

Ref: care.data/Programme Board/Paper 02
Title: care.data Programme Board Highlight Report
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Programme Board Sponsor: Eve Roodhouse, Programme Director
Purpose: 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 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 for each workstream in the programme).
Desired outcome(s): 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.

Reporting period: For Programme Board on 16th July 2014

Report date: 10/07/2014

1. Overall delivery confidence RAG	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14
	A	A/R	A/R	A/R	A	A

Overall delivery confidence commentary

A revised plan for the delivery of primary-secondary care linked data for a number of 'pathfinder' GP practices is in place and the programme is progressing against this. The key elements for this are the delivery of a number of pre-requisites (including technical readiness and appropriate stakeholder and public engagement) to enable the programme board to decide whether the pathfinder stage can launch. The implementation of the primary care extract for pathfinder GP practices will launch only when the board is happy for it to and they will also seek independent advice (the Independent Information Governance Oversight Panel (IIGOP) has agreed to support the programme board in this respect) and, when launched, the success of it will be evaluated before any decisions on future rollout activity are taken by the programme board (again supported by independent advice). Outputs and approaches in relation to this pathfinder stage are also being tested with the care.data Advisory Group, whose input is valuable for the programme.

The care.data programme board has now been fully re-established (with revised membership and ToR) and, in June, it approved the pathfinder approach and planning principles for the programme (these were also tested with the Advisory Group). The critical path for the pathfinder stage is being established for the board so that progress can be tracked against the key identified pre-requisites.

In support of this agreed pathfinder approach, the intention is that 'expression of interest' letters will go out to the CCGs in w/c 14th July. There is a wide range of activity taking place for the pathfinder stage, particularly as regards engagement and this is now supported by a communications and engagement plan. This activity is being shared with the Advisory Group (including discussion with a sub-group of this body) and indeed Advisory Group members are attending and scheduled to attend events and workshops alongside stakeholders and the wider public. In support, a host of supporting materials are being prepared and are being shared including Q&As and progress/update communications. Additionally, a roadmap for the primary care extract is near completion and will be tested with the Advisory Group on 18th July, and a document highlighting responses to what has been heard during the listening period ('You said, We will do') is being prepared.

The programme is still delivering without a business case and remains under intense scrutiny, with the SRO having attended the Health Select Committee on 1st July. Resource gaps are being addressed quite rapidly, with a number of staff joining the team in key roles through the June-August period. This will make a significant difference, including in regard to business case development, but there are gaps in resourcing (particular in controls and support areas) and recruitment is ongoing to ensure that the team is adequately resourced at all levels.

The recommendations from the recent Major Projects Authority (MPA) Project Validation Review (PVR) are being addressed, with a formal action plan being developed to enable the programme board (and the MPA) to assure progress.

The Amber Red status for the programme reflects the direction of the programme board, who felt that, despite good progress being made towards the first stage of delivery, with no business case in place for the programme, this was a realistic reflection of the programme as a whole.

2. Key Programme RAG areas	RAG status	RAG status 'headline' commentary
Key delivery milestones over the next 3 months	A	Emphasis is focused 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 programme committed to delivery of primary care activity only (separate funding arrangements were put 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 programme committed to delivery of primary care activity only (separate funding arrangements were put in place for research activity to support awareness extension).
Benefits realisation confidence	A	Benefits were initially drafted as part of business case development and will be picked up again when this business case development commences.
Quality management against plan	A	Quality management measures/plan being developed in support of the wider programme definition (the Programme Definition Document will specifically detail this).
Programme end date	A	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. Proposal that business case development will take approach of overall Programme Business Case and business justifications falling from this (e.g. for primary care extract; for Strategic Platform) – this will be considered for approval by the programme board.
ICT Spend Approval status	R	ICT Spend Approval will be developed (as standard) 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 controls and support areas.

3. Progress this period

Workstream	Key areas of progress and upcoming activity
Communications, Stakeholder Engagement and Media	<p><u>Marketing and Research</u></p> <p>Funding was previously confirmed for £1.8m 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. This is being followed up with the DH digital portfolio team.</p> <p>Marketing agency has yet to be contracted but this is anticipated w/e 11th July.</p> <p><u>Engagement</u></p> <p>National engagement public activities continued with the Healthwatch National Conference. Valuable feedback received that will be incorporated into policy, communications and marketing developments to be tested during the Pathfinders stage.</p>

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Workstream	Key areas of progress and upcoming activity
	<p>You Said, We Will Do: draft briefing paper (highlighting what the programme has heard during the listening phase) currently in internal review and intention to share it with the Advisory Group when they meet on 18th July.</p> <p>Advisory Group stakeholder engagement meetings (x 5 events): First event scheduled for 26th July. 2 draft business cases submitted for permission to release funding to cover digital content and event management costs. There is a risk that budget may not be released in time for events, and Advisory Group responses have been low, although these risks are being managed.</p> <p>Stakeholder engagement process continues with the stakeholder log now being shared widely.</p> <p>Vulnerable and excluded groups: June 26th workshop – positive feedback - MENCAP managed attendance at the event.</p> <p><u>Research Progress (Ipsos MORI)</u></p> <p>Research Activity: Research materials for deliberative events being finalised. Proposals for quantitative research being prepared, pending confirmation of number and geographical location of pathfinders.</p> <p>Public Deliberative Research events: Draft discussion guide currently being reviewed. GP agreed to present programme at GP Practice Manager London event (24th July) and currently seeking GP support for the Leeds event (28th July).</p> <p><u>Regional Engagement:</u></p> <p>Pathfinder selection: Continued development of Pathfinder Proposals on selection process for first 100-500 GPs in the first pathfinders phase. Feedback from regional areas incorporated. Working to complete the pathfinder materials (pathfinder pack) and expression of interest letters to go out to CCGs w/c 14th July.</p> <p><u>Communications & Marketing</u></p> <p>Creative Agency Procurement: Briefing meeting held to commence scoping of creative requirements.</p> <p>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.</p> <p>Website Updates: Work continues to align language across websites. In the meantime care.data comms have recommended updates to patient-facing FAQs on the NHS Choices website.</p>
Commissioning Strategy & Policy	<p>Roadmap on scope of GP dataset: Has been developed (and been further reworked following internal review comments from the care.data policy group) and is being updated for submission to the Advisory Group for discussion on 18th July (and subsequently to the programme board). A letter to stakeholders explaining the reasons for not including additional codes in the pathfinder stage has been drafted. A consultation document on</p>

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	<p>expanding the dataset is being drafted.</p> <p>Legislation: DH consultation has been published.</p> <p>Objections: A briefing note is being prepared for DH officials to send to the Secretary of State, the content of which will be informed through discussion at the deliberative events being led by Ipsos MORI (see above) and by discussion at the Advisory Group.</p> <p>Fair Processing Guidance for GP practices:</p> <ul style="list-style-type: none"> • 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.
<p>Technical Delivery</p>	<p><u>HES- Primary Care linkage</u></p> <ul style="list-style-type: none"> • 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 for consideration by the Advisory Group and programme board. • 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. <p><u>Platform and Technology</u></p> <ul style="list-style-type: none"> • Business justification (OBJ) for platform completed for consideration (in HSCIC, this is governed through the Strategic Capability Platform (SCP) project board) and cost model updated. • Project plan for build stage elaborated. • Workshop held to begin to build service model. • Funding approach being agreed. The funding for this initial investment is expected to come from HSCIC contingency fund. <p><u>Maternity and Children's Data Set (MCDS)</u></p> <p>The full technical re-design of the infrastructure to align MCDS with care.data and to meet the requirements of the HSCIC Hosting Strategy is now complete. An outcome of re-design work is the need for less upfront capital but more on-going revenue than was originally approved. The interim assurance letter between NHS England and HSCIC, ahead of the Memorandum of Understanding (MoU), for MCDS is now in place so this will now enable the work to progress (infrastructure spend can commence).</p>
<p>Programme Office / Controls</p>	<p>Programme Board re-established and reconvened for first time on 25th June with revised membership and ToR.</p> <p>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:</p> <ul style="list-style-type: none"> • Pre-requisites (prior to the launch decision); and

3. Progress this period

Workstream	Key areas of progress and upcoming activity
	<ul style="list-style-type: none"> • Post launch criteria (to inform the decision on how to proceed to future phases). <p>Assurance: Project Validation Review (PVR) recommendations communicated and a formal action plan has been drafted.</p> <p>Care.data business case and funding: Proposal put together re care.data business case approach going forward for consideration by programme board.</p> <p>Resources: Resource gaps are being addressed, with a number of staff joining the team in key roles through June, including Programme Heads for Data Delivery and Strategic Capability Platform (David Corbett and David Ibbotson respectively). This will make a significant difference, but there are still gaps in resourcing and recruitment is ongoing to ensure that the team is adequately resourced at all levels.</p> <p>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.</p> <p>Job adverts for NHS England additional programme staff due on NHS jobs covering Regional Engagement, Comms and programme management support.</p> <p>Advisory Group meeting – Next meeting on 18th July.</p>

4. Key upcoming milestones for programme

	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. This phase 1 development is via separate business justification. (This is now approved by SCP Project Board and by HSCIC Portfolio Board).	Dependencies: SCP Project Board and HSCIC Portfolio Board approval (HSCIC governance). Completed (Approved May 2014)
2	Marketing and research funding approved	G	Complete	Department of Health approval for the marketing spend Dependencies: Cabinet Office approvals body (ERG).	Completed (Approved early June 2014) £1.8m Business Case Cabinet Office ERG final approval letter received 28/5/14.
3	Commencement Order of CAG Elements of Care Bill	G	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).	Completed (Received Royal Assent late May 2014)

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	Key milestone	RAG	Current forecast date	Description	Progress
4	Marketing, research and stakeholder events launched	A	Mid-late July 2014	Funded marketing supported by regional stakeholder events. Research activity commenced to support engagement campaign. Dependencies: Approval of funding (<i>Dependency on milestone 2 above</i>).	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	<i>Pathfinder objectives and selection approach agreed</i>	C	<i>Complete</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>Dependencies:</i> <ul style="list-style-type: none"> • <i>Approval by Programme Board.</i> • <i>Advisory Group consultation (anticipated sub-group in June).</i> • <i>IIGOP consultation.</i> • <i>GP consultation.</i> 	<i>Pathfinder objectives and approach documented, tested/discussed with stakeholders, including Advisory Group and approved by programme board 25th June.</i>
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.	Expression of interest letters due to go out w/c 14 th July. Pathfinder comms pack put together (supported by other stakeholder and internal comms materials).
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: <ul style="list-style-type: none"> • 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). 	IIGOP support in place for providing independent guidance for the programme board in relation to the pathfinder stage.
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: <ul style="list-style-type: none"> • Primary Care Directions (late August) • Privacy Impact Assessment (late August) • Data Controliership Agreement (HSCIC & NHS England – late August) • Marketing Communication materials produced and made available (mid-August) 	<ul style="list-style-type: none"> • 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 Controliership Agreement • Marketing Communication materials for GPs, the public and for engagement events. This is linked to research activity above.

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	Key milestone	RAG	Current forecast date	Description	Progress
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 <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 (<i>Dependency on milestone 10 above</i>).	
12	Programme governance fully established including board re-establishment and sign-off/approvals	A	Late 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.	Advisory Group and programme board established and working with agreed ToRs. Operational governance (next layer) to be addressed as resources come in in July.

6. Top 5 risks and issues

Risk / Issue ID	Type (Risk / Issue)	Risk/Issue Title	Risk/Issue Description	Impact Description	Impact	Likelihood	RAG Status	Mitigation Plan
1	Risk	Lack of appropriate positive clinical engagement for the programme (primary care extract)	There is a risk that GPs/clinicians will not be fully engaged with the pathfinder stage (primary care extract) of care.data, may not have confidence in care.data, and that will impact the realisation of benefits as the programme progresses.	<p>TIME: Impact through delays – need to make further efforts – via professional bodies and on the ground in regions (CCGs) – to secure engagement</p> <p>COST: Impact on cost through wider, more intense engagement/comms strategy</p> <p>BENEFITS: Potential impact on benefits further down line if not engaged early</p> <p>REPUTATIONAL: Perception</p>	4	3	Amber	<p>Now being addressed through specific programme 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.</p> <p>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</p>

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				that GP Data Controllers have to defend patient data against HSCIC extraction				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	Although committed to the pathfinder stage of delivery, 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.	<p>TIME: Impact on business case approval will lead to impact upon delivery timescales</p> <p>COST: Impact on cost through timescales for delivery moving out and also could mean uncontrolled cost and budget setting/tracking</p> <p>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).</p>	5	6	Red	<p>Business case approach options developed and appropriate approach being agreed (intention to follow approach utilising a Programme Business Case and justifications falling from this as opposed to via a SOC as per original development) – for programme board agreement.</p> <p>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.</p> <p>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).</p>
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.	<p>TIME: Potential impact on delivery timescale where any lack of confidence/support would halt progress.</p> <p>COST: Cost implications in relation to any delay/additional work required to restore support/confidence.</p> <p>REPUTATIONAL: Reputational impact as a wider organisation and for the programme itself.</p>	4	3	Amber	<p>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.</p> <p>Sir Nick Partridge has conducted an audit of all the data releases made by the predecessor organisation, NHS Information Centre, and this was published on 17th June and was followed</p>

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								<p>by an appearance at the Health Select Committee on 1st July (with Tim Kelsey).</p> <p>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.</p> <p>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.</p>

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 July 16th.		