Ref: care.data/Programme Board/Paper 02

Title: care.data Programme Board Highlight Report

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<u>Purpose:</u> 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.

Background: 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).

<u>Desired outcome(s)</u>: 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.

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

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 9th 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 25th June.

2. Key Programme RAG areas	RAG status	RAG status 'headline' commentary
Key delivery milestones over the next 3 months	Α	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	Α	Benefits were initially drafted as part of business case development, will be picked up again when this commences.
Quality management against plan	Α	Quality management measures/plan being developed in support of the programme definition (specifically for the Programme Definition Document).
Programme end date	Α	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	A	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
Formal Approval letter from Cabinet Office received confirming £1.8m Professional Services Business Case approved with 2 conditions: 1) DH / NHS England to set out a final position on the need for strategic agency support, or alternative arrangements. 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.	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.	Open House Day events June 17th – 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'.	You Said, We Will Do: Analysis of stakeholder engagement log completes Friday 20 th 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. Updates will be made to policy as a result of feedback. Additionally, the programme approached will be aligned to stakeholder feedback across the programme.

3. Progress against plan this reporting period	Key areas of focus for next period		
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Vulnerable and excluded groups: June 26th workshop ready to go ahead - MENCAP are managing attendance at the event.	Vulnerable and excluded groups: Outcomes from this workshop will feed into the 'You Said, We Will Do' work above.		
Advisory Group stakeholder engagement meetings/workshops (x 5 events): - Members have been updated on proposed approach for meeting locations, which will be aligned with pathfinder areas.	Advisory Group stakeholder engagement meetings/workshops (x5): The first event is now scheduled for late July.		
Public Deliberative /Dialogue Workshops: first scoping meeting held with Ipsos Mori to develop research elements.	Public Deliberative /Dialogue Workshops: 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	Regional Engagement		
Continued development of Pathfinder Proposals on selection process for first 100-500 GPs in the first pathfinders phase. Feedback from regional areas incorporated. To be presented to and discussed with sub-group of Advisory Group on 20 th June, the full Advisory Group and the Programme Board on 25 th June.	Finalised Pathfinder Proposals to be presented for ratification: to present and agree proposals. GPs to join Pathfinders thereafter (pathfinders proposed to volunteer to participate).		
17 th June Open House Meetings: Finalised plans and content. Regional staff now lined up to support facilitation at events which are to run next week.	Facilitate Open House events on 17 th June in regions.		
Progressing with Regional Engagement staff recruitment: Agenda for Change approval now received and job adverts to be released imminently.	Progressing with Regional Engagement staff recruitment.		
	Research		
Research Commenced work with Ipsos Mori to design research/discussion guides.	Further develop research brief. Research implementation plan to be reviewed in light of revised Pathfinder approach.		
Communications & Marketing	Communications & Marketing		
Creative Agency Procurement: Briefing meeting held to commence scoping of creative requirements.	Creative Agency Procurement: The creative agency is re-planning the approach to marketing, to accommodate pathfinder proposals.		
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.	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		
Website Updates: Work continues to align language across websites. Considering FAQ	to plot further comms opportunities now that ERG clearance has been given for		

3. Progress against plan this reporting period	Key areas of focus for next period
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.	paid spend.
The second of th	Pathfinder communications scoping will commence once Pathfinder approach is agreed.
<u>Policy</u>	Policy
Roadmap on scope of GP dataset 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.	Primary Care Directions: Primary Care Directions will be reviewed to determine whether any amendments are required to the original issued to HSCIC in December 2013.
 Fair Processing Guidance for GP practices Discussions with IG alliance seeking their support and advice. Discussions with ICO clarifying guidance they may provide either solely or jointly, in relation to care.data and a broader piece on fair processing. 	amendments are required to the original issued to riscic in December 2013.
Patient Objections management: Workshop discussions objections process has been held based on listening exercise feedback. Considered scope, communication, and consent models across the health service.	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.
 FOIs/PQs/CDO mailbox continued low levels of new queries: NIL FOI received this week. Nil PQs received. Only 1x CDO query received this week about patient clarity of what opting out means. 	Continue to monitor FOIs/PQs/CDO mailbox
HES- Primary Care linkage	HES- Primary Care linkage
 GPES participation meetings ongoing to ensure technical readiness. 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. 	 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. Pathfinder proposals to be issued to care.data Advisory Group and

3. Progress against plan this reporting period

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.

Patient Objections

- First Patient Objections self-assessment forms returned and clarifying Patient Objection Management (POM) implications for LD Census.
- Project Brief being finalised.

Platform and Technology

- Business justification (OBJ) under development, cost model updated.
- Project plan for build stage elaborated.
- Briefing presentation presented to HSCIC Board and all documentation being progressed is going through the Strategic Capability Platform (SCP) project board.
- Workshop held with Service management and Data Management Environment (DME) to begin to build service model.
- Funding approach for phase 1 of the platform being discussed.

Enterprise De-identification Solution & Index Solution (EDS&I)

Project on hold, due to need to divert all available resources to platform work.

HSCIC Patient Information Line

- Low number of calls to the patient information line in the period, top patient FAQs /feedback(cumulative) were:
 - -Information Governance Security of Data / 3rd Party Access
 - -How do I opt out / object?
- Service is operating in line with the contract and customer satisfaction levels remain good at 93.8%.

GP Information Line (Contact Centre)

 Very few queries from GP practices in relation to care.data. Those queries mainly relate to being able to get care.data leaflets and posters and when the data extract will begin.

Maternity and Children's Data Set (MCDS)

The full technical re-design of the infrastructure to align MCDS with care.data and to meet

Key areas of focus for next period

programme board on 25th June.

Patient Objections

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

- 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.
- Procurement approach to SAS and laaS agreed and elaborated.
- Secure data lab requirements under development.

Maternity and Children's Data Set (MCDS)

• The interim assurance letter between NHS England and HSCIC, ahead of the Memorandum of Understanding (MoU), for MCDS is awaiting

3. Progress against plan this reporting period Key areas of focus for next period the requirements of the HSCIC Hosting Strategy is now complete. An outcome of re-design approval within NHS England. There is a concern the timeline will be work is the need for less upfront capital but more on-going revenue than was originally impacted, as procurement cannot take place within the required approved. A Tolerance Exception Report has been submitted to HSCIC Portfolio Board timeframe if this assurance is not in place by the end of June 2014. seeking agreement to fund the shortfall. Attend the HSCIC Portfolio Board to present Tolerance Exception Report on 26th June. Primary Care Pathology (PCP) project PCP project has been put on hold. Resources from this project have been re-assigned to support the time critical care data infrastructure delivery which PCP is also dependent upon. **Governance and Controls Governance and Controls** Programme Board in process of re-establishment. Invites with draft ToR gone out - next Develop revised governance structure and TOR beneath the **Programme** meeting scheduled for 25th June. Board, to support Programme and address PVR comments. Pathfinder Critical Success Factors draft further developed and comprises a list of Review and further refine Pathfinder decision point criteria, and to be Dependencies to inform the Pathfinders 'launch' decision. These dependencies have been communicated and agreed (inc programme board). split between: **Pre-requisites** (prior to the launch decision); and **Post launch criteria** (to inform the decision on how to proceed to future phases). Assurance: Project Validation Review (PVR) recommendations A formal Assurance: Project Validation Review (PVR) recommendations communicated and a action plan will be finalised in advance of the July programme board. formal action plan is in development. Care data business case and funding: Care.data business case and funding: Recommence the business case development with appropriate resource in Options put together and discussed re care.data business case approach going forward. This place. Approvals timeline to follow and be communicated when approach approach to be agreed and communicated although will follow Cabinet Office agile approach (a Programme Business Case with justifications falling from it). agreed. Resources: Resource gaps are being addressed, with a number of staff joining the team in key roles from Resources: the end of June, including Programme Heads for Data Delivery and Strategic Capability Continue recruitment activity into the Programme team, including the following Platform. This will make a significant difference, but there are still significant gaps in key roles: resourcing and recruitment is ongoing to ensure that the team is adequately resourced at all business case specialist levels. risk manager/planner Programme Administrator. 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

Recruitment of Programme Administrator is in train (advert close date of 13th June).

has been earmarked to support the development of the business case.

Risk management: Currently working towards the position of a single

Tracking Database (with set-up and training).

programme log for NHSE and HSCIC team members, for baseline and via the

3. Progress against plan this reporting period	Key areas of focus for next period
Job adverts for NHS England additional programme staff due on NHS jobs covering Regional Engagement, Comms and programme management support.	Programme Definition Document (PDD) – development of PDD including
Advisory Group meeting – next scheduled for 25 th June.	workstream definition – alongside business case development to ensure consistency of scope definition.

4. Key upcoming milestones for programme **Current forecast RAG Key milestone Description Progress** date Strategic Capability Complete Brief for phase 1 of Strategic Capability Platform (SCP) Dependencies: SCP Proiect Board and HSCIC Portfolio Platform Phase 1 (infrastructure uplift in the HSCIC to enable appropriate data Board approval (HSCIC governance). platform for care.data) approved by the SCP Project Board – to approved enable procurement, development and delivery to commence. Completed (Approved May 2014) This phase 1 development is via separate business iustification. (This is now approved by SCP Project Board and by HSCIC Portfolio Board). Marketing and research Complete Department of Health approval for the marketing spend Completed (Approved early June 2014) £1.8m Business Case Cabinet Office ERG final approval funding approved Dependencies: Cabinet Office approvals body (ERG). letter received 28/5/14. Commencement Order Complete Commencement of Order of Confidentiality Advisory Group Completed (Received Royal Assent late May 2014) of CAG Elements of (CAG) elements of Care Bill & associated elements (i.e. Care Bill receives Royal Assent). Dependencies: Department of Health (outside of care.data). Marketing, research A/G Late June 2014 Funded marketing supported by regional stakeholder events. Briefing meetings with newly appointed research agency and stakeholder events Research activity commenced to support engagement taking place and approach being finalised - will feed the pre-requisites for launch and the success factors for launched campaign. Dependencies: Approval of funding evaluation. (dependency on milestone 2 above). Pathfinder objectives A/G End June 2014 Objectives, the approach to GP pathfinder practice selection Pathfinder objectives and approach documented and and selection approach (including the criteria) to be agreed and approved by being tested/discussed with stakeholders, including subgroup of Advisory Group (20th June) and for review and agreed Programme Board with a clear plan of delivery (selection). approval by programme board 25th June. Dependencies: Approval by Programme Board. Advisory Group consultation (anticipated sub-group in June). IIGOP consultation. GP consultation.

4. I	Key upcoming m	ilestone	es for programi	ne	
	Key milestone	RAG	Current forecast date	Description	Progress
6	Pathfinder practices selected	A/G	End July 2014	GP practices selected and fully engaged with appropriate communication and delivery plans available. Dependencies: Milestone 5 (approach) above	
7	Pathfinder stage success criteria agreed	A/G	End Aug 2014	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. Dependencies: Pathfinder stage success criteria approved Programme Board. Pathfinder plans including pre-requisites for launch baselined (mid-July) IIGOP consultation and agreement. Advisory Group consultation. Will be informed by research work (for engagement effectiveness elements of evaluation).	
8	Decision made to proceed to pathfinder launch		Date to be confirmed (when Board deems dependencies are met)	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: • Primary Care Directions (late August) • Privacy Impact Assessment (late August) • Data Controllership Agreement (HSCIC & NHS England – late August) • Marketing Communication materials produced and made available (mid-August)	 First review of Primary Care Directions completed and advice sought from Information Governance team. Work has commenced on Privacy Impact Assessments and is progressing; dependency on research work providing a selection of relevant results. Meetings are taking place to progress the Data Controllership Agreement Marketing Communication materials for GPs, the public and for engagement events. This is linked to research activity above.
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).
10	Assurance of pathfinder stage complete		Date to be confirmed	IIGOP assurance complete and recommendations made to Programme Board. This is dependent on milestone 7 above.	
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	

4. I	4. Key upcoming milestones for programme								
	Key milestone	RAG	Current forecast date	Description	Progress				
				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	Α	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. To	6. Top 5 risks 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 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.	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 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	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 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	TIME: Impact on business case approval will lead to impact upon delivery timescales	5	6	Amber Red	Business case approach options developed and appropriate approach being agreed (will follow a Cabinet Office agile approach utilising a	

Risk / Issue ID	Type (Risk / Issue)	Risk/Issue Title	Risk/Issue Description	Impact Description	Impact	Likelihood	RAG Status	Mitigation Plan
			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.	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).				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 impacting on programme	Unless the controls around data release are fully transparent there is a risk that healthcare professionals and the public will not support the programme.	TIME: Potential impact on delivery timescale where any lack of confidence/support would halt progress. 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.	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 the data is being put. This report will be updated on a quarterly basis and is intended to encourage public scrutiny of HSCIC decisions. 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 th June. 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. The programme team is working with

6. To	6. Top 5 risks 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	
								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.	

7. Key Programme details		Key Programme contacts	
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 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.		