**Ref:** care.data/Programme Board/310314\_03

<u>Title:</u> care.data Programme Governance

(This is for information - document was originally approved by the Programme Board – version as per submitted to programme board and last considered and approved in July 2013)

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**Programme Board Sponsor(s):** SRO; care.data Programme Director

**Purpose:** To set out the governance structure for the care.data programme. It also sets out further detail by way of a Terms of Reference, including membership, relating to the care.data programme board – as was originally approved by the care.data programme board in July 2013.

**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.

The care.data programme needs to be underpinned by a strong governance structure, including within the delivery organisation (HSCIC) that supports both agile delivery and a flexible structure (with new data sets to be introduced through its lifecycle) and also complements existing programme governance structures in place.

**Key Points:** The document illustrates the full governance structure that links up the commissioning body (and provides a clear structure for assuring delivery) the delivery organisation (HSCIC) and its constituent governance and delivery workstreams. The governance is designed to be flexible in that more/further data sets and associated requirements (e.g. linkage requirements) can be brought into delivery in the future and the effective governance will not be impacted adversely.

The document also provides further detail and membership of the programme board.

<u>Desired outcome(s):</u> For information – to enable the programme board to consider proposed changes to programme governance in context of the agreed ToR for the programme board and the current, agreed governance arrangements.

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	Programme Governance Document					
	Programme	NHS England Patients & Information	Document Record ID Key			
	Sub-Prog / Project	care.data programme	Status	Re-draft for Board approval		
	Owner	Christine Outram	Version	1.4		
	Author	David Farrell	Version Date	17th July 2013		

# care.data Programme Governance

**Amendment History:** 

Version	Date	Amendment History	
0.1	2/11/12	Draft for initial internal programme team review	
0.2	8/11/12	Second draft for further programme team review	
0.3	15/11/12	Third draft for review	
0.4	10/12/12	Fourth draft for internal review (following changes to delivery governance)	
0.5	13/12/12	Fifth draft for full review	
0.6	02/01/13	Changes and sixth draft sent for Bill and Christine review	
0.7	28/01/13	Changes to board and associated group definition and membership (Bill McAvoy review), and seventh draft for final review and submission to programme board for approval	
1.0	31/01/13	Approved in current form by care.data programme board	
1.1	19/04/13	Rewrite to reflect subsequent landscape change including further clarity as regards relationship with ISCG and also delivery workstream definition	
1.2	23/04/13	Further changes following Geraint Lewis and Chris Outram review (including review of board membership)	
1.3	16/05/13	Re-draft with board membership updates (for May board approval)	
1.4	17/07/13	Re-draft following board feedback and further definition of structure as well as addition of ToR for (HSCIC) delivery group heads	

#### **Reviewers:**

Following update, this document is reviewed by care.data programme individuals from both HSCIC (as primary delivery organisation) and NHSE (as primary commissioning organisation).

#### Approvals:

This document must be approved by the following:

Name	Signature	Title / Responsibility	Date	Version
care.data programme board				

#### **Distribution:**

As above, plus Helen Arthur (NHS England), Wesley Dale (NHS England) and HSCIC programme delivery team.

#### **Related Documents:**

These documents will provide additional information.

Ref no	Doc Reference	Number	Title	Version

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#### 1 Purpose

This document sets out the governance structure of the care.data programme. It also provides further details, such as the membership, of the care.data programme board, which is being established as a sub-group of the Informatics Services Commissioning Group (ISCG).

#### 2 Background

The care.data programme is a major infrastructure programme that will link a wide range of national data at record level, in many cases for the first time in England. It will collect, collate and link clinical and other data from all health and care settings, including hospital, primary care, community, mental health and social care. The combined datasets will be made available to others with all appropriate safeguards to protect confidentiality. The programme outputs will be an invaluable resource to support the business objectives of a wide range of responsible authorities including, but not limited to, members of the ISCG.

To achieve this ambition, the care.data programme will combine a number of existing and emerging programmes, bringing together key stakeholders to ensure that the requirements of the ISCG are being met; that the direction of the programme is clear and consistent; and that the benefits of the programme are fully realised. The Patients and Information (P&I) Directorate of NHS England is supporting the NHS by designing and implementing a world-class data service for the NHS and will lead the implementation of this programme.

To assure the delivery of the programme, care.data is aligned with the governance arrangements at the Health and Social Care Information Centre (HSCIC), which will be delivering the programme on behalf of NHS England.

#### 3 Scope

The care data programme will collate a range of data sets within a safe haven, specifically within the "care data platform" (formerly known as the "Open Data Platform" or "ODP"). These collated data sets will be linked, pseudonymised and quality assured so as to be ready for analysis by a wide range of users including NHS commissioners, providers, regulators, public health bodies, and researchers.

The governance structure described in this document relates to the first phase of the care.data programme (ending in March 2014); therefore, only the Phase 1 workstreams are included. However, the governance structure is sufficiently flexible to accommodate new workstreams and new data sets as they arise.

There are currently five delivery workstreams (in the first phase 1 of the care.data programme):

- WS1 Data acquisition
- WS2 Data platform and technology
- WS3 Data linkage

- WS4 Service delivery and the operating model
- WS5 Engagement, stakeholder relations and communications management

Some 15 data sets have been identified for inclusion in the first phase of the programme (anticipated for delivery through 2013-14). While many of these data sets already have their own governance arrangements in place, all of the data sets will fall under WS1 for care.data governance purposes (i.e. for ensuring that the data sets are landed and made available).

Note that the governance structure set out in this document may need to be revised in light of the recent delivery assurance review (DAR) that was completed for care.data in March 2013.

#### 4 Governance Structure

The governance structure is illustrated in Figure 1, with the following points drawn out for reference.

#### 4.1 Informatics Services Commissioning Group

The Informatics Services Commissioning Group (ISCG) formally establishes all informatics programmes that are to be commissioned by its member organisations, including the care data programme.

Commissioning of delivery of the programme is via a Memo of Understanding (MoU) between the appropriate parts of NHS England (as the primary commissioning organisation) and the HSCIC (as the delivery organisation). In this case, agreement of this MoU is between the Patients & Information Directorate (in NHS England) and the Information and Data Services Directorate (in the HSCIC).

#### 4.2 care.data programme board

The care.data programme board, acting as a sub-group of the ISCG, provides assurance for the commissioned programme. To do so, it provides governance and control to assure the delivery of the programme, for example by receiving progress reports (covering all care.data delivery workstreams) and by addressing all risks and issues that have been escalated. The board also sets the strategic direction of the programme, and ensures that this is fully understood by the delivery partner (the HSCIC) and is being delivered.

The board engages with stakeholders, requirement groups, external reference groups and small and medium sized enterprises (SMEs). It also links with other internal groups (e.g. Design Authority) to ensure that the strategic design of the programme is both appropriate and is meeting the requirements of stakeholders.

Further details of the care.data programme board can be found in Appendix A.

#### 4.3 care.data delivery structure

As the principal delivery partner, the HSCIC is responsible for the overall delivery of the care.data programme.

The care.data delivery group heads is the co-ordinating group for the delivery structure. It provides assurance and controls for the HSCIC in relation to delivery of the programme, and also acts as an approval body (i.e. for formal approval requirements that fall below the remit/tolerances of the programme board; or for items requiring pre-board approval; or for change request items outside the tolerance levels of the programme board) and a route for escalations and resolution (e.g. risks) for the delivery workstreams. To this aim, it therefore acts as an overall conduit for these delivery elements through to the programme board and reports key decisions (e.g. delivery approvals) to the board.

As the enabling activities in support of delivery of the care.data programme are key activities/projects within the HSCIC portfolio, this group also has responsibilities for reporting, assurance and controls through to the HSCIC Portfolio Board (and HSCIC Exec Team) as per existing organisational governance arrangements, which include the organisational links between the HSCIC and the ISCG.

Additionally, governance arrangements are in place, both within the care.data delivery workstreams, and through to NHS England (Patients & Information Directorate) in relation to agreed reporting, assurance and controls requirements.

#### 4.4 care.data delivery workstreams

#### WS1 - Data acquisition workstream

This workstream is responsible for: the delivery of all associated data migrations, the landing of these data set, short-term tactical solutions, and the medium to long-term strategic solution. This workstream will also coordinate the governance arrangements for those data sets with existing governance structures in place.

#### WS2 - Data platform and technology workstream

This workstream is responsible for the medium to long-term strategic delivery of the care.data platform (formerly known as the 'Open Data Platform' (ODP)). It is also responsible for the delivery of interim tactical solutions to support the delivery of care.data. Key links for this workstream will include NHS providers, NHS England, Public Health England, and other HSCIC programmes such as Exeter, GPES, and the Data Management Environment (DME).

#### WS3 - Data linkage workstream

This workstream is responsible for the development and enhancement of the data linkage business unit and will provide a schedule of data linkages that will help support the objectives of the care.data programme. It has links with the existing data linkage programme within HSCIC and with other NHS England programmes.

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#### WS4 - Service delivery and the operating model workstream

This workstream is responsible for establishing and maintaining the service delivery and operating model of care.data, and indeed wider elements of HSCIC operations where change is likely to impact the wider organisation. It includes links with other HSCIC and NHS England programmes.

## WS5 – Engagement, stakeholder relations and communications management workstream

This workstream is responsible for the development of the stakeholder engagement strategy and for co-ordinating and overseeing the delivery of this strategy. It is also responsible for communications and will work closely with colleagues in NHS England and also within HSCIC to ensure that key messages and communications are aligned.

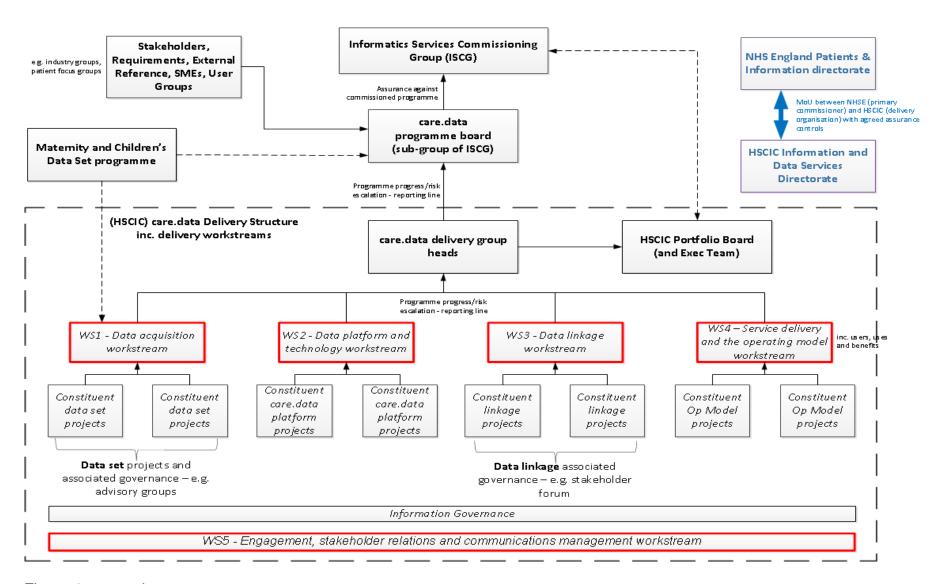


Figure 1 – care.data governance structure

#### 5 Appendices

#### 5.1 Appendix A: care.data programme board

#### Scope

Delivery focused, taking strategic leadership and direction from the ISCG (acting as a sub-group of the ISCG).

The care.data programme board includes members representing:

- 1. Commissioning
- 2. Customers
- 3. Delivery partner(s) including private sector representation where appropriate
- 4. Independent assurance
- 5. Communications

The formal planning, control and delivery of individual projects and programmes commissioned by the care.data programme rests with the respective delivery partners. The delivery partner manages any delivery risks and issues on behalf of the customer, and escalates to the care.data programme through the named commissioning Senior Responsible Owner (SRO) or her nominated representative.

#### Membership

These member roles (and named individuals where nominated) constitute the core membership of the care.data programme board. However the board may call upon others to act as external reference members or subject matter experts when required.

	Represented organisation/body (and specific function/role represented)	Name
Commissioner (NHS England)	Director of Strategy & Intelligence, NHS England, and care.data SRO (and Chair)	Christine Outram
	Chief Data Officer, NHS England	Dr Geraint Lewis
	Director, Data and Information Management Systems, NHS England	Ming Tang
	Operations Directorate representative, NHS England	
	Director of Clinical Informatics, NHS	Dr Jonathan Kay

	England	
	Chief Analyst, NHS England	Richard Murray
ISCG member organisations	Monitor	Neil Stutchbury /
Organisations		Mark Smith (Deputy)
	NICE	Alexia Tonnel /
		Andrew Fenton (Deputy)
	NHS Trust Development Authority	lain Wallen
	CQC	Tom Ward /
		Oladunni Amode (Deputy)
	Health Education England	Nicki Latham /
		Laura Roberts (Deputy)
	Public Health England	Prof. John Newton
	NHS Business Services Authority	Alistair McDonald
Department of Health	DH External Relations Directorate (DH ERD)	Peter Hall
Clinical commissioners	Clinical Commissioning Groups (CCGs)	Dr. Pete Green (NHS Medway CCG)
Research community	Clinical Practice Research Datalink (CPRD)	John Parkinson
Community	(CI ICD)	Alan Barcroft (Deputy)
	Research & Development Directorate, Department of Health	Peter Knight /
	Dopartinon or ribatin	Justin Riordan- Jones (Deputy)
NHS Providers	NHS Provider organisation	Mike Foster (University College Hospital London)
External experts	Head of Research, Nuffield Trust	Dr. Martin Bardsley
	Vice-President, Research and Analysis, Canadian Institute for Health Information	Dr. Jeremy Veillard

Patients and public	Patient and public representative(s)	tbc
Associated programmes	Maternity and Children's Data Set (MCDS) programme	Karen Turner (DH)
Delivery organisation (HSCIC)	Director of Information and Data Services, HSCIC	Max Jones
	Executive Medical Director, HSCIC	Dr. Mark Davies
	care.data Programme Director, HSCIC	TBC

**Meetings**The Programme Board currently meets every two months (VC link between Leeds and London).