Ref: care.data/Programme Board/Paper 02					
Title: care.data Programme Board Highlight Report					
Author: David Farrell					
Programme Board Sponsor: Eve Roodhouse, Programme Director					
<b>Purpose:</b> To provide an update for the programme board in relation to delivery against					
plan/milestones, by workstream, as well as an overall position for the programme (delivery					
confidence) and key risks.					
<b>Background:</b> The Patients and Information (P&I) Directorate of NHS England is supporting the					
NHS in designing and operating a world-class patient service. The care data programme will collect					
and publish detailed clinical data linked across multiple care settings, to include hospital, primary					
care, community, mental health and social care.					
Key Points: The document provides a general update (highlights) for the programme board and is					
fed by updates from workstreams (weekly reports are currently developed as an input to the SRO					
Accountability meetings).					
<b>Desired outcome(s):</b> That the programme board is provided with an appropriate update for the					
programme and is able to challenge elements of delivery and assure delivery based upon the					
information provided.					
Circulation: Programme Board attendees.					

#### **Programme Board Highlight Report for:**

care.data programme

# Reporting period: Period to Programme Board 2014 Report date: 13/06/2014

1. Overall delivery confidence RAG	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14
	А	А	А	A	A	А

#### **Overall delivery confidence commentary**

The programme has now stabilised and started to see progress in a number of key areas. Governance has been reviewed and is being strengthened; and a revised plan for the delivery of primary-secondary care linked data for a number of 'pathfinder' GP practices is in development (milestone, critical path with agreed decision points and associated criteria) and is now supported by a developing communications and engagement plan of activity. This activity is being shared with the Advisory Group and indeed Advisory Group members are also scheduled to attend events/workshops.

The implementation of the primary care extract for pathfinder GP practices will launch only when a number of pre-requisites (inc technical readiness and appropriate stakeholder and public engagement) have been met and, when launched, it will be evaluated before decisions on future rollout activity are taken. The Advisory Group is also engaged with the development of the pathfinder objectives and approach, as well as overarching planning principles.

The programme is still delivering without an approved business case and remains under intense scrutiny. Resource gaps are being addressed, with a number of staff joining the team in key roles from the end of June, including Programme Heads for Data Delivery and Strategic Capability Platform. This will make a significant difference, but there are still significant gaps in resourcing and recruitment is ongoing to ensure that the team is adequately resourced at all levels.

The Major Projects Authority (MPA) completed a Project Validation Review (PVR) for the programme during week commencing 28th April and the final report was delivered to the SRO, Tim Kelsey in May. All the recommendations were accepted by the SRO and a detailed action plan is being developed. An interim statement of progress against the recommendations was provided to the MPA w/c 9<sup>th</sup> June and shared with the Programme Board alongside this highlight report.

In a further refinement of the governance process and in line with the recommendations from the recent PVR, the existing programme board membership was stood down at the board meeting on 13th May and new board members are being appointed with a revised Terms of Reference (ToR). The ToR will be reviewed at the first meeting of the new board on 25<sup>th</sup> June.

2. Key Programme RAG areas	RAG status	RAG status 'headline' commentary
Key delivery milestones over the next 3 months	А	Emphasis is on primary care extract for pathfinder GP practices (stage 1 of first phase of programme).
Current year financial forecast vs. budget	R	No business case in place – funding through GIA source and care.data programme funding (and separate business case in place for research activity to support awareness extension).
Investment justification (BC, MoU etc) forecast spend status	R	No business case in place – funding through GIA source and care.data programme funding (and separate business case in place for research activity to support awareness

		extension).
Benefits realisation confidence	А	Benefits were initially drafted as part of business case development, will be picked up again when this commences.
Quality management against plan	А	Quality management measures/plan being developed in support of the programme definition (specifically for the Programme Definition Document).
Programme end date	А	The end date will be specified in agreed scope in overall (programme) business case.
Current Investment Justification approval status	R	No business case in place. Anticipated that business case development likely to take agile approach with an overall Programme Business Case and business justifications falling from this (e.g. for primary care extract; for Strategic Platform).
ICT Spend Approval status	R	ICT Spend Approval developed to accompany the business case (see above).
Resourcing against plan	А	Resource gaps now being filled although clarity of working arrangements across organisations is still forming and there is pressure in admin/support areas.

3. Progress against plan this reporting period	Key areas of focus for next period
Engagement and Research Funding	Engagement and Research Funding
<ul> <li>Formal Approval letter from Cabinet Office received confirming £1.8m Professional Services Business Case approved with 2 conditions:</li> <li>1) DH / NHS England to set out a final position on the need for strategic agency support, or alternative arrangements.</li> <li>2) The £250k budget allocated for the digital marketing agency will need to go through Government Digital Service (GDS) Approvals. DH / NHS England to ensure they follow up with the DH digital portfolio team.</li> </ul>	Funding: follow-up on 2 conditions stated to the left.
Key Stakeholder Engagement	Key Stakeholder Engagement
Stakeholder engagement process continues with the stakeholder log now being shared widely.	<b>Open House Day events June 17th</b> – approve content for session including SRO introduction, questions for discussion by delegates, background info for delegates and briefing/lines for facilitators.
You Said, We Will Do: Listened to all stakeholders and documented what they said. Commenced analysis of stakeholder engagement log to support 'You Said, We Will Do' work. Liaising with analyst in NHS England and Policy team to link to 'We Will Do'.	<b>You Said, We Will Do:</b> Analysis of stakeholder engagement log completes Friday 20 <sup>th</sup> June. 'We Will Do' statement will be formulated as a result of this analysis, incorporating actions already taken in response to feedback received during the initial listening period.

Key areas of focus for next period
Updates will be made to policy as a result of feedback. Additionally, the programme approached will be aligned to stakeholder feedback across the programme.
<b>Vulnerable and excluded groups:</b> Outcomes from this workshop will feed into the 'You Said, We Will Do' work above.
Advisory Group stakeholder engagement meetings/workshops (x5): The first event is now scheduled for late July.
<b>Public Deliberative /Dialogue Workshops</b> : Next steps to finalise agenda and brief facilitators.
Healthwatch National Conference July 3 & 4: agreed attendance on July 3rd to engage on care.data.
Regional Engagement
<b>Finalised Pathfinder Proposals to be presented for ratification:</b> to present and agree proposals. GPs to join Pathfinders thereafter (pathfinders proposed to volunteer to participate).
Facilitate Open House events on 17 <sup>th</sup> June in regions.
Progressing with Regional Engagement staff recruitment.
Research
Further develop research brief. Research implementation plan to be reviewed in light of revised Pathfinder approach.
Communications & Marketing
<b>Creative Agency Procurement:</b> The creative agency is re-planning the approach to marketing, to accommodate pathfinder proposals.

3. Progress against plan this reporting period	Key areas of focus for next period
Comms Core Toolkit Iteration 1 of the Comms Core Toolkit is in use across the programme, and for external briefings, including in regions. High level feedback has been logged. Detailed analysis of all comms feedback is now underway, prior to the release of Iteration 2 of the toolkit Website Updates: Work continues to align language across websites. Considering FAQ updates in light of work being led by HSCIC. In the meantime care.data comms have recommended updates to patient-facing FAQs on the NHS Choices website.	Comms Core Toolkit Detailed analysis of all comms feedback is now underway, prior to the release of Iteration 2 of the toolkit Comms and Marketing Timeline under development- work being undertaken to amalgamate all relevant comms and marketing activity in order to plot further comms opportunities now that ERG clearance has been given for paid spend. Pathfinder communications scoping will commence once Pathfinder approach is agreed.
Policy	Policy
<b>Roadmap on scope of GP dataset</b> The Roadmap document which sets out proposals to expand the utility and range of data covered by the current primary care extract specification has been further reworked following internal review comments from the care.data policy group.	Roadmap on scope of GP dataset Proposal to be finalised and ready for consideration by Programme Board by late July.
The impact of legislative developments (specifically secondary legislation) upon the programme has been analysed and plans are in the process of being updated.	<b>Primary Care Directions:</b> Primary Care Directions will be reviewed to determine whether any amendments are required to the original issued to HSCIC in December 2013.
<ul> <li>Fair Processing Guidance for GP practices</li> <li>Discussions with IG alliance seeking their support and advice.</li> <li>Discussions with ICO clarifying guidance they may provide either solely or jointly, in relation to care.data and a broader piece on fair processing.</li> </ul>	
<ul> <li>Patient Objections management:</li> <li>Workshop discussions objections process has been held based on listening exercise feedback.</li> <li>Considered scope, communication, and consent models across the health service.</li> </ul>	Patient Objections management: Outcomes to be taken to policy decision then can be released into wider care.data programme for information / ratification.
Hospital Data Sets: Initial work packages document sent to HSCIC for comment.	Hospital Data Sets: Methodology for data set development to be developed. Agree initial work package with HSCIC. HSCIC to develop staged work packages.
<ul> <li>FOIs/PQs/CDO mailbox continued low levels of new queries:</li> <li>NIL FOI received this week.</li> </ul>	Continue to monitor FOIs/PQs/CDO mailbox

3. Progress against plan this reporting period	Key areas of focus for next period		
<ul> <li>Nil PQs received.</li> <li>Only 1x CDO query received this week about patient clarity of what opting out means.</li> </ul>			
HES- Primary Care linkage	HES- Primary Care linkage		
<ul> <li>GPES participation meetings ongoing to ensure technical readiness.</li> <li>Comments on Pathfinder proposals received from HSCIC and NHS England clinical leads. Responses were incorporated into the Pathfinder proposal document ready for consideration by the Advisory Group and programme board.</li> <li>The Pathfinder Proposals paper was distributed to Joint GP IT Committee (JGPITC) members and feedback has now been received. The overall response has been to say that the plans for the pathfinder phase seem appropriate and that the JGPITC are keen to be kept in the loop as things progress.</li> </ul>	<ul> <li>Technical readiness against plan, including meetings with GPES; looking at lessons learned from the SCR programme; and ensuring the data standards process (SCCI) is fully considered.</li> <li>Pathfinder proposals to be issued to care.data Advisory Group and programme board on 25<sup>th</sup> June.</li> </ul>		
Patient Objections	Patient Objections		
<ul> <li>First Patient Objections self-assessment forms returned and clarifying Patient Objection Management (POM) implications for LD Census.</li> <li>Project Brief being finalised.</li> </ul>	Patient Objection Management (POM) Working Group meeting to take place, self- assessment form sifting exercise scheduled, and Reference Data Specs / requirements workshop also taking place in immediate period.		
Platform and Technology	Platform and Technology		
<ul> <li>Business justification (OBJ) under development, cost model updated.</li> <li>Project plan for build stage elaborated.</li> <li>Briefing presentation presented to HSCIC Board and all documentation being progressed is going through the Strategic Capability Platform (SCP) project board.</li> <li>Workshop held with Service management and Data Management Environment (DME) to begin to build service model.</li> <li>Funding approach for phase 1 of the platform being discussed.</li> </ul>	<ul> <li>SCP Phase 1 business case to be reviewed and updated following feedback. Approach for the business case development to be agreed and draft version to go for wider review and subsequent approval.</li> <li>Procurement approach to SAS and IaaS agreed and elaborated.</li> <li>Secure data lab requirements under development.</li> </ul>		
Enterprise De-identification Solution & Index Solution (EDS&I)			
Project on hold, due to need to divert all available resources to platform work.			

3. Progress against plan this reporting period	Key areas of focus for next period
<ul> <li>HSCIC Patient Information Line         <ul> <li>Low number of calls to the patient information line in the period, top patient FAQs //feedback(cumulative) were:</li></ul></li></ul>	<ul> <li>Maternity and Children's Data Set (MCDS)</li> <li>The interim assurance letter between NHS England and HSCIC, ahead of the Memorandum of Understanding (MoU), for MCDS is awaiting approval within NHS England. There is a concern the timeline will be impacted, as procurement cannot take place within the required timeframe if this assurance is not in place by the end of June 2014.</li> <li>Attend the HSCIC Portfolio Board to present Tolerance Exception Report on 26th June.</li> </ul>
Governance and Controls	Governance and Controls
<b>Programme Board</b> in process of re-establishment. Invites with draft ToR gone out - next meeting scheduled for 25 <sup>th</sup> June.	Develop revised governance structure and TOR beneath the <b>Programme Board</b> , to support Programme and address PVR comments.
<ul> <li>Pathfinder Critical Success Factors draft further developed and comprises a list of Dependencies to inform the Pathfinders 'launch' decision. These dependencies have been split between:</li> <li>Pre-requisites (prior to the launch decision); and</li> <li>Post launch criteria (to inform the decision on how to proceed to future phases).</li> </ul>	Review and further refine <b>Pathfinder decision point criteria</b> , and to be communicated and agreed (inc programme board).

Programme Board Highlight Report for:	care.data programme
3. Progress against plan this reporting period	Key areas of focus for next period
Assurance: Project Validation Review (PVR) recommendations communicated and a formal action plan is in development.	Assurance: Project Validation Review (PVR) recommendations A formal action plan will be finalised in advance of the July programme board.
<b>Care.data business case and funding:</b> Options put together and discussed re care.data business case approach going forward. This approach to be agreed and communicated although will follow Cabinet Office agile approach (a Programme Business Case with justifications falling from it).	<b>Care.data business case and funding:</b> Recommence the business case development with appropriate resource in place. Approvals timeline to follow and be communicated when approach agreed.
<b>Resources:</b> Resource gaps are being addressed, with a number of staff joining the team in key roles from the end of June, including Programme Heads for Data Delivery and Strategic Capability Platform. This will make a significant difference, but there are still significant gaps in resourcing and recruitment is ongoing to ensure that the team is adequately resourced at all levels.	Resources: Continue recruitment activity into the Programme team, including the following key roles:
PSBC for a business case specialist now approved by HSCIC CEO and has gone to DH for approval by the Financial Approvals Panel (FAP). Additional Programme Manager resource has been earmarked to support the development of the business case. Recruitment of Programme Administrator is in train (advert close date of 13 <sup>th</sup> June).	<b>Risk management:</b> Currently working towards the position of a single programme log for NHSE and HSCIC team members, for baseline and via the Tracking Database (with set-up and training).
Job adverts for NHS England additional programme staff due on NHS jobs covering Regional Engagement, Comms and programme management support. Advisory Group meeting – next scheduled for 25 <sup>th</sup> June.	<b>Programme Definition Document (PDD)</b> – development of PDD including workstream definition – alongside business case development to ensure consistency of scope definition.

	Key milestone	RAG	Current forecast date	Description	Progress
1	Strategic Capability Platform Phase 1 approved	G	Complete	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.	Dependencies: SCP Project Board and HSCIC Portfolio Board approval (HSCIC governance). Completed (Approved May 2014)

	Key milestone	RAG	Current forecast date	Description	Progress
				This phase 1 development is via separate business justification. (This is now approved by SCP Project Board and by HSCIC Portfolio Board).	
2	Marketing and research funding approved		Complete	Department of Health approval for the marketing spend Dependencies: Cabinet Office approvals body (ERG).	<i>Completed (Approved early June 2014)</i> £1.8m Business Case Cabinet Office ERG final approval letter received 28/5/14.
3	Commencement Order of CAG Elements of Care Bill		Complete	Commencement of Order of Confidentiality Advisory Group (CAG) elements of Care Bill & associated elements (i.e. receives Royal Assent). Dependencies: Department of Health (outside of care.data).	<i>Completed (Received Royal Assent late May 2014)</i>
4	Marketing, research and stakeholder events launched	A/G	Late June 2014	Funded marketing supported by regional stakeholder events. Research activity commenced to support engagement campaign. Dependencies: Approval of funding (dependency on milestone 2 above).	Briefing meetings with newly appointed research agency taking place and approach being finalised – will feed the pre-requisites for launch and the success factors for evaluation.
5	Pathfinder objectives and selection approach agreed	A/G	End June 2014	<ul> <li>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).</li> <li>Dependencies: <ul> <li>Approval by Programme Board.</li> <li>Advisory Group consultation (anticipated sub-group in June).</li> <li>IIGOP consultation.</li> <li>GP consultation.</li> </ul> </li> </ul>	Pathfinder objectives and approach documented and being tested/discussed with stakeholders, including sub-group of Advisory Group (20 <sup>th</sup> June) and for review and approval by programme board 25 <sup>th</sup> June.
6	Pathfinder practices selected	A/G	End July 2014	GP practices selected and fully engaged with appropriate communication and delivery plans	

	Key milestone	RAG	Current forecast date	Description	Progress
				available. Dependencies: Milestone 5 (approach) above	
7	Pathfinder stage success criteria agreed	A/G	End Aug 2014	<ul> <li>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.</li> <li>Dependencies: <ul> <li>Pathfinder stage success criteria approved Programme Board.</li> <li>Pathfinder plans including pre-requisites for launch baselined (mid-July)</li> <li>IIGOP consultation and agreement.</li> <li>Advisory Group consultation.</li> <li>Will be informed by research work (for engagement effectiveness elements of evaluation).</li> </ul> </li> </ul>	
8	Decision made to proceed to pathfinder launch		Date to be confirmed (when Board deems dependencies are met)	<ul> <li>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, including:</li> <li>Primary Care Directions (late August)</li> <li>Privacy Impact Assessment (late August)</li> <li>Data Controllership Agreement (HSCIC &amp; NHS England – late August)</li> <li>Marketing Communication materials produced and made available (mid-August)</li> </ul>	<ul> <li>First review of Primary Care Directions completed and advice sought from Information Governance team.</li> <li>Work has commenced on Privacy Impact Assessments and is progressing; dependency on research work providing a selection of relevant results.</li> <li>Meetings are taking place to progress the Data Controllership Agreement</li> <li>Marketing Communication materials for GPs, the public and for engagement events. This is linked to research activity above.</li> </ul>
9	Primary Care pathfinder data extract launch		Date to be confirmed	Data extract commenced for pathfinder GP practices with linkage to HES.	As per date confirmed following Board decision (see milestone 8 above).

	Key milestone	RAG	Current forecast date	Description	Progress
10	Assurance of pathfinder stage complete		Date to be confirmed	IIGOP assurance complete and recommendations made to Programme Board. This is <i>dependent on milestone 7 above</i> .	
11	Decision and definition in relation to future implementation stages		Date to be confirmed	Following the pathfinder stage, decisions and further definition will follow regarding next steps and future stages (including potentially to national rollout, if deemed successful) Recommendations as made to the programme Board to enable them to make informed decisions re future (dependency on milestone 10 above).	
12	Programme governance fully established including board re- establishment and sign-off/approvals	A	Early July	Programme board re-established with revised ToR (to be agreed) and reviewed governing structure beneath, although some elements still to be introduced (e.g. operational board). Advisory Group fully working. Programme board will provide oversight/approvals and internal approval processes being introduced.	

6. Тор	o 5 risł	ks and issues	(impacting current	plan/deliverables)				
Risk / Issue ID	Type (Risk / Issue)	Risk/Issue Title	Risk/Issue Description	Impact Description	Impact	Likelihood	RAG Status	Mitigation Plan
1	Risk	Lack of clinical engagement for programme	Due to the pace of rollout of the primary care extract (including comms and engagement), limited time to meet fair processing requirements (GP role as Data Controller), limited funding or resource to help GP Practices to manage	TIME: Impact through delays – need to make further efforts – via professional bodies and on the ground in regions (CCGs) – to secure engagement COST: Impact on cost through wider, more intense engagement/comms strategy	4	3	Amber	Now being addressed through specific Phased Extension workstream activity (with focused comms and engagement plan) and a wider Stakeholder and Comms workstream providing overall framework and strategy for the programme (i.e. stakeholder mapping, stakeholder engagement strategy, comms plan), working across

6. To	p 5 risl	ks and issues	s (impacting current	t plan/deliverables)				
Risk / Issue ID	Type (Risk / Issue)	Risk/Issue Title	Risk/Issue Description	Impact Description	Impact	Likelihood	RAG Status	Mitigation Plan
			patient communications and GP Practice users potentially being unfamiliar with GPES, there is a risk that GPs/clinicians will not be fully engaged with care.data, may not have confidence in care.data, and that will impact the realisation of benefits as the programme progresses.	BENEFITS: Potential impact on benefits further down line if not engaged early REPUTATIONAL: Perception that GP Data Controllers have to defend patient data against HSCIC extraction				organisations, including regionally. The pathfinder approach means that the risk is mitigated in that areas of concern can be addressed quickly before any further rollout (judged by success criteria) and also is ensuring concentrated engagement efforts at a regional level. This is being supported by research activity and engagement with professional groups.
2	Issue	No approved business case for the programme	Development of the business case for care.data did begin in late 2013 but was placed on hold due to resource constraints. This means that, in a number of areas, the programme is effectively working at risk. Some aspects of the programme are funded through other routes (Grant In Aid and NHS England programme budget for resource) but this is required urgently to move the programme forward.	TIME: Impact on business case approval will lead to impact upon delivery timescales COST: Impact on cost through timescales for delivery moving out and also could mean uncontrolled cost and budget setting/tracking BENEFITS: Potential impact on benefits in that there could be difficulty in defining benefits against the delivery taking place (should all be defined in one place).	5	6	Amber Red	Business case approach options developed and appropriate approach being agreed (will follow a Cabinet Office agile approach utilising a Programme Business Case and justifications falling from this as opposed to via a SOC as per original development). PSBC for business case specialist support has now been approved by the HSCIC and with the DH for final approval and programme management resource has now been identified to lead the development. Development of phase 1 of the Strategic Capability Platform, a dependency element of the programme, is now being taken forward in HSCIC via a separate business justification (this is in development).
3	Risk	Lack of transparent HSCIC data release controls	Unless the controls around data release are fully transparent there is a risk that healthcare professionals	TIME: Potential impact on delivery timescale where any lack of confidence/support would halt progress.	4	3	Amber	The HSCIC published a report detailing all data released under the HSCIC, including the legal basis on which data was released and the purpose to which

6. To	p 5 risl	ks and issues	s (impacting curren	t plan/deliverables)				
Risk / Issue ID	Type (Risk / Issue)	Risk/Issue Title	Risk/Issue Description	Impact Description	Impact	Likelihood	RAG Status	Mitigation Plan
		impacting on programme	and the public will not support the programme.	COST: Cost implications in relation to any delay/additional work required to restore support/confidence. REPUTATIONAL: Reputational impact as a wider organisation and for the programme itself.				<ul> <li>the data is being put. This report will be updated on a quarterly basis and is intended to encourage public scrutiny of HSCIC decisions.</li> <li>Sir Nick Partridge has conducted an audit of all the data releases made by the predecessor organisation, NHS Information Centre, and this will be published on 17<sup>th</sup> June.</li> <li>The HSCIC has established a Transparency and Information Assurance Programme which will be responsible for ensuring the effective implementation of changes resulting within the HSCIC.</li> <li>The programme team is working with HSCIC colleagues, NHS England and departmental colleagues to develop a straightforward overview of the target governance for communication purposes and this has already been tested with the care.data Advisory Group.</li> </ul>

7. Key Programme details		Key Programme contacts	S
Programme start date	Activity started on the programme in September 2012	Senior Responsible Owner (SRO)	Tim Kelsey, NHS England
Programme end date	tbc	HSCIC Programme Director	Eve Roodhouse
Current Delivery Framework stage	Initiation (Brief approved; programme accepted		

# Programme Board Highlight Report for:

	onto HSCIC work portfolio; PVR taken place at end April; Programme Definition Document (PDD) to follow; business case in development)
Current Investment Justification type, stage and approval status	Development (business case in development)
Next Investment Justification type, stage	Quality Assurance then Approval
Primary Funding Organisation	Funding detail (proposed breakdown) being detailed in business case
Commissioning Organisation	NHS England (primary commissioning organisation); care.data programme board is being re-established and is next meeting on June 25th.