered by Parliament which will prevent the Health and Social Care Information Centre (HSCIC) from sharing information that may identify an individual unless the purpose is for the provision of health and social care services or for the promotion of health. The uses of data will be subject to robust independent scrutiny and no uses will be permitted that are not for the benefit of patients. However, some private organisations are likely to meet the criteria and on that basis would be able to request access to data. All access to data will be strictly controlled by the HSCIC in accordance with the law. Initially, data will be used to support commissioning. Further down the line, data may be used to support those looking at public health issues such as outbreaks of diseases or with those researching new treatments, which could include private organisations such as life sciences organisations.

### **12. Will other Government departments be allowed access to this data?**

The data being collected will be used to support commissioning initially and, further down the line, data may be used to support those looking at public health issues such as outbreaks of diseases or with those researching new treatments. New legislation is currently being considered by Parliament which will prevent the Health and Social Care Information Centre (HSCIC) from sharing information that may identify an individual unless the purpose is for the provision of health and social care services or for the promotion of health. The uses of data will be subject to robust independent scrutiny and no uses will be permitted that are not for the benefit of patients. This would mean that NHS-funded services would be able to access the data but it wouldn't be accessible to other Government departments as they would be unlikely to meet the criteria set out in the new legislation.

### **13. Can anyone make money out of this?**

Whilst the main purpose of the collecting this data is to be able to improve the quality of care for patients, the data will also be made available under strict terms and conditions to organisations that show a clear purpose related to the provision of health care or adult social care, or the promotion of health. This can mean that data is released to private organisations

such as the life sciences that as a result are able to develop new products from which they are able to generate income. Data users are not given full access to all data, but limited access to the information they require in order to fulfil the purpose of their request.

The government has previously made it clear that it wishes to encourage innovation and investment in UK life sciences and to champion data based innovations in health and life sciences. More information can be found in Further Detail on Open Data Measures in the Autumn Statement 2011 at

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/61959/Further\\_detail\\_on\\_Open\\_Data\\_measures\\_in\\_the\\_Autumn\\_Statement\\_2011.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/61959/Further_detail_on_Open_Data_measures_in_the_Autumn_Statement_2011.pdf)

From this it would be reasonable to assume that the Government ambition is to realise economic growth for the UK by encouraging more investment in life sciences & research in the UK which could result in the creation of more jobs based in the UK.

#### **14. Can my data be sold?**

The Health and Social Care Information Centre (HSCIC) does charge a fee to cover its cost, it does not make a profit from providing data to other organisations nor does it subsidise any applicants to receive the data.

#### **15. Can I have all my data deleted from the database at a later stage if I change my mind?**

A patient can ask the Health and Social Care Information Centre (HSCIC) to stop processing any identifiable data they hold about them for purposes beyond their direct care by completing and submitting the relevant form available online at:

[www.hscic.gov.uk/policyprocs](http://www.hscic.gov.uk/policyprocs)

#### **16. Why can't you pseudonymise at source?**

The Health and Social Care Information Centre (HSCIC) has secure ways of transferring information into the organisation where we use key items to link the data that we collect to other sources of data about an individual. For example, as under care.data, linking data from GP records to information from hospital records. Currently, if data is pseudonymised at source (for example at the GP practice) before coming to the HSCIC then it is not possible for the HSCIC to link that data with the other sources of data that it already holds which will limit the utility of that data. This would mean, for example, that it would not be possible to see a patient's journey through their interactions with the different providers of their care.

#### **17. What is the secure data facility?**

The Health and Social Care Information Centre (HSCIC) is working to see how best it can develop and implement "secure data facility" technology, to enable researchers and others to query and analyse the data it holds, whilst the linked data which could be used to identify individuals itself never leaves the secure environment of the HSCIC.