



InterPARES Trust Project

Research Report

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Abstract

Background. The care.data programme is an initiative of the UK National Health Service, officially announced in December 2012. The programme will eventually collect and link together data from all health and social care settings, both hospital and community based, with the purpose of planning and monitoring services. The programme therefore provides a contemporary, high profile case example of trust issues and online records played out in the public arena. This

Methodology. This research project explored issues about professional and public trust in online records. It contributes to the 'Access' domain of the InterPARES research programme on trust. A purposive sample of publicly available online sources was used. These sources documented a wide range of stakeholder views and provided contemporary, topical information. This data was analysed by: (i) production of a timeline of key events; (ii) thematic analysis of the content of all the sources; (iii) discourse analysis of a small sample of the sources. The project was conducted from January to May 2015. There were a number of challenges with this methodological approach.

Results. A detailed timeline of the care.data programme was produced from 2011 to April 2015. The thematic analysis identified six themes and 26 sub-themes. The themes comprised: governance; purpose; consultation and communication; informed consent; data security; trust. The discourse analysis demonstrated a high level of concern and mistrust in care.data expressed by MPs, health professionals, health research charities, health consumer groups, the public and the media.

Discussion and conclusion. The unfolding story of care.data provides a good case example of how the poor handling of a new programme for using public digital records resulted in a crisis of public trust. NHS England and HSCIC demonstrated poor governance of the care.data programme. Key factors that establish trust in a digital records programme were handled badly. However, the public furore and the government's changes in response have significantly improved the care.data programme. The care.data programme is a candidate for a government blunder (an avoidable mistake).

1. INTRODUCTION

1.1 The care.data Programme

The care.data programme is an initiative of the UK National Health Service (NHS), overseen by NHS England (<http://www.england.nhs.uk/>) an executive non-departmental public body. NHS England is responsible for overseeing the commissioning of NHS services: their budget, planning, delivery and day-to-day operation. The care.data programme will eventually collect and link together data from all health and social care settings, both hospital and community based, with the purpose of planning and monitoring services. The organisation charged with handling this data is the Health and Social Care Information Centre (HSCIC; <http://www.hscic.gov.uk/>), an executive non departmental public body sponsored by the Department of Health, established in 2013 from its progenitor department, the NHS Information Centre (NHSIC) which was itself established in 2005 (as a merger of parts of the Department of Health, parts of the NHS Information Authority, and the Prescribing Support Unit). A range of care data sets has been collected for a number of years, including HES Episode Statistics (HES) (<http://www.hscic.gov.uk/hesdata>) which provide information about the care and treatment of individuals from visits to hospital. HES contain information about individual patients, including clinical, personal, administrative and geographical information. It is pseudoanonymised using a custom-designed patient ID. The care.data programme comprises the addition of data sets from general practices (primary care practices) with the aim of linking the general practice data to the hospital data (<http://www.hscic.gov.uk/gpes/ caredata>). Though GPs (general practitioners/primary care physicians) have been providing aggregated data previously, the care.data programme will extract individual patients' personal and clinical data, i.e. NHS number, date of birth, postcode, gender and coded clinical information - identifiable personal and sensitive data. The GP data is far more individually identifiable than HES data, e.g. date of birth compared with age group, NHS ID with is specific to an individual and used in all NHS activities compared with HES ID with is generated by an algorithm using a number of identifiable data types. GP data also covers effectively the whole population (as nearly everyone is registered with a GP from birth to death) and GP care is 24/7. Hospital activity only covers a small proportion of the population at any one time and is episodic.

1.2 The Health and Social Care Act 2012

The care.data programme needs to be set into the context of the wider reorganisation of the NHS undertaken by the Coalition Government, comprising the Conservative and Liberal Democratic political parties and in office from 11 May 2010 to 8 May 2015. This reorganisation was set out by the Health and Social Care Act 2012. This reorganisation was hugely controversial as it was viewed by many as being part of a privatisation agenda. The Act was resisted by

both health care professionals, and their professional bodies (e.g. the British Medical Association (BMA) and the Royal College of General Physicians (RCGP)), and the public, and various lobbying groups. Indeed new groups were set up to fight this reorganisation, e.g. 'Keep Our NHS Public' (<http://www.keepournhspublic.com/index.php>) and 'Doctors for the NHS' (<http://www.doctorsforthenhs.org.uk/>). Despite the passage of the Act, the resistance and lobbying has continued with various attempts to repeal or mitigate the Act, e.g. a private member's bill, the 'NHS Reinstatement Bill' (<http://www.nhsbill2015.org/>). The NHS was an important issue during the election campaign leading up to the 7 May 2015 national election.

The Health and Social Care Act, 2012, enabled the care.data programme as NHS England can require the HSCIC to request data from any health service provider. Health care staff only became aware of the care.data programme in late 2012 with publication of NHS England's initial health service guidance.

1.3 Rationale for This Research Project

The care.data programme was announced in late 2012 with plans to add the routine collection of data from general practitioner (GP) primary care practices to the other data sets held by the HSCIC. Resistance built up during 2013 amongst health professionals and privacy groups, with growing media coverage. With care.data's imminent implementation in early 2014, this resistance finally triggered a high profile public uproar. Though GPs/primary care physicians had been providing aggregated data previously, the care.data programme will extract individual patient's personal and clinical data, i.e. NHS number, date of birth, postcode, gender and coded clinical information - identifiable personal and sensitive data. The concerns from GPs and other medical practitioners about consent and privacy quickly spread to the professional media and privacy advocacy groups, then to traditional mass media, online media and campaign groups. An additional concern was who would see this data, as HSCIC offers standard and bespoke data products to organisations inside and outside the NHS. The response of the government to these criticisms was also considered to be badly flawed, in particular, a subsequent leaflet campaign to all households. The leaflets were not addressed to people by name but came in the form of a bulk mailing that got confused by many people with junk mail. This leaflet did not give the name of the programme nor provide details of how people could opt-out of the scheme (opt-in was automatic). The public outcry was so huge that the government was forced to postpone the programme in February 2014 for six months. The programme will now be undertaken in phases. A small number of GP practices have been identified as Pathfinder projects with the aim of testing and refining the process. Full implementation of the programme will follow. However, all the issues about consent and privacy have not been fully addressed and public concern and lobbying continues.

Patient records are public records in the UK, but individual patients obviously regard their records as their own, and GPs are data controllers of patient records under the UK Data Protection Act. Because of the personal and sensitive nature of their contents a raft of laws and regulations govern their management and use (Caldicott, 2013).

The care.data programme therefore provides a contemporary, high profile case example of trust issues and online records played out in the public arena. This project contributes to the 'Access' domain of the InterPARES research programme on trust. It contributes to two of the InterPARES Trust objectives, viz:

- To discover how current policies and practices regarding the handling of digital records by institutions and professionals affect the public's trust in them, in light of the exponential growth of and reliance on Internet services
- To anticipate problems in maintaining any trust in digital records under the control of entities suffering a waning level of confidence from the public (including legal, law enforcement, financial, medical, broadcasting, "hacktivist", and governmental organizations and professionals).

2. METHODOLOGY

2.1. Aims and Objectives

The project addressed the research question: what lessons about professional and public trust in online records can be obtained from a study of the care.data programme? Its objectives were:

- To explore different stakeholder views of trust in online records by taking a 360° view of the care.data programme initiative in the UK
- To develop a reproducible methodological approach using analysis of public discourse
- To identify issues to be addressed in policy, procedure and/or practice for managing digital records in programmes like care.data which contain personal data.

2.2 Methodological Approach

A purposive sample was obtained of relevant items from publicly available online sources providing contemporary, topical information. These sources documented a wide range of stakeholder views, i.e. governmental (e.g. NHS England, HSCIC); health professionals (e.g. BMA); mass media (e.g. 'The Guardian', the Daily Telegraph; readers' comments to individual articles); online health media (e.g. 'eHealth Insider'; readers' comments to individual articles); campaign groups (e.g. 38 Degrees). Sources and individual items were obtained using a snowball technique. The starting point was online health media (eHealth Insider, now digitalhealth.net) subscribed to by the authors, and knowledge of the activities of 38 Degrees. Links in these were followed to other organisations and sources, supplemented with Google searches to track down poorly identified items. Sources covered the period from 2011 to April 2015.

This data was analysed in three ways:

- production of a timeline of key events
- thematic analysis of the content of all the sources
- discourse analysis of a small sample of the sources, based on the approach of interpretive policy analysis (Fairclough, 2001)

Thematic analysis was used to look for broad subject themes/sub-themes in the data. Under these themes, brief summaries of points extracted from the sources are listed. Discourse analysis is the analysis of the language used in the sources. Critical discourse analysis seeks to find the connection between language and social interactions and relations, such as power and politics (or in this research trust issues). Thematic and discourse analyses are complimentary: thematic analysis describes what is said, discourse analysis explores the social setting and the social and political interactions manifested in the way things are said.

The project was conducted from January to May 2015. The results were presented at the InterPARES meeting in London, 21/22 May 2015.

2.3 Methodological Issues That Arose During the Project

The benefits of the methodological approach were three fold: (i) use of these online sources provided topical coverage of a contemporary issue; (ii) including health consumer groups and reader comments as well as government and health professionals provided a 360° view of the issue; (iii) use of thematic and discourse analysis complemented each other; the discourse analysis was particularly useful at providing understanding of an emotional and complex issue such as trust.

The authors needed to be in regular contact with the field, keeping up to date with information sources about what is happening. The authors' initial route to information on care.data was via news items and press releases. The stories appeared first in specialised online health media, with coverage in mass media sources coming later as the topic became a more active story. Information in these news stories allowed the original organisations and sources to be traced, and then followed as applicable.

There were however a number of challenges with this methodological approach, mainly related to the characteristics of the sources used as data. Examples of the challenges are given below.

News sources often do not provide accurate details of where they get there 'story' from so it can be difficult to track down the original source.

A news source can pick up stories weeks, even months, after they were first released elsewhere. However the news source still presents them as if they were a current event. This makes production of an accurate timeline difficult.

When tracking an emerging issue it is difficult to identify the early items, which may be covered as a small part of another news story, and be discussed using terminology that is not the same as that used later on. Even when the authors were following these types of issues by subscribing to eHealth Insider, it was sometime before they realised the importance of the care.data issue and started to read and download relevant items. Some of these early items can be obtained retrospectively by links from later sources and from Google searches. But the very first stages in the timeline are likely to be missing.

News sources and online sources are ephemeral. It is up to the originator to curate, or not, their material. 38 Degrees do not keep publicly available their

original email petition requests. The main specialised health news source used by the authors was eHealth Insider. This was combined with other related sources and relaunched as a new company Digital Health Intelligence (digitalhealth.net): the URLs of the individual news items were changed. The BMA maintains a link to its online statements on care.data, however these show only the current statement and historic statements are lost. HSCIC has completely restructured its website. There is therefore a need for the researcher to download the items (subject to copyright) or capture a summary as soon as they are identified as a precaution against their disappearance. However, when future researchers wish to validate the research they may not be able to find the original items.

When dealing with matters that are conducted by a government department or public body it can be difficult for outsiders to get precise details of when things were done or agreed. Though often non-controversial, these details are often not placed in the public domain, or might appear in other types of outputs such as annual reports but in an obscure way. Some actions which are politically sensitive will never be publicly known, or only known decades later. It can be a long time span from an action to when it becomes publicly known (e.g. the Independent Information Governance Oversight Panel (IIGOP) raised concerns about the care.data leaflet in late 2013, but this was not publicly known till its annual report in 2014 (produced in December 2014, first published on 2 January 2015) and subsequent news stories).

Poor bibliographic details are provided in reports, e.g. no date, no author, no publisher.

The thematic and discourse analysis can elucidate what was done and said, and when, but not necessarily why. For a full picture the data needs to be supplemented with interviews and focus groups. For example, these techniques could be used to explore why 38 Degrees decided to raise a petition on care.data in February 2014.

3. RESULTS

3.1 care.data Programme Timeline

2011

December 2011

- 6 December 2011. Story in 'The Register' about a government announcement of a consultation "to change the NHS Constitution so that patient data is automatically included in clinical research, but giving patients a clear opportunity to opt-out if they wish to do so".

2012

March 2012

- 27 March 2012 the Health and Social Care Act 2012 becomes law. Under this Act NHS England has the power to direct the HSCIC to collect information from all providers of NHS care, including general practices.

August 2012

- 2 August 2012. Story about making clinical data available for research is picked up by the Daily Mail

December 2012

- Care.data programme listed in NHS England's initial planning guidance for the health service
- BMA and RCGP's joint IT committee request a meeting to discuss care.data with NHS England – then work with NHS England and HSCIC to plan for care.data, produce GP guidance and public information etc.

2013

January 2013

- medConfidential founded "as a direct response to the imminent and serious threat posed by radical changes in the way two new arms-length bodies, the NHS Commissioning Board ('NHS England') and the Health and Social Care Information Centre (HSCIC), planned to extract and pass on patients' medical information from NHS health record systems in England" <https://medconfidential.org/about/>

February 2013

- 2 February 2013. National news story that care.data could be a risk to patient confidentiality, citing both the BMA and Big Brother Watch

April 2013

- 26 April 2013. News story about Minister for Health announcement that patients will have the right to opt-out of care.data by requesting that their data does not leave their GP practice (type 1 objection)

May 2013

- 17 May 2013. News story that Bupa (a private health care provider) has been approved for access to sensitive/identifiable patient data held by HSCIC (based on information released by HSCIC)
- 29 May 2013. BMA News item about GP guidance for care.data. Includes suggestions/statements (in this and later news items) that BMA is negotiating to protect patients' confidentiality, to share only pseudoanonymised or anonymised data, and to ensure the provision of an opt-out.

August 2013

- 22 August 2013. NHS England news item announcing the care.data programme
- August. Joint statement for GPs by NHS England, HSCIC, BMA, RCGP
- August to September 2013. Pack of publicity material (developed by NHS England, HSCIC, BMA and RCGP) sent out to GP practices.

September 2013

- Some GP practices consider boycotting the care.data programme
- HSCIC launches "A guide to confidentiality in health and social care". It states that patients can request that no identifiable information about themselves can leave the HSCIC (type 2 objection)

October 2013

- 3 October 2013. Q&As about care.data published in Pulse, a GP professional magazine
- 16 October 2013. BMA news item that BMA and RCGP are backing the public awareness campaign

2014

January 2014

- NHS send out a leaflet - "Better information means better care" - to all households in England.
- 15 January 2014. NHS England publishes a privacy impact assessment for care.data (as a controlled document not available for download)
- 17 January 2014. News story that the strategic business case for care.data has not yet been finalised and sent to the Treasury for approval
- 23 January 2014. An animated video developed by NHS England and HSCIC to raise awareness about care.data

- 28 January 2014. News story about care.data safeguards (details from the privacy impact assessment)

February 2014

- 17 February 2014. BMA news item about GPs concerns and patients lack of awareness of care.data: a strengthened campaign is required. BMA is to hold an urgent meeting with NHS England
- 17th February 2014. First action by 38 Degrees
- 19 February 2014 . NHS England postpones Care.data's implementation by six months
- 19 February 2014. BMA news item welcomes delay in care.data implementation. This decision followed their meeting with NHS England.
- 24 February 2014. Daily Telegraph news story that the NHSIC (a precursor of HSCIC) had released hospital admissions data, from 1989 to 2010, to the Institute and Faculty of Actuaries
- 25 February 2014. House of Commons Health select Committee takes its first oral evidence on the care.data database. Decides to widen its remit to the 'Handling of NHS Patient Data'

March 2014

- The All-Party Parliamentary Group for Patient and Public Involvement in Health and Social Care (APPG) sets up an Inquiry into care.data. Written evidence from healthcare charities in March 2014; oral evidence June 2014. Written evidence from the research community and Royal Colleges' evidence in August 2014: oral evidence October 2014 (including NHS England). Report published November 2014. Continues to hold a watching brief.
- 3 March 2014. News story about MP criticising usage of HSE data obtained by PA Consulting and uploaded to Google servers
- 4 March 2014. News story that Health Secretary proposes new legislation to restrict the purposes for which health care data can be used and to set up scrutiny mechanisms
- 21 March 2014. BMA news item – ethical concerns about care.data raised at BMA conference
- 21 March 2014. NHS England sets up a care.data independent advisory group to improve governance of the programme. The group is chaired by the Chief Executive of Macmillan Cancer Support, and has representatives from professional and citizen groups including the British Medical Association, Healthwatch, the Association of Medical Research Charities, the British Heart Foundation, Big Brother Watch and MedConfidential (<http://www.england.nhs.uk/ourwork/tsd/ad-grp/>).

Early 2014

- Independent Information Governance Oversight Panel (IIGOP) to advise the care.data Programme Board on the pathfinder stage of the programme.

April 2014

- 1 April 2014. Original date for first data flow from GP practices to HSCIC
- 3 April 2014, news story that HSCIC has released a register of its data releases.

May 2014

- The care.data Programme Board agreed that they would work with two to four CCGs and up to 500 GP practice Pathfinders to test and refine the communication and technical processes needed to implement care.data
- 27 May 2014. BMA news item – BMA conference calls for patient opt-in for care.data

June 2014

- The All-Party Parliamentary Group for Patient and Public Involvement in Health and Social Care (APPG) Inquiry into care.data. Oral evidence from healthcare charities in June 2014.
- 14 June 2014. Publication of review into data releases by the NHSIC (the progenitor organisation of HSCIC) – lapses were identified
- 25 June 2014. BMA news item – confidentiality concerns about care.data raised at BMA conference; debate over opt-in versus opt-out
- 26 June 2014. Department of Health sets up a consultation – “Protecting health and care information: a consultation on proposals to introduce new regulations” – that suggests allowing local organisations to set up safe havens. The consultation ran till 8 August 2014. No individual responses have been posted by the Department of Health and they have not produced their report nor new regulations.

July 2014

- BMA passes policy that the care.data should not continue in its current form

August 2014

- The All-Party Parliamentary Group for Patient and Public Involvement in Health and Social Care (APPG) Inquiry into care.data. Written evidence from the research community and Royal Colleges' evidence in August 2014.

September 2014

- New launch date after 6 month postponement (not actioned but programme further delayed)
- 23 September 2014 care.data Pathfinder Proposal report published

October 2014

- The All-Party Parliamentary Group for Patient and Public Involvement in Health and Social Care (APPG) Inquiry into care.data. Oral evidence from the research community and Royal Colleges, plus NHS England, in October 2014.
- 7 October 2014. The CCG areas of Somerset, West Hampshire, Blackburn with Darwen, Leeds North, Leeds West and Leeds South and East were selected as Pathfinders.
- Pathfinder phase starts.

November 2014

- The All-Party Parliamentary Group for Patient and Public Involvement in Health and Social Care (APPG) Inquiry into care.data. Report published in November 2014. APPG continues to hold a watching brief.
- 17 November 2014. The care.data Programme Board accepted a proposal for publishing the agenda, minutes and finalised papers from their meetings

December 2014

- 18 December 2014. IIGOP report on pathfinder stage published. This set out 27 questions that needed to be answered at national level, and 7 conditions for each pathfinder to meet, before the pathfinders could proceed

2015

March 2015

- 3 March 2015. Data extraction held off till after General election, to give time for all IIGOP concerns to be addressed

Summary and Analysis of Timeline

The text in [] is the authors' comments on the event.

Coverage of care.data is low key in 2012, until December when it comes to the awareness of health professional bodies (BMA and RCGP). They become involved in advising NHS England and HSCIC, but behind the scenes.

In January 2013 privacy experts become aware of the care.data plans and are so concerned that they set up a group to lobby and inform on this. [This group has a

public presence on the Web and NHS England should have been alerted at this early stage that care.data was likely to have public acceptancy problems.] The advice of BMA and RCGP has some effect and the Health Secretary announces in April 2013 the provision of an opt-out to care.data. [Why was such a key provision not in the original implementation plans?] A national news story in May 2013 reports that NHS data is being made available to a private health company. [The media knows that this type of story will raise public concern and privacy, particularly linked to the high level of public concern about NHS reorganisation and privatisation. This was another alert for NHS England that there were problems ahead. The fact that the media were focusing on stories about private companies, should have triggered proactive PR management of information about past data releases and whether or not these types of uses would occur with care.data]. In August 2013 the care.data programme is announced [though not in a source that most members of the public would be aware of]. Information and patient publicity materials are sent out to GP practices. In September 2013 GP concerns with care.data start to appear in the health professional press. Public support by the BMA and RCGP continues [though probably they are expressing private concerns to NHS England and HSCIC.]

The public information leaflet is sent out in January 2014. Though developed with the BMA and RCGP, the IIGOP expresses concerns that it is 'not fit for purpose'. These are ignored [probably because NHS England contacted the IIGOP too late in the publicity campaign to be able to stop it]. In February 2014 BMA sends out a news item about concerns with care.data. 38 Degrees becomes involved, threatening an opt-out campaign, and are called to a meeting with NHS England to discuss their concerns. On 19 February NHS England postpones the rollout of care.data for 6 months: the original implementation date is 1 April 2014 [no joke]. [The postponement results from concerns on all fronts: health professionals and related bodies, the public, the media. NHS England cannot ignore such pressure.] Concern is now expressed in Parliament and a Health Select Committee Inquiry into care.data is set up. A national paper releases a story about inappropriate data release by NHSIC the day before the launch of the Inquiry. [The media and campaigners are accused of scaremongering.] After the first meeting of the Inquiry, the level of concern is such that the Inquiry's remit is widened to the handling of NHS patient data. In March 2014 further news stories about inappropriate data releases by NHSIC appear. The Health Secretary announces plans for new legislation to restrict the purposes for which healthcare data can be used and to set up scrutiny mechanisms. [This indicates that the legislation in the Health and Social Care Act 2012 that set up care.data is not sufficient to provide the protection that the public and health professionals are calling for. It validates the media's 'scare' stories.] NHS England sets up a care.data independent advisory group with membership from professional and citizen groups. [Why was such a group not set up in 2012 as soon as the plans for care.data were started?] A pathfinder (pilot) project is planned. [Why was such a pilot project not set in motion as soon as the plans for care.data were

started, with the rollout date dependent on the pilot results?] In April 2014 HSCIC releases a register of its data releases, as requested to do so by the Health Select Committee. [NHS England and HSCIC should therefore be prepared for unwelcome media stories.] In June 2014 a review of the data releases by NHSIC is published which demonstrates there has been procedural lapses. [NHS England and HSCIC should therefore be prepared for unwelcome media stories.] In July 2014 BMA announces their policy that care.data should not continue in its current form. In September 2014 the roll out date is further delayed. In October 2014 the pathfinder sites are announced. IIGOP's report in December 2014 states there are numerous questions that need to be answered before the pathfinder sites can start work.

In March 2015 rollout of care.data is further postponed until after the general election. The authors stopped data collection in April 2015, however the care.data story is still continuing and is still controversial.

3.2 Thematic Analysis

Broad subject themes/sub-themes from the data are given below. Under these themes, brief summaries of points extracted from the sources are listed. The text in [] is the authors' comments on the point.

Governance

- ***Lack of preparation***
 - NHS England produced detailed documentation on rules and procedures produced (in January 2014) but this did not receive much media coverage. It did not alter people's concerns. [Was this information inadequate/incomplete or poorly communicated or both?]
 - NHS England and HSCIC could not answer many questions about procedures at the Health Select Committee session
 - negotiations with BMA and RCGP early on resulted in changes, but this was occurring during the initial implementation phase when it should have occurred during the planning stage
 - the required code of practice document was not written at time of the first delay in the rollout of care.data
 - do hospitals and GP practices have the IT systems, and staff resources, to collect/process the required data?
 - the need for an enhanced technical platform was only recognised after the furore and a project to develop this was then set up
 - tasks for the first six-month hiatus period included: additional guidance and materials for GPs, increasing awareness amongst GPs; publication of an HSCIC confidentiality code of practice, legislative changes to become statute

- **Poor communication** and lack of necessary information to both health care professionals, particularly GPs the data controllers of this data, and to the public (see also Consultation and Communication theme)
- **Poor financial administration**
 - financial permission not obtained at time of original rollout
 - still writing business case after initial launch date
 - before the postponement, informing patients was pushed on to GP practices by NHS England with little warning and no extra resources
 - the 'failed' public leaflet campaign cost £1,230,000
 - a proper opt-out communication process will be expensive
- **Sub-contracting to mistrusted private company.** The work to gather the data has been sub-contracted to ATOS. ATOS has a bad public reputation. [This bad reputation results from its operation of the 'Work Capabilities Assessment' scheme. ATOS has withdrawn early from this scheme with accusations of poor quality work and the payment of a penalty. The decision to award them the care.data contract increases mistrust in care.data – although the decision was made by NHSIC, HSCIC must still take responsibility.]
- **Lapses in procedures.** Evidence of lapses in procedures and record keeping for data releases by NHSIC (HSCIC's progenitor organisation) – the non-executive director of the HSCIC accepted that they were responsible for addressing these as (i) they inherited many of the same staff and procedures, and (ii) agreements with some organisations are still operational
- **Safe haven concept little discussed.** The HSCIC is the 'safe haven' for this data. [However, little of the discussion covered this concept, despite clear articulation of this in the Caldicott information governance review.]
- **Raised public profile for information governance.** Care.data "moved information governance out of the backwater of clinical management into the mainstream of political, media and public interest" (IGOP annual report, 2014, p.11)

Purpose

- **Disputes over what data should be included in the care.data programme**
 - Historical limits on the data, e.g. compromise that only data from April 2013 will be extracted initially. Researchers complain that this restriction will negatively impact on research.
 - Data held by GPs comprises intensely personal and sensitive data, often covering issues wider than the specific clinical condition. It covers the whole lifespan of the patient.
 - Data is not necessarily accurate. How can this be corrected?

- Identifiable data is required from GP practices because of the need to link this with other data, e.g. HES. (See also the Data Security theme)
- Pseudoanonymised data is being released. (See also the Data Security theme)
- Calls for a framework of patients' rights, with patients owning their own data. [Currently under the NHS Constitution patients only have the rights to see their records and correct factual errors.]
- **Disputes over what the data can be used for and who can use it** (See also the Trust theme)
 - Government assurances that the data is for purposes related to health and social care and health and social care services only [These assurances are mistrusted]
 - Administration of health services
 - Official approval of data release from GP practices to HSCIC is currently only for commissioning purposes. Approval for other purposes, such as research, requires identification of what are appropriate organisations to receive this data and establishment of governance controls
 - With the NHS opened up to private health care providers, as well as NHS health care providers, private companies will be allowed to see the data
 - Benefits in improved service design and delivery are envisaged
 - Research
 - This is the area where the most benefits are envisaged
 - Health care research is carried out by public (e.g. NHS bodies, universities), not for profit (e.g. health research charities) and commercial organisation (e.g. Big Pharma)
 - Fears expressed that other public bodies might be able to access the data, e.g. HMRC (HM Revenue and Customs), the police, local authorities
 - Fears expressed that other private organisations, e.g. insurance companies, particularly health insurance companies, might be given access to the data. [These fears are supported by the type of organisations who accessed data under the NHSIC regime]
 - Patient groups, individuals want the data to be used by public-sector health-related organisations/individuals (e.g. health professionals and academics) only, and for the public good, not for commercial or political reasons. Research organisations are rather less restrictive, because of the involvement of private companies in research, but are concerned about use by non-health related government departments and by non-health related organisations.
 - Health Secretary announces that proposed new legislation will restrict the purposes for which the data can be used. [This suggests

that the legislation that set up care.data did not provide sufficient clarity and/or safeguards.]

- **Complex legal basis**
 - Under the Health and Social Care Act 2012 GPs are required to release the data. However, this conflicts with their responsibility as a Data Controller under the Data Protection Act (DPA).
 - DPA – three bodies have responsibility for the data - i.e. the GP, HSCIC and NHS England - causing conflicting responsibilities and confusion.
 - Proposed legislation to deal with concerns raised but this has not yet been enacted, so the detail of such legislation is unclear.
 - Need for legally binding rules about identification and use, and sanctions if these are broken, e.g. one strike and you're out, or criminal offence.
 - Consent process and its interrelationship to other laws (UK and EU), e.g. confidentiality, mental capacity
- **Controls on use need to be strengthened, monitored and enforced** (see also the Governance theme)
 - Strict controls are required to ensure that only the right groups access the data for the right purposes.
 - This use needs to be effectively monitored and enforced. Results of monitoring should be placed in the public domain
 - Transparency of actual uses and users is needed. The controversy has made the HSCIC produce regular reports of their data releases
 - HSCIC data releases (of HES) for April to December 2013: 347 releases of pseudoanonymised data; 75 releases of identifiable data; releases to 160 organisations - 104 health and social care organisations (e.g. NHS trusts, universities, charities), 56 private sector organisations. Release is missing details of long standing contracts with commercial organisations
 - Evidence of past inappropriate (although probably legal at the time) data releases of HES by the HSCIC's progenitor organisation NHSIC
 - Release of hospitals admissions data, from 1989 to 2010, to the Institute and Faculty of Actuaries. NHSIC linked the HES data to Experian Mosaic data (socio-demographic data) on behalf of the end user and supplied the pseudoanonymised output. The Institute and Faculty of Actuaries is a not-for-profit organisation and their purpose for the data was to conduct non-commercial research analysing general variances in critical illness. This data was used to produce a report to aid actuaries in critical illness pricing. Data was handed over in January 2012 on payment of a small administrative fee (£2,220).

- Providing PA Consulting with pseudoanonymised HES data in November 2011. The data covered a number of different topics and covered periods from 1990 to 2012. NHSIC knew that PA Consulting would be using Google BigQuery to analyse the data and obtained written assurances that no Google staff would be able to access the data. PA Consulting Group (<http://www.paconsulting.com/>) is a large consulting company with offices in the States, Europe and Asia
- Evidence of lapses in procedures and record keeping for data releases by the NHSIC (HSCIC's progenitor)
- ***care.data will have many benefits, but benefits realisation has been jeopardised***
 - To the design and delivery of health and social care services: better management of existing services, design of improved models of care, linkage of health and social care data for design of new types of services
 - To health research: epidemiology, treatment, etc.
 - There is agreement across all groups that care.data will have benefits – but all the concerns raised need to be addressed
 - The poor management of care.data has jeopardised the realization of these benefits (see also Informed Consent theme)

Consultation and Communication

- ***Lack of consultation*** and consultation undertaken was flawed
 - BMA and RCGP not initially informed; had to request a meeting with NHS England but from then on they advised NHS England
 - no consultation with the wider public
 - no consultation with patient groups and health charities who have expertise, particularly of the special needs of patients with specific conditions
 - NHS England sent out information to thousands of patient groups, charities, and voluntary organisations. [What did this information comprise?] NHS England says they consulted with numerous organisations. [Has information provision been conflated with consultation?]
- ***Public publicity campaign 'not fit for purpose'***
 - NHS England consulted on their public leaflet with bodies such as the BMA and the RCGP. However, although IIGOP said the leaflet was 'not fit for purpose', NHS England went ahead with the mailing (they'd already sent it to the printers before they consulted with IIGOP).
 - Information campaign was flawed, e.g. public leaflet sent as a mass mailing. It appears many households did not receive/read the

- leaflet, either because they had a mailing preference set up or because the leaflet was discarded as 'junk mail'. Leaflet content was confusing and unclear (e.g. did not use the name care.data), and the opt-out procedure was inadequately explained (e.g. no opt-out form was attached). Different leaflet formats, voice contact and translation services were made available.
- An animated video about care.data was produced. Except for NHS England's news item no-one else mentions this. Did anyone ever see it?
 - **Lack of transparency** (see also Purpose theme)
 - When it comes to health consumers' lack of trust in government this lack of transparency compounds the problem. It suggests that the government is undertaking things in an underhand fashion, that things are being deliberately hidden and that the publicly available information does not provide the true picture. It encourages conspiracy theories. [The Freedom of Information Act can be a blunt tool to ensure transparency of government actions and full disclosure of information. Much greater proactive publication of government information would help to create trust. Is the Information Commissioner's model publication scheme for public bodies sufficient, and or is it being interpreted widely enough?]
 - **Poor communication of details to GPs and the public**
 - NHS England produced a privacy impact assessment of care.data which gave details of procedures and extra assurances for protecting patient's confidential data. However this does not seem to have been well promoted. [There is a challenge in précising down such complexity into understandable public information, but to do so is key to gaining trust.]
 - GPs are the initial Data Controllers – NHS England required them to inform patients, without prior consultation with them of the need to do this. Cost and time of this falling on individual GP practice budgets
 - Public need to be given far more detailed information about purpose and security procedures (see also Purpose theme)
 - Poor communication of the benefits to the public
 - **Accusations that media and campaigning groups are scaremongering**
 - Many of the national media stories focus on inappropriate use of HES data, raising people's fears of their data falling into the hands of private companies and being misused. There are accusations that this is scaremongering.
 - One key focus of the campaigning groups is the fear of people's personal and sensitive data falling into the hands of private companies and being misused. There are accusations that this is scaremongering.

- The fact that under NHSIC HES data was accessed by private companies and that there were procedural lapses gives supports to these public fears.

Informed Consent

- **Public lack information so are not properly informed** (see also Consultation and Communication theme)
 - Because of poor communication, members of the public are not fully informed
 - Opt-out process not clearly explained to patients nor to GPs who were supposed to administer it.
 - Issues are complex and therefore well designed information is required
 - A full explanation is required of the consent process and what opt-out entails and results in
- **Consent procedures complex, poorly explained and in dispute**
 - BMA and RCGP advised NHS England to provide patients with an opt-out to care.data. [Was consent not in the original plans for care.data?]
 - Opt-in, Opt-out
 - Opt-in is ethically preferred.
 - Campaigning groups prefer opt-in.
 - BMA's policy is now for opt-in.
 - Opt-out is what is available.
 - Opt-out better from administrative and research viewpoints as it creates a more complete dataset: many fewer people would opt-in, making the programme inoperable/ineffective.
 - If too many people opt-out this will damage benefits realisation.
 - Consent process for people with capacity issues (e.g. dementia) not properly considered
 - Consent process and its interrelationship to other laws (UK and EU), e.g. confidentiality, mental capacity. Opt-out process could be legally challenged, e.g. GPs could be challenged under DPA. Therefore for ethical and legal reasons, an opt-out process must be very clearly explained in detail and an opt-out campaign must reach as many of the population as possible and feasible.
 - What does opt-out comprise? Appears to be two types: Type 1 objection (patient requests that none of their data leaves the GP practice); Type 2 objection (patient requests that their identifiable data does not leave the HSCIC). This complexity seems unnecessary. The opt-out procedures are being changed.
 - There are many questions about the opt-out procedures that need answering. For example, once identifiable data has been given to

the HSCIC can this be withdrawn if a person changes their mind?
Patients have to ask their GP to opt-out: how do they know this has been done by the GP; how do they know it has been respected by the HSCIC? [Such questions are being addressed by the pathfinder projects under the guidance of IIGOP.]

Data Security

- **Data security methods to protect identifiable data in dispute**
 - Data linkage is required to combine the GP and hospital data to realise the benefits for research and service improvement. Therefore identifiable or pseudoanonymised data is required.
 - Pseudoanonymised data has the potential to re-identify individuals via a jigsaw attack (i.e. combining different bits of information)
 - Pseudoanonymisation at source, i.e. within the GP practice, suggested but not considered appropriate by some experts.
 - The NHS ID is an insecure way to pseudoanonymised data as it is a commonly used code in all clinical practice.
 - Data for commissioning does not need to be identifiable: it should be anonymised/aggregated.
 - Except under very specific circumstances, data leaving the safe haven should be anonymised/aggregated.
- **Safe haven concept**
 - Identifiable data only held within the safe haven. Data linkage can occur within the safe haven, and outputs can be pseudoanonymised/anonymised/aggregated as applicable.
 - HSCIC is the safe haven for care.data.
 - Government has consulted on the idea of enabling many other organisations to become safe havens. Some people think this is a risky idea, increasing complexity and threatening security.
- **Accusations of scaremongering versus genuine public concerns.**
Accusations that data security fears are scaremongering versus the idea that people's fears are genuine and have to be addressed

Trust

- **Bodies/individuals mistrusted by the public**
 - Government
 - MPs, particularly because of the expenses scandal
 - Department of Health, NHS England, particularly because of the reorganisation of the NHS
 - HSCIC, particularly because of the past history of NHSIC (its progenitor organisation) and use of private subcontractors, e.g. ATOS

- private health care providers, particularly when running 'NHS' services
- other public bodies accessing such sensitive personal data - mission creep
- private organisations accessing such sensitive personal data (e.g. Big Pharma, insurance companies, employers) - privatisation of public services, mission creep
- poor handling of the care.data programme and the resulting uproar has massively increased this distrust
- **Bodies/individuals trusted by the public**
 - NHS, where publicly funded and publicly run: not where privately run; not the newly created bodies such as NHS England. [A commonly used, though difficult to source, quote is “the NHS is the closest thing the English have to a religion”.]
 - Researchers, where NHS, University or not for profit; not where commercial, Big Pharma
 - health professionals, particularly GPs
- **Crisis of public trust.** The care.data programme became a crisis of public trust
- **Safe havens and trust.** The role of HSCIC as a safe haven has been damaged: a safe haven has to be a trusted body.
- **Lack of trust can become contagious.** GP bodies and health research charities fear the distrust created by the care.data organisation will lead the public to mistrust them too
- **Climate of distrust.** Any government policy or activity now functions within a climate of distrust of government, e.g. privatisation of the NHS; Snowden revelations; use of private companies to run public services and scandals of their incompetence and fraud, etc.

Summary of themes and sub-themes

Governance

- Lack of preparation
- Poor communication
- Poor financial administration
- Sub-contracting to mistrusted private company
- Lapses in procedures
- Safe haven concept little discussed
- Raised public profile of information governance

Purpose

- Disputes over what data should be included in the care.data programme
- Disputes over what the data can be used for and who can use it
- Complex legal basis

- Controls on use need to be strengthened, monitored and enforced
- care.data will have many benefits, but benefits realisation has been jeopardised

Consultation and Communication

- Lack of consultation and consultation undertaken was flawed
- Public publicity campaign ‘not fit for purpose’
- Lack of transparency
- Poor communication of details to GPs and the public
- Accusations that media and campaigning groups are scaremongering

Informed Consent

- Public lack information so are not properly informed
- Consent procedures complex, poorly explained and in dispute

Data Security

- Data security methods to protect identifiable data in dispute
- Safe haven concept
- Accusations of scaremongering versus genuine public concerns

Trust

- Bodies/individuals mistrusted by the public
- Bodies/individuals trusted by the public
- Crisis of public trust
- Safe havens and trust
- Lack of trust can become contagious
- Climate of distrust

3.3 Discourse Analysis

The text in [] is the authors’ comments on the points.

38 Degrees care.data blog entries

The information that 38 Degrees (<https://home.38degrees.org.uk/>) posts about itself describes who they are, what they believe in and what they are trying to do.

38 Degrees is one of the UK's biggest campaigning communities, with over 2.5 million members. We share a desire for a more progressive, fairer, better society and come together to decide which issues we campaign on and the actions we'll take to help us achieve that. ... We are a community of people who want positive change. We are a loud and persistent knock on the door of the politicians, influencers and institutions who make the decisions that affect us all. We hold them to account and

make sure they listen and respond to our calls for positive change. 38 Degrees is the angle at which an avalanche happens. Join 38 Degrees and be part of the avalanche for change. Anyone can become a member of 38 Degrees - it's free and you can join just by signing a petition, or taking another action.

38 Degrees has a small team of staff in London (<https://home.38degrees.org.uk/about/our-people/>) and is overseen by a Board (<http://www.38degrees.org.uk/pages/board>). This team contacts members via email and social media, and organises and runs petitions, meetings and other activities. As the power of 38 Degrees has grown, staff are now asked to meetings with ministers and officials and to be witnesses at parliamentary select committees, etc. Members sign petitions, email, phone or write to MPs, fund newspaper ads, and more recently act locally by holding public meetings, meeting their MPs and so on. Email and social media allow members to tell the team about issues of concern. The team regularly send out questionnaires to members asking them to vote on and prioritise the issues that 38 Degrees should campaign on. 38 Degrees is funded by donations.

Items on the 38 Degrees blog tagged with care.data were analysed.

The first item, dated 17 February 2014, comprises a call for action – organisation of a mass opt-out. The stance is already one of mistrust of the care.data scheme, emphasising that it will enable private companies to buy people's data. The companies named as examples have a bad public reputation. The issue is also placed within the wider issue of NHS reorganisation: an issue 38 Degrees had been campaigning on. There is much public distrust of the motives of the Coalition government's reorganisation of the NHS: it is perceived as thinly disguised privatisation. The item refers to trusted people – GPs and 38 Degrees members – who have raised concerns about care.data. There is not much information about care.data, and references so people can check the evidence are lacking. The concerns cover who can see confidential data, insufficient security measures, and selling data to third parties. The item asks members to vote on whether or not 38 Degrees should organise a mass opt-out from care.data. The emphasis is that 38 Degrees members can take action, that they have power, that they can pressurise NHS England to 'fix' (improve) care.data. Language is emotive, colourful (with use of metaphors), combative and empowering.

The next item, dated 18 February 2014, states that over 150,000 people answered the poll of which 92.8% agreed to an opt-out campaign. The item follows the same pattern as the previous one. 38 Degrees intends to contact NHS England with the poll result and threaten the mass opt-out unless security concerns are addressed. Comments to the blog post offered specific suggestions on how care.data could be improved.

The next item, dated, 19 February 2014, was written on the day that NHS England formally announced a 6 month delay in care.data. 38 Degrees were in a meeting with NHS England (called by NHS England in response to the opt-out campaign threat) the day before when the news of the delay first broke. The item highlights points that were made to NHS England that NHS England tried to dismiss, calling them 'myths' and 'nonsense'. NHS England were unable to answer some questions about risks to the data and their reassurances were not accepted. Language used showed 38 Degrees on the offensive: asking searching questions, pressing hard. The item stated that 38 Degrees people at the meeting were backed up by thousands of their members, 'making their presence felt' – telling members that they were involved and they had power. NHS England had a large pile of documents demonstrating the complex rules and procedures that would govern care.data. 38 Degrees pointed out that the public were expected to grasp all this complexity on the basis of a 'junk mail' leaflet and then be able to make an informed decision. NHS England 'conceded' that the communication could have been better. NHS England stated that responsibility for informing patients lay with GPs – passing the buck. The item finishes with a call to use the delay to 'ramp up the pressure' – demonstrating a combative stance. There is mistrust of the delay as a tactic to diffuse concerns rather than an opportunity to improve the scheme. Comments to the post welcomed the pause. Mistrust was demonstrated. Fears that data would be sold to Big Pharma, Big Business, private health companies taking over the NHS. Accusations were made that care.data was being sneaked in; that there was an unwritten agenda.

Another item, dated 19 February, 2014, claims credit for NHS England's forced delay of care.data – with the title 'we've won a breakthrough'. The use of 'we' emphasises that it's the 38 Degrees members, not just the staff team, who have been successful. References to mass media coverage of 38 Degrees emphasises that its campaigning was the 'key trigger'. However, other wording is more realistic that 38 Degrees was just part of the pressure that made NHS England retract.

An item dated October 14 2014 calls for further action to block the roll out of care.data (with the pathfinder stage starting). This post is much weaker in content and information than previous posts, with coverage only about selling data to private companies and NHS privatisation. However, in the post of 20 October 2014, 98% of members had agreed to block the roll out (although the total number responding was not given). A further post on 7 November 2014 continued the theme of resistance to care.data. It suggested acting in pathfinder areas with leafletting and advertisements plus an opt-out campaign. It accused that the new version of care.data 'stinks' but provided no information or evidence to back up this claim. [The work by IIGOP on the pathfinder stage would result in many of the improvements that people had called for.] The post finished with a

call for donations. Some of the comments to this post were critical, calling this petition 'disjointed', 'a rant', 'Daily Mail fear-mongering' [The Daily Mail is a tabloid newspaper with a right wing political stance], an excuse just to ask for money.

There were no other care.data posts.

care.data public information leaflet

This printed leaflet was mailed out to all households in England in January 2014. The leaflet was developed by NHS England in consultation with the BMA and RCGP. It later emerged that IIGOP did not think it 'fit for purpose' but the mailing proceeded with no changes to the leaflet content. There was criticism of the delivery mechanism as the bulk mailing could be confused with 'junk mail'. People queried whether households who had opted out of junk mail received a copy. Many people denied receiving the leaflet, or did not recognise its importance and binned it as 'junk mail'.

The leaflet is badged with the NHS logo – a trusted brand. The title is 'Better information means better care'. This theme is carried throughout the leaflet with the main emphasis being the benefits of sharing data – this is the largest section of the leaflet. The front page stresses the importance of the leaflet and that people have a choice. The content of the leaflet is structured under questions, and sub-headings:

- What are the **benefits** of sharing my information? (benefits emphasised)
 - Information will also **help** us to: (help emphasised)
- What will we do with the **information**? (information emphasised)
- What **choice** do I have? (choice emphasised)
- Do I need to **do anything**? (do anything emphasised)
- Where can I get **more information**? (more information emphasised)

The Introduction section is a very brief summary of care.data. Unfortunately, the rest of the leaflet does not really provide any further details, except for the section on benefits. The section 'What will we do with the information?' just states that strict rules will be followed. It states that "Information that we publish will never identify a particular person" which is asking people to take them on trust. Considering that this is one of the key areas of public concern, more detail of procedures to ensure security and confidentiality was required. The section 'What choice do I have?' lists three types of information that a patient might not want to be shared. The only advice given is for the patient to ask their GP practice to place three separate notes in their medical record. Besides being confusing to the patient about what they need to ask for, the extra workload for GP practices would be extreme as people contacted them in person – the leaflet tells them to 'speak to' their GP practice. Many critics of the leaflet felt that an opt-out form should have been supplied with the leaflet that could have been completed and posted to, or handed in at, the GP practice. In fact, a number of

organisations provided such a form (e.g. medConfidential <https://medconfidential.org/how-to-opt-out/>, though the situation is now confused as the opt-out arrangements are being changed). At the date of the leaflet mailing, concern about care.data amongst GPs was rising, and a number of GP practices were still unclear about the programme themselves and not in a position to fully advise their patients. The section ‘Do I need to do anything?’ starts with an emphasised paragraph stating that: “If you are happy for your information to be shared you do not need to do anything.” Critics felt that there was not sufficient information in the leaflet for people to be able to make an informed choice. The section ‘Where can I get more information?’ lists: (i) an NHS website – part of this URL contains the word ‘caredata’, the only mention of this name anywhere in the leaflet; (ii) speaking to staff at your GP practice; (iii) an 0300 phone number (charged only at the normal national rate) dedicated to care.data – it could be argued that a free phone line should have been provided; (iv) a link to a section on the HSCIC website on ‘Looking after your health and care information’ - this provides much more useful and necessary detail (however this is the current content of this link after many months of consultation and improvement of care.data; was this the information provided at the time the leaflet was sent out?). The leaflet carries a ‘Crystal Mark’ from the Plain English Campaign, another trusted brand. However, a Crystal Mark is about the ‘way’ things are said, not ‘what’ is said. The leaflet clearly fulfils the Crystal Mark criteria (see <http://www.plainenglish.co.uk/services/crystal-mark/frequently-asked-questions.html>) but what it says is inadequate; ‘not fit for purpose’. The overall feel of the leaflet is one of paternalism, and the message is that data sharing is ‘good for you’ and that you can trust the NHS with your data.

House of Common, Health Select Committee, Handling of NHS patient data inquiry

Select Committees are part of the functioning of the UK parliament. “House of Commons Select Committees are largely concerned with examining the work of government departments. ... There is a Commons Select Committee for each government department, examining three aspects: spending, policies and administration. These departmental committees have a minimum of 11 members, who decide upon the line of inquiry and then gather written and oral evidence. Findings are reported to the Commons, printed, and published on the Parliament website. The government then usually has 60 days to reply to the committee's recommendations.” (<http://www.parliament.uk/about/how/committees/select/>) The Health Select Committee examines the policy, administration and expenditure of the Department of Health and its associated bodies, which would include NHS England and the HSCIC. The Inquiry ‘Handling of NHS patient data’ developed from an inquiry into care.data. “The Committee originally decided to take evidence on issues connected with the proposed care.data database which is intended to link patient data from GPs with records of hospital treatment. Following the evidence taken on 25 February, the Committee has decided to look

at the issue of the handling of patient data more generally, under the current arrangements for disclosure and those that were in place under NHS Information Centre (the predecessor to the Health and Social Care Information Centre).” (<http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/cdd-2014/>)

The session covered here is the oral evidence given on 25 February 2015. The session was in two parts: part 1 took evidence from consumer and medical groups, part 2 from the Department for Health. The MPS present at the session comprised five Conservative, five Labour and one Liberal Democrat. The witnesses at part 1 comprised: medConfidential, Big Brother Watch, Association of Medical Research Charities, British Heart Foundation, and the BMA General Practitioners Committee. The witnesses at part 2 comprised: the Parliamentary Under-Secretary of State for Health, the National Director for Patients and Information, NHS England, the Director of Information and Data Services, HSCIC. The session was formal with the Chair asking introductory questions of each witness and then opening the questioning to the MPS who could ask for information from any of the witnesses. The witnesses responded to questions, but did not engage in a dialog with other witnesses, though they could comment on what another witness had said when they answered a question themselves. The Chair controlled the questioning to ensure that it did not get out of hand and all parties had the chance to speak. The witnesses did not read out prepared speeches but answered extempore (though clearly their responses were informed by detailed understanding of, and expertise in, the issue).

In part 1 the proceedings on the whole were conducted professionally, calmly and fairly. Witnesses responded in a measured fashion, and the content of their replies was information rich. Though they might disagree with what another witness had said they respected their views. The MPs weren't too challenging or aggressive to the witnesses. Their questions were genuinely trying to understand the witnesses' points of view and to look for suggestions to improve care.data. And the MPs seemed to feel a lot of agreement with what the witnesses were saying – this applied to MPs from all parties represented. MPs were more emotive in their speech, and there was some, though not much, political point scoring. Towards the end of this part of the session the tone heated up. There was some disagreement between Vaz (Labour) and Percy (Conservative) over whether there had been scaremongering, with Vaz saying 'no' and Percy saying 'yes'. George (Liberal Democrat) also strongly pushed the health consumer groups about where they would balance benefits versus data confidentiality and security, emotionally citing that their stance blocking care.data would be causing thousands of avoidable deaths. The terms trust/entrust/mistrust/confidence were often used in the discussion.

In part 2 the MPs were far more aggressive and forensic in their questioning. Many of them demonstrated a deep understanding of the issue and its wider

context. They had become annoyed with the Department of Health because of a revelation from the health consumer groups who had received a letter from the Secretary of State with reassurances about changes in the opt-out procedures. However, this information had not been shared with Parliament. The Parliamentary Under-Secretary of State for Health's response was a political message in support of care.data, emphasising the benefits of data sharing, and stating that the current situation could be because of the way the message was communicated. He also did not agree with the analysis presented in the first part of the session. He continued with statements that there were laws and codes that governed the handling of the data. He kept being interrupted, but kept going on with his message. He was accused of not answering the MPs questions. The witnesses were pressed on why the HSCIC had not produced the required code of practice [which would not have been in existence at the original time for the roll out of care.data]. The minister used the excuse that HSCIC was a newly established body. The MPs pressed the witnesses on the release of data to the 'Institute and Faculty of Actuaries' and would not accept the statement that HSCIC was not responsible. [HSCIC was a merger of bodies that included the one who released the data, and many of the same staff and procedures are used by HSCIC.] The MPs asked many detailed questions of the witnesses, mainly answered by NHS England and HSCIC – the bulk of the responses came from these two bodies. Quite a few of these detailed questions about procedures could not be answered by the witnesses. There were a number of occasions when the witnesses were asked to send a document with the required details to the Committee after the session. The MPs did not accept that the problem was solely a communication issue, as there were fundamental issues of what data will be shared and for what purpose, and details about procedures that needed clarification.

Daily Telegraph news story

The Daily Telegraph is a daily, morning broadsheet paper. A broadsheet paper is considered to be a quality newspaper, providing in-depth coverage of the news, aimed at an educated audience. The Daily Telegraph takes a right-wing political stance and is supportive of the Conservative party. At the time of the writing of the article it would have been supportive of the Coalition Government's policies, including reorganisation of the NHS. The story was published a few days after the first pause in the roll out of care.data. It covers the fact that the NHS Information Centre (NHSIC, a precursor of HSCIC) released hospital admissions data, from 1989 to 2010, to the Institute and Faculty of Actuaries. NHSIC linked the HES data to Experian Mosaic data (socio-demographic data) on behalf of the end user and supplied the pseudoanonymised output. The Institute and Faculty of Actuaries is a not-for-profit organisation and their purpose for the data was to conduct non-commercial research analysing general variances in critical illness. This data was used to produce a report to aid actuaries in critical illness pricing.

Data was handed over in January 2012 on payment of a small administrative fee (£2,220).

The title of the story is very emotive: ‘Hospital records of all NHS patients sold to insurers’. It is in fact not strictly accurate, as further reading of the story shows, although the full details of the story can only be obtained from searching out press releases from all the parties concerned. However, the title captures the readers’ attention and encourages them to read further. The words used in the story are mostly straightforward and factual. A few phrases such as the organisation ‘boasts’ of obtaining the data, and experts (unspecified) say insurers are likely to increase premiums, are likely to trigger a strong response in the reader. Clearly the journalist has read the full report published by the Institute and Faculty of Actuaries but gives no reference to this. The rationale for the story is to challenge the statements by NHS England and HSCIC that care.data data would not be sold to insurance companies. The story is deliberately published the day before the Health Select Committee starts their inquiry into care.data. The story gives details of the care.data issue to that date and obtains comments from medConfidential and the Department of Health.

804 comments were posted on the story. The first 50 have been analysed. Some are factual statements and challenge or support points raised in the article. A few provide further information. Some challenge the political stance of the paper and the political slant of the story. There is some general party political point scoring, and one person states their political point on immigration. Mistrust in government is demonstrated, giving both specific and wider examples of why, including the reorganisation of the NHS. There is some argument about the pros and cons of health insurance, within the context of the NHS reorganisation. There is personal abuse.

Guardian news story

The Guardian is a daily, morning broadsheet paper. It takes a left-wing political stance and is supportive of the Labour Party. At the time of the writing of the article it would have been critical of the Coalition Government’s policies, including reorganisation of the NHS. The story was published a few days after the Daily Telegraph story. It covers the fact that NHSIC provided PA Consulting with pseudoanonymised HES data in November 2011. The data covered a number of different topics and covered periods from 1990 to 2012. NHSIC knew that PA Consulting would be using Google BigQuery to analyse the data and obtained written assurances that no Google staff would be able to access the data. PA Consulting Group (<http://www.paconsulting.com/>) is a large consulting company with offices in the States, Europe and Asia. They carry out work for a wide range of clients. It is not clear who the client was in this instance: PA Consulting’s statement said the project was “to show the NHS” how such analysis could be helpful.

The title of the story – “NHS England patient data 'uploaded to Google servers', Tory MP says” – is not emotive, but it uses the source of a Tory MP to demonstrate it is not making a party political point. In addition it uses the name ‘NHS England’ rather than just ‘NHS’ as in the Daily Telegraph story. The right-wing papers are accused by some people of using negative stories about the NHS to damage it the public’s eye so that proposed privatisation can be presented as a way of saving and improving the NHS. It could be that this is one of the motives behind the Daily Telegraph story, as well as the fact that it is a dramatic topic in its own right. The Guardian story is also linked to the Health Select Committee as the Tory MP named as the source is a member. It is noted that she used to be a family doctor: a trusted group, and therefore implying the story can be trusted. [It should be noted that MPs of all parties, particularly after the expenses scandal, are mistrusted by the public.] She tweeted her comment, but the PA Consulting issue was also raised during the Inquiry. The story also notes that the Chair of the Committee, another Tory MP, has called for the HSCIC to publish details about who has accessed data, both currently and in the past under NHSIC. Once again, the story is reported straightforwardly and factually, with reference to the delay in the roll out of HSCIC. Points made that could cause alarm in readers were that the “entire start-to-finish HES dataset” was obtained which “was so large it took up 27 DVDs and took a couple of weeks to upload”. Unnamed campaigners and privacy experts were reported to be alarmed because the data must have contained location information, implying it could be identifiable. The issues being pushed are that under care.data the data is not completely anonymous and that insurers and drug companies could gain access to the data [organisations that are publicly mistrusted]. Once again medConfidential gave a comment. PA Consulting and HSCIC had not responded at the time of publication. However, their latter statements were uploaded to the online version of the story. The Daily Telegraph and Guardian stories are very similar in content and tone, showing that this issue is not a party political one but one of wide relevance and concern.

There were 591 comments. The first 50 have been analysed. There was some discussion that the source of the story was a Tory MP. The reorganisation of the NHS was mentioned. A link was given to further negative stories about PA Consulting. There was a discussion about Google and its claims to rights to the data on its servers. Queries were made about how assurances by companies on how they use the data are monitored and enforced. Mistrust of private companies was shown, including a statement that they are allowed to get away with data misuses that normal researchers are not allowed to do. There was total mistrust of the Health Secretary and health ministers. The story was tied to the Snowden revelations, with people stating that our health data is now in the hands of the US National Security Agency (NSA). Other people stated that the story is scaremongering as it’s encrypted data and anyway is being used for research with health benefits. Others also felt the posts about the NSA were also

scaremongering. “Trust. Everything is based on it. It's so *trivially* destroyed. Humans just lap up FUD [Fear, Uncertainty and Doubt] like the sweetest poisoned honey. I hate my gullible species at times.” There was a debate over research benefits of using health data versus personal data protection. Abusive messages had been deleted by the moderator.

4. DISCUSSION AND CONCLUSION

The unfolding story of care.data provides a good case example of how the poor handling of a new programme for using public digital records (i.e. patient records from GP practices) resulted in a crisis of public trust.

NHS England and HSCIC demonstrated poor governance of the care.data programme. They were accused in the House of Commons Health Select Committee Inquiry of putting 'implementation before planning'. The major problems with the governance of the programme are:

1. ***Involving key professional stakeholders too late in the planning.***
Either NHS England accepted their advice, but the announcements of these changes gave the public the idea that NHS England/HSCIC had not done the necessary planning and/or were reluctant to make the kind of changes the public wanted. Or NHS England had to ignore their advice as they were too far along in the planning/implementation phase to make the necessary changes.
2. ***Not properly involving health research charities and health consumer groups.*** Though NHS England say they consulted with thousands of such groups, many groups complained that they had not been consulted and that the changes they would have suggested had not been considered. There was a disconnect between organisations/managers views of consultation and the views of stakeholders. Many organisations/managers call information provision 'consultation'. Stakeholders believe 'consultation' should be the seeking of their advice (as 'experts') with the aim of acting on such advice.
3. ***Not setting up an independent advisory group at the outset.*** After the first postponement of care.data, NHS England set up a care.data independent advisory group to improve the governance of the programme. This group comprises representatives from professional and health consumer groups. Such an advisory group should have been set when the programme was officially announced.
4. ***Inadequate procedures.*** Although NHS England/HSCIC had undertaken preparatory work on the procedures (and had inherited procedures from NHSIC), and other governance issues, this was incomplete. There were still many details that had not been adequately thought through (and would have not been in place by the original implementation date). These details are very complex, documented in many different sources, and therefore very difficult to explain simply to the public.
5. ***A very poor public information campaign:*** the leaflet was a PR disaster as it was widely regarded as 'not fit for purpose'.
6. ***There was no piloting of the programme:*** planning for a pilot should have started as soon as the official announcement of the programme. Pathfinder projects, advised by the IIGOP, were planned for in early 2014

- after the first postponement, and therefore not in operation by the original implementation date (April 2014). The Pathfinder proposal was not published until September 2014, with the choosing of the sites in October 2014. A report by IIGOP in December 2014 stated that numerous questions needed to be answered before the Pathfinder sites could proceed.
7. ***Underestimation and lack of understanding of the concerns and fears of GPs and the public*** on what would be done with such highly personal and sensitive data. BMA and RCGP advised NHS England/HSCIC to add in an opt-out for patients, i.e. they needed to be able to consent to the use of this data. Though patient records are public records, in the eyes of the public, and in the views of many health professionals, they 'belong' to the individual patient. The opt-out system set up was very complex, with many procedural points unanswered: this system is being amended. Another major public concern was who would be able to use their data and for what purposes. Although NHS England provided reassurances and stated the data could only be used for health and social care purposes the public remained unconvinced. The Health Secretary proposing new legislation to restrict the purposes for which health data could be used once again implied a government department reluctantly putting into place safeguards demanded by the public: these were presumably not provided for by the original legislation setting up care.data. A further major public concern was data security, in particular how identifiable data would be used and protected.
 8. ***Underestimation and lack of understanding of the climate of public distrust in which governments have to operate.*** In particular, the huge public concern and lobbying over NHS reorganisation (seen as thinly disguised privatisation) and which was in place at the time care.data was officially announced. This should have alerted NHS England that very careful handling of the planning and implementation of the care.data programme would be required. It is vital with such programmes to establish good communication and 'true' consultation with health consumer groups and the public from the outset.
 9. ***Poor reputation management*** (in the original PR use of the term). On such a sensitive topic of high public concern, NHS England/HSCIC should have been prepared for poor publicity about controversial uses of HES data. They should have prepared for this proactively, rather than reacting after the negative news story had been published. Making the excuse that HSCIC is a new body and not responsible for NHSIC (when NHSIC is the progenitor of HSCIC, who uses many of the same staff and procedures and continues contracts put into place by NHSIC) is not a good PR ploy. Accusing the media and health consumer groups of scaremongering is also not helpful.

In summary, this research has identified the following key factors that are needed to establish trust in a digital records programme:

- Meaningful consultation and good communication with all stakeholders
- Agreement between all stakeholders about the purpose of the programme: what data is required, for what uses, and who can access it
- Agreement between all stakeholders about the procedures and governance arrangements
- A strong, well communicated informed consent procedure
- Good data security procedures, protecting personal, sensitive and identifiable data

However, the public furore and the government's changes in response will have had a positive result. The care.data programme (which everyone agrees has enormous potential benefits for health care and health care services) will be much more effective, better designed, better run, and more publicly acceptable when it is eventually implemented.

Could the care.data crisis of public trust have been averted by good governance? In the current climate of public distrust that it is difficult to judge. Good governance would have mitigated the concerns about care.data. Good governance is also necessary to implement and properly conduct any such programme.

The care.data programme is a candidate for a government blunder (an avoidable mistake) (King and Crew, 2014).

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