Ref: care.data/Programme Board/Paper 03

Title: **care.data Draft Communications Plan**

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Programme Board Sponsor: SRO

Purpose: This document sets out the communications plan and related engagement and marketing activities for the phased extension to the care.data programme. It is a live document, outlining these critical elements and subject to amendment to reflect the iterative nature of the process and ensure deliverables are informed by evidence and responsive to feedback.

Background: The success of the activities outlined in the document aim to address issues of awareness and confidence around data usage and thereby contribute significantly to fulfilling the objective of providing timely, accurate data linked across the different components of the patient journey and positively affecting outcomes resulting from their treatment and care.

Key Points: This document sets out the communications plan and related engagement and marketing activities.

Desired outcome(s): That the programme board is provided with appropriate information to ensure confidence in a robust communications plan for the programme.

Circulation: Programme Board attendees – this version was presented to the Advisory Group on May 2nd 2014.

Care.data

Six month extension

DRAFT Communications plan

as at **28 April 2014**

SRO: Tim Kelsey

Project Head: Ronan O'Connor

Communications Lead: Simon Enright supported by Helen Dennis

Media & Stakeholder Lead: Simon Enright supported by Tim Carter

Marketing lead: John Coulthard & Phil Bastable

Introduction

This document sets out the communications plan and related engagement and marketing activities for the six month extension to the care.data programme. It is a live document, outlining these critical elements and subject to amendment to reflect the iterative nature of the process and ensure deliverables are informed by evidence and responsive to feedback.

The success of the activities outlined here aim to address issues of awareness and confidence around data usage and thereby contribute significantly to fulfilling the objective of providing timely, accurate data linked across the different components of the patient journey and positively affecting outcomes resulting from their treatment and care.

Background/Issues

- The care.data programme aims to link information from primary and secondary care providers to provide healthcare commissioners with a more complete picture of local, regional and national health requirements and services - and information on how well they treat and care for patients across community, GP and hospital settings.

- The care.data programme will mean that data will be drawn from GP practices, analysed and linked to secondary care data, for the first time (hospital data has been examined in this way for over 20 years).

- In order to do this, coded data (without name but with other identifiers such as, date of birth, NHS number) needs to be extracted from people's medical record and transferred to the Health & Social Care Information Centre (HSCIC). The HSCIC then 'de-identifies' the data (by using different codes) in order to pass it on to commissioners.

- Members of the public have a right to object to their data being extracted.

- The purpose of care.data is to improve health outcomes for people by analysing and interpreting existing data ***across*** primary and secondary care. This is the only way to get a complete picture of how the NHS is working and to understand what happens to patients before and after they have been treated. Commissioners can both monitor health and care activity and invest resources to provide the best possible services for their local communities.

- NHS England announced a six month extension to the implementation of the data extraction element of the care.data programme at the end of February 2014, to allow more time to listen and respond to the concerns of stakeholders and to further raise public awareness of the benefits of the programme.

- This extension is ***primarily*** focusing on four broad concerns;
    1. the privacy and safety of patient data
    2. who data is shared with
    3. lack of information on opting out
    4. the lack of understanding of benefits

- To engage key stakeholders in the programme, an independent advisory group was established in March 2014 with the aim of providing guidance and steer to the programme. This group will support the rolling programme outlined in this plan, facilitating a cyclical process of consultation and checking to ensure iterations are fit for purpose. This autonomous group is led by Ciaran Devane, Chief Executive of Macmillan Cancer Support and NHS England's non-executive director. Members of the group are listed at Annex B to this document.

  Proposals for a phased roll out of the GP data extraction process to begin in the autumn with between 100-500 GP practices, are also being discussed and developed with key stakeholders.

  The Department of Health is drafting a wider strategy (that this communications plan sits within) setting out the approach to aligning all key messages to ensure a consistent position to public and key stakeholders

Other issues

- The care.data programme carries both inherent and perceived risks – most notably around patient confidentiality and the safeguarding/security of the data itself which are being addressed as a matter of policy.

- There remain elements of potential care.data policy that are yet to be discussed and agreed (and which will be subject to further consultation with key stakeholders and the advisory group). This poses challenges to creating a coherent communications strategy and supporting narrative at this stage. This plan will therefore be a live and evolving document until we can move forward with clarity over the policy, refine the communications objectives, messages and activities to deliver the right results

What we've done so far

- We have led a number of local, regional, and national activities to raise awareness of the programme among patients and to explain the opt out to them.

- We sent leaflets - 'Better information means better care' - and posters to every GP practice in England in August 2013 and published information on the NHS Choices and NHS England websites; disseminated information via social media; a short video animation; information cascaded via a network of patient groups and charities, and sent a leaflet to every possible household.

- The leaflet to households cost £1.2 million to print delivered by Royal Mail, which equates to approximately 7 pence per household. The leaflet is available in Braille, BSL, easy read and large print formats online or by calling the dedicated patient information line.

- For this type and level of marketing the leaflet was successful: it achieved nearly 50% public awareness. The full evaluation report can be seen by colleagues upon request but key highlights are covered further below.

- The lead message is established as – Better information means better care. Detailed messages have been developed to explain: the purpose of the sharing of data and the benefits to the wider NHS; the measures taken to protect people's privacy; and the process for people to register an objection to prevent the sharing of their data.

- A patient information line was established to answer any questions or concerns that people may have about how their data are used to improve care for all, and the choices that are available to them.

- Research was commissioned by NHS England to evaluate the effectiveness of the door drop leaflet distribution in January 2014. This measured unprompted awareness of the NHS plans to share patient data at 33% nationally and total awareness at 47%. This indicates that further public awareness raising activity is required.

- The research indicated that the content of the leaflet was well received, of those that said they had read the leaflet: 76% said it contained the right amount of information; 68% agreed that is was clear and concise; 53% agreed it helped them understand the benefits of sharing their data; and 59% agreed the information was relevant to them.

- The research also demonstrated that audiences that had been exposed to our communications were less likely to register an objection with their GP to prevent their data being shared. Of those questioned that were not aware of the leaflet 19% said they would register an objection, this fell to 13% of those that recalled the leaflet.

- The research highlighted that the confidentiality of data is a concern, with only 29% recalling that identifying information will be removed before data sharing. The research concluded that getting this message across more clearly may make respondents more comfortable with data sharing. Information about the measures being taken to protect people's privacy will be a key message for the proposed engagement and communications activity.

- Though this research highlights that the door drop leaflet was effective in raising awareness it also shows that further engagement and communications work is required. 17% of people questioned said that they needed more information before deciding whether or not to allow their information to be shared.

Communications objectives for the 6 month extension

All audiences

- To listen, engage with and address the concerns of patients, the public and key stakeholders throughout the six month extension to the care.data programme
- To dispel the myths that have built up around care.data – including targeted communications to neutralise the inaccurate and misleading representations of the programme that are being perpetuated by its opponents
- To achieve alignment and consistency of messages through NHS England and across the NHS
- To build confidence and support for the care.data programme prior to the commencement of GPES data extraction.
- A systematic approach based upon effective stakeholder engagement – no big bang in terms of media or marketing activity

Patients and Public

- To proactively communicate the benefits and risks of care.data and setting out how it will lead to improved healthcare
- To myth bust
- To communicate that everyone has a right to object to their data being extracted for the purposes of care.data
- To provide assurance that the systems underpinning the care.data programme are robust and secure
- To provide clarity on the purposes for which data will be shared and used under the care.data programme

GPs and GP practices

- To provide GPs and GP practice managers with the support and tools they need to effectively communicate care.data to their patients
- To provide clarity over key issues of policy directly relevant to GPs To engage those GPs and clinicians who are supportive of the programme as advocates/spokespeople to help build awareness with GPs, patients and in the media

Other key stakeholders (see annexes H and I)

Including representative groups of above e.g. royal colleges and patient groups

- To ensure that our stakeholders are informed about the programme
- To enable them to raise their concerns
- To involve them in the development and implementation of the programme on an ongoing basis.

Approach

All our proposed engagement and communications activity will be informed by the views of our stakeholders and wider audiences to ensure our plans are as effective as possible and deliver good value for money.

This will work will include:

- Developing our engagement and communication plans with the advice of our key stakeholders via the advisory group;
- Holding a workshop with accessibility and vulnerable groups to inform our communications to these audiences;
- Conducting qualitative research with our key audiences to ensure that we have a clear understanding of their views, concerns and information requirements;
- Conducting creative development research to thoroughly test our stakeholder communications materials to ensure that they meet the needs of our audiences at the various engagement events that we are planning;
- Conducting creative development research to review our existing public facing marketing materials.

We are planning to commission a specialist agency to ensure that all this activity is effectively coordinated and that our materials meet the differing needs of our various audiences.

The regular polling of GP & practice staff and limited public polling will be used to determine the effectiveness of the engagement and communications activity and this will be used to further refine our engagement and communication plans.

The communications activity will make best use of NHS England owned and earned communication channels. We are proposing to use NHS Choices as a key channel to reach the public. We will also continue to work closely with our national partners, including the BMA and the RCGP, to help raise public and professional awareness.

All proposed ‘paid-for’ activity is listed with the ERG submission, a précis of which is listed at Annex J , of this document and outlined further below.

Communications to support the six month extension exercise will take place over three phases.

Phase one - listen and engage March to May 2014: We will conduct qualitative research with our key audiences. Meetings and events with a wide range of stakeholders will be organised to explain the programme and, gather views
Phase two - engage and respond May to July 2014: We will conduct quantitative research to measure levels of awareness and understanding. Engagement activity will continue with stakeholders to respond to issues and concerns. Materials will be developed and tested with our audiences.
Phase three – deliver July to October 2014**:** We will continue to conduct quantitative research with our key audiences. Materials will be produced and provided to stakeholders. Engagement events will continue. We will deliver communications through our owned and earned channels.

Research (from May to October 2014)

The research workstream will be managed by the Insight and Feedback Team within NHS England's Patient and Public Voice Division, supported by the Strategic Coordination agency. A specialist research agency will be commissioned to deliver the various proposed quantitative and qualitative research projects.

The research workstream has been planned to:

- provide us with a comprehensive understanding of the views, concerns and requirements of the different audiences. This will help to inform our engagement and communications activity and ensure that it meets the needs of our audience and is as effective as possible;
- test content and creative with GPs & practice staff and the public. This is to help ensure that all our engagement and communications materials are clear, concise, understandable and provide the level of information that our different audiences require. This is also to help ensure that the most effective communications are delivered through GP practices to patients; and
- evaluate the effectiveness of the engagement and communications activity as it is undertaken. Low profile tracking research to measure GP support of the programme, as well as public awareness and understanding will enable the programme team to understand progress and to identify areas of priority as the communications activity is delivered

A budget of £350,000 has been allocated for the specialist research agency to deliver the following activity:

- GP Practice workshops: we will run 4 national workshops with GPs and practice staff to collate an in-depth understanding of their views on the Care.data Programme, including what the concerns are and which positive aspects of the programme resonate the most.
- Deliberative events with general public: We will run 2 national deliberative events with members of the public to collate an in-depth understanding of the views of different segments about the Care.data Programme to help develop effective messages.
- Workshops with stakeholder groups: We will run 2 national events with stakeholders to understand and collate feeling among our different stakeholder groups (including relevant voluntary organisations, such as National Voices) towards the programme, in order to understand what would give reassurance and enable support.
- Focus groups to test materials with GPs and practice managers: We will run 2 focus groups to test draft communications materials with GPs, practice staff and clinical staff to ensure they are fit for purpose.
- Focus groups to test materials with the general public: We will run 2 focus groups to test draft communications materials with the general public to ensure they are fit for purpose.
- Polling of GPs and practice managers: We will run 4 waves of polling to measure levels of awareness and understanding among this key audience and to evaluate the effectiveness of the engagement activity
- Polling of the public: We will run 3 waves of public polling to measure levels of awareness and understand and to evaluate the effectiveness of the engagement activity.

Engagement (from May to October)

The engagement work will be managed by NHS England's Patient and Public Voice Division, supported by the Strategic Coordination agency and by the regional Patients and Information teams. This work will be informed by the research workstream, which will ensure that we have a good understanding of the views, issues, concerns and requirements of our audiences.

The aim of this activity is to ensure that we are able to address the concerns of our stakeholders, that they are informed about the programme and are supportive of its implementation.

A budget of £500,000 has been allocated for the engagement work (a detailed breakdown is provided in the Expenditure section). This budget is to fund the delivery of the following activity:

- Advisory group - we will undertake 5 workshops hosted in each region (Leeds, Birmingham, London, Exeter) to develop the conversation with stakeholders from where we are now – the issues, concerns and questions – through to testing solutions, sticky issues and potential recommendations. Stakeholders will include: LMC members / GPs, Local Healthwatch, CCGs, Charities, Patient Groups (PPGs), Privacy activists, Researchers, Academics. Workshops are planned to be held in May, June, July, September and October.
- Public dialogue - we will actively engage with the public through patient groups, charities and activist networks including digital channels, to undertake a process of public dialogue that seeks to hear, consider and respond to the public concerns in a way where they can influence the design and delivery of the Care.data programme. This will include hosting 6 public dialogue workshops which will seek to identify, discuss and develop the issues where there is scope for the public to influence the design of the programme. Key stakeholders will include GPs, Practice Managers, Local Healthwatch, Health and Wellbeing Boards, Local Government and Voluntary / Patient Organisations.
- Healthwatch – we will ensure that the Local Healthwatch Network has factual and detailed information about Care.data available in ways that they can understand, apply and use with their local communities. We will work with a small number of Local Heathwatch organisations to coproduce, design and test materials that support their staff and volunteers to hold informed conversations and provide feedback to Healthwatch England and NHS England. The Healthwatch England National Conference in July 2014 will be used to share materials, host a discussion and identify areas of ongoing concern to the network.
- Accessibility and Vulnerable Groups – We will run a design and planning workshop with leading communication, disability and access charities to ensure that the materials developed and the approaches to engagement are accessible and appropriate for people with specific support needs.
- Open House events – NHS England's Patients & Information (P&I) Directorate Open House is a quarterly engagement event aimed to involve key partners, patients and the public in the development of P&I programmes. We are planning for the Open House event in June to focus specifically on care.data and the use of big data in healthcare. Four parallel open house workshops are planned to be hosted in each of the four regions and be simultaneously webcast and digitally connected to discuss and debate the key issues and opportunities of the Care.data Programme. This is a new approach that aims to connect the country on one day to debate the same issues.

Local engagement events – The regional Patients and Information teams will arrange a series of local engagement events for the Care.data Programme. These will be organised to engage with a variety of local stakeholders, including GPs & Practice Managers, CCGs, Local Medical Councils, Patients representative groups (such as Patient Participation Groups) and Local Healthwatch. These events will aim to explain the details of the programme, the benefits and risks and to listen to views and address the concerns of our local audiences.

Communications (from May to October)

The proposed communications activity will be informed by the research work and will be supported by the Strategic Coordination agency as referred to in the ERG submission. This activity will also support the engagement activity, through producing content and marketing materials.

The communications workstream will be managed and implemented by NHS England's communications division and the marketing team.

All communications activity will make the best use of any free channels available to NHS England and our partners (eg original draft toolkit has issued at no cost) in addition to making use of other owned (including 'paid for') and earned channels:

- **Owned Channels**: Information is available on the NHS website (www.nhs.uk/caredata) and on the NHS England website (www.england.nhs.uk/caredata). We are planning to develop a micro-site that will be accessible on mobile devices. This will provide detailed information about the sharing of data, and include a downloadable opt-out form to simplify the process and enable 'closed loop' monitoring of numbers.
  We are also intending to run banners on all pages of the NHS Choices website that will reach all 27 million monthly users of the site and provide a link to the micro-site and the detailed information they require.

  NHS England Social media channels will continue to be used communicate with different audiences about the programme and to direct people to the detailed information that is available online. We will also publish further blogs on the NHS England website from key senior leaders involved in the programme.

  We will produce regular updates on the programme for stakeholders, this will include email bulletins and will enable feedback directly to the programme team.

- **Earned Channels:** We will continue to send information packs to GP practices in England, the development of these will be informed by the research activity and feedback on earlier iterations. These will be developed to inform GPs and practice staff about the Care.data Programme. We will also develop and provide marketing materials (including leaflets and posters) to assist them in explaining the programme to their patients. Easy-read, braille and audio versions of the leaflets will continue to be available to GP practices to order.

  We will also develop resource packs to be provided to other stakeholder groups as part of the engagement activity. These will be tested with stakeholders through the research work.

Whilst as much of the communications activity as possible will be done in-house, some of the proposed marketing work will be delivered by specialist external agencies to provide expertise and resources that are not available within NHS England. This will include a segmentation & coordination agency, a creative agency, and a digital marketing agency. Further details on what this will cover are outlined at Annex J and are subject to Cabinet Office agreement.

A **tactical plan** (subject to change and refinement as feedback is received), of proposed/potential activity across owned, earned and paid for channels, is included at **ANNEX A** to this plan.

Media

1. We will demonstrate to the media that we have been listening. We will set out all listening activity including the number of events and memberships and actions of the advisory group. We will build this into our core narrative for all of our media and published materials.

2. We will provide the media with analysis of all the listening we have done, clearly articulating the issues that need to be addressed. This will be communicated via an article for a national publication by our Deputy Medical Director Dr Mike Bewick.

3. We will announce to the media all of the actions that we plan to take in response to the listening exercise. We will issue a press release including quotes from stakeholders, including key critics, saying we have addressed the concerns expressed. We will get a number of these organisations to issue statements of support at the same time as our press release.

4. We will identify at least four key advocates/reformed critics to write articles setting out the benefits of care.data – eg Wellcome Trust and place these in relevant publications and websites. We will target publications that have addressed audiences that have previously expressed concerns. We will prepare an op-ed for The Times describing the way forward.

5. We will carry out media work as necessary to support other activity.

6. We will provide interviews to GP and Pulse magazine setting out our programme for implementation focusing on how we are making this as straightforward as possible for GP practices.

Roles & responsibilities:

Working collaboratively and strategically with communications colleagues in regional and local NHS England roles will be vital to both the development and implementation of staff and public-facing information during listening, as well as encouraging the communication of consistent findings/messages to the local and regional media as each phase develops. In terms of roles and responsibilities, these would include:

National role

- Provide the governance framework for the six month extension programme of work
- Developing and sharing key messages, core narrative and key benefits (examples at **Annexes C, D & E**) and stakeholder map and grid of activity (**Annexes H and I)**
- Developing and sharing the timeline for communications activities to ensure alignment across the system
- Delivering a suite of communications materials that can act as a framework for local tailoring
- Use of senior clinical leader voices wherever possible to support communications

- Working with national stakeholders such as professional bodies and national patient representative groups
- Limited national and trade media
- Design of local and in surgery marketing campaign (see below)
- Checking and ratifying plans throughout with the Advisory Group

Regional role (Directors of P&I/Communications)

- Pivotal role in feedback
- Working with regional media
- Cascading the information to NHS England area teams and working with them to deliver a programme of aligned activities

Local role

- Developing the suite of communications materials to create a locally tailored narrative
- Sharing with CCGs and supporting their understanding of the campaign
- Working with local GPs, LMCs, local patient staff and stakeholder groups to provide consistent support materials as identified through the listening period
- Using the national timeline to identify local opportunities for aligned engagement activities
- Managing local media

Communications risks

- All communications and engagement activities need to align to a clear programme plan including key milestones (e.g. implementation of products and processes) in order to achieve objectives
- Publication of historical releases by HSCIC past and present
- Local elections and purdah may slow down the opportunities to engage
- Advisory group receives conflicting recommendations and calls for more time
- NHS England, HSCIC and DH are delivering programmes of work that impact on the use of data and the way patient information is shared across the health and care system
- There has been considerable media interest in the Care.data Programme and a lot of the articles have been negative. This has primarily focused on concerns raised by external groups regarding the privacy of the data and the process for this to be shared with organisation outside of the NHS. Our research highlights this as the most important issue for those that have concerns about their data being shared. Addressing these concerns will be important to gaining professional and public confidence in the data sharing programme, but information about earlier processes to protect other NHS data that weren't as robust will make this challenging.
- The engagement activity to secure the support of key stakeholders and in particular GPs and practice staff will be very important to counter this negative commentary. External credible advocates for the Care.data Programme will be key to reassuring the public and providing them with effective materials to support their communications will be important.

Evaluation of communications activities

The proposed Care.data Programme engagement and communications activity will be evaluated in accordance with Cabinet Office best practice using a range of performance indicators. This will measure outputs as well as outcomes, including: number of events held and stakeholder attendees; number of materials ordered; and the number of objections registered with GP practices.

The proposed research activity also includes a number of quantitative research projects to measure the effectiveness of the engagement and communications. This will regularly measure awareness and understanding of GPs and practice staff and the public through polling.

The findings of the proposed research activity will be used to refine all the Care.data Programme content for all key stakeholder groups and the public. This material will continue to be available throughout the period of the implementation of the programme and beyond.

The polling research will be used to measure the effectiveness of the engagement work and the communications. This will be used to inform changes to these plans.

ANNEXES TO CARE.DATA COMMS STRATEGY

There are 10 annexes to the care.data communications strategy. These are:-

A – tactical delivery plan (evolving)

B – membership of the care.data independent advisory group

C – key messages for public (evolving)

D – core narrative for public (evolving)

E – benefits of data sharing (evolving)

F – case studies of data sharing (evolving)

G- frequently asked questions for public (evolving)

H- Stakeholders

I – stakeholder engagement grid (evolving – attached as separate excel spreadsheet)

J- precis of submission to the Efficiency Reform Group, Cabinet Office

ANNEX A

TACTICAL PLAN: a phased communications approach

NB. Press Office will provide an evolving supporting plan of action for media engagement including opportunities for coverage, harnessing supportive channels and advocacy. This will be broken down into national and local media plans and will set out how we can make best use of clinical and other stakeholder spokespeople identified through stakeholder engagement.

Phase one: Listen and engage - MARCH TO APRIL 2014

Key activity: meeting with wide range of stakeholders, gathering views and updating and refining core materials as an iterative process

To undertake a comprehensive period of engagement to listen to the views of patents and stakeholders During this phase we are making plans about the shape of activity over the next six months and will be fluid and responsive to feedback.

Timing	Activity	Owner
Imminent x X DONE 14.04.14 DONE 10.04.14 DONE 14.04.14 & in progress re FAQs and more detailed aspects	• Sharing of detailed regional engagement plans with timelines • Announcement on appointment of Advisory Group and Terms of Reference • Letter to all key stakeholders on six month extension – rationale, planned activity, what we've heard so far, how to get involved, new legislation • Toolkit of comms materials (e.g. core script to facilitate early conversations) • Update all web material including NHS Choices	Andrew Chronias Tim Carter Helen Dennis Helen Dennis Helen Dennis
April	Seek procurement, DH Communications Control Panel and Cabinet Office ERG approval for potential spend on • Create stakeholder engagement plan across NHS England, HSCIC and DH	Phil Bastable Tim Carter & Anouska Curry
April V10.submitted 28.04.14 DONE 25.04.14	• ERG approval for research, marketing etc budget given (or not) • Research procurement (contingent on above)/focus groups and polling commences • Issue a CORE care.data toolkit – to be tailored by region & issued via regional leads [reflect regional plans] - covering details of o The six month extension and why being undertaken o A plain English description (narrative) of what care.data is o A list of core messages about the intentions of the	Phil Bastable Helen Dennis and Andrew Chronias

	care.programme [this will be updated and refined as we listen to views] o The benefits of sharing data o Case studies about sharing data o Frequently asked questions for patients NB the purpose of the CORE toolkit would be to provide consistent and plain English information for use with the public. It will only issue after views of the following groups have been sought and reflected o DH and HSCIC comms groups on care.data o Local and regional colleagues o Advisory group o Through programme governance process	
Undated May	• Procure research contractor (subject to ERG clearance) • Brief research contractor for both qualitative and tracking research	Dan Wellings/Phil Bastable
May	• Qualitative research with key audiences • Meeting and events with stakeholders to explain programme and gather views	TC / OB / PB

Phase two: Engage and respond - MAY TO JUNE 2014

[NB rolling process of submission of findings and feedback with Advisory Group throughout, as identified by governance process]

Timing	Activity	Owner
	• **UNDATED WITHIN THIS PERIOD [depends on if/when ERG clearance given for spend]** • 4 national GP practice workshops • National workshops with stakeholders • Polling of GPs, practice managers and public • Public deliberative events •	
May- June Ongoing	• Undertake focus groups with GPs, practice managers and public • Further quantitative work • Top line findings reported • Recommendations made to inform communications and public marketing campaign • Full report received • Use research findings to set KPIs for engagement and refocus communications objectives and approach	Dan Wellings Helen Dennis
May - June	• Refine policy • develop potential public information campaign [marketing options to be finalised]	Eve Roodhouse? Phil Bastable

May-June	- Refinement of national communication strategy covering all aspects and channels, and segmentation of key target audiences, including development of - Tactical media plan – including working with national broadcast media on benefits of data sharing, offering case studies and spokespeople as part of a regular and systematic process. Full timelined proposals required - Further/ongoing engagement proposals and timeline - Advisory group workshops - Public dialogue workshops - Healthwatch materials co-produced - Healthwatch national conference - Accessibility and vulnerable groups design and planning workshops - Open House events - Local engagement events	Helen Dennis & Tim Carter Agency TBC media team Tim Carter P&I team
June	• Communications collateral for each target audience and timelines for issue to be identified	Helen Dennis
June	• Prepare a parliamentary briefing for all MPs and Peers? Offer regular updates to the Chair of the Health Select Committee?	Tim Carter
June	• Create process for updated and coordinated newpieces on NHS England, DH and HSCIC websites and prepare • Prepare articles, with links to supporting materials/marketing collateral, for NHS England owned channels – such as GP bulletin, NHS News, CCG bulletin • Prepare social media strategy – eg twitter campaign, series of blogs from key stakeholders, GPs, NHS England clinicians etc. get involved in online conversations about data sharing reflecting and reinforcing key messages and benefits	Helen Dennis With support from wider comms, media and marketing teams
June/July	• Further specific materials (as identified by research and stakeholder engagement & if available as part of marketing collateral) need to be prepared too, such as… o Narrative for patient reference groups? o Patient Ref Groups supporting patients in the practice environment o Materials for PALs/Patient support and advice services (via CCGs)? o Template core copy for practice websites which can be tailored as necessary? o Template core copy for practice newsletters for adaptation? o new patient packs? o Posters o Leaflets o Case studies which explain the benefits of sharing health data [Tech team have some of these readily available] o Template letters which practices can send to patients o Core script about the programme & key messages o Information on how patients can see their own records o care.data animation further syndicated for use on practice screens (such as life channel) and websites	Helen Dennis with support from marketing team and regional colleagues and stakeholder lead + agency

	○ Plain English information about other programmes of work which might be associated with care.data ie SCR, Patient online etc ○ Clear details about the risks of sharing information and what is being done to mitigate this ○ An opt out form (if decided upon after listening phase) developing a dedicated version would allow NHS England to describe what people are opting out of and the rights people have about accessing data ○ CCGs – provide template copy for CCGs to include in their member practice newsletters, websites and in communications with staff and stakeholders ○ Engage CCG clinical leads, especially those with responsibility for data and quality ○ Health and Wellbeing board briefing paper/ pack for CCG leads to share ○ Local Medical Committee (LMC) representatives – share information with the LMC secretaries ○ MP/ elected member briefing – to be provided via CCGs? • The above needs to be prepared and set out with agreed timelines overlaid with all stakeholder & proactive media activity clearly mapped. The role of regional teams is pivotal in execution of all of above and regional/local implementation plans need to form part of this communications strategy, again with dates, once further detail is known, so the next phase is clearly defined and dovetailed with national/core messages and materials. • All of above needs to be refined and check throughout with advisory group and other stakeholder channels such as BMA patient groups	

Phase Three: Deliver - END JULY TO OCTOBER 2014

[NB no big launch – quiet and steady roll out with majority of activity happening within July and August]

Timing	Activity	Owner
July – August ongoing	• All elements of Phase 2 are executed [detailed timeline will have to follow once detailed marketing plans and dates are known and (potential) media booked]	All – coordinated mainly by Helen Dennis
Sept - Oct	• Evaluation of achievement of objectives and KPIs (established during listening phase)	Dan Wellings & Helen Dennis

Ongoing – activity throughout all phases

- **Ongoing stakeholder dialogue**
  - Updating (via the web, social media etc. what we are hearing and how this is influencing developments)

- **Oversight of the communications and engagement approach**
  - Ensuring that we remain on track and provided an aligned approach across all parties through daily calls and weekly meetings of the cross-organisation communications sub-group (DH, HSCIC and NHS England)

- **Routine reporting**
  - Research proposals revolve around both quantitative and qualitative [more]
  - Track awareness
  - Track how supported GPs and practices feel
  - Stats at information line
  - Look at KPIs and targets

- **Case study file**
  - We are collecting case studies illustrating benefits of data sharing. These are being added to on a weekly basis

ANNEX B

Membership of Independent Advisory Group to the care.data programme

Chair:

- Ciaran Devane, Chief Executive of Macmillan Cancer Support and NHS England non-executive director

Representatives of:

- Academy Medical Royal Colleges
- Association of Medical Research Charities
- Big Brother Watch
- British Heart Foundation
- British Medical Association
- Diabetes UK
- Healthwatch
- Health and Social Care Information Centre
- Hurley Group
- Independent journalists
- Kings College London
- MacMillan
- Med Confidential
- MIND
- MS Society
- National Institute for Health Research
- National Voices
- NHS England
- Royal College of General Practitioners
- Royal College of Psychiatrists
- Torbay Clinical Commissioning Group
- Wellcome Trust
- Whizz-kidz

Care.data - key public messages

Key messages for **the public** need to focus on the concept of data sharing and associated benefits, and their options in terms of how their data is used (or not):

- **Every patient should expect the highest quality care.** To provide the best possible care, the analysis of detailed, high quality information about patients' illnesses, their treatments and outcomes, is vital.
- Those who plan and monitor services in the **NHS are currently missing information about the care provided outside hospital**, in GP and community settings and after patients return home. This is a problem because it means no-one really knows how well all the different parts of the system are working together.
- **By piecing all the different information together** as people move between the different parts of the system, **the NHS will have a more complete picture of the care being delivered,** know where more money needs to be invested in treating diseases and conditions and quickly understand where there might be local problems that need to be fixed.
- **Everyone has a choice about taking part.** If you are happy for your information to be used like this by the NHS, by researchers and other approved organisations who are working with the NHS, then you don't need to do anything. But if you'd prefer not to take part, just contact your GP practice by phone or by calling in. They will record your decision on your records so your wishes will be respected.
- Collecting the parts of people's data that are needed will be done through a **secure system which is managed by the Health and Social Care Information Centre** (HSCIC), which is a public body. Already changes in the law will **improve safeguards to protect patient data** and ensure greater privacy. Data will **no longer be shared and used for commercial purposes**.
- **The care.data programme will be phased in with a selection of GP practices** from autumn 2014. This will allow us to ensure the collection of data is **thoroughly trialled and demonstrate that it is safe before a national roll out**. This approach has been agreed with patient groups, the BMA, Healthwatch, Royal College of General Practitioners and a new independent advisory group on care.data.
- Parliament is adding **important new legal protections to safeguard patient data**, whilst also ensuring that patients are able to benefit from the quality improvement and breakthrough health advances that the care.data initiative will enable.

ANNEX D

care.data narrative

Every patient should expect the highest quality care. One of the most powerful ways in which the NHS can be sure it is providing patients with the best possible care is by analysing detailed, high quality information about illnesses, treatments, and health outcomes.

Sharing information about your care when you visit the GP helps us to understand your health needs and how well you are being treated. If we link this information together with everyone else's health information, from both GP records and hospital records, we will have a more rounded picture of what is happening in our health and care services across the country.

This means we can see where things are working well but also see where there may be problems that need to be addressed. Using patient information to identify gaps in this way – whilst protecting everyone's personal confidential data – is the purpose of care.data.

The NHS in England already has some of the best information and data systems in the world and our hospital episode statistics (HES) system has been collecting information about every hospital admission, nationwide, since the 1980s. However, we are currently missing information for most of the care provided outside of hospital which means there is a gap in our knowledge. For example, we would like to know the average time taken – in every area of the country - between someone seeing their GP with bowel symptoms, to being diagnosed with colon cancer at the hospital. In order to know this, we need to link GP and hospital data.

The care.data programme will mean that for the first time, the NHS will find out about the quality of care being provided in all GP practices, and how well GP practices and hospitals are working together to provide joined-up care for patients. By studying this information in formats that identify conditions but not people, analysts can check that patients are receiving safe care in every NHS setting.

We all benefit from sharing our information in this way. Analysis of this type of data can help identify where a hospital is providing unacceptable care. Other uses of the data include identifying where the NHS needs to invest more in different diseases and in different parts of the country, illustrating examples of excellent care that should be rolled-out across the NHS, planning new services, and researching new treatments. Without this joined-up information it is impossible to commission joined-up care or to address variations in the quality, efficiency and equity of health and care provision.

We've been listening and acting on the views of patients, the public, doctors and others, and are making key changes to the care.data programme in response. These include proposals for a phased roll out of data collections with a selection of GP practices from autumn 2014. Parliament is also adding important new legal protections to ensure that patient data is safe and secure, while also ensuring that patients are able to benefit from the quality improvement and breakthrough health advances that the care.data initiative will enable

ANNEX E

Care.data - benefits of sharing data

The care.data programme will benefit patients by:

- helping to ensure the highest standards of care and clinical safety are consistently met throughout the NHS and alert us to where standards drop, allowing us to take prompt action to improve patient safety

- ensuring the needs of patients, especially those with long term conditions, are met by helping us understand what happens to people cared for away from hospitals

- providing us with the vital information needed to assist and support research into new medicines, and the better treatment of disease

care.data is key to improving the quality and safety of care for patients in health and care. Without this type of joined-up data, our ability to deliver improvements to local health services and to medical research is limited.

Examples of where care.data could help us with what we don't know:

- how many patients in England received chemotherapy last year
- what proportion of patients in any given hospital were reviewed by a consultant at least once a day
- for patients in Birmingham versus Bristol, what was the average time between presenting to their GP with bowel symptoms to being diagnosed with colon cancer?
- the proportion of patients on Ward 20 who had highly abnormal nursing observations were reviewed by the intensive care outreach team within an hour
- how many people are under therapy services in both health and social care and how these services can complement each other for the most effective care
- what the outcomes are for patients once they have been discharged from hospital and whether they maintained independence
- how many people are prescribed statins and what is the evidence base for how this helps them to manage the health effects of cholesterol.

Some examples of the benefits of sharing data already in practice in health care

There are many examples of where using linked data has brought about key benefits to patients and clinical practice:

Cancer care

One in three people in the UK will develop some form of cancer during their lifetime. Yet at the moment, the NHS cannot answer basic questions about cancer care such as how many people are treated with chemotherapy each year or the success of different combinations of treatments.

Statistics show that there are important differences in cancer outcomes in different parts of the country. At the moment, however, we are missing the detailed information needed to understand the full reasons for these differences.

Bringing together de-identified information from all GP practices, hospitals, and specialist cancer centres will allow analysts to determine how well all the different parts of the health service are working together to provide high quality, joined-up care for cancer patients.

Mental illness

In terms of its human, societal, and economic costs, mental illness has the largest burden of all diseases in the UK.

We know that there are significant differences in mental health outcomes for patients from different socioeconomic, educational, and ethnic backgrounds. At the moment, however, we lack joined-up information needed to understand fully how well GP practices, hospitals, and mental health services are working together for different patient groups.

Across the country, there are examples of GPs and their specialist colleagues working together to provide exemplary care for patients. However, there may be certain groups of patients in some parts of the country who are receiving substandard services. Our current lack of joined-up information means that clinicians and those planning NHS services may not be fully aware of these problems and cannot make informed decisions on ways to improve care services and patient safety.

Diabetes

Every hour, the NHS spends £1.5 million on diabetes care. However, an estimated 80 per cent of these costs are spent treating avoidable complications of diabetes, such as diabetic eye disease and kidney disease. Together, these complications are responsible for an estimated 24,000 premature deaths each year. By adhering to guidance published by the National Institute for Health and Care Excellence (NICE), many of these deaths could potentially be avoided.

By studying de-identified hospital data, analysts can see which parts of the country have unusually high rates of diabetic complications, such as amputations. Then, using de-identified primary care data, they will be able to determine the quality of care provided in the community prior to the complication.

Using this evidence, those planning services can work with clinicians to improve or redesign diabetes services. This type of analysis should help improve the quality of diabetes care for patients across England. In particular, it should lead to lower rates of diabetic complications such as heart attacks, diabetic coma, and lower leg amputations.

Heart Disease

Heart disease remains the biggest killer in the UK with over 45,000 deaths each year for patients aged under 75.

We know that there are significant differences in survival for patients from different backgrounds. At the moment, however, we do not know how well primary care and secondary care services are working together for different patient groups.

Around the country, there are examples of GPs and their consultant colleagues working together to provide excellent care for patients. But there may also be certain patient groups who are receiving disjointed services. By highlighting any unwarranted variations in the quality of care provided, we will be able to improve the standards of cardiac care for all.

Monitoring the safety of oral contraceptives

3.5 million women take oral contraceptives in the UK.

By studying de-identified GP data, analysts can identify the side-effects and complications experienced by patients taking oral contraceptive. They can then test to see if any of these side-effects were associated with particular characteristics, behaviours or different combinations of medications.

The guidance for prescribing oral contraceptives can be improved as a result of this type of research, leading to safety improvements.

Monitoring the safety of drug treatments: obesity

Over a quarter of UK adults are obese, and obesity will cost the NHS in England an estimated £6.4bn per year by 2015.

There have been concerns that a drug used to treat obesity called Orlistat might increase the risk of liver problems. By looking at joined GP and hospital records, researchers were able to check if patients with obesity who were prescribed Orlistat experienced liver problems after taking the medication.

In this example, the data showed that the concerns were unfounded. As a result, the medication continues to be used to help patients lose weight.

Public health: Influenza

Around 600 people in the UK die each year from complications of ‘flu. In certain years, the number of deaths can rise to 13,000 or more.

The 2010/11 flu season was particularly severe. Analysts used joined-up, de-identified GP and hospital records to look at why so many people had ‘flu that year. The data suggested that the infection was being passed from children to adults.

As a result of this analysis, the ‘flu vaccination programme was extended to include children.

Improving patient care: Chronic kidney disease

Around 45,000 people die prematurely as a result of chronic kidney disease (CKD) each year, and the disease costs the NHS about £1.5 billion per year.

CKD is a serious and growing problem but it can be slowed down or even stopped if identified early. De-identified GP data joined to hospital data have been used to compare different approaches to managing this disease to see if certain treatments were more effective than others.

As a result of these analyses, new combinations of treatments are now being trialled to see if they improve the management of CKD.

Stroke

Every 5 minutes, someone in the UK has a stroke. Stroke costs the NHS £4.8 billion each year but the emotional effects of a stroke can be as devastating as its physical effects.

De-identified hospital data can be used to study the care provided to patients who have had a stroke. By linking de-identified hospital data to de-identified GP data, analysts can see if there are any events, characteristics or other triggers that might act as an early warning of a stroke. Once identified, the occurrence of these triggers could be monitored so that patients at risk of a stroke are given earlier preventive treatment.

Service improvement

In 2012-13, a hospital in the West Midlands experienced a 15 per cent increase in unplanned hospital admissions via its A&E department. This increase in patients led to higher numbers of patients spending more than 4 hours in A&E.

Some clinical staff at the hospital believed that many of the patients presenting to A&E could have been better managed in the community. However, their hypothesis can only be tested by analysing data joined together between hospital, GP practices, and community health services.

Adherence to NICE guidelines after a heart attack

Heart attacks cost the NHS around £1.6 billion per year. Patients who have had a heart attack are offered preventive treatments aimed at avoiding another heart attack in the weeks and years to come. The National Institute for Health and Care Excellence (NICE) produces guidelines recommending the most effective preventive treatments.

The NHS needs to check if patients are being treated in line with these ‘best practice’ guidelines across England and to identify any local or regional variation in adherence to these guidelines.

Without primary care data, it is not possible for the NHS to check what prescriptions patients are receiving after having a heart attack.

Asthma

Three people die every day from asthma. There are 5.4 million people in the UK with asthma. Asthma costs the NHS £1 billion per year but three quarters of hospital admissions for asthma are avoidable.

In order to improve the quality and efficiency of asthma care, it is important to consider how all parts of the NHS are working together for patients – including GP practices, outpatient clinics, A&E departments, hospital wards, and intensive care units.

At the moment, the NHS lacks the data necessary to check the quality of asthma care across England. Linked data are particularly useful for conditions such as asthma, which if managed well in the community, can greatly reduce demands on hospitals and free up limited resource to improve overall patient care.

Falls

Most people aged over 80 fall at least once a year, and falls are the commonest cause of death from injury among older people. Falls already cost the NHS more than £2 billion per year. However, the number of people aged 65 and over is predicted to increase by 2 million by 2021, so these costs are set to rise still further.

By studying joined-up, de-identified GP and hospital data, analysts can assess the impact of changes in clinical practice. In particular, these data can be used to assess the effectiveness of different preventative measures and treatments before and after a fall. They can be used to highlight areas of the country that are managing falls effectively and those areas that need to raise their standards.

Multiple sclerosis

Around 100,000 people in the UK have multiple sclerosis (MS). People with MS tend to die 10 years sooner than they would be expected to otherwise.

Joining together de-identified GP and hospital records will allow analysts to look at the time between a patient’s first presentation to a GP with symptoms and receiving a diagnosis. The NHS will also be able to monitor the effectiveness of treatments and to see if GP practices, hospitals, and community health services are working together to provide high quality, joined-up care for patients with MS.

Aspirin

Aspirin is a common drug given to everybody, but it is almost certainly causing permanent disability and death in children when given for febrile illness. It took years to make the link between aspirin and Reye’s syndrome. When the link was made and the drug controlled, Reye’s syndrome all but went away. A case-controlled study on anonymised data would very quickly identify this type of issue.

Beta blockers

Beta blockers are commonly used drugs; one of the first ones on the market was called practolol. In a rare instance, it caused a potentially fatal fibrotic disease idiosyncratic to that particular drug. It was too rare to be picked up at a clinical trial but would be revealed through mining data.

Annex F

Case studies of sharing data

Sharing data in health care has already provided benefits to patients such as the examples provided below. These benefits can be extended through the care.data programme and by widening the amount of joined up data available.

1. Diagnosing you earlier

Mr. Jones is a 45 year old who has a family history of bowel cancer. He notices blood in his stools and visits his GP.

His GP refers him to the local hospital and he is diagnosed with bowel cancer. Fortunately, Mr. Jones has been diagnosed early so the cancer can be removed by surgery and he makes a full recovery.

Not all cancers are picked up early by their GP. Using linked data, researchers have traced back patients' journeys, so see what happens before cancer is diagnosed. One in four bowel cancer patients present as emergencies. For almost all cancer types, you are less likely to survive if you present as an emergency.

There are huge variations in cancer survival across England. Using linked data we can analyse the different routes taken by patients across the country. This helps us in planning services and helps to ensure cancers are diagnosed as early as possible helping to save lives.

The "A Year in the Life" project improved the care of more than 30,000 people living with Chronic Obstructive Pulmonary Disease (COPD) in North East London while simultaneously reducing healthcare costs.

Partners including academics, commissioners, primary and secondary care clinicians were keen to improve the treatment of long-term conditions through earlier diagnosis.

The initial challenge was getting an accurate picture of patients' health needs across four London boroughs so GPs could address long standing problems of recurring hospital admissions and poor health.

Linked GP and hospital data were analysed, leading to improvements in diagnosis and prescribing. Patient reviews were structured around reports generated from the data.

This project led to significant reductions in unnecessary hospital admissions, saving an estimated £6.5 million over two years.

2. Giving you the best possible chance of surviving cancer and leading a healthy life after treatment

By 2020 nearly half of us can expect to get cancer in our lifetime but our chance of surviving has significantly increased. However a quarter of those living with cancer face poor health and disability after treatment. In order to support people affected by cancer better, we need a detailed understanding of what happens after diagnosis. How long am I likely to survive if I get breast, lung, prostate cancer or a brain tumour? What is the chance of me getting cancer again if I survive? Do I have a higher risk of getting other diseases?

Macmillan's 'Routes from Diagnosis' research programme links information collected nationally about cancer with hospital data to build a detailed national picture of what happens after a patient has been diagnosed with four types of cancer. With this information we will know which groups of patients in particular need more support and when.

This national insight is being used in places like South Yorkshire, Bassetlaw and North Derbyshire Clinical Commissioning Groups (CCGs) which has some of the highest levels of cancer in the country. Using the Routes from Diagnosis approach those planning services and clinicians are re-designing services so that patients get the right level of support at the right time in the right place.

If we were able to link GP data into this picture we could understand the needs of many people with cancer who have less serious health conditions that do not require hospital treatment, and therefore support cancer patients to live healthier lives after their treatment.

In the words of Macmillan:

> '90% of care takes place outside of hospital. For the first time, care.data will enable us to truly understand the whole of the healthcare experience, and to spot crucial patterns and connections that would otherwise go unnoticed'.

3. Ensuring that NHS resources are targeted where they are needed

The NHS has limited resources and must adapt to growing demands. Evidence suggests that poor care often means costly care and that if we improve a patient's health and quality of life then this can diminish costly hospital stays.

Macmillan's Routes from Diagnosis programme included an economic analysis looking at the cost of what happens to patients in hospital. This showed for example that the cost of ongoing care and support can be higher than the cancer treatment itself. In South Yorkshire, Bassetlaw and North Derbyshire CCG, trigger points are being identified in each patient journey where there is likely to be either additional or reduced need for follow up or treatment. Some evidence suggests that tailoring care in this way for patients with breast, colorectal or prostate cancer could result in cost improvements with net savings in England estimated to be £86m.

Macmillan's Routes from Diagnosis programme was not able to look at the costs for the whole patient journey because GP and community care data was not linked. We do not know how costs build up along a patient's journey and the economic impact of implementing particular treatments or taking certain actions. Care.data will link datasets so that we have an even better picture of how resources are being spent, not just for cancer but so that we can target funding where it is needed.

4. Access to the best treatment available for everyone

Variation exists in access to treatments, such as surgery for lung cancer. The likelihood of receiving surgery for lung cancer varies significantly between different areas of England. There is also evidence that some older people with cancer may not be receiving treatment because of their chronological age.

Mavis is 85 and has been diagnosed with lung cancer. She has seen a specialist who has recommended medication that will reduce the size of the tumour and then hopefully prevent any growth and spread to other areas of the body. Mavis is otherwise fit and well for her age and still cycles when running errands around the village. Mavis has done some research on the internet with her daughter and believes she would benefit from surgery to remove the tumour. She believes that the reason she has not been offered this is due to her age.

The research that Mavis and her daughter found was only possible because data from patient interviews and the cancer registry was linked to hospital data. However, much more research could be done if this information was routinely linked. This could be improved even more if it included data from other areas, such as GP data. For example, it may show that certain GPs never refer certain groups of cancer patients for surgery, despite research showing it would be effective. This would reduce inequalities in healthcare and improve outcomes.

5. Safety first with medicine

Evie is three years old and has a high temperature. Her mum reads the instructions on some asprin in her medicine cabinet and realises that it must not be given to under 16s.

This advice is based on research which linked aspirin with Reye’s Syndrome when the drug was given to feverous children. Reyes syndrome can cause permanent disability and death in children.

Without data this link would not have been made as Reye’s Syndrome is rare - therefore children died. Reye’s Syndrome has now almost disappeared and children like Evie are safer.

care.data would allow a case-controlled study, using linked GP prescribing data and hospital data, to make this association.

6. Everyone should have the best possible care

Elsie is an 82 year old who has been admitted into hospital following a fall. The hospital has a good local reputation and receives positive ratings on NHS Choices.

Millions of people are treated by the NHS every year. Collecting partial data makes it harder to pick up trends such as high death rates. Linking health data from across the NHS with patient experience data would help us spot variations in standards of care.

Because of the gaps in data there may be patients receiving unacceptable levels of care.

7. Helping patients make choices

Mrs. Palmer is a 51 year old woman going through the menopause. She asks her GP, Dr. Browne, about the different types of Hormone Replacement Therapy (HRT). Mrs. Palmer has heard in the media there is an increased risk of cancer if taking HRT.

Dr. Browne is able to provide information using valuable research into the effects of taking HRT. The Million Women study is a national study of women's health, involving more than one million UK women aged 50 and over. For example, from research using the linked data, we know that taking HRT can increase the risk of heart disease and breast cancer.

Whilst Mrs. Palmer is unaware of the study, and the million women who are involved, the research help her make an informed decision about her care.

[1] http://www.nature.com/bjc/journal/v110/n3/full/bjc2013734a.html

[1] http://www.hscic.gov.uk/catalogue/PUB12719

ANNEX G

care.data –patient FAQs for six month extension

Contents

1. What is this about?

The NHS needs information to know whether it is providing high quality care for all. The care.data programme will:

- **ensure the highest standards** of care and clinical safety are consistently met throughout the NHS and highlight where standards drop, allowing prompt action to be taken;
- **help understand what happens to people**, especially those with long term conditions, who are cared for away from hospital, and leads to the better treatment of diseases
- provide the vital information needed to **assist and support research into new medicines**, and the better treatment of disease.

2. What is changing?

Those who plan and monitor services in the **NHS are currently missing information about the care provided outside hospital**, in GP and community settings, and after patients return home. This is a problem because it means no-one really knows how well all the different parts of the system are working together.

The **NHS is going to start collecting information about the care provided in GP practices**. In the future, we plan to start collecting information from ambulances and from community health services such as district nursing too.

By joining up all the different information together, **the NHS will have a more complete picture of the care being delivered,** know where more money needs to be invested in treating diseases and conditions, and quickly understand where there might be local problems that need to be fixed. Having **coordinated data like this will have long-term benefits for everyone**

3. How will this affect me?

It affects you because **you need to decide whether you are happy for your information to be shared** for purposes beyond your care.

It also affects you because by using information in medical records we can improve the care provided to all NHS patients.

4. What are the risks?

We understand that people are concerned about the security of their information and it is right that patients should seek reassurance about the controls in place.

The Health and Social Care Information Centre (HSCIC) will collect confidential data from your GP practice. There are risks for example, even though the HSCIC may remove any information that could identify you and put data sharing contracts in place a researcher could decide to act unlawfully and attempt to work out who you are (it is highly unlikely that this is possible but it is a remote risk).

We have also been listening to concerns about privacy. Legislation is going through parliament to **improve the safety of data and to introduce tough penalties**. We will ensure that:

- Those who misuse data will not be allowed to have a further contract with the HSCIC (a one strike and you are out policy).
- The public are clear that their information should be used to help improve the care and treatment of people in England.
- The HSCIC will be restricted in sharing this data only with those that can show there will be benefit to patients and/or the English health and social care services.

5. What data will be extracted from my GP record?

We will collect your NHS number, date of birth, gender, and postcode. We also collect information about referrals, prescriptions or health information such as diagnoses. These diagnoses relate to health conditions such as diabetes, heart disease, stroke, cancers (including bowel, breast, and cervical), chronic liver disease, chronic kidney disease, asthma, damage to the retina of the eye, high blood pressure and dementia.

GPs record this information in the form of codes (for example, code C10E for diabetes). We will collect the coded information. We will not collect information that GPs record as written notes, such as details of any conversations that they have had with the patient. Further information is available at: http://www.hscic.gov.uk/article/3915/What-we-will-collect-from-GP-records-under-caredata

6. Who will see my data?

The HSCIC will collect and link your information using computers.

The HSCIC analyses the data and publishes statistical reports using information that does not identify you, for example the numbers of people in England who have stopped smoking or the percentage of patients at a GP practice who have received the flu vaccine. Anyone can access these reports as you cannot be identified.

New legislation will prevent the HSCIC from sharing information that may identify you unless the purpose is **for the provision of health and social care services or for the promotion of health**. So your data may be shared with those planning services, with those looking at public health issues such as outbreaks of diseases or with those researching new treatments. It will not be shared with those who wish to use the data solely for commercial purposes such as for commercial insurance. Proposals for a data laboratory service are also under development with organisations accessing data in a controlled environment sometimes referred to as a ‘data-lab’ or ‘fume-cupboard’.

7. What do I have to do?

If you are happy for your information to be shared to help improve health services, then you do not need to do anything. Your information will continue to be used for that purpose and to benefit all patients.

If you have questions or concerns, you can call the patient information line on 0300 456 3531 or talk to staff at your GP practice.

If you want to opt out you should simply inform a member of staff at your GP practice.

8. When do I have to make a choice by?

We will not be extracting any data until **autumn 2014** so you don't have to make any choice until then. You can opt out at any time before this date.

9. If I opt out of care.data will it affect the treatment I receive?

No. This is about using information for purposes beyond your direct care. Your healthcare record will continue to be shared for the purposes of treating you.

10. I can't get into my GP practice to opt out?

You do not need to make an appointment to see your GP in order to register your opt out and you may not even have to visit your practice in person. Please contact your GP practice by telephone or email to discuss with them what arrangement would work best. If you have a query or a question you can call our patient information line on 0300 4563531.

11. Where can I find out more?

We will be testing the data extraction with up to 500 GP practices from Autumn 2014 and developing new materials over the coming weeks so keep an eye out for updates on the http://www.england.nhs.uk/ourwork/tsd/care-data/

To find out more:

- Visit the NHS England website at http://www.england.nhs.uk/ourwork/tsd/care-data/
- Watch our animation at: http://www.nhs.uk/caredata/Pages/caredata.aspx
- Call our dedicated patient information line on: 0300 456 3531.
- Talk to a member of your GP practice

ANNEX H

Stakeholder Prioritisation

NHS England

Key players – work closely

- HSCIC
- Department of Health
- Health watch England
- British Medical Association
- Royal College of General Practitioners
- National Patient Representative Groups
- Charity Groups (Richmond Group)
- 38 Degrees
- Information Commissioners Office
- Media

Active consultation

- Public/Patients
- NHS England staff
- Regional and local teams
- Ministers/MPs
- Health Select Committee
- Shadow Health Team
- Health and Wellbeing Boards
- Royal Colleges
- NHS Business Services Authority
- Strategic partners (NHSE)
- Voluntary and Charity Sector
- Medical Defence organisations
- Civil Liberty Groups
- Individual charities (Wellcome Trust campaign)

Keep informed

- NHCCGs/CSUs
- AHSNs
- NHS Clinical Commissioners
- Provider Organisations
- Think Tanks
- Wider Clinical bodies
- NHS Regulators
- NHS Business Services Authority
- Wider Civil liberty groups
- Local Authorities

Channels

- Media
- Social Networks
- Key opinion makers

ANNEX I

STAKEHOLDER ENGAGEMENT

See excel spreadsheet of stakeholder engagement grid accompanying this strategy (latest version – as at 28.04.14 attached)

ANNEX J

Cabinet Office Efficiency Reform Group (ERG) - Submission

To gain approval of the budget for the research, engagement and communications detailed proposals have been submitted to the Department of Health's Comms Control Panel and the ERG team within the Cabinet Office.

The following is a summary of the proposals that were submitted.

Introduction

The strategic aim of the research, engagement and communications activity is to increase the awareness and understanding of the programme among the primary audiences to ensure its successful implementation.

This will build on the engagement work that has already been delivered. This work began in August 2013: information packs including posters and leaflets were sent to all GP practices in England; information was published on the NHS Choices website including a short introductory video; and media engagement work, which has resulted in significant media coverage of the programme. In January 2014, a leaflet explaining the data programme and how people can raise an objection to having their data shared was delivered to every possible household in England via the Royal Mail.

GP practices have a key role to play in explaining the Care.Data Programme to the public and patients. It is essential that GPs and practice staff have a good understanding of the programme and in particular the process for someone to register their objection to having their identifiable data shared. This requires a lot of information to be communicated to this audience and the engagement activity has been developed to achieve this.

The engagement and communications activity to date has increased public awareness of the data sharing plans, but further communications activity is required as a consequence of the new legislation and also to continue to build awareness and understanding.

Timing

The proposed research, engagement and communications strategy will be delivered through three phases:

- Phase one – listen and engage March to May 2014: We will conduct qualitative research with our key audiences. Meetings and events with a wide range of stakeholders will be organised to explain the programme and gather views.
- Phase two – engage and respond May to July 2014: We will conduct quantitative research to measure levels of awareness and understanding. Engagement activity will continue with stakeholders to respond to issues and concerns. Materials will be developed and tested with our audiences.
- Phase three – deliver July to October 2014: We will continue to conduct quantitative research with our key audiences. Materials will be produced and provided to stakeholders. Engagement events will continue. We will deliver communications through our owned and earned channels.

The proposed research, engagement and communications strategy will involve a significant range of different activities, ranging from qualitative and quantitative research, local and national engagement events, to media engagement and the development of communications content and creative (detailed later in this section). To ensure that all the planned activity of these workstreams are as effective as possible and address the different requirements of our audiences we are planning to commission a specialist agency to work with the programme team to strategically coordinate the activity across these workstreams.

Strategic coordination
The agency will work with the teams involved in the delivery of the research, engagement and communications strategy to strategically coordinate these workstreams. The agency will ensure that we have a good understanding of each of our different audience segments to maximise the effectiveness of our engagement and communications activity. The agency will provide the necessary expertise and resources that are not available within NHS England.

This agency will:
- Work with NHS England's Insight and Feedback Team and research agency to coordinate the research activity to segment our audiences and identify their differing issues, concerns, information and creative requirements.
- Consult with key representatives from our different audiences to ensure our materials have their approval and that they support their distribution.
- Coordinate the research work to ensure that we effectively evaluate all our activity.
- Work with the Patient and Public Voice Division, and the local engagement teams to coordinate the engagement activity to ensure that this is informed by the research work, that our communication resources address the requirements of our various audiences and continually refine the work.
- Work with Communications and the marketing team to coordinate the communications activity to ensure that effective content is developed for our different audiences and collateral across all channels. This will include helping to develop the brief for the creative agency for each audience segment.

The details of the research, engagement and communications workstreams are provided below:

Research
The research workstream will be managed by the Insight and Feedback Team within NHS England's Patient and Public Voice Division, supported by the Strategic Coordination agency. A specialist research agency will be commissioned to deliver the various proposed quantitative and qualitative research projects.

The research workstream has been planned to:
- provide us with a comprehensive understanding of the views, concerns and requirements of the different audiences. This will help to inform our engagement and communications activity and ensure that it meets the needs of our audience and is as effective as possible;
- test content and creative with GPs & practice staff and the public. This is to help ensure that all our engagement and communications materials are clear, concise, understandable and provide the level of information that our different audiences require. This is also to help ensure that the most effective communications are delivered through GP practices to patients; and
- evaluate the effectiveness of the engagement and communications activity as it is undertaken. Low profile tracking research to measure GP support of the programme, as well as public awareness and understanding will enable the programme team to understand progress and to identify areas of priority as the communications activity is delivered

A specialist research agency will be commissioned to deliver the following activity:
- GP Practice workshops: we will run 4 national workshops with GPs and practice staff to collate an in-depth understanding of their views on the Care.Data Programme, including what the concerns are and which positive aspects of the programme resonate the most.

- Deliberative events with the general public: we will organise events which will bring together a representative cross-section of the public to: a) establish current understanding of the Care.Data Programme, b) present the case for Care.Data in a balanced and nuanced way c) assess the issues this may raise among participants and d) consider the way that communications could address these issues or concerns. Recruitment for each event will ensure that minority groups and those who are less engaged with their health are included.
- Workshops with stakeholder groups: We will run 2 national events with stakeholders to understand and collate feeling among our different stakeholder groups (including relevant voluntary organisations, such as National Voices) towards the programme, in order to understand what would give reassurance and enable support.
- Focus groups to test materials with GPs and practice managers: We will run 2 focus groups to test draft communications materials with GPs, practice staff and clinical staff to ensure they are fit for purpose.
- Focus groups to test materials with the general public: We will run 2 focus groups to test draft communications materials with the general public to ensure they are fit for purpose.
- Polling of GPs and practice managers: We will run 4 waves of polling to measure levels of awareness and understanding among this key audience and to evaluate the effectiveness of the engagement activity.
- Polling of the public: We will run 3 waves of public polling to measure levels of awareness and understand and to evaluate the effectiveness of the engagement activity.

Engagement

The engagement work will be managed by NHS England's Patient and Public Voice Division, supported by the Strategic Coordination agency and by the regional Patients and Information teams. This work will be informed by the research workstream, which will ensure that we have a good understanding of the views, issues, concerns and requirements of our audiences.

The aim of this activity is to ensure that we have an ongoing dialogue with stakeholders to inform them about the programme and its wider context, listen to their concerns, work with them on shared solutions, and influence them to be supportive of its implementation.

A budget of £500,000 has been allocated for the engagement work (a detailed breakdown is provided in the Expenditure section). This budget is to fund the delivery of the following activity:

- Advisory group - we will undertake 5 workshops hosted in each region (Leeds, Birmingham, London, Exeter) to develop the conversation with stakeholders from where we are now – the issues, concerns and questions – through to testing solutions, sticky issues and potential recommendations. Stakeholders will include: LMC members / GPs, Local Healthwatch, CCGs, Charities, Patient Groups (PPGs), Privacy activists, Researchers, Academics. Workshops are planned to be held in May, June, July, September and October.
- Public dialogue workshops- we will actively engage with the public through patient groups, charities and activist networks including digital channels, to undertake a process of public dialogue on how the NHS can use data in a socially and economically beneficial way while meeting concerns on issues such as privacy. This will frame the Care.Data Programme in the wider context of transparency and open data and provide evidence and insights to inform future policy. Key stakeholders will include GPs, Practice Managers, Local Healthwatch, Health and Wellbeing Boards, Local Government and Voluntary / Patient Organisations.
- Healthwatch – we will ensure that the Local Healthwatch Network has factual and detailed information about Care.Data available in ways that they can understand, apply and use with their local communities. We will work with a small number of Local Heathwatch organisations to coproduce, design and test materials that support their staff and volunteers to hold informed conversations. These organisations will be asked to report to Healthwatch England and NHS England on activities completed and feedback

received from members and networks. The Healthwatch England National Conference in July 2014 will be used to share materials, host a discussion and identify areas of ongoing concern to the network.

- Accessibility and Vulnerable Groups – We will run a design and planning workshop with leading communication, disability and access charities to ensure that the materials developed and the approaches to engagement are accessible and appropriate for people with specific support needs.
- Open House events – NHS England's Patients & Information (P&I) Directorate Open House is a quarterly engagement event aimed to involve key partners, patients and the public in the development of P&I programmes. We are planning for the Open House event in June to focus specifically on Care.Data and the use of big data in healthcare. Four parallel open house workshops are planned to be hosted in each of the four regions and be simultaneously webcast and digitally connected to discuss and debate the key issues and opportunities of the Care.Data Programme. This is a new approach that aims to connect the country on one day to debate the same issues.
- Local engagement events – The regional Patients and Information teams will arrange a series of local engagement events for the Care.Data Programme. These will be organised to engage with a variety of local stakeholders, including GPs & Practice Managers, CCGs, Local Medical Councils, Patients representative groups (such as Patient Participation Groups) and Local Healthwatch. These events will aim to explain the details of the programme, the benefits and risks and to listen to views and address the concerns of our local audiences.

Communications

The proposed communications activity will be informed by the research work and will be supported by the Strategic Coordination agency. This activity will also support the engagement activity, through producing content and marketing materials.

The communications workstream will be managed and implemented by NHS England's communications division and the marketing team.

The communications strategy will make use of our owned and earned channels:

- **Owned Channels**: Information is available on the NHS website (www.nhs.uk/caredata) and on the NHS England website (www.england.nhs.uk/caredata). We are planning to develop an area within the NHS Choices website that will be accessible on mobile devices. This will provide detailed information about the Care.Data Programme, and include a downloadable opt-out form to simplify the process and will provide detailed user data. We are also proposing to develop a secure access area of NHS England's website for GPs to download information and tools, and to also help develop an information management process to help gather data relating to patient opt-outs. A specialist digital marketing agency will be commissioned to deliver this (see details below).

  We are also intending to run banners on all pages of the NHS Choices website that will reach all 27 million monthly users of the site and provide a link to the microsite and the detailed information they require.

  NHS England Social media channels will continue to be used communicate with different audiences about the programme and to direct people to the detailed information that is available online. We will also publish further blogs on the NHS England website from key senior leaders involved in the programme.

  We will produce regular updates on the programme for stakeholders, this will include email bulletins and will enable feedback directly to the programme team.

- **Earned Channels:** We will continue to send information packs to GP practices in England, the development of these will be informed by the research activity. These will be developed to inform GPs and practice staff about the Care.Data Programme. We will also develop and provide marketing materials (including leaflets and posters) to assist them in explaining the programme to their patients. Easy-read, braille and audio versions of the leaflets will continue to be available to GP practices to order.

  We will develop resource packs to be provided to other stakeholder groups as part of the engagement activity.

  We are proposing to commission a specialist creative agency to develop these materials. This will be tested with our audiences through the research and in consultation with key stakeholder groups.

Media Engagement
NHS England's communications division will continue to engage with the media on the Care.Data Programme. The media engagement strategy aims to:

- demonstrate we have been listening (e.g. number of events, participants and actions of the advisory group);
- demonstrate that we are responding by provide clear analysis of the listening including issues to be addressed, including preparing an article for national publication by Deputy Medical Director Dr Mike Bewick;
- demonstrate that we are taking action in response to listening, including stakeholders quotes and statements from key organisations;
- publish articles in strategic publications and on websites from key advocates/reformed critics on the benefits of the Care.Data Programme and an op-ed for The Times;
- respond in a timely manner to all media enquiries as necessary to support the programme; and
- arrange regular interviews in key trade titles to provide updates on the programme.

The proposed communications work will be supported by specialist external agencies to provide expertise and resources that are not available within NSH England. We are planning to commission a creative agency and a digital marketing agency to deliver the following work:

<u>Creative Agency</u>
We will commission a creative agency to deliver the following:

- Develop information materials for our various stakeholder groups to inform them about the programme.
- Develop materials for GPs and practice staff to enable them to explain data sharing to their patients.
- Develop public facing materials for use in our owned and earned channels.
- Work with the Digital Marketing agency to develop consistent content for digital communities.

<u>Digital Marketing Agency</u>
The digital marketing agency will deliver a solution to provide a seamless user experience for both GP practices and patients.

This will include using the NHS England website as a portal for providing information and instructions to GP surgeries. For example, developing a secure area to provide access to all relevant care.data information and tools for GPs. Access would be by registration only for GPs and allow information to be uploaded and recorded to provide a manageable database for providing national and local insight, i.e. establishing which areas of England are the most/least effectively engaged etc.

The NHS Choices website will provide detailed information about the Care.Data programme for patients. It will include a downloadable opt-out form to simplify the process and also provide detailed user data. This will help provide greater digital insight and personalisation at a user level. It will deliver curated and adaptive campaign messaging to facilitate the personalisation of experience to users on NHS England's owned channels, and develop greater insight and evaluation data about user behaviour to inform further targeting, development and evaluation of an effective and engaging Care.Data campaign.

We will commission a digital marketing agency to deliver the following:

- Architectural/technical and content revisions to the NHS England and NHS Choices websites; including mobile development where relevant.
- Develop a solution to link the downloadable opt-out form on NHS Choices website to the GP information held on the information database on NHS England's website.
- Develop a digital marketing platform to deploy curated content and creative across NHS England's owned channels.
- Map relevant digital content and key journey trigger points across NHS England's owned channels and develop a digital profiling technique.
- Identify digital users that match profiles to drive traffic to the right content at the right time. This will enable users to be served with relevant content based on their persona (i.e. location, pervious browsing history, search terms).
- Implement user journey and behaviour tracking on NHS England's owned channels to understand how users enter, move through, interact with and leave the campaign and associated touch points.
- Deliver a care.data command dashboard to enable real-time monitoring of online behaviour and KPIs, including measurement of conversion rates and engagement with the campaign. This will involve tracking click throughs and downloads across NHS England's Owned Channels.
- Ensure interoperability with existing NHS England systems.

We are also intending to make use of existing contracts for print and distribution to produce the stakeholder resource packs and marketing materials to provide to GP Practices, and other stakeholders to enable them to effectively communicate with patients, the public and professionals.

Print & distribution

- Print the required quantities of marketing materials.
- Develop materials for people with communication support needs; easy read versions, BSL, translated materials, audio versions, etc.
- Send out materials to GP Practices and other stakeholders.
- Store quantities of the materials and provide an ordering system to allow stakeholders to order additional quantities.
- Resource partners to reach excluded groups that will be missed by mainstream mailing.