

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.

1. Overall delivery confidence RAG	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14
	A/R	A/R	A/R	A/R	A/R	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 area are the completion of a number of pre-requisites (including technical readiness and appropriate stakeholder and public engagement and awareness within the pathfinder areas) to enable the programme board to decide whether data can be extracted from practices participating in the pathfinder stage. The implementation of the primary care extract for pathfinder GP practices will commence only when the board is happy for it to and they will make their decision based (amongst other things) on advice received from the Independent Information Governance Oversight Panel (IIGOP) and the care.data Advisory Group. The decision on future rollout activity will be taken by the programme board only after the pathfinder stage has been evaluated, and will again be informed by independent advice.

The critical path for the pathfinder stage has been established for the board so that progress can be tracked against the key identified pre-requisites. The original intention was to write to all CCGs inviting them to express an interest in becoming a pathfinder. Following advice, it was felt that a targeted approach to CCGs was more appropriate. This will be led by regional NHS England colleagues based on insight and informal expressions of interest received from CCGs throughout the ongoing engagement. Deliberative research events led by Ipsos MORI (12 & 19 July) and GP Practice Manager workshops (24 & 28 July) have taken place. Ipsos MORI has now been delivered to the care.data programme and the Advisory Group (6 & 13 August). This research will be presented to the Programme Board on 26 August 2014.

The programme is still delivering without a business case and remains under intense scrutiny, with the SRO having attended the Health Select Committee on 1 July. Funding for large parts of the programme (including HSCIC resources for FY 14-15) is not yet agreed (neither the source nor the funding). The Director of Finance and Corporate Services and the Director of Information and Analytics were presented with a financial report. This is being addressed with urgency by the Programme Director.

Resource gaps are still being addressed, with a number of staff joining the team in key roles through the current period. This includes dedicated resources to ensure that the business case development can now recommence. The programme board approved the proposed business case approach i.e. initial development of a programme business case at their meeting on 16 July. Interviews have now taken place and a suitable candidate is expected to be in place September 2014.

Recommendations from the recent Major Projects Authority (MPA) Project Validation Review (PVR) are being addressed, with a formal action plan now developed to enable the programme board (and the MPA) to approve and 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	R	No business case in place – funding through GIA source and care.data programme funding and

spend status		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>Research</u> Public Deliberative Research events: First deliberative event took place in London on 12 July. Second deliberative event took place on 19 July in Leeds.</p> <p>GP / Practice Manager workshops: Ipsos MORI held two workshops in London (24 July) and Leeds (28 July).</p> <p>Ipsos MORI Debrief sessions: The Ipsos MORI de-brief to feedback findings from the deliberate events took place on 6 August (Programme) & 13 August (Advisory Group). Whilst members felt that the findings weren't a surprise, there was a good open discussion on what needed to be addressed moving forwards. A follow on session was held with some of the attendees to discuss the draft wording to describe patient objections. The Programme Board presentation will occur on 26 August.</p> <p><u>Stakeholder Engagement</u></p> <ul style="list-style-type: none"> • A Letter has been drafted to Dr Sarah Wollaston MP (Chair HSC) updating her on programme. • Q&A for Practice Manager Magazine has been drafted • Script/Briefing note for use when talking to Pathfinders has also been drafted • HealthWatch England briefed verbally and in writing of potential Pathfinder CCGs following formal request <p><u>Communications</u></p> <ul style="list-style-type: none"> • Reactive Q&A for pathfinder selection process in preparation • Still awaiting sign off of revised public FAQs

3. Progress this period

Workstream	Key areas of progress and upcoming activity
	<p>Creative DLKW Lowe appointed and first meeting taken place to brief on background and requirements. Next steps for agency to immerse selves in findings in order to come up with preliminary proposals</p> <p>Patient and Public Voice Advisory group event was held on Saturday 26 July (Peterborough), chaired by Ciaran Devane</p>
<p>Commissioning Strategy & Policy</p>	<p>Objections</p> <ul style="list-style-type: none"> • Process for sign off of the SOS brief pending programme board sign off clarification • SOS brief updated (minus objection wording) <p>Expanding scope of GP dataset</p> <ul style="list-style-type: none"> • First draft of IAG benefits paper finalised and with IAG team - Monitor contacted for examples following initial feedback and MacMillan reviewing current version. • Roadmap paper finalised for Programme Board on 26 August <p>'Unresolved' policy areas</p> <ul style="list-style-type: none"> • Paper prepared for policy workshop to establish outstanding issues- pending comments from communications. <p>Commercial uses of data</p> <ul style="list-style-type: none"> • Draft Proforma finalised and sent for review. <p>Fair Processing Guidance</p> <ul style="list-style-type: none"> • ICO redrafting guidance to include clarification about there being three data controllers. Timescales requested from ICO. • Agreement that can plain English the guidance and that both the programme and the ICO should distribute the same guidance. <p>Directions</p> <ul style="list-style-type: none"> • Agreement that SCCI approval will not be achievable for the pathfinder stage. • Discussions with IG team and DH with regards to updates required for primary care directions. <p>Pathfinders</p> <ul style="list-style-type: none"> • Liaison with BMA, RCGP and PPV to progress selection panel • Meeting set up with NHS England contract team to discuss a fair processing enhanced service post pathfinder stage. • Agreement reached on GP/patient line for next 3 months subject to costing under 20K
<p>Data Delivery</p>	<p>Primary Care – Hospital Episode Statistics Linkage (PCHES)</p> <ul style="list-style-type: none"> • Regional Heads of Intelligence have continued discussions with CCGs that expressed an interest in becoming pathfinder CCGs and we expect to confirm which CCGs will go forward to the selection panel towards the back end of next week. The pro-forma we are using to capture information on each CCG which will feed into the selection panel has been finalised, and has been pre-populated with GP System/SCR status information for those CCGs that are likely to go through to the selection panel.

3. Progress this period

Workstream	Key areas of progress and upcoming activity
	<ul style="list-style-type: none"> • BMA, RCGP, HealthWatch England and the National Association of Community Action (NAVCA) have all confirmed that they will be represented on the selection panel. • A session was held with Tim Kelsey in Skipton House on Tuesday 12 August to walk through the outline plan for the pathfinder stage. The plan and timeframe will be discussed with the Programme Board on 26 August. • Engagements have taken place with the GPES programme and NHS England Policy team to go through IAG submission to extend access beyond commissioning purposes. • Care.data workshop on GP Dataset to look at the roadmap for future changes to primary care took place on 1 August. The main objectives of the workshop were to manage expectations, be clear that no changes to the dataset will take place before data starts to be extracted in the pathfinder stage and to engage with group about how we can move forward in developing proposals to change the scope and range of use for care.data primary care extracts in the future. • The Q-Divert function has been confirmed successfully implemented by Atos into GPET-Q on 18 July - this is a key element of functionality required to make sure the care.data extract can be redirected so that it goes direct to the HSCIC for processing. <p><u>Patient Objections</u></p> <ul style="list-style-type: none"> • A Patient Objection Management (POM) Working Group meeting was held on 21 July. Progress on completing self-assessment questionnaires was discussed. It was agreed that next stage meetings needed to be planned and that no proactive communications should be progressed at this point in time. • The HSCIC working group established to support the implementation of Patient Objections into the HSCIC has completed two sifting exercises on received self-assessment forms to identify which datasets and which teams will need to implement new controls on the release of Patient Confidential Data. This has confirmed as expected that the majority of Clinical Audits will be in scope for POMs and that they need to make changes regards patient consent. <p><u>Maternity and Children's dataset (MCDS)</u></p> <ul style="list-style-type: none"> • A Technical specification for Systems and Service Delivery (SSD) development infrastructure has been completed. • Discussions progressed on the potential use of "Oracle super-cluster" • Engagement has taken place with Child and Adolescent Mental Health Services (CAMHS) stakeholders to define their new requirements for additions to the CAMHS dataset. <p><u>Primary Care Pathology Project (PCPP)</u></p> <ul style="list-style-type: none"> • Project pause communications have been circulated to stakeholders • Data discovery work is in progress and will continue over the next four months
Technical Delivery	<p><u>HES- Primary Care linkage</u></p> <p><u>SCP - Phase 1</u></p> <ul style="list-style-type: none"> • Supplier negotiations have been continuing to finalise technical design and pricing • User engagement to develop secure data facility design requirements have also continued. • Service Design pack drafted that will be presented for approval at the next SCP Board. • PSBC for Technical Architect resource presented to CAP on 11 August 2014, approval granted with one caveat. <p><u>SCP</u></p> <ul style="list-style-type: none"> • Developing an infrastructure/commercial strategy working. Next steps to socialise and align with programme/HSCIC strategy/direction of travel.

3. Progress this period

Workstream	Key areas of progress and upcoming activity
	<p>Operating Model</p> <ul style="list-style-type: none"> Final Customer Needs Analysis steering group held 31 July, where BAE presented the Future Service Design proposal Working through the PSBC approach and requirements to take forward the 3 work packages where we're looking for external support
Programme Office / Controls	<p>Programme Board The next Programme Board is scheduled for 23 September 11:30 – 13:30. The Programme board session on vision and scope of the business case is scheduled for 17 September from 10:00 – 12:00.</p> <p>Assurance: Project Validation Review (PVR) recommendations A review meeting is scheduled for 16 September for the recommendations made by PVR. Action plan has been updated and circulated to the programme board. This now reflects a more realistic time set of timeframes.</p> <p>Resources: Resource gaps are being addressed, with a number of staff joining the team in key roles through July and August. 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. A job advert for NHS England for Communications, Stakeholder Engagement and Media lead is now closed. Interviewing will take place during September.</p> <p>Business Case Business case approach approved by programme board in July. The Programme Board session to discuss scope and vision will be held on 17 September. PSBC for a specialist resource to support business case development has now been advertised and interviewed. Candidate expected to start mid-September.</p> <p>Advisory Group The next Advisory Group (AG) will take place on 8 September 2014 from 10:30 – 11:00. A sub group of the Advisory Group will meet to discuss the Secure Data Facility on 1 September from 15:30 – 17:00.</p>

5 Key upcoming milestones for programme

	Key milestone	RAG	Current forecast date	Description	Progress
1	Marketing, research and stakeholder events launched	C	Mid-late July 2014	Funded marketing supported by regional stakeholder events. Research activity commenced to support engagement campaign.	Deliberative research events and GP Practice Manager workshops have taken place and plan of engagement/stakeholder events now in place.
2	Pathfinder CCGs selected	R	29 August 2014	CCGs selected i.e. to have been identified by the selection panel and contacted for them to formally confirm the offer for them to become a pathfinder area.	The original intention was to write to all CCGs inviting them to express an interest in becoming a pathfinder area. Following advice, it was felt that a targeted approach to CCGs was more appropriate. This will be led by regional NHS England colleagues based on insight and informal expressions of interest received from CCGs throughout the ongoing engagement phase.

5 Key upcoming milestones for programme

	Key milestone	RAG	Current forecast date	Description	Progress
					The current date stated in the forecast is no longer achievable and will be put to the programme board on 26 August.
3	Pathfinder stage success criteria agreed	A/G	End Aug 2014	<p>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.</p> <p>Dependencies:</p> <ul style="list-style-type: none"> • Pathfinder stage success criteria approved Programme Board. • Pathfinder plans including pre-requisites for data extract baselined • IIGOP consultation • Advisory Group consultation. • Will be informed by research work (for engagement effectiveness elements of evaluation). 	Success criteria and pre-requisites' to enable decision being produced for programme board consideration.
4	Decision made to proceed to pathfinder data extraction	R	Date to be confirmed (when Board deems dependencies are met)	<p>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:</p> <ul style="list-style-type: none"> • 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) 	<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 Controllership Agreement • Marketing Communication materials for GPs, the public and for engagement events. This is linked to research activity above. <p>The current dates detailed in the description are no longer achievable and will be put to the programme board on 26 August.</p>
5	Primary Care pathfinder data extraction		Date to be confirmed	Data extract commenced for pathfinder GP practices with linkage to HES.	As per date confirmed following Board decision (see <i>milestone 4 above</i>).
6	Assurance of pathfinder stage complete		Date to be confirmed	Assurance including independent advice	
7	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)	

5 Key upcoming milestones for programme

	Key milestone	RAG	Current forecast date	Description	Progress
8	Programme governance fully established including board re-establishment and sign-off/approvals	C	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.
9	Programme Business Case with Programme Board for review	A	October 2014	Programme business case developed and ready to go through approval process. The achievement of this milestone has a dependency on resources.	

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 communications 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.	<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/communications strategy</p> <p>BENEFITS: Potential impact on benefits further down line if not engaged early</p> <p>REPUTATIONAL: Perception that GP Data Controllers have to defend patient data against HSCIC extraction</p>	4	2	Amber/Green	<p>Now being addressed through concentrated engagement activity (with focused communications and engagement plan) and a wider Stakeholder and Communications workstream providing overall framework and strategy for the programme (i.e. stakeholder mapping, stakeholder engagement strategy, communications plan), working across organisations, including regionally. For example recent GP & Practice manager events have taken place.</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 criteria) and also is ensuring concentrated engagement efforts at a regional level. This is being supported by research activity and engagement with professional groups.</p>

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. Without a business case there is no clear scope or strategic direction after the pathfinder delivery.	<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	4	Amber/Red	<p>Business case approach options developed and approved by the programme board (will follow a Cabinet Office approach utilising a Programme Business Case and justifications falling from this as opposed to via a SOC as per original development).</p> <p>PSBC for business case specialist support has now been fully approved. Programme management resource is now in place to lead the development.</p> <p>Development of SCP – Phase 1, a dependency element of the programme, is now being taken forward in HSCIC via a separate business justification (this is in development).</p>
3	Issue	No approved funding for large parts of the programme	Funding for large parts of the programme (including HSCIC resources and GPES supplier costs for FY 14-15) is not yet agreed (neither the source nor the funding). Funding for a number of areas is however in place e.g. research activity and initial platform development	<p>TIME: Potential impact on delivery timescale where any lack of funding would halt progress.</p> <p>COST: Direct cost implication of lack of funding.</p> <p>REPUTATIONAL: Internally with delivering programme at risk. Externally with supplier costs</p>	5	6	Red	Programme director in discussions with HSCIC finance and exec director

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.	