InterPARES Trust Research Report



Team Europe EU27 Project 2015-2016: The Role of the Records Manager/Records Management in an Open Government Environment in the UK: The National Health Service 2 (local records)

Final Report

Katherine Chorley, Andrew Flinn and Elizabeth Shepherd, UCL

Abstract

Purpose: This report will help to develop an understanding of how an Open Government Data (OGD) environment will affect both the role of the Records Manager and the practice of Records Management within the public sector in the UK. By exploring the challenges that the proactive release of information presents to practice and professionals within a case study of a National Health Service (NHS) Trust in the South East of England, areas of practice and policy that will need to be developed to ensure compliance with obligations of an OGD environment are identified.

Design/Methodology/Approach: An introductory chapter exploring relevant literature and introducing the concept of OGD, the synergy between OGD and Records Management and the legislative and regulatory framework in which the NHS operates, provides the context for report. The report then presents a discussion and analysis of data collected through qualitative research, in the form of interviews with professionals from the case study NHS Trust and a survey distributed to a specialist health sector professional group. The research for this report was carried out between April and August 2016 by Graduate Research Assistant and MA student Katherine Chorley, guided by Andrew Flinn and Elizabeth Shepherd, all at UCL, Department of Information Studies.

Findings: A series of interconnected practical challenges face Records Managers and Records Management at a local level as the OGD environment continues to develop.

The infancy of this development leaves vital questions, such as what data to publish and for what purpose, unanswered. Furthermore, these broad challenges overshadow equally important technical challenges, such as ensuring the creation of full, accurate metadata sets about, and the accuracy of, data that is to be proactively published.

Research limitations: The main limitation of this report is the small number of interviews conducted and the restriction of data collection to the Information Governance (IG) Department of the NHS Trust in the South East of England. The IG Department, deals only with Corporate Records, meaning that policy and practice relating to Health Records (i.e. patient records) is therefore not assessed.

Originality/value: The relevance of recordkeeping to the Open Government Data environment stimulates a need for further research and development in the field. The report builds upon previous research by seeking to identify the implications of OGD policy and practice on Records Managers and Records Management. The originality of this research lies in the exploration of a case study of an individual NHS Hospital Trust, which allows for a specific insight into the challenges that OGD presents to Records Management within a single operational unit.

Keywords: Open Government Data, Open Government, Open Data, Records Manager, Records Management, Records, Information Governance, National Health Service, Public Sector, United Kingdom, Policy, Practice, Guidance, Legislation.

Table of Contents

List of Tables and Illustrations3		
List	of Abbreviations	4
Cha	pter One: Introduction	5
	1.1 Introduction	5
	1.2 Open Government, Open Data and Open Government Data	7
	1.3 Open Government Data and Records Management: Challenges and	
	Opportunities	9
	1.4 Open Government Data, Records Management and the NHS	11
	1.5 Legislative and Regulatory Framework	15
Cha	pter Two: Methodology	19
	2.1 Reasons to Focus on a Case Study of an NHS Trust	19
	2.2 Literature Search and Review	19
	2.3 Qualitative Interviews	22
	2.4 Survey	24
	2.5 Research Ethics	25
	2.6 Research Limitations	26
Cha	pter Three: Case Study – Discussion and Data Analysis	27
	3.1 Discussion and Data Analysis	27
	3.2 Role, Responsibilities and Context	28
	3.3 Policies	33
	2 A Practice	40

Chapter Four: Conclusion	50
4.1 The Future of Open Government Data	50
4.2 Conclusion	52
Bibliography	58
Appendices	67
Appendix A: Seven Stage Interview Process	67
Appendix B: Structure Charts	68
Appendix C: Informed Consent Form	71
Appendix D: Interview Schedules	72
Appendix E: Detailed Summary Transcriptions of Interviews	78
Appendix F: Survey Results and Analysis	96

List of Tables and Illustrations

Figure 1: The Challenges of an Open Government Data Environment in the NHS
Trust in the South East of England53
Appendix A: Seven Stage Interview Process67
Appendix B: Structure Charts68
Appendix E: Detailed Summary Transcriptions of Interviews78
Appendix F: Survey Results and Analysis96

List of Abbreviations

ACRM Assistant Corporate Records Manager

CRM Corporate Records Manager

DPA Data Protection Act 1998

EDRMS Electronic Document and Records Management System

FOI Freedom of Information

FOIA Freedom of Information Act 2000

HARG Health Archives and Records Group

HSCIC Health and Social Care Information Centre

ICO Information Commissioner's Office

IG Information Governance

IGM Information Governance Manager

NHS National Health Service

OGD Open Government Data

Chapter One: Introduction

1.1 Introduction

The Open Government environment is described by Worthy as an 'evolving ecology', as ideas about what comprises openness, accountability and transparency continue to develop, and 'mechanisms to enable users and innovators to harness...data for these different ends' continue to advance. 1 Current trends 'on opening government data encourage information sharing', in a world where technology provides the capacity to do so, in the form of 'platforms to improve collaboration and participation'. While the term 'open government', according to Yu and Robinson, has it's origins in the 1950s³, the global movement to which it relates, as noted in international journal Government Information Quarterly, 'is not new but...has followed a process that started with the constitutional right to know.'4 Ideas of openness and transparency are promoted through legislative and regulatory frameworks in many nations across the world; 'many national governments have adopted the idea of the "right to access information" or "freedom of information" as an essential element' of citizen's rights to 'freedom of opinion and expression of human rights' and 'trust in public discourse'. 5 The agendas of public sector organisations wishing to demonstrate their transparency and accountability are met by public expectations and opinions about the amount and type of information that

_

¹ B Worthy, *Making Transparency Stick: The Complex Dynamics of Open Data* (2014), at http://papers.ssrn.com/sol3/papers.cfm?abstract id=2497659>. Accessed 28 June 2016, p.3.

² Editorial, 'Open Government, Open Data and Digital Government', *Government Information Quarterly* 31 (2014), p.4.

³ H Yu and D G Robinson, 'The New Ambiguity of "Open Government"', *UCLA Law Review Discourse* 59 (2012), p.178.

⁴ Editorial, 'Open Government, Open Data and Digital Government', p.4.

⁵ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data: Who is at the Table?', *The Commonwealth Journal of International Affairs* 104:6 (2015), p.715.

should be freely, and readily, available to access online as Open Government Data (OGD).

Building on the previous research of InterPARES Trust projects into the Open Government environment and Records Management, in both local government⁶ and NHS England⁷, this research explores the role of the Records Manager and the practice of Records Management within an OGD environment in the context of a case study of a National Health Service (NHS) Trust. Seeking to identify challenges that it will present to public sector Records Managers, by assessing their current role and responsibilities, and the function of recordkeeping, the research will establish an enhanced understanding of areas of both policy and practice that will need to be developed to ensure compliance with obligations of OGD environments. Research into the relationship between Records Management and OGD is of vital importance given the dependency of accurate, useable data on good Records Management, and also the intended responsibility of Records Managers for OGD. This research, therefore, will help to develop an understanding of how Open Government and Open Data initiatives will affect both the practice of Records Management and the role of the Records Manager, and also, conversely, how current Records Management practice will influence the OGD environment, within the public sector in the UK.

Chapter One of this report presents a contextual introduction to the Open

⁶ J Page, A Flinn and E Shepherd, 'The Role of the Records Manager in an Open Government Environment in the UK', *InterPARES Trust Research Project EU03 – Research Report* (2014).

⁷ E Harrison, E Shepherd and A Flinn, 'Research Report into Open Government Data in NHS England', InterPARES Trust Research Project EU19 – Research Report (2015).

Government environment, briefly explores OGD, recordkeeping and the NHS, and discusses the legislative and regulatory framework in which it operates. Chapter Two outlines and justifies the methodology used in this report, with Chapter Three containing a structured account and selective analysis of data collected through interviews and a survey. The aim of the interviews was to examine current professional responsibilities and practice within the NHS, and the survey was distributed with the purpose of setting the case study in the context of similar recordkeeping environments to determine whether the experience of the case study NHS Trust can be considered typical of Records Management and OGD within the health sector. The report is concluded in Chapter Four with a summary of the challenges posed to Records Managers, and the practice of Records Management, by an OGD environment at a local level, which amount to a series of interconnected practical and technical challenges. Additionally, insights into the future of OGD gained through the interviews are used to posit suggestions and recommendations as to the direction of both practice of, and research into, OGD at local and national levels.

1.2 Open Government, Open Data and Open Government Data

Discourse relating to the Open Government environment presents an immediate challenge: definitions. The remarkable inconsistency with which the terms Open Government, Open Data and Open Government Data are both used and defined throughout professional literature, official policies and amongst practitioners, highlights the complexity of this issue. For the researcher, the ambiguity surrounding Open Government discourse can be frustrating, with a lack of coherent definitions

complicating attempts to create and convey a simple narrative, and for the professional, as will be explored in Chapter Three, the lack of clarified concepts seems, at best, to cause confusion and, at worst, hinder progress; Yu and Robinson comment on the seriousness of this ambiguity, maintaining that 'the vagueness of "open government" has undercut its power.' Furthermore, the lack of dependency between "Open Government" and "Open Data" creates boundaries between the 'politics of open government' and the 'technologies of open data'9, and highlights the existence of two distinct agendas; the former relating to 'political openness' 10, the latter to the technological potential to disseminate data online. Of course Open Government and Open Data can overlap – using Open Data for an Open Government purpose is 'mak[ing] data machine readable and accessible in order to promote government transparency and accountability.' Because this research explores both Open Government, political, and Open Data, technological, environments, the term Open Government Data is adopted for use throughout the remainder of this report¹², and is defined as information released by public sector bodies, for a variety of purposes, which is free for anyone to re-use. This definition is an adaptation of those used by NHS England¹³ and the UK Government¹⁴, as these sources are most relevant to the context of this study. Use of Open Government Data also ensures consistency with the terms used in the previous similar research outlined in 1.1.

⁸ H Yu and D G Robinson, 'The New Ambiguity of "Open Government"', p.208.

⁹ Ibid., p.178.

¹⁰ Ibid., p.208.

¹¹ Ibid., pp.192.

¹² The inconsistent use of the terms Open Government, Open Data and Open Government Data throughout the interview and survey questions reflects the fact that the data collection process was used to shape the definitions of terms to be used in this thesis.

¹³ NHS England, *Open Data* (2015), at https://www.england.nhs.uk/ourwork/tsd/data-info/open-data/. Accessed 18 June 2016.

¹⁴ Data.gov.uk, *Home* (2016), at . Accessed 18 June 2016.

1.3 Open Government Data and Records Management: Challenges and Opportunities

For public sector organisations, OGD is intended to promote the accountability, transparency and efficiency of their services by allowing increased public access to proactively published data. 'Good records management is fundamental' to this process; without effectively managed records, accurate and reliable data cannot be disseminated. It is important to comment on the relationship between records and data. Records and data are not the same thing; rather the latter can be contained within, or gleaned from, the former. In the context of OGD for example, 'when records are reliable, open data become[s] [a] powerful means of ensuring government transparency and enabling citizens to participate in governments'. Despite their differences in form, a "record" is a more complete, tangible object than "data", which exists often in the form of 'raw, unprocessed information' the two are subject to the same management needs, with their accuracy and integrity underpinning their reliability and, ultimately, their usefulness.

Current discourse explores the dependency between good Records Management and OGD. McLeod maintains that 'open data and data sharing offer huge opportunities for the information and records management profession' with regards to working towards creating systems that will ensure the accessibility and usability of

-

¹⁵ Ibid., p.720.

¹⁶ International Records Management Trust, *Open Government and Trustworthy Records:***Institutional/Regulatory Framework and Capacity Benchmarking Tool (2013), at http://www.irmt.org/portfolio/open-government-trustworthy-records-final-2. Accessed 28 June 2016.

¹⁷ H Yu and D G Robinson, 'The New Ambiguity of "Open Government"', p.189.

information, as well as new contexts in which professionals can apply their skills. ¹⁸ Differing from the compliance agenda of legislation, in which Records Managers have traditionally operated within the confines of statutory requirements to either allow or deny access to information, there is now an opportunity to take the practice of Records Management 'beyond transparency and accountability into the realm of innovation, enterprise, economic growth and return on investment'. ¹⁹

Janssen et al, however, warn against the dangers of adopting 'a conceptually simplistic view...which automatically correlates the publicising of data with use and benefits.'²⁰ The benefits of OGD can be easily, and conveniently, framed by official rhetoric, which in the UK has 'shifted in favour of free access to government data for commercial exploitation, asserting that this will boost the economy and be a general benefit.'²¹ In practice, publishing OGD can present a variety of challenges to Records Management and Records Managers. Firstly, not all data created is suitable for immediate public release²², just as material that can be requested under FOI is seldom created with the prospect of being made public in mind. Work undertaken to prepare information for public release, that in the context of FOI often takes the form of the redaction of personal confidential information, can be time-consuming, and in an OGD environment consisting of large datasets, could present technical challenges to Records Managers without the resources or skills to undertake such a

_

¹⁸ J McLeod, 'Thoughts on the opportunities for records professionals of the open access, open data agenda', *Records Management Journal* 22:2 (2012), pp.91-95.

¹⁹ Ibid., p.96

²⁰ M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data and Open Government', *Information Systems Management*, 29:4 (2012), p.258.

²¹ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data: Who is at the Table?', *The Commonwealth Journal of International Affairs* 104:6 (2015), p.718.

²² S S Dawes, 'Stewardship and usefulness: Policy principles for information-based transparency', *Government Information Quarterly* 27 (2010), p.378.

task. The technicalities of managing data files, often existing in Excel or CSV formats, are likely to require collaboration between Records Managers, 'technology experts and experts in the data management field'. ²³ Such collaboration 'could provide a means of getting far more value from our open data', which would include 'realizi[ing] the power of existing best practice'²⁴ across Records Management, OGD, IT and Data Management communities, and result in shared understanding and a common aim.

The challenges posed by the OGD environment cannot, and should not, be underestimated. Neither, however, should the opportunities that they present to Records Management. For the profession, a chance to advocate the importance of good Records Management to society and an opportunity to become more outward looking, developing relationships with communities outside of the boundaries of the information profession; and for professionals, on a personal level, the opportunity to gain a host of new skills, an enlightened outlook, and a renewed sense of purpose knowing that they have been involved in developing the OGD environment which forms a 'piece of a puzzle in the modernisation process of public administration.'

1.4 Open Government Data, Records Management and the NHS

The NHS was founded in 1948 with the purpose of 'bring[ing] good healthcare to

_

²³ A Gregory, 'Open Data and Metadata Standards: Should We Satisfied with "Good Enough"?', *Open Data Foundation* (2011), at

http://odaf.org/papers/Open%20Data%20and%20Metadata%20Standards.pdf>. Accessed 20 July 2016, p.4.

²⁴ Ibid., p.4.

²⁵ C P Geiger and J VonLucke, 'Open Government and (Linked) (Open) (Government) (Data)', *JeDEM:* eJournal of eDemocracy and Open Government 4:2 (2012), p.275.

all'.²⁶ The central principle was that 'the health service will be available to all and financed entirely from taxation, which means that people pay into it according to their means.'²⁷ At this time, the services of 'hospitals, doctors, nurses, pharmacists, opticians and dentists' were 'brought together under one umbrella organisation'²⁸, which has since been divided into NHS England, NHS Scotland, NHS Wales and NHS Northern Ireland, and further sub-divided into self-directed NHS Trusts and NHS Foundation Trusts.²⁹ The 'size and complexity of the NHS'³⁰ creates a complicated landscape for the management of records, a large majority of which contain personal and confidential information.

Recordkeeping within the NHS is recurrently criticised in the media for a variety of reasons, from the need to find a solution to its 'costly digital headache', to the lack of direction and leadership in information management and security, resulting from 'challenges around who the data controller actually is.' ³¹ The most recent criticism, however, has come as a result of the termination of the controversial care.data

²⁶ NHS, The history of the NHS in England (2015), at

http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx. Accessed 15 July 2016.

²⁷ Ibid.

²⁸ Ibid.

²⁹ NHS Foundation Trusts 'differ from other existing NHS trusts [and are]...independent legal entities'. NHS, *The NHS in England* (2016), at

http://www.nhs.uk/NHSEngland/thenhs/about/Pages/authoritiesandtrusts.aspx. Accessed 15 July 2016.

³⁰ O Williams, *Open data could save the NHS hundreds of millions, says top UK scientist* (29 May 2015), at https://www.theguardian.com/media-network/2015/may/29/open-data-nhs-healthcare-nigel-shadbolt>. Accessed 8 July 2016.

³¹ G Hitchcock, *NHS seeks cure for its costly digital headache* (1 July 2016), at headache. Accessed 8 July 2016.

programme, which The Guardian claims was 'killed off by privacy paranoia' ³² following the unsolicited sharing, and even selling, of patient data in 2014. ³³ Data security has 'been pushed to the forefront of the public's attention by a number of recent, high profile data breaches' ³⁴, which prompted a Care Quality Commission review. Launched in 2015, upon the request of the Rt. Hon Jeremy Hunt MP, Secretary of State for Health, into the 'effectiveness of current approaches to information security by NHS organisations when it comes to handling confidential patient information' ³⁵, the review found that 'there is widespread commitment to keeping data secure, but effective action is not always being taken where necessary.' ³⁶

Intensified by the loss of trust caused by the 'failing' of the care.data programme³⁷, the National Data Guardian for Health and Care, Dame Fiona Caldicott, admits that 'the case for data-sharing still needs to be made to the public'.³⁸ There is a great deal of public confusion surrounding the sharing of data by the NHS; 'whenever you talk about health data people think you must be talking about personal data and patient

³² P Toynbee, *A viable shot at a better NHS has been killed off by privacy paranoia* (7 July 2016), at https://www.theguardian.com/commentisfree/2016/jul/07/better-nhs-killed-privacy-paranoia-caredata. Accessed 8 July 2016.

³³ L Donnelly, *Millions of NHS records sold to insurance firms* (17 June 2014), at http://www.telegraph.co.uk/news/health/news/10906390/Millions-of-NHS-records-sold-to-insurance-firms.html. Accessed 18 June 2016.

³⁴ Care Quality Commission, Safe data, safe care: Report into how data is safely and securely managed in the NHS (2016), at

http://www.cqc.org.uk/sites/default/files/20160701%20Data%20security%20review%20FINAL%20for%20web.pdf>. Accessed 15 August 2016, p.2.

³⁵ Ibid., p.6.

³⁶ Ibid., p.2.

³⁷ S Knapton, 'How the NHS got it so wrong with care.data', *The Telegraph* (7 July 2016), at http://www.telegraph.co.uk/science/2016/07/07/how-the-nhs-got-it-so-wrong-with-caredata/. Accessed 18 June 2016.

³⁸ The King's Fund, *Dame Fiona Caldicott on data-sharing in health and care* (3 May 2016), at http://www.kingsfund.org.uk/publications/articles/dame-fiona-caldicott. Accessed 18 June 2016.

data³⁹. Of course security and privacy safeguards must be in place to manage confidential patient data, but the sharing of information is deemed to be 'essential for the provision of high quality health and care⁴⁰ and for 'advanc[ing] medical knowledge'. Shadbolt makes the case that 'there's lots of data in the health service that is not about personal patient data at all that would be hugely useful to just have as machine-readable data⁴², which is where the case for OGD in the health sector, and more specifically within the NHS, can be made.

Benefits of opening NHS data sets have been expressed in terms of 'improv[ing] patient care...sav[ing] hundreds of millions of pounds a year' and 'encouraging transparency and accountability', and have been quantified by the publication of league tables within the organisation, for example, '[t]he publication of league tables on MRSA [which] was followed by a 76-79% drop in infections'⁴³; conscious of their position in the league tables, there was, across hospitals at the lower end of the rankings, 'a very rapid diffusion of understanding of best practice', which ultimately resulted in better care for patients and 'many millions of pounds being saved.'⁴⁴

Attempts to increase public trust in the NHS, then, can be seen in the publicising of transparency and accountability agendas by NHS England, which 'allow [the NHS] to shine a light on...unacceptable practice and bring about a revolution in transparency'. It is here that OGD can be, and is, heralded as 'key enabler' of

-

³⁹ O Williams, *Open data could save the NHS hundreds of millions*.

⁴⁰ The King's Fund, *Dame Fiona Caldicott on data-sharing in health and care.*

⁴¹ P Toynbee, A viable shot at a better NHS has been killed off by privacy paranoia.

⁴² O Williams, Open data could save the NHS hundreds of millions.

⁴³ Ibid.

⁴⁴ Ibid.

transparency within the organisation.⁴⁵

1.5 Legislative and Regulatory Framework

The NHS operates within a complex framework of UK Government legislation and internal NHS regulations. Before exploring the case study in detail it is necessary to consider the most relevant of these to this report, to set the OGD environment, in the health sector, in context.

Most important to the NHS is the *Data Protection Act 1998* (DPA), which 'controls how...personal information is used by organisations, businesses or the government.'⁴⁶ The NHS must 'collect personal information about people with whom it deals in order to carry out its business and provide its services'⁴⁷, which means that it also has a responsibility to comply with DPA in ensuring that personal, confidential data is used appropriately, and processed and managed fairly and securely.⁴⁸ The NHS Constitution 'outlines patient rights to privacy, confidentiality [and] security of their medical records' and also to be 'informed about how their information is used'.⁴⁹ It is important to note that, in the context of the health sector, for reasons of improving the care and services provided, the 'duty to share

-

⁴⁵ NHS England, *Open Data*.

⁴⁶ Gov.uk, *Data Protection* (7 December 2015), at https://www.gov.uk/data-protection/the-data-protection-act. Accessed 23 July 2016.

⁴⁷ NHS England, *Data Protection Policy* (June 2014), at https://www.england.nhs.uk/wpcontent/uploads/2013/06/dpa-policy-1.pdf>. Accessed 23 July 2016.

ibid., p.6.

⁴⁹ NHS Confederation, *Legislation and guidance relating to medical records explained by House of Commons Library* (10 October 2015), at http://www.nhsconfed.org/resources/2015/10/legislation-and-guidance-relating-to-medical-records-explained-by-house-of-commons-library. Accessed 27 June 2016.

information can be as important as the duty to protect patient confidentiality.'⁵⁰ There are concerns, as articulated with reference to the care.data programme, that privacy and confidentiality are compromised by openness and transparency agendas, and in particular by data-sharing. It is necessary to confirm that openness agendas do not advocate the sharing of personal, confidential information; rather they refer to large, anonymous datasets with 'limited risks in terms of confidentiality and patient data'.⁵¹

At the opposite end of the legislative spectrum, dealing with the disclosure rather than closure of information, is the *Freedom of Information Act 2000* (FOIA). Freedom of Information (FOI) gives the public 'the right to access recorded information held by public sector organisations'⁵² by making requests for it. FOI and OGD are both part of a Government reform agenda, 'designed to enhance transparency'⁵³ in the public sector; the two are, however, distinctly different. The former is a reactive process, in which information is released upon request, the latter a proactive one, in which information is readily available for access and use; as Shepherd summarises, 'although FOI established a statutory right to access information, it does not in itself guarantee free and unlimited information access.'⁵⁴ Under FOI all public authorities *are*, however, required to maintain a Publication Scheme, which outlines 'their high-

_

⁵⁰ Department of Health, *Information – to share or not to share: The Information Governance Review* (March 2013), at

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_ InfoGovernance accv2.pdf>. Accessed 28 June 2016.

⁵¹ NHS England, *Open Data*.

⁵² Gov.uk, *How to make a freedom of information (FOI) request* (12 November 2014), at https://www.gov.uk/make-a-freedom-of-information-request/the-freedom-of-information-act. Accessed 27 July 2016.

⁵³ B Worthy, 'Making Transparency Stick', p.13.

⁵⁴ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.717.

level commitment to proactively publish information' ⁵⁵ including spending and decision making information and organisational policies and procedures. ⁵⁶

A number of NHS regulations and policies also govern the management of information within the organisation, on a national scale. The NHS Constitution for England 'establishes the principles and values of the NHS in England' and summarises the responsibilities and rights of both staff and the public, which include a number of clauses about the protection and confidentiality of information. ⁵⁷ Additionally, a number of policies relating specifically to information management exist in the form of the following documents:

- Data Protection Policy
- Freedom of Information Policy
- Confidentiality Policy
- Document and Records Management Policy
- Information Security Policy
- Information Sharing Policy⁵⁸.

This section has offered a brief overview of the legislative and regulatory framework of the NHS. It is not an exhaustive list of all the legislation and regulations by which

⁵⁵ ICO, What information do we need to publish? (2016), at https://ico.org.uk/for-organisations/guide-to-freedom-of-information/publication-scheme/. Accessed 28 June 2016.

⁵⁶ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.720.

⁵⁷ Gov.uk, *The NHS Constitution – the NHS belongs to us all* (27 July 2015), at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution WEB.pdf>. Accessed 27 July 2016.

⁵⁸ List of 'Associated Documents' from NHS England, *Data Protection Policy*.

the organisation is bound, instead a contextual introduction to the environment in which OGD exists.

2.1 Reasons to Focus on a Case Study of an NHS Trust

The decision to focus this research on a case study of a NHS Trust originates from a desire to supplement the previous, more broad, research carried out on NHS England, as outlined in Chapter One, by focusing on a smaller operational unit; in order to understand fully the extent of the challenges facing records managers in the NHS, it is important to gain a detailed understanding of current practices and the implications of OGD obligations at a local level. Further analysis of Records Management within the large, complex, public body can be seen as directly relevant to both Open Government and Records Management agendas. Using a single case study as the primary method of research allowed for the targeted investigation of 'a contemporary phenomenon within its real-life context'. 59 The case study is fully anonymised and is referred to throughout this report as 'NHS Trust in the South East of England'. Value and originality is added to this research by its focus on the NHS at a local level; there has been relatively little focus on the Open Data in the health sector in comparison with existing research into Open Government more generally, which often assesses the public sector as a whole.

2.2 Literature Search and Review

Research for this report began with a systematic literature search and review, which, as a research method, served as 'preparation for further empirical investigation'.⁶⁰

The aim of the literature review was to gain an understanding of academic and

⁵⁹ R K Yin, *Case Study Research* (London, 2008), p.23.

⁶⁰ A J Pickard, *Research Methods in Information* 2nd ed., (London, 2013), p.25.

popular discussions about the OGD environment. The four-step process of information seeking, evaluation, critical analysis and research synthesis recommended by Pickard was followed for the literature review process. ⁶¹ The review then served as the foundation for the report, particularly in underpinning Chapter One and the interview schedules, in which questions asked to interviewees reflected the main issues and themes from relevant literature.

The starting point for the literature search was the consultation of previous InterPARES Research Reports and UCL MA theses written by Emma Harrison and Jessica Page. 62 The bibliographies of these works were helpful in forming an initial reading list of published sources. The literature search then developed by exploring references to literature relevant to this study and also by searching the UCL Library Catalogue for further sources using key words and terms. Search terms included the following:

- "Open Government Data"
- "Open Government"
- "Open Data"
- Open Government AND record*/health*

⁶¹ Ibid., p.26.

C 1

⁶² E Harrison, E Shepherd, and A Flinn, 'Research Report into Open Government Data in NHS England', InterPARES Trust Research Project EU19 – Research Report (2015) and J Page, A Flinn and E Shepherd, 'The Role of the Records Manager in an Open Government Environment in the UK', InterPARES Trust Research Project EU03 – Research Report (2014), E Harrison, "The Future Will Be Open': Open Government Data and Recordkeeping in NHS England', MA thesis, University College London (2015) and J Page, 'The Role of the Records Manager in an Open Government Environment in the UK', MA thesis, University College London (2014).

- Open Data AND record*/health*
- Open Government Data AND record*/health*
- Record* AND role⁶³

Throughout the literature search particular attention was paid to the date and place of publication of sources, with much of the search focused on recent literature (i.e. published within the last 5 years) published in the UK.

Additionally, a number of websites, including those of NHS England, the NHS Trust in the South East of England, the Health and Social Care Information Centre (HSCIC)⁶⁴ and national newspapers, were searched for relevant information, guidance, policy documents and articles. These targeted searches ensured that the official view of the NHS could be balanced against that of the media, academics and practitioners.

The literature review was crucial in identifying key thinking and current issues, which influenced the direction of research for this report. The distinction made by Smith between the motivations of governments and organisations towards OGD and the opinions of the public, was useful in setting the Open Government environment in the context of 'the movement towards greater openness [and] the growing demand

-

⁶³ The use of the asterisk (*) allowed the search to return results including variations of the words 'record' and 'health', such as 'recordkeeping' and 'healthcare'.

⁶⁴ NB: From July 2016, HSCIC changed its name to NHS Digital. The old name of HSCIC is used to refer to service throughout this thesis. Gov.uk, *HSCIC changing its name to NHS Digital* (2016), at https://www.gov.uk/government/news/hscic-changing-its-name-to-nhs-digital>. Accessed 17 August 2016.

for access to government information'⁶⁵, while the chapter written by Lowry in the same publication draws distinctions between the proactive disclosure of Open Government initiatives and the reactive disclosure of FOI.⁶⁶ An article by Janssen, Charalabidis and Zuiderwijk was also very useful in providing a comprehensive overview of the benefits and barriers of 'Open Data and Open Government'⁶⁷ and informed questions in both the interview schedule and the survey.⁶⁸

Just as the literature search and review was useful in revealing the availability of many relevant sources, it also highlighted gaps in academic literature, particularly with regards to Open Government and Open Data initiatives in the health sector. While Azberger, Conway and VanLare discuss the importance of Open Government and Open Data for the health sector in a US context, support for OGD in the UK is demonstrated in medical journals, such as The Lancet⁶⁹ but remains largely missing from Records and Information Management discourse.

2.3 Qualitative Interviews

Data to form the case study for this report was collected through qualitative, semistructured interviews with the purpose of gaining an 'in-depth understanding of

⁶⁵ K Smith, 'The Importance of Records in the Right to Information' in J Lowry and J Wamukaya (eds.), Integrity in Government through Records Management – Essays in Honour of Anne Thurston (Farnham, 2014), p.159.

⁶⁶ J Lowry, 'Opening Government: Open Data and Access to Information', in Lowry and Wamukaya (eds.), *Integrity in Government through Records Management*, pp.161-169.

⁶⁷ M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data', pp.258-268.

⁶⁸ Such as Question 4.3 in the interviews and Questions 3.1-3.2 in the survey.

⁶⁹ For example, M Walport and P Brest, 'Sharing research data to improve public health', *The Lancet* 377 (2011), pp.537-539.

individual perceptions'⁷⁰. Two interviews were conducted with three information professionals within the NHS Trust in the South East of England. Both interviews were conducted face-to-face which was beneficial in being able to pick up visual and oral clues...by listening to and watching' respondents.⁷¹ Following the 'seven stages of the interview process' detailed by Pickard, semi-structured interviews were selected to allow for a certain amount of leniency during the interview and the exploration of topics of conversation outside of the prepared interview schedule.⁷² Both interviews were recorded using handheld recording equipment, with the transcription process starting soon after each interview had taken place. The recordings formed the basis for detailed summary transcriptions, with particularly relevant parts of the interviews being transcribed in full; this was a time-efficient way of ensuring that the most relevant parts of the interviews were easily available for analysis. The detailed summary transcriptions can be found in Appendix E. A table format, including columns for recording time and keywords allowed for the easy retrieval and use of the data throughout the analysis process.

The three interviewees, comprising the Information Governance Manager, the Corporate Records Manager and the Assistant Corporate Records Manager, were questioned about their professional responsibilities, policies and practice with regards to both Records Management and OGD and their professional outlook on the future of Open Government in the NHS Trust in the South East of England. The interview schedules, which can be found in Appendix D, were developed using key

⁷⁰ Pickard, *Research Methods in Information*, p.196.

⁷¹ Ibid., p.199.

⁷² Ibid., pp.196-197. A diagram showing the 'seven stages' can be found in Appendix A.

themes and issues identified during the literature search and review, with attention being paid to the authenticity, integrity and reliability of data and the day-to-day challenges that working in an OGD will present to information professionals.

2.4 Survey

In order to supplement data collected through the case study interviews, a short descriptive survey was designed and distributed to the Health Archives and Records Group (HARG) 73 with the purpose of exploring Records and Information Management practices, policies and views towards OGD within similar recordkeeping environments to that of the case study NHS Trust. The structure of the survey followed that of the interview schedules, to allow for comparisons, and covered professional responsibilities and policy and practice relating to OGD, comprising of multiple choice and short written answer questions. The survey was produced using online questionnaire facility SurveyMonkey. 74 SurveyMonkey was selected 'for its simplicity', both in terms of creating a professional looking survey and ease of distribution it to participants via a hyperlink. 75 The survey was distributed to participants via the HARG mailing list, which has approximately 60 subscribers. 12 members of the group took part in the survey, with responses being stored on SurveyMonkey before being analysed 'using descriptive statistics'. 76 This was decided to be the most appropriate method of interpreting the data, given the small number of responses received. The survey results and analysis can be found in

⁷³ Health Archives and Records Group (2016), at http://healtharchives.co.uk/. Accessed 8 August 2016.

⁷⁴ SurveyMonkey, *Home* (2016), at https://www.surveymonkey.co.uk/. Accessed 15 June 2016.

⁷⁵ J Biggam, *Succeeding with your Master's Dissertation* 3rd ed., (Maidenhead, 2015), p.155.

⁷⁶ Pickard, Research Methods in Information, p.112.

Appendix F. The survey responses were supplemented by attendance at a HARG meeting held at the London School of Hygiene and Tropical Medicine in July 2016, at which a discussion about OGD within the workplace, led by the author, took place; approximately 15 members of the group attended the meeting. The discussion proved to be useful in engaging with Information professionals from a variety of organisations across the health sector and gaining a further insight into their experiences, or lack of, of dealing with OGD.

2.5 Research Ethics

Each interviewee was made aware of 'the purpose of the research and the intended use of the data' provided⁷⁷ prior to data collection; this was formalised through the use of an informed consent form, which acted as both an information sheet and a certificate of consent. A copy of the Informed Consent Form can be found in Appendix C. The form was emailed to each participant in advance of their interviews, together with a summary of the key themes that the questions would cover. The consent form was read, signed and dated at the beginning of the interviews (or in advance, upon receipt of the electronic copy in one case) by the participants. As with the name of the case study, the participants are anonymised in this research; as such the informed consent form required confirmation of the job title that is used to refer to points made by the interviewees throughout this report. Participants also had the option to receive summary transcriptions of the interview via email, which one participant requested. No amendments were made to the transcription as a result of this.

_

⁷⁷ Pickard, *Research Methods in Information*, p.90.

2.6 Research Limitations

The main limitation of this research is the small number of interviews conducted. Additionally, two of the interviewees were interviewed together, at the discretion of the participants, perhaps inhibiting the expression of some personal opinions. This said, the practicalities of the small number of information professional staff at the Trust and the time-limited nature of the research did not allow for the expansion of the sample size. All three interviewees are part of the IG Department, which deals with Corporate Records, meaning that policy and practice relating to Health Records (i.e. patient records) is therefore not assessed, neither is that of professionals responsible for the official statistics of the Trust, which are managed by the Business Intelligence Unit, within the Informatics Directorate. A series of structure charts showing these departments can be found in Appendix B. Comparisons to wider literature and the results of the survey, however, do help to place data collected for the case study in context.

3.1 Discussion and Data Analysis

This chapter presents the case study of a NHS Trust in the South East of England, through discussion and selective data analysis. Data collected during two interviews, as described in Chapter Two of this report, is discussed by theme, following the order of the interview schedule: role, responsibilities and context, policies and practice, with the future of the Open Government environment being considered in the Conclusion in Chapter Four. The data is compared across the answers of the three interviewees, with similarities and differences being highlighted, and is also compared to the survey responses received from HARG and relevant literature, as also outlined in Chapter Two. The interviewees' job titles are used to reference quotations taken from the interviews. Detailed summary transcriptions of both interviews can be found in Appendix E. It is important to note, as previously mentioned, that official statistics (birth rates, death rates etc.) of the NHS Trust in the South East of England are managed by the Business Intelligence Unit, within the Informatics Directorate, and as such references to OGD in the case study interviews most probably did not allude to this data. Additionally, it is necessary to state that the experience of Corporate Records Management at the NHS Trust in the South East of England is not considered, by the interviewees, to be typical of the NHS more generally; not all NHS Trusts have Corporate Records Managers, with corporate records tending to be managed by Information Governance rather than by a specialist team. The management of health records in the Trust, although not directly assessed in this report, is considered to be typical of NHS practice on a national scale.⁷⁸

3.2 Role, Responsibilities and Context

All three interviewees are part of the IG Department, which is part of the Corporate Affairs Directorate of the NHS Trust in the South East of England. The Trust does not proactively publish any records or data, other than that specified its Publication Scheme and requested under the FOIA; therefore none of the interviewees have professional responsibilities relating specifically to OGD. The author was made aware of this before the data collection interviews took place, via email correspondence with the main contact from the case study Trust. Questions in this section aimed to understand the professional perspective of each individual by focusing on the background and qualifications of the participants, and their views towards the context of the proactive publication of OGD in their working environment. It is important to bear in mind that individual perspectives reflect, and are influenced by, professional backgrounds.

Interviewee One is the Information Governance Manager (IG Manager) at the NHS Trust in the South East of England. A broad and varied role, the IG Manager leads the IG team which works over the whole of the Trust to respond to requests or queries 'around IG in general' from both staff and the public, and 'make[s] sure that staff know what their responsibilities are' in terms of legislation affecting IG. The IG Manager is responsible for overseeing the implementation of systems which process

⁷⁸ Interview One – IG Manager, Question 3.1 and Interview Two – ACRM, Question 3.2.

⁷⁹ A series of organisational structure charts can be found in Appendix B.

personal or confidential information and for dealing with 'IG related incidents', including cyber security issues, data breaches and missing files, by working closely with the Caldicott Guardian and the Information Security division of ICT within the Trust. Additionally the IG Manager line manages the Corporate Records Management team ⁸⁰ and is part of the Trust Policy Committee, a strategically beneficial position to hold in both 'find[ing] out about some things that are going on [in the Trust] that you may not...have realised' and advocating the importance of good IG and Records Management across the Trust. ⁸¹

The first IG related post held by the IG Manager was that of a Data Quality Manager in the NHS from c.2002, in which the interviewee worked on Data Accreditation standards, used to measure the management of data within the Trust in the South East of England. The IG Toolkit replaced Data Accreditation when it was introduced in 2003, and the interviewee then became the IG Manager for the NHS Trust in the South East of England. ⁸² Relevant qualifications held by the interviewee include a short course in Data Protection and an Open University module in Information Security; recognising the existence of degree-level qualifications specific to IG, the interviewee sees little benefit in completing such training while there is not a professional requirement to do so.⁸³ Answers to questions in this section of the interview also reflected on the fact that IG professionals tend to come from different backgrounds, which include 'those...who come from the health records/data quality

⁸⁰ Interview One – IG Manager, Question 1.1.

⁸¹ Interview One – IG Manager, Question 2.5.

⁸² Interview One – IG Manager, Question 1.2.

⁸³ Interview One – IG Manager, Question 1.2.

side, and then those who come from the ICT side⁷⁸⁴. A further comment about these differing backgrounds revealed how the specific skills sets and interests of individuals may have implications for Records Management and OGD in practice; 'you can tell the difference because those who come from the IT side are more into the IT security side.' Discussing the 'open government data community' in the US, Garvin comments of the diversity of backgrounds among its members, reporting, albeit, that the majority 'tend to come from the technology community'. One of the opportunities that OGD presents to information professionals, then, is increased collaboration, for the sharing of ideas and expertise, with communities with which they have not previously been associated, such as 'system designers and data creators' 'technology experts and experts in the data management field'.

In contrast, Interviewees Two and Three followed traditional routes into Records Management by completing postgraduate Archives and Records Management qualifications; Interviewee Two is the Corporate Records Manager (CRM) at the NHS Trust in the South East of England, a position held since 2013, and Interviewee Three is Assistant Corporate Records Manager (ACRM) at the Trust, a position held since 2012. Both individuals have extensive experience in a variety of both Archive and Records Management roles. ⁸⁹ The CRM and ACRM work very closely together, and as a team are responsible for the management of Corporate Records, relating to policy and governance within the Trust, and any health records that fall outside of

⁸⁴ Interview One – IG Manager, Question 1.2.

⁸⁵ Interview One – IG Manager, Question 1.2.

⁸⁶ P Garvin, 'The Era of Open Government Data', *Information Today* 29:10 (2012), p.34.

⁸⁷ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.724.

⁸⁸ A Gregory, 'Open Data and Metadata Standards: Should We Satisfied with "Good Enough"?', p.4.

⁸⁹ Interview Two – CRM and ACRM, Question 1.2.

the core Health Records in both digital and hard copy format, and also for FOI requests on behalf of the Trust. 90

Prior knowledge about the lack of any current proactive publication of OGD at the Trust was confirmed in both interviews, as was the presupposition that OGD does not influence the roles of any of the interviewees at present. 91 Attempts to gain contextual information about the OGD environment within the Trust highlighted the complexity of the issue, with a variety of challenges becoming immediately obvious through the responses of all three interviewees to Question 1.4 of the interview schedule. From the perspective of the IG Manager, the Trust feels under some pressure to publish OGD, particularly from stakeholders interested in using the data for research purposes. The challenges to this are widespread and complex, lying not only in 'trying to work out what can be published' but also in the process of how this is going to be done, by whom, and particularly how it is going to be resourced given 'the way the NHS is at the moment...the money's not there'. 92 This was a view reflected in the survey results, with pressure felt towards publishing OGD originating mainly from researchers wanting to access information, and being further exacerbated by the time and resources that this requires. 93 The interest of the general public in OGD, however, was presumed to be low⁹⁴, which correlates with the findings of research into the use of OGD; Halonen, Martin and Worthy⁹⁵, for

⁹⁰ Interview Two – CRM, Question 1.1.

 $^{^{91}}$ Interview One – IG Manager, Question 1.3 and Interview Two – CRM and ACRM, Question 1.3.

⁹² Interview One – IG Manager, Question 1.4.

⁹³ Survey, Question 1.4.

⁹⁴ Interview One – IG Manager, Question 1.4.

⁹⁵ B Worthy, 'Open data – a very local revolution', *Local Government Chronicle* (2012), at https://www.lgcplus.com/politics-and-policy/open-data-a-very-local-revolution/5046797.article. Accessed 29 June 2016, and B. Worthy, 'Open data: how far have we got?', *Local Government*

example, all observed a 'low level of demand for OGD'⁹⁶ among a small 'number of individual data users'⁹⁷ in the public. The Corporate Records team at the NHS Trust in the South East of England detected less of an appetite for publishing OGD, but did still reference the lack of resource as one of the main challenges of the proactive publication of data; not only is it 'not something that the Trust is that interested in', the proactive publishing of datasets is not something that 'it has the capability to do either at the moment'.⁹⁸ The involvement of the ACRM in the IG community as a regular attendee at NHS IG Forum meetings also highlighted uncertainty around the prominence of the Open initiatives within the NHS more widely; 'Open Government and Open Data hasn't really been mentioned there either, so how much it's on the NHS as a whole's agenda, I'm not sure'.⁹⁹ Clearly in the context of the NHS, OGD has, as Martin maintains, 'yet to complete a breakthrough into the mainstream', with the 'opening of data' far from 'being incorporated into the daily practice of...[the] organisation'.¹⁰⁰

Additionally, the challenge of defining OGD was highlighted indirectly by both the IG Manager and the CRM, with the former questioning whether 'when we say it's going to be open', means that 'it's just going to be for those researchers who are asking for it', or "open" data is something 'that we're going to stick on our website that anyone

Chronicle (2014), at https://www.lgcplus.com/politics-and-policy/open-data-how-far-have-wegot/5068285.article. Accessed 29 June 2016.

⁹⁶ C Martin, 'Barriers to the Open Government Data Agenda: Taking a Multi-Level Perspective', *Policy & Internet* 6:3 (2014), p.232.

⁹⁷ A Halonen, 'Being Open About Data: Analysis of the UK open data policies and applicability of open data', *The Finnish Institute in London* (2012), at http://www.finnish-institute.org.uk/en/articles/48-reports. Accessed 27 July 2016, p.120.

⁹⁸ Interview Two – CRM, Question 1.3.

⁹⁹ Interview Two – ACRM, Question 1.3.

¹⁰⁰ C Martin, 'Barriers to the Open Government Data Agenda', p.218.

can come onto and look at.' 101 Furthermore, a trend towards the increased publishing of information within the Trust, presumably for reasons of increasing accountability and transparency, is likened to, yet not attributed to, pressures of OGD, with the CRM commenting: 'I think it's a case that we would probably see it or interpret it in another way rather than strictly Open Government or Open Data'. 102 Ambiguity surrounding what OGD is and how it is, and will be, interpreted in the case study Trust, exemplifies the extent of the challenges facing OGD in the health sector. Without clarity of what OGD is and a sense of the direction of its development, it is clear that the OGD agenda in the NHS Trust in the South East of England is in the very early stages of its development 103; a development, nonetheless, that can, and should, be framed as an 'innovation process' within the 'wider emergence of the digital infrastructure'. 105

3.3 Policies

Questions in this section aimed firstly to explore existing policy and guidance materials relating to IG, Records Management and FOI, and secondly, to consider policy and guidance materials relating to, or that would be required for, the management and publication of OGD in the NHS Trust in the South East of England.

A series of standalone internal policy documents were referred to by all three interviewees including the NHS Records Management Code of Practice, IG Policy,

¹⁰¹ Interview One – IG Manager, Questions 3.6 and 3.7.

¹⁰² Interview Two – CRM, Question 1.4.

¹⁰³ B Worthy, 'Making Transparency Stick', p.3.

¹⁰⁴ C Martin, 'Barriers to the Open Government Data Agenda', p.236.

¹⁰⁵ A Halonen, 'Being Open About Data', p.118.

Freedom of Information Policy and the Data Protection Policy, with the IG Manager and Corporate Records team also identifying policies which support their more specific roles and responsibilities, such as the Information Security Policy and the Trust Retention and Disposal Policy respectively. 106 These findings correlate with those of the survey, from which a very similar set of policies were cited. 107 Interestingly, perhaps a reflection of their positions within the structure of the organisation, the IG Manager referenced legislation, namely the DPA, and sources of external guidance, such as the Data Guardian, before listing internal policies, whereas the CRM and ACRM appear to be supported much more by internal Trust policies, which are based on the guidance of a number of external sources, including those mentioned by the IG Manager. 108 All three interviewees were confident that the guidance available to them, and their colleagues within the Trust, is suitable in supporting the effective and secure management of authentic, reliable and trustworthy records, a view also reflected in the survey results. 109 The IG Manager commented, however, that while 'people are aware of [them] and...do use [them] as reference', it is the responsibility of individual employees, and their managers, to ensure that policies are adhered to; this could present a problem in the context of both Records Management and OGD, if individuals are unsure what procedures they are to follow to ensure the safeguarding and management of information, particularly given that the Trust 'inform staff that the policies are out there

 $^{^{106}}$ Interview One – IG Manager, Question 2.1 and Interview Two, CRM and ACRM, Question 2.1.

¹⁰⁷ Survey, Question 2.2, Records Management and Information Governance Policies were the most frequently cited sources of guidance and support available for managing Open Data.

¹⁰⁸ Interview One – IG Manager, Question 2.1 and Interview Two – CRM and ACRM, Question 2.1.

¹⁰⁹ Survey, Question 1.3.1, The majority of respondents felt that they have sufficient guidance and support for managing records effectively.

but...don't have any system in place where you actually sign you've read them'. 110 The importance of good Records Management in ensuring that 'accurate and reliable records are created and remain accessible, usable and authentic for as long as required' 111 is fundamental; Lowry notes that the dependency between 'trustworthy, reliable and accurate records' and OGD is the only 'true means of ensuring government transparency and openness'. 112 As Shepherd maintains, with reference to FOI legislation, which 'is only as good as the quality of the records and other information to which it provides access'113, so too is OGD only as good as the accuracy and quality of the information that it contains. To this end, an annual audit undertaken by the Corporate Records team highlights departments that create large numbers of records and presents an opportunity for information professionals to 'influence the way records are created, ensur[e] that they are created in the correct way and identify any problems' with current recordkeeping. 114 In addition to this the IG Department carry out mandatory training sessions for staff across the Trust to maintain an awareness of the need to manage confidential and sensitive information responsibly, and to highlight the existence and usefulness of Trust policies to staff in their day-to-day roles. 115 The number of existing policies, however, was commented on by the IG Manager, who remarked that 'you could probably argue that [there are]...too many' policies. 116 This is a useful insight given that the OGD environment would likely require the creation of further support and guidance documentation. In

¹¹⁰ Interview One – IG Manager, Question 2.2.

¹¹¹ International Records Management Trust, Open Government and Trustworthy Records'.

¹¹² J Lowry, 'Opening Government: Open Data and Access to Information', p.169.

¹¹³ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.720.

¹¹⁴ Interview Two – ACRM, Question 2.2.

¹¹⁵ Interview One – IGM, Question 2.2 and Interview Two – ACRM, Question 2.2.

¹¹⁶ Interview One – IGM, Question 2.2.

the context of the health sector, it is also interesting to note that in the opinion of the ACRM 'people are quite responsive to the elements [of practice] around personal data because that's been drilled into [them] ever since they've been in the NHS'¹¹⁷; the awareness of Data Protection by employees on a day-to-day basis will certainly be beneficial in an OGD environment, where compliance with DPA would likely be highly scrutinised.

Outlining what information the NHS Trust in the South of England is committed to making 'routinely available' ¹¹⁸, in accordance with the FOIA, the Publication Scheme should also be considered a key policy document for IG and Records Management within the Trust. Coordinated by the Corporate Records Management team, the Publication Scheme is based on guidance issued by the Information Commissioner's Office (ICO). ¹¹⁹ The opinions of the interviewees differ somewhat with regard to the Scheme; to the IG Manager, the Trust does what it *has* to do to comply with the FOI legislation, commenting that 'we don't put on anything more [on the Publication Scheme] than we have to put on'. The Scheme itself is considered by the IG Manager to be 'too bureaucratic' a view shared by other professionals in the Records Management sector¹²¹, and is not considered to be 'a good use of...resource' In contrast, the CRM can see the benefit of the Publication Scheme in 'push[ing] the proactive publishing of information rather than responding' to requests, particularly

¹¹⁷ Interview Two – ACRM, Question 2.2.

¹¹⁸ ICO, What information do we need to publish?

¹¹⁹ ICO, *Definition documents* (2016), at https://ico.org.uk/for-organisations/guide-to-freedom-of-information/publication-scheme/definition-documents/. Accessed 28 June 2016.

¹²⁰ Interview One – IG Manager, Question 2.3.

¹²¹ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.719.

¹²² Interview One – IG Manager, Question 2.3.

for 'record series that are routinely asked for, such as workforce data and patient treatment data...things that...[are] deal[t with] an awful lot with under FOI'. 123 The CRM also recognised the potential benefit of publishing other record series, such as meeting agendas and minutes, which currently are not all published, an increased amount of organisational and Trust policies and patient literature 124; these suggestions provide a possible starting point, or direction, for the development of OGD in the NHS Trust in the South East of England. It seems possible that the early development of OGD in the Trust will take the form of an evolution of the Publication Scheme¹²⁵; whether this is the either the best use of the Scheme, or the best way for the Trust to publish and promote OGD is questionable, however, given that, at present, the view is that 'no one reads it'. 126 It is possible, however, that opinions about the use of the Trust's current Publication Scheme may be tainting views of the potential use of any OGD that it may publish in the future. It is also possible that the documented low levels of national, general public, demand and use of OGD 127 reflect an interest in a different sort of data, i.e. not 'spending information'128, rather than a disinterest in OGD as a concept.

This aside, the responses of all three interviewees relating to policies reveal that national level 'open data and transparency agendas' of NHS England do not seem to be reflected at a local level in the case study Trust; while internal policies are

¹²³ Interview Two – CRM, Question 2.4.

¹²⁴ Ihid

¹²⁵ Interview Two – CRM, Question 2.1.

¹²⁶ Interview One – IG Manager, Question 2.3.

¹²⁷ C Martin, 'Barriers to the Open Government Data Agenda', p.233 and B. Worthy, 'Open data: how far have we got?'.

¹²⁸ B. Worthy, 'Open data: how far have we got?'.

¹²⁹ NHS England, *Open Data*.

updated to reflect changes in national agendas, they are only reviewed 'every three years unless there are...major changes'. As a result of this, for agendas that are not legislated, such as OGD, it is likely that there will be a considerable delay between policy making at national level, and the filtration of policy and associated practice to local level. Certainly within the Corporate Records Management team at the Trust in the South East of England the impression is that, both within the Trust and across the NHS, 'the culture is more around publishing as little as possible'. Attributed 'partly [to] the culture [of the organisation], partly [to] a lack of awareness and also partly [to]...the technical capability' 131, the local agenda for OGD contrasts directly with that of the parent body. This is not to say that the interviewees do not see the benefits of proactively publishing data, as previously referred to in terms of reducing FOI requests and using OGD for research purposes, rather that their professional environment limits what progress that they can make. 133

All three interviewees anticipate that should the Trust choose to take a more proactive publishing data, or OGD be legislated, responsibility for compliance would rest with the Corporate Affairs Directorate, and within that, most likely with IG. 134 The key role that both IG and Corporate Records Management would therefore play in the development of the OGD environment in the Trust adds original value to this report. That OGD is expected to become a responsibility of the IG Department in the

¹³⁰ Interview One – IG Manager, Question 2.5.

¹³¹ CRM, Question 2.5.

¹³² NHS England, *Open Data*.

¹³³ Interview Two – ACRM, Question 4.6.

¹³⁴ Interview One – IG Manager, Questions 2.6, 3.10 and 4.4 and Interview Two – ACRM, Questions 2.6 and 3.12.

NHS Trust in the South East of England can be considered typical of the health sector, based on the survey findings, with respondents from organisations that already publish OGD naming similar individual roles or departments as being responsible its overall management.¹³⁵

Resources to support the publication of OGD in the NHS Trust in the South East of England are expected to take the form of internal formal policy documents and guidance notes, which would be produced by the Corporate Records team, rather than anything akin to the IG Toolkit, which supports IG across the NHS on a national scale. 136 The IG Manager commented that given the financial position of the NHS, the creation of such new resources is very unlikely to happen, despite the fact that 'there would be a need' for them. 137 The CRM views the future direction of OGD support and guidance on a national level, commenting on the possibility of the UK National Archives playing a role in creating toolkits which will provide assistance to professionals responsible for OGD across the public sector. 138 It is possible to see, then, that OGD presents some immediate practical challenges both locally and nationally, in the form of an increased workload for staff in IG within the Trust in creating guidance documents and managing OGD, and a lack of uniform and consistent guidance across NHS England for employees to refer to. The survey responses echo this, with respondents detailing a series of internal and organisational guides, as opposed to national guidance and support as offered, for example, to the practice of Records Management in the form of professional

¹³⁵ Survey, Question 2.1.

¹³⁶ Interview Two – ACRM, Question 2.7.

¹³⁷ Interview One – IG Manager, Questions 2.7, 2.8 and 4.4.

¹³⁸ Interview Two – CRM, Question 2.7.

standards. Without clear leadership or legislation to say 'yes you've got to publish all of this data'¹³⁹, uncertainty surrounding the demand and use of OGD, and the lack of resource available to publish OGD ¹⁴⁰, the 'efficiency, accountability and the commercial value of data' emphasised in central government, and NHS, policies and agendas, is diluted at local level, where the 'usability of and the user interest in the data, the costs of the scheme and the workload it causes' forces the prevalence of 'a much more practical mindset.'¹⁴¹

3.4 Practice

The final part of discussion and analysis will explore the current practices of IG, Records Management and FOI, and the potential implications of OGD on the roles of the three interviewees at the NHS Trust in the South East of England. Questions during this section of the interviews also aimed to gain an insight into metadata processes, data security and the users of OGD.

In an OGD environment, simply 'publishing data is not enough' – it needs to exist within an infrastructure which renders it meaningful and usable to the public. ¹⁴² The significance of the challenge that this would pose to the case study Trust was something hinted at, but not explored fully, during the interviews; commenting on the amount of work that preparing OGD for publication would entail, the IG Manager aired concerns about the misconception that publishing data is easy and

¹³⁹ Interview One – IG Manager, Question 1.4.

¹⁴⁰ C Martin, 'Barriers to the Open Government Data Agenda', p.233

¹⁴¹ A Halonen, 'Being Open About Data', p.76.

¹⁴² K O'Hara, 'Transparency, Open Data and Trust in Government: Shaping the Infosphere', WebSci (2012), p.231.

straightforward; 'I'm sure the politicians do just think it's the click of a button, but it's not'. 143 Dawes writes of the problems that the OGD agenda presents to the management of information which is 'not collected with public release in mind'; because 'it is seldom managed in the structured way that census data or other standard statistics are managed' not only is it 'more difficult for others to use and interpret'144, but also is likely to require a considerable amount of work to ensure that it exists in a suitable reusable, 'machine readable' form, and that problems with data redundancy, inconsistency and data integrity are avoided. 146 In addition to this, 'you would need to check whether things can be published or need to be redacted', to avoid the publishing of any sensitive or confidential information. 147 While this checking of data is recognised within the NHS Trust in the South East of England as an indispensible step in the publishing of OGD, there is an admission of uncertainty around 'how that will work' in practice 148; utilising technology to automate some of these processes was mentioned by the CRM, but it is clear that the specifics of any such venture will require much planning and development.

An additional part of the infrastructure needed to support OGD is complete, accurate metadata sets. The importance of metadata to OGD is paramount; 'unconnected to the context of its creation, left without the essential information needed for its interpretation'¹⁴⁹, data is far from clear and useful. At present, given

¹⁴³ Interview One – IG Manager, Question 3.9, 4.2 and 4.4.

¹⁴⁴ S S Dawes, 'Stewardship and usefulness', p.378.

¹⁴⁵ O Williams, Open data could save the NHS hundreds of millions.

¹⁴⁶ E Shepherd, 'Freedom of Information, Right to Access Information, Open Data', p.724.

¹⁴⁷ Interview Two – CRM, Question 3.11.

¹⁴⁸ Interview One – IG Manager, Questions 3.9, 4.2 and 4.4.

¹⁴⁹ J Lowry, 'Opening Government: Open Data and Access to Information', p.163.

the lack of proactive publication of data by the Trust, the absence of any standardised metadata processes does not seem to be considered a hindrance to the current management of records and information, but it does present an immediately significant challenge to the publication of OGD. Available metadata for electronic records (both Health and Corporate) amounts only to that captured automatically by computer software programmes, with some additional contextual information for paper records provided on the transfer forms that accompany records from the creator to the records centre. 150 A current project to implement an Electronic Document and Records Management System (EDRMS) is expected to increase the amount and consistency of metadata held for electronic records across the Trust. 151 There is, therefore, an awareness of the importance of capturing metadata for ease of access to data; for example, if records were going to be requested more frequently there would be a 'need [for] more information on the contents than generalised information so that [they] can [be found]... a lot more easily'152. Careful consideration of what metadata would be published online with OGD is also needed to ensure that any available data is both identifiable and usable. In terms of providing contextual information about OGD datasets, metadata raised concerns in both interviews, with allusions to the fact that contextual information can be 'matched up' 153 'to make [data] identifiable', even if it is anonymised 154; any such situation poses security and privacy risks to the Trust, and perhaps not so much in an

¹⁵⁰ Interview Two – CRM, Question 3.1.

¹⁵¹ Interview Two – CRM, Question 1.4 and ACRM, Question 3.1.

¹⁵² Interview Two – CRM, Question 3.1.

¹⁵³ Interview One – IG Manager, Questions 3.6 and 3.7.

¹⁵⁴ Interview Two – ACRM, Question 3.9 and

OGD environment where the focus is on high-level datasets rather than detailed information, but also to the data subjects that the data refers to.

Of course the concept of OGD 'is that with openness it is about bulk openness, not about individual records' 155, but given the responsibility to manage such a large volume of complex records, including many that contain sensitive and confidential information on behalf of the NHS Trust in the South East of England, the caution expressed by the interviewees is certainly understandable. The CRM appreciates that 'given the quantity of records [and data] produced by the Trust, the task [of publishing data] would be fairly significant' 156, a view which mirrors that of Shadbolt, who maintains that 'the size and complexity of the NHS is a stumbling block for open data'. 157 External challenges facing the NHS OGD agenda, however, equally, cannot be overlooked, embedded as they are 'within wider distrust of government, NHS management and commercial organisations'. 158 Exacerbated by the issues surrounding the data sharing of patient information through the care.data programme, as discussed in Chapter One, there is much work to be done to regain the public trust in the NHS that has been lost through the mismanagement of information in the past. 159 This effort must be driven, first and foremost, by the appropriate management of information, which should include improving the

¹⁵⁵ Interview One – IG Manager, Questions 3.6 and 3.7.

¹⁵⁶ Interview Two – CRM, Question 3.11.

¹⁵⁷ O Williams, Open data could save the NHS hundreds of millions.

¹⁵⁸ S Childs and J McLeod, 'A case example of public trust in online records – The UK care.data programme', *InterPARES Trust Project EU17 – 4th ITRUST European Team meeting presentation* (2015)

¹⁵⁹ Interview One – IG Manager, Questions 3.6 and 3.7 and Questions 4.3 and 3.9.

'quality of government information' through the use of metadata and accuracy and integrity checks, but can also be assisted by utilising relevant legislation to demonstrate that information is being effectively managed in accordance with privacy or disclosure obligations. Legislation, such as DPA and FOIA, increases public confidence by ensuring that the rights and restrictions of individuals are bound by regulatory powers.

The Corporate Records team within the NHS Trust in the South East of England deal with approximately 75 FOI requests per month, a figure that has increased considerably over the last year¹⁶¹ and reflects the trend of rising request levels in both local and central government reported by Worthy et al in 2011. ¹⁶² The increased number of requests in the Trust is attributed to the fact that 'the media have used Freedom of Information to uncover wrongdoing, such as MPs expenses' and an existing 'groundswell in the public wanting to know more' about public sector organisations. ¹⁶³ This could certainly be used to evidence a public appetite for an increased amount of publically available information, which, if satisfied by OGD, amounts to a proactive response to the disclosure of information, as opposed to the reactive nature of the existing provisions of FOI. ¹⁶⁴ Despite this, it is still possible to sense a reticence to publishing data; the CRM at the case study Trust believes that 'a reluctance...to accept public scrutiny of the work that is done' is a civil service wide

¹⁶⁰ M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data', p.267.

¹⁶¹ Interview Two – CRM, Question 3.3.

¹⁶² B Worthy, J Amos, R Hazell and G Bourke, 'Town Hall Transparency? The Impact of Freedom of Information on Local Government in England', *The Constitution Unit* (2011), at

https://www.ucl.ac.uk/constitution-unit/research/foi/foi-and-local-government/town-hall-transparency.pdf>. Accessed 1 July 2016, p.10.

¹⁶³ Interview Two – CRM, Question 3.4.

¹⁶⁴ J Lowry, 'Opening Government: Open Data and Access to Information', p.161.

feeling. ¹⁶⁵ This correlates with the results of the survey, in which organisational fears about publishing data were expressed as one of the main barriers to OGD. ¹⁶⁶

Current practices of IG, Records Management and FOI in the NHS Trust in the South East of England, then, present a series of challenges to an OGD environment, from the creation and capture of suitable and sufficient metadata for records to ensure that datasets can be interpreted, retrieved and used, to the safeguarding of records and data by all staff to prevent security or sensitivity breaches, and the uncertainty over who would use any published OGD. The size and complexity of this task cannot, and within the case study Trust is not, underestimated. The IG Manager admits that 'it's obviously something that as a Trust we do need to sit down and consider' but that at present, referring to the failings of the care.data programme, 'there are more pressing things than releasing data for third parties to make money out of'. 167 In addition to this there is a considerable amount of work to do in deciding what data should be published and 'getting that balance right between what is an appropriate use and access to information and what isn't.' While OGD remains unlegislated, it is at the discretion of individual organisations whether they proactively publish datasets, what they publish, and indeed for what purpose; as previously noted, the 'primary focus of central government policies and statements has been around efficiency, accountability and the commercial value of data¹⁶⁹, which gives little consideration to the users, researchers, the general public or otherwise, of OGD. This

¹⁶⁵ Interview Two – CRM, Question 3.10.

¹⁶⁶ Survey, Question 3.2.

¹⁶⁷ Interview One – IG Manager, Question 1.4.

¹⁶⁸ Interview Two – CRM, Question 3.9.

¹⁶⁹ A Halonen, 'Being Open About Data', p.76.

is a view largely reflected in the interviews and survey, with the Corporate Records team stating that increased accountability and transparency are likely to be the key drivers for the OGD within the NHS Trust in the South East of England. Responses to the survey, similarly, indicate that the demonstration of transparency and accountability of actions and decisions taken and made is considered to be of greater benefit to organisations than the opportunity for public access to OGD and the possibility of increased public engagement with data through participation in organisations. The fact that flittle is known about the conversion of public data into services of public value suggests that either OGD is not currently being used to this end, which is entirely possible given that the public interest towards it is as low as it is 7173, or that the data currently released is not the kind of data that can be translated into such, tangible, benefits.

While OGD is unlegislated it remains possible to speculate exactly what a prevalent OGD environment would look like in reality, both in the case study Trust and in the NHS more widely. There is no formal IG strategy within the NHS Trust in the South East of England, so there are no formalised plans for the development of an OGD environment. The IG Manager comments on the fact that 'with IG things change so quickly' so 'a strategy doesn't really help'. Here it is possible to see the challenge of developing and incorporating an OGD environment into an already flexible way of working. This lack of strategic direction may go some way towards explaining the

¹⁷⁰ Interview Two – ACRM, Question 4.3.

¹⁷¹ Survey, Question 3.1.

¹⁷² M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data', n.266.

¹⁷³ A Halonen, 'Being Open About Data', p.76.

¹⁷⁴ Interview One – IG Manager, Questions 3.2, 3.3.

certain feeling of powerlessness that can be detected among the interviewees. Additionally, the opportunity to influence, or have an input into, the NHS OGD agenda seems very limited, if impossible, from a local Trust level; 'whatever the government might be saying about Open Government, that is what will happen...obviously [the Trust will] do what the government...tell [them]'. 175 Of course, ultimately, if OGD was legislated 'then there would be a requirement to [publish data and the Trust]...would have to do it'. 176 For the Corporate Records Management team 'a higher level of support to drive' the initiative throughout the Trust is expressed as being more important than increased staff capacity to deal with added OGD responsibilities. The challenge of implementing OGD practices across the Trust is seen as greater than dealing with it on a day-to-day basis 178, particularly given that 'as records managers', the interviewees feel limited as to 'how much [they] can promote it...within the organisation. The lack of support and direction from senior management in the Trust with regards to OGD demonstrates the value of assessing the OGD environment at local level; it is possible to explore and assess the day-to-day challenges that will face Records Managers, not always reflected in the literature, which tends to focus on OGD at a high level.

Nevertheless, in practice, OGD will have a number of implications for the information professionals interviewed at the NHS Trust in the South East of England.

All three interviewees saw it unlikely that new roles would be created to manage the

-

¹⁷⁵ Interview One – IG Manager, Question 1.4.

¹⁷⁶ Interview Two – ACRM, Question 4.1.

¹⁷⁷ Interview Two – ACRM, Question 3.12.

¹⁷⁸ Interview Two – ACRM, Question 4.4.

¹⁷⁹ Interview Two – ACRM, Question 4.6.

proactive publishing of datasets, which would mean that staff would add any extra work generated by OGD to their workloads 'and then just do it as [they] go along.'180 The CRM anticipates that the process of publishing data online would be an extension of the team's current role, given that they 'have editing rights to the website...to publish on there'181, although it is not yet certain how OGD would be disseminated. 182 It is also uncertain what impact OGD would have on FOI requests, other than that it is expected that any OGD legislation would exist in conjunction with FOIA, not as a replacement for it. As previously noted, the Corporate Records team do have 'a strategy around reducing FOI requests by proactively publishing material'183, which could result in fewer requests in an OGD environment. In reality, however, many of the FOI requests received by the team ask for information more specific than that likely to be published as OGD; there is a chance, then, that even if more information is published, 'the requests...will just get even more specific [as] people look at the [published] data...and then use FOI to get down even further into that information.' 184 There is also the possibility, as Halonen maintains, that a lack of 'relevant context' for published data will generate more requests, as data alone 'lacks informational value'. 185

In addition to changes to day-to-day professional responsibilities, an OGD environment would also present a number of practical and technical challenges to the case study Trust. As stated by the CRM, 'the other side of the problem...is a

¹⁸⁰ Interview One – IG Manager, Questions 2.7, 2.8 and 4.4.

¹⁸¹ Interview Two – CRM, Question 2.8.

¹⁸² Interview One – IG Manager, Questions 3.9, 4.2 and 4.4.

¹⁸³ Interview Two – CRM, Question 2.1.

¹⁸⁴ Interview Two – ACRM, Impact of any future open government legislation on FOI.

¹⁸⁵ A Halonen, 'Being Open About Data', p.77.

technical one'186; at present the Trust does not have a portal that could be used to disseminate OGD. While practically, in terms of ease of publishing data, this may seem a necessity, this was not a view shared by all the interviewees, with the IG Manager stating that 'in theory for most of...[the] data we have got the technology to publish that data'. 187 Instead, most important, it is argued, is the need to discuss what the demand for OGD will be, and what will be useful for its users, with the suggestion being made that pilot programmes should be launched, 'working with researchers and third parties', to work out the most efficient and useful way of disseminating data, whether this be locally, on the websites on individual Trusts, or nationally via HSCIC. 188 Shadbolt et al emphasise that OGD is not 'a rigid government IT specification, but that it demands productive dialogue between data providers, users and developers.' 189 The amount of work required to do this, however, is not underestimated, with challenges existing in both monetary and manpower terms; 'with the way the NHS is at the moment...the money's not there, the resource is not there', and quite simply there 'are far more pressing priorities' than working out how to publish OGD. In the context of the NHS Trust in the South East of England one of 'the main challenge[s] is that open data has no value in itself' - with no mandate, a lack of resource and no immediately tangible benefits the Trust currently has little incentive to publish OGD.

¹⁸⁶ Interview Two – CRM, Question 1.4.

¹⁸⁷ Interview One – IG Manager, Questions 3.9, 4.2 and 4.4.

¹⁸⁸ Interview One – IG Manager, Questions 3.9, 4.2 and 4.4.

¹⁸⁹ N Shadbolt, K O'Hara, T Berners-Lee, N Gibbins, H Glaser, W Hall and M C Schraefel, 'Linked Open Government Data: Lessons from Data.gov.uk, *IEEE Intelligent Systems* (2012), p.23.

¹⁹⁰ M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data', p.260.

Chapter Four: Conclusion

4.1 The Future of Open Government Data

This report began by acknowledging the evolving nature of the Open Government environment. Currently unlegislated, and lacking in formal leadership and direction, policy and practice of the proactive publication of OGD will continue to develop as research is undertaken, challenges are identified and questions are answered. In the meantime, 'yet to suffer...a clear defeat', the OGD agenda 'retains the potential' to succeed and to reshape the UK's 'transparency agenda', and beyond this, its legislative landscape. The current infancy of the OGD agenda, however, highlights the complexity of the challenges that lie in its path. Having considered the current policies and practice of the case study NHS Trust in the South East of England it is both interesting and useful to reflect upon the potential future of OGD from a professional perspective, as per the interview schedule, in concluding this research.

The interviews revealed the extent of unanswered questions relating to OGD. The main concerns voiced by the interviewees related to practical challenges; the lack of clarity about *what* data would be published, *how it would be used*, and the *resource* needed to do it, but comments highlighted, indirectly, a number of further challenges. The most pressing, the lack of clarity in defining what OGD is – it remains very difficult to develop a sustained response to OGD without agreement over what the term means. The effect of the loss of public trust in the way the NHS handles data, largely as a result of the failure of the care.data programme, has also had

¹⁹¹ B Worthy, 'Making Transparency Stick', p.3.

¹⁹² Ibid., p.2

implications for the development of the OGD environment; not only do the distinctions between data-sharing and OGD need to be publically made, the NHS must 'st[an]d up', and advocate, for the benefits of the proactive publication of data¹⁹³ to an audience most likely sceptical of any agenda which involves the making public of large amounts of data. This loss of trust also has practical implications; as 'the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care'¹⁹⁴, the HSCIC is, in theory, well placed to disseminate OGD. Now, however, 'people have got issues with sending the data to HSCIC in the first place'¹⁹⁵, which raises questions over how OGD will be published; it remains possible to speculate whether the NHS' response to OGD will amount to a collaborative, national, or individual, Trust by Trust, local, response.

The future direction of OGD within the NHS Trust in the South East of England is uncertain, with all three interviewees agreeing that there has not 'been enough proper discussion about it.' ¹⁹⁶ It is possible to sense a feeling of powerlessness among the Records Managers with regards to their ability to influence the development of the local OGD agenda, while it is not a priority of the Trust. Despite this, the interviewees are 'not worried' by the idea of OGD ¹⁹⁷ and are confident that 'it's an area which will only increase and be a requirement.' ¹⁹⁸ Issues surrounding the resourcing of the proactive publication of data, however, remain, at present,

¹⁹³ Interview One – IG Manager, Questions 4.3 and 3.9.

¹⁹⁴ Gov.uk, Health and Social Care Information Centre (2016), at

https://www.gov.uk/government/organisations/health-and-social-care-information-centre. Accessed 15 June 2016.

¹⁹⁵ Interview One – IG Manager, Questions 3.9, 4.2 and 4.4.

¹⁹⁶ Ibid.

¹⁹⁷ Interview Two – CRM, Additional question: Are you worried by the idea of Open Government? Time: 53:43.

¹⁹⁸ Ibid.

unsolved, and indeed yet to be fully exposed. Additionally, the lack of consistent metadata applied to records and the current ambiguity surrounding the awareness of Trust staff to existing records and information policies amounts to a further challenge; creating policy and guidance documents about how to ensure the accuracy and integrity of data is one thing, cascading that information to staff is another.

For now, awaiting direction in the form of OGD policy or legislation, Records Managers, at the NHS Trust in the South East of England can be confident in the fact that their current skillset is suited to the new responsibilities that they will assume in an OGD environment; 'a lot of the skills involved in Open Government are a lot of the same sort of skills needed for dealing with FOI requests.' The principles of managing OGD are expected to be very similar to those of managing records, and although requiring IT skills, the management and publishing of data sets is not expected to be beyond the capabilities of existing staff members.

4.2 Conclusion

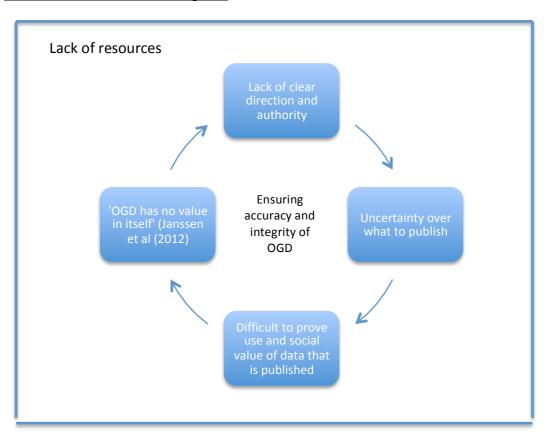
The challenges identified in the case study of a NHS Trust in the South East of England largely mirror those discussed in the literature reviewed for this report, and are comparative with similar recordkeeping environments in the health sector, as considered in the survey. Focusing on a single case study of an organisational unit has allowed for the comparison of perceived and actual challenges, and for the consideration of disparities between experiences at a national and local level. At

¹⁹⁹ Interview Two – ACRM, Question 4.5.

present, given the undeveloped state of OGD in the NHS Trust in the South East of England, challenges are expressed in practical terms, at a high level; broad questions of what, why and how seem to precede those of data authenticity and integrity. Cyclical practical challenges, exacerbated by the lack of resources, dominate views towards OGD in the case study Trust, somewhat overshadowing the technical challenges of the data itself. This is demonstrated in Figure 1.

Figure 1: The Challenges of an Open Government Data Environment in the NHS

Trust in the South East of England



The infancy of the OGD initiative, while presenting a comprehensive series of interconnected practical and technical challenges to Records Managers, also offers

'huge opportunities'²⁰⁰ to the profession of Records Management to contribute to the development of the Open Government environment. There are a number of parallels between OGD and Records Management; firstly, the benefits of transparency and accountability that OGD offers to public sector organisations align with two of the key requirements of good governance that Records Management is employed to deliver. Additionally, both agendas require attention to digital detail, in the form of ensuring data authenticity, integrity, and accessibility. And furthermore, both have communities with the drive and ambition needed to steer the initiatives forward, to ensure that the benefits of OGD can be fully realised.

On a national level, the successful development of an OGD environment will benefit from reflection upon the similar agendas of both transparency legislation, namely FOI, and previous attempts at data sharing; Worthy asserts that 'FOI may offer some lessons' in highlighting the type of data that is likely to be used, and also the form in which it will be most useful²⁰¹, and McLeod identifies the lack of clarity and agreement over the requirements for data during the development of the care.data programme as one of the reasons for its failure.²⁰² The small number of current OGD users²⁰³, then, should prompt investigations into the type of data that the public would like to access, for reasons of both streamlining practice, and making the best use of available resource; it is no coincidence that the IGM at the NHS Trust in the South East of England suggested piloting an OGD programme, as McLeod reports 'no

²⁰⁰ J McLeod, 'Thoughts on the opportunities for records professionals', pp.92-97.

²⁰¹ B Worthy, 'Open data – a very local revolution', p.1.

²⁰² S Childs and J McLeod, 'A case example of public trust in online records – The UK care.data programme', *InterPARES Trust Project EU17 – Research Report* (2015), pp.15-16.

²⁰³ C Martin, 'Barriers to the Open Government Data Agenda', p.232.

piloting of the [care.data] programme' as being a 'major problem' with the governance of the initiative. 204

At a local level, at this early stage of the evolution of the OGD environment, without clear direction from legislation, and limited by resources and lack of interest, Records Managers are limited how they can progress. Certainly there is little they can do with regards to the cyclical challenges noted in Figure 1. Where progress can be made, however, is in the preparation for publishing OGD. Firstly, it is important that records professionals realise the importance of their profession to the development of the OGD environment; it is not an agenda that Records Management can champion alone, but it is certainly an opportunity 'for social learning that brings together the diverse perspectives that coexist within the OGD community.'205 Secondly, recordkeeping professionals can work to ensure that current Records Management practice reflects the requirements of OGD, such as data accuracy and the creation and capture of appropriate metadata, for 'the success of open data...depends to a large extent on the use and the quality of the data provided.' 206 Related to this, with a knowledge and appreciation of the importance of the integrity and authenticity of information, Records Managers can prepare for the OGD environment by ensuring that data, most of which is not managed with 'public release in mind'207, is in a suitable state to be disseminated, accessed and understood. There is a need for policy and guidance documents that

 $^{^{204}}$ S Childs and J McLeod, 'A case example of public trust in online records', p.33.

²⁰⁵ C Martin, 'Barriers to the Open Government Data Agenda', p.235.

²⁰⁶ M Janssen, Y Charalabidis and A Zuiderwijk, 'Benefits, Adoption Barriers and Myths of Open Data', p.266.

²⁰⁷ S S Dawes, 'Stewardship and usefulness', p.378.

outline the requirements of data to be prepared for publication; progress can be made here without knowing the specific technical details of dissemination software and portals that may be utilised, while these questions, as yet, remain largely unanswered.

The development of OGD relies on its purpose being relevant to the agenda that it represents, and its agenda must be appropriate for the organisations in which it will become a part. To ensure that this is the case, continuing research is required. This report has considered one Trust within NHS England; it is recommended, firstly, that future research explore further Trusts, on an individual case study basis. There would be benefit in considering Trusts in the NHS nationally, in Scotland, Wales and Northern Ireland, given that any OGD legislation would likely apply to all four countries within the UK. Additionally, research into OGD in the health sector at an international level would assist with further developing an understanding of OGD practice and policy, and also offer the possibility of benchmarking against established OGD environments, such as that of Norway. 208 More practically, as what information to publish, and what value publishing data has to society, remain considerable barriers to the progress of the OGD initiative, further research into the users of OGD, what would be beneficial to publish and how, and how use of OGD can be both measured and translated into social benefit, would be invaluable.

²⁰⁸ O H Sataslaatten, 'The Norwegian Noark Model requirements for EDRMS in the context of open government and access to governmental information', *Records Management Journal* 24:3 (2014), pp.189-204.

Challenges facing the OGD initiative, as demonstrated throughout this report, are considerable, but the opportunities that it presents are far greater. To society, the benefits of OGD reach beyond the accountability and transparency of public sector organisations, increasing the 'richness and diversity of the information sources available to the citizen'²⁰⁹ and 'letting people create new, innovative ways of using it.'²¹⁰ To public sector organisations, OGD offers the potential to 'unlock new ideas for delivering public services...[and]...help communities and societies work better together'²¹¹. And for Records Management, the emergence of an OGD environment can be used 'as a vehicle for bringing wider attention to the value'²¹² of the practice. Ultimately, the success of OGD rests on 'government's ability to create and maintain reliable, trustworthy and accurate information'²¹³; while Records Managers may not be placed to control the OGD movement single-handedly, they certainly have a vital role to play in unlocking its potential.

²⁰⁹ K O'Hara, 'Transparency, Open Data and Trust in Government', p.227.

²¹⁰ T Berners-Lee in B McKenna, 'U.K. Coalition Government Opens Data Chest', *Information Today* 28:3 (March 2011), p.14.

²¹¹ B McKenna, 'U.K. Coalition Government Opens Data Chest', *Information Today* 28:3 (March 2011), p.14.

²¹² J Lowry, 'Opening Government: Open Data and Access to Information', p.161.

²¹³ A Thurston in J Lowry, 'Opening Government: Open Data and Access to Information', p.161.

Bibliography

Published Sources

Anderson, K, Engvall, T, and Klett, E, 'Open Data Through The Archive: A New Role For Archivists', *Arxius i Industries Culturals* (2014), pp.1-9.

Armstrong, C L, 'Providing a clearer view: An examination of transparency on local government websites', *Government Information Quarterly* 28 (2011), pp.11-18.

Azberger, P, Schroeder, P, Beaulieu, A, Bowker, G, Casey, K, Laaksonen, L, Moorman, D, Uhlir, P, and Wouters, P, 'An International Framework to Promote Access to Data', *Science* 303:5565 (2004), pp.1777-1778.

Biggam, J, Succeeding with your Master's Dissertation 3rd ed., (Maidenhead, 2015).

Borglund, E, and Engvall, T, 'Open data?: Data, information, document or record?', *Records Management Journal* 24:2 (2014), pp.163-180.

Childs, S, McLeod, J, Lomas, E and Cook, G, 'Opening research data: issues and opportunities', *Records Management Journal* 24:2 (2014), pp.142-162.

Clark, D, 'Open government in Britain: Discourse and practice', *Public Money & Management* 16:1 (1996), pp.23-30.

Cusker, J P, Lebo, T, Chang, C and McGuinness, D L, 'Parallel Identities for Managing Open Government Data', *IEEE Intelligent Systems* (2012), pp.55-62.

Data.gov.uk, Home (2016), at https://data.gov.uk/. Accessed 18 June 2016.

Dawes, S S, 'Stewardship and usefulness: Policy principles for information-based transparency', *Government Information Quarterly* 27 (2010), pp.377-383.

Donnelly, L, *Millions of NHS records sold to insurance firms* (17 June 2014), at http://www.telegraph.co.uk/news/health/news/10906390/Millions-of-NHS-records-sold-to-insurance-firms.html. Accessed 18 June 2016.

Editorial, 'Open Government, Open Data and Digital Government', *Government Information Quarterly* 31 (2014), pp.4-5.

Garvin, P, 'The Era of Open Government Data', *Information Today* 29:10 (2012), pp.33-34.

Geiger, C P, and von Lucke, J, 'Open Government and (Linked) (Open) (Government) (Data)', eJournal of eDemocracy 4:2 (2012), pp.265-278.

Gregory, A, 'Open Data and Metadata Standards: Should We Satisfied with "Good Enough"?', *Open Data Foundation* (2011), at http://odaf.org/papers/Open%20Data%20and%20Metadata%20Standards.pdf>. Accessed 20 July 2016.

Gov.uk, *Data Protection* (7 December 2015), at https://www.gov.uk/data-protection/the-data-protection-act. Accessed 23 July 2016.

Gov.uk, *How to make a freedom of information (FOI) request* (12 November 2014), at https://www.gov.uk/make-a-freedom-of-information-request/the-freedom-of-information-act. Accessed 27 July 2016.

Gov.uk, *Health and Social Care Information Centre* (2016), at https://www.gov.uk/government/organisations/health-and-social-care-information-centre. Accessed 15 June 2016.

Gov.uk, *HSCIC changing its name to NHS Digital* (2016), at https://www.gov.uk/government/news/hscic-changing-its-name-to-nhs-digital. Accessed 17 August 2016.

Gov.uk, *The NHS Constitution – the NHS belongs to us all* (27 July 2015), at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/4 80482/NHS_Constitution_WEB.pdf>. Accessed 27 July 2016.

Hall, A, and Walton, G, 'Information overload within the health care system: a literature review', *Health Information and Libraries Journal* 21 (2004), pp.102-108.

Halonen, A, 'Being Open About Data: Analysis of the UK open data policies and applicability of open data', *The Finnish Institute in London* (2012), at http://www.finnish-institute.org.uk/en/articles/48-reports. Accessed 27 July 2016.

Health Archives and Records Group (2016), at http://healtharchives.co.uk/. Accessed 8 August 2016.

Heise, A, and Naumann, F, 'Integrating open government data with stratosphere for more transparency', *Web Semantics: Science, Services and Agents on the World Wide Web* 14 (2012), pp.35-56.

Hendler, J, Holm, J, Musialek, C, Thomas, G, 'US Government Linked Open Data: Semantic.data.gov', *IEEE Computer Society* 12 (2012), pp.1541-1672.

Hitchcock, G, *NHS seeks cure for its costly digital headache* (1 July 2016), at https://www.theguardian.com/healthcare-network/2016/jul/01/nhs-seeks-cure-costly-digital-headache. Accessed 8 July 2016.

ICO, *Definition documents* (2016), at https://ico.org.uk/for-organisations/guide-to-freedom-of-information/publication-scheme/definition-documents/. Accessed 28 June 2016.

ICO, What information do we need to publish? (2016), at https://ico.org.uk/for-organisations/guide-to-freedom-of-information/publication-scheme/. Accessed 28 June 2016.

International Records Management Trust, *Open Government and Trustworthy Records: Institutional/ Regulatory Framework and Capacity Benchmarking Tool* (2013), at http://www.irmt.org/portfolio/open-government-trustworthy-records-final-2. Accessed 28 June 2016.

Janssen, M, Charalabidis, Y, and Zuiderwijk, A, 'Benefits, Adoption Barriers and Myths of Open Data and Open Government', *Information Systems Management* 29:4 (2012), pp.258-268.

Knapton, S, 'How the NHS got it so wrong with care.data', *The Telegraph* (7 July 2016), at http://www.telegraph.co.uk/science/2016/07/07/how-the-nhs-got-it-so-wrong-with-caredata/. Accessed 18 June 2016.

Lowry, J and Wamukaya, J (eds.), *Integrity in Government through Records*Management – Essays in Honour of Anne Thurston (Farnham, 2014).

Martin, C, 'Barriers to the Open Government Data Agenda: Taking a Multi-Level Perspective', *Policy & Internet* 6:3 (2014), pp.217-240.

McKenna, B, 'U.K. Coalition Government Opens Data Chest', *Information Today* 28:3 (March 2011), pp.14-15.

McLeod, J, 'Thoughts on the opportunities for records professionals of the open access, open data agenda', *Records Management Journal* 22:2 (2012), pp.92-97.

NHS, *Information Governance Toolkit* (2016), at https://www.igt.hscic.gov.uk/. Accessed 10 May 2016.

NHS, The history of the NHS in England (2015), at http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx. Accessed 15 July 2016.

NHS Confederation, Legislation and guidance relating to medical records explained by House of Commons Library (10 October 2015), at http://www.nhsconfed.org/resources/2015/10/legislation-and-guidance-relating-to-medical-records-explained-by-house-of-commons-library. Accessed 27 June 2016.

NHS England, *Data Protection Policy* (June 2014), at https://www.england.nhs.uk/wp-content/uploads/2013/06/dpa-policy-1.pdf>. Accessed 23 July 2016.

NHS England, *Open Data* (2015), at https://www.england.nhs.uk/ourwork/tsd/data-info/open-data/. Accessed 18 June 2016.

O'Hara, K, 'Transparency, Open Data and Trust in Government: Shaping the Infosphere', *WebSci* 12 (2012), pp.223-232.

Pickard, A J, *Research Methods in Information* 2nd ed., (London, 2013). Sataslaatten, O H, 'The Norwegian Noark Model requirements for EDRMS in the context of open government and access to governmental information', *Records Management Journal* 24:3 (2014), pp.189-204.

Shadbolt, N, O'Hara, K, Berners-Lee, T, Gibbins, N, Glaser, H, Hall, W and Schraefel, M C, 'Linked Open Government Data: Lessons from Data.gov.uk, *IEEE Intelligent Systems* 12 (2012), pp.16-24.

Shepherd, E, 'Freedom of Information, Right to Access Information, Open Data: Who is at the Table?', *The Commonwealth Journal of International Affairs* 104:6 (2015), pp.715-726.

Shepherd, E, 'Open government, open data: where is the records manager?', 1st Annual ICA Conference (2012), at http://www.ica.org/en/elizabeth-shepherd. Accessed 16 June 2016.

SurveyMonkey, *Home* (2016), at https://www.surveymonkey.co.uk/. Accessed 15 June 2016.

The King's Fund, *Dame Fiona Caldicott on data-sharing in health and care* (3 May 2016), at http://www.kingsfund.org.uk/publications/articles/dame-fiona-caldicott. Accessed 18 June 2016.

Tough, A, 'Accountability, open government and record keeping: time to think again?', *Records Management Journal* 21:3 (2011), p.225-236.

Toynbee, P, A viable shot at a better NHS has been killed off by privacy paranoia (7 July 2016), at https://www.theguardian.com/commentisfree/2016/jul/07/better-nhs-killed-privacy-paranoia-care-data. Accessed 8 July 2016.

Vezyridis, P, and Timmons S, 'On the adoption of personal health records: some problematic issues for patient empowerment', *Ethics Information Technology* 17 (2015), pp.113-124.

Walport, M, and Brest P, 'Sharing research data to improve public health', *The Lancet* 377 (2011), pp.537-539.

Williams, O, Open data could save the NHS hundreds of millions, says top UK scientist (29 May 2015), at https://www.theguardian.com/media-

network/2015/may/29/open-data-nhs-healthcare-nigel-shadbolt>. Accessed 8 July 2016.

Worthy, B, 'Making Transparency Stick: The Complex Dynamics of Open Data' (2014), at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2497659. Accessed 28 June 2016.

Worthy, B, 'Open data – a very local revolution', *Local Government Chronicle* (2012), at https://www.lgcplus.com/politics-and-policy/open-data-a-very-local-revolution/5046797.article. Accessed 29 June 2016.

Worthy, B, 'Open data: how far have we got?', *Local Government Chronicle* (2014), at https://www.lgcplus.com/politics-and-policy/open-data-how-far-have-we-got/5068285.article. Accessed 29 June 2016.

Worthy, B, Amos, J, Hazell, R and Bourke, G, 'Town Hall Transparency? The Impact of Freedom of Information on Local Government in England', *The Constitution Unit* (2011), at https://www.ucl.ac.uk/constitution-unit/research/foi/foi-and-local-government/town-hall-transparency.pdf>. Accessed 14 June 2016.

Yin, R K, Case Study Research (London, 2008).

Yu, H and Robinson, D G, 'The New Ambiguity of "Open Government", UCLA Law Review Discourse 178 (2012), pp.178-208.

Zuiderwijk, A, Janssen, M, Choenni, S, Meijer, R and Sheikh Alibaks, R, 'Sociotechnical Impediments of Open Data', *Electronic Journal of e-Government* 10:2 (2012), pp.156-172.

Zuiderwijk, A, Janssen, M and Davis, C, 'Innovation with open data: Essential elements of open data ecosystems', *Information Polity* 19 (2014), pp.17-33.

Unpublished Sources

Childs, S, and McLeod, J, 'A case example of public trust in online records – The UK care.data programme', InterPARES Trust Project – 4th ITRUST European Team meeting presentation (2015).

Childs, S, and McLeod, J, 'A case example of public trust in online records – The UK care.data programme', *InterPARES Trust Project EU17 – Research Report* (2015).

Harrison, E, "The Future Will Be Open': Open Government Data and Recordkeeping in NHS England', MA thesis, University College London (2015).

Harrison E, Shepherd E, and Flinn A, 'Research Report into Open Government Data in NHS England', *InterPARES Trust Research Project EU19 – Research Report* (2015).

McDonald, J, 'Open Data and Open Government: Implications for the Management of Records', InterPARES Trust Project – Trust and Digital Records in an increasingly Networked Society: Digital Information Governance meeting presentation (2014).

McDonald, J, 'Open Data and Records Management', *International Records*Management Trust – presentation (2011).

Page, J, 'The Role of the Records Manager in an Open Government Environment in the UK', MA thesis, University College London (2014).

Page J, Flinn A and Shepherd E, 'The Role of the Records Manager in an Open Government Environment in the UK', InterPARES Trust Research Project EU03 – Research Report (2014).

Thomas, H, 'What challenges does the current legislative, regulatory and organisation context within the NHS pose for Records Management?', MA thesis, University College London (2013).

Policies, Reports and Documentation

Care Quality Commission, Safe data, safe care: Report into how data is safely and securely managed in the NHS (2016), at

http://www.cqc.org.uk/sites/default/files/20160701%20Data%20security%20review%20FINAL%20for%20web.pdf. Accessed 15 August 2016.

Department of Health, Information – to share or not to share: The Information Governance Review (March 2013), at

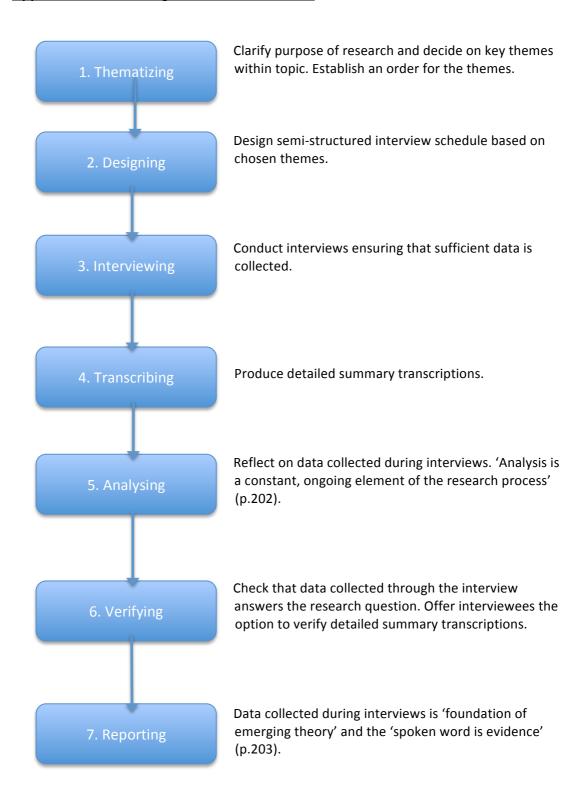
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/1
92572/2900774_InfoGovernance_accv2.pdf>. Accessed 28 June 2016.

Hospital Trust in the South East of England, *Annual Report 2014-2015* (2015). Accessed online.

NHS, Records Management: NHS Code of Practice (2006), at https://www.gov.uk/government/publications/records-management-nhs-code-of-practice. Accessed 10 May 2016.

Appendices

Appendix A: Seven Stage Interview Process²¹⁴

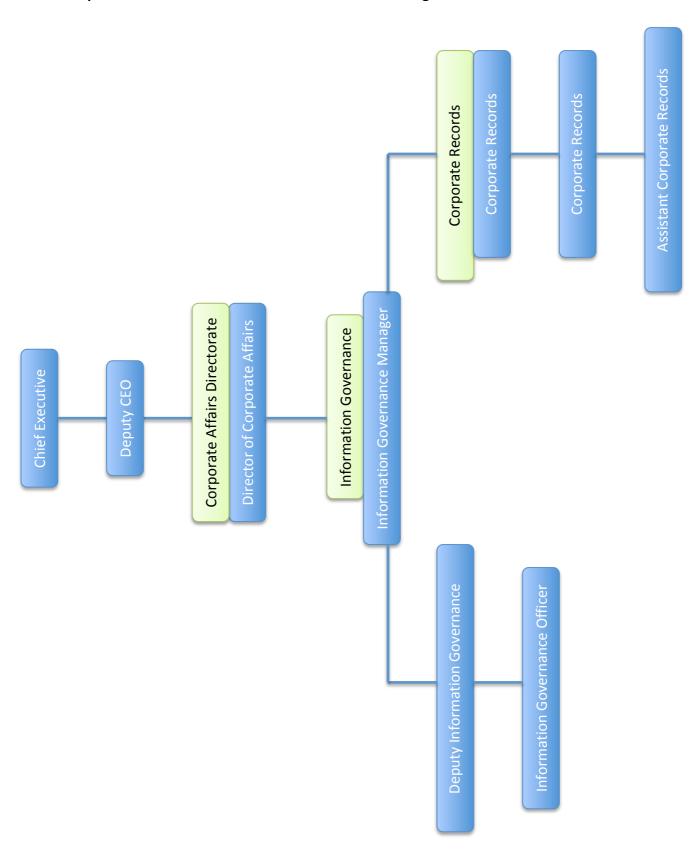


-

²¹⁴ Diagram created using the 'seven stages of the interview process' outlined by Pickard in A J Pickard, *Research Methods in Information* (London, 2013), pp.196-203.

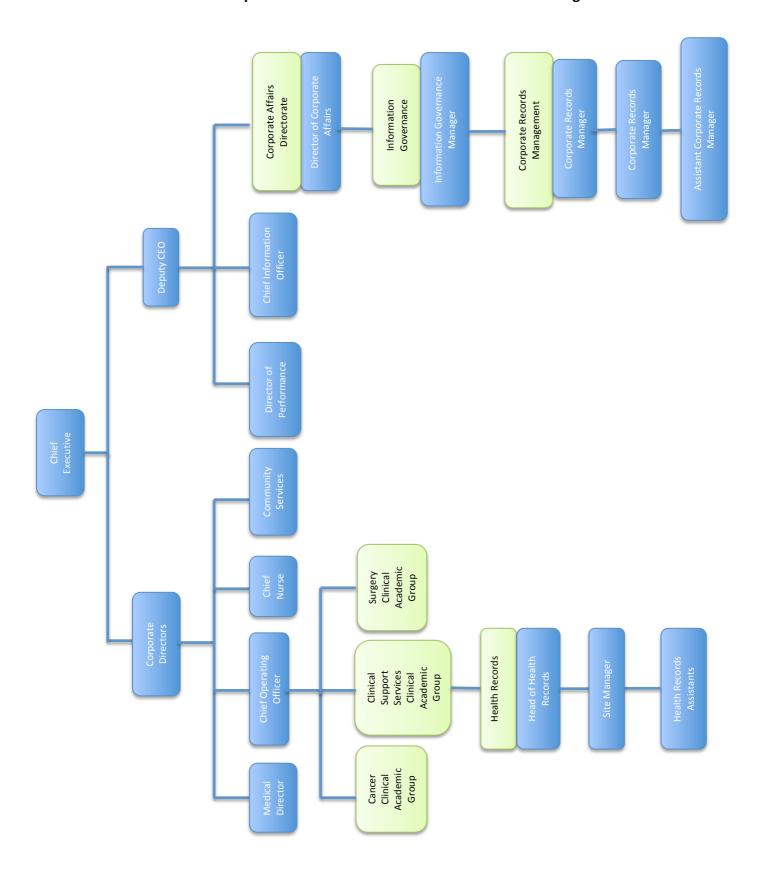
Appendix B: Structure Charts

Author's representation of the Information Governance and Records Management Departments at the NHS Trust in the South East of England



Author's representation of the Health Records Department at the NHS Trust in the **South East of England** Community Services Surgery Clinical Academic **Chief Nurse** Group Chief Executive Corporate Health Records Assistants Clinical Support Services Clinical Academic Group Head of Health Records Chief Operating Officer Health Records Site Manager Cancer Clinical Academic **Medical Director** Group 69

Author's representation of the Information Governance Department in relation to the Health Records department at the NHS Trust in the South East of England



Appendix C: Informed Consent Form

Informed Consent Form

Department of Information Studies, University College London

Project Title: The challenges of an Open Government environment facing public sector Records Managers in the UK: A case study of a National Health Service Hospital Trust

Researcher: Katherine Chorley, katherine.chorley.15@ucl.ac.uk

Thank you for agreeing to participate in the above research project, which is being carried out as part of the multinational *InterPARES Trust Project* (https://interparestrust.org/). The central aim of the project is to examine the role of the Records Manager within the NHS and the extent to which this is changing in the new context of an Open Government environment.

As a participant you have agreed to take part in a short interview covering your professional and practical experiences of operating Information Governance, privacy and Open Government policies within the NHS, as well as your outlook on how this might change in the future. I will be using your answers to build a case study of current practice in an anonymised NHS Trust, with the intention of identifying how the role of the recordkeeper is changing in the new context of open government data and the proactive release of public sector information.

Certificate of consent for interview respondents 30 June 2016 – 6 July 2016

- I agree that I will be interviewed for the purposes of data collection in this project.
- I understand that my participation will be audio-recorded and that detailed summary transcriptions will be made and I consent to use of this material as part of the project.
- I understand that I can request a copy of the detailed summary transcriptions and I can correct the detailed summary transcriptions if necessary. Please indicate here and provide contact details if you would like to receive copies of the detailed summary transcriptions......
- I agree that the data collected can be used in any reports and other outputs from the research project and the researcher's MA thesis, to be submitted to University College London (UCL). I understand that the research is part of the multinational *InterPARES Trust Project* and the results may be published in, for example, the form of a journal article, and that the text may be made available by UCL in its digital repository or in print.
- I understand that respondents will not be individually named but will be referred to by their job title in the above outputs. If you wish to be further anonymised please indicate here
- The data will be collected and stored in accordance with the *Data Protection Act 1998*. It will be retained for the duration of the project and for a period of up to 5 years afterwards in order to allow for the re-examination of the data by the researcher or her supervisors or examiners, and for further publications.
- I understand that participation is voluntary.

Please contact my research supervisors, Dr Andrew Flinn (<u>a.flinn@ucl.ac.uk</u>) and Dr Elizabeth Shepherd
(e.shepherd@ucl.ac.uk), at the Department of Information Studies, UCL, if you have any questions or concerns

e.shepherd@ucl.ac.uk), at the Department of Information Studies, UCL, if you have any questions or concerns.			
Job title:			
Date:			

Appendix D – Interview Schedules

<u>Interview Schedule One</u> <u>Information Governance Manager – Case Study NHS Hospital Trust</u> Thursday 30 June 2016

Thank you for taking part in this research. The central aim of the project is to examine the role of the Records Manager within the NHS and the extent to which this is changing in the new context of an Open Government environment.

1. Role, Responsibilities and Context

- 1.1 What are your main responsibilities in your role as Information Governance Manager?
- 1.2 Please can you give an overview of your current role and briefly explain your professional background and qualifications?
- 1.3 I understand that your Trust does not proactively publish data other than that specified in the publication scheme and requested under the FOIA. With this in mind, would you say that the 'open' initiatives influence your current role in any way?
- 1.4 Do you feel any pressures from either within, or outside of, the trust with regards to open government and open data?

2. Policies

Information Governance

- 2.1 What are the main policies and guidance documents supporting you in your work in Information Governance?
- 2.2 Would you say that these documents support you and staff in the Trust effectively in ensuring that information created, captured and managed is authentic, reliable and trustworthy and not in breach of sensitivity requirements?
- 2.3 The publication scheme of your Trust outlines what information is publically available. How was it decided what would be included in this and who is the intended audience for this information?
- 2.4 Do you think the existing publication scheme would form the basis for open government policy documents?

Open Government

2.5 Do the policies that you have mentioned reflect the open government data and transparency agendas within NHS England?

- 2.6 Are there any additional internal requirements that you know of relating to the proactive publishing of data anywhere within the trust?
- 2.7 The Open Government Data initiative is not currently underpinned by any legislation. If this changed, where within the trust would responsibility for ensuring compliance lie?
- 2.8 The NHS Records Management Code of Practice is supported by the Information Governance Toolkit – do you think it would be necessary for NHS England to create similar resources to support the proactive publication of open data?
- 2.9 Within your Trust, who would be responsible for the creation of guidance materials for professionals detailing how to manage open government data within the trust?

3. Practice

Information Governance

- 3.1 Do you think, or would you say, that the experience of Records Management and Information Governance in this Trust is typical of the NHS more generally?
- 3.2 Could you explain a bit about the Information Governance strategy within the Trust?
- 3.3 How do you think the future of Information Governance will look within the Trust? In particular how do you think it will be affected by the 'open' initiatives?

Additional questions for health records

- 3.4 How are sensitive records managed? What are the main differences between the management of health and corporate records?
- 3.5 Do you think the management of sensitive and personal records will alter in an Open Government environment?
- 3.6 Do you see Open Government and Open Data as a privacy threat, particularly in terms of health records?
- 3.7 A number of articles in the media have suggested that the public availability of health data, such as patterns of usage of medication, is important for research that can be used to improve patient care and save the NHS money. Would you agree with this and why/why not?

Open Government

3.8 Can you comment on why the trust would or would not want to proactively publish datasets?

- 3.9 What do you see as the main challenges for you and your team in proactively publishing data?
- 3.10 Do you see the management of open government data as the responsibility of an existing department or professional, or do you think it will require the creation of new roles?
- 3.11 Who do you think the intended audience of this initiative will be?
- 3.12 Who would decide what data is published, and how would they do this?

4. Future and Professional Outlook

- 4.1 Is the proactive publishing of data something that you feel the trust is prepared to do if it were to be legislated in the coming years?
- 4.2 Do you think that approaches to open government across the NHS will amount to a collaborative response or will each trust work separately?
- 4.3 Open Government data can serve many purposes, such as social accountability, increasing citizen engagement and encouraging innovation and economic development. What do you think the rationale will be for the open government initiative in this Trust? And how do you think the benefits of open government will translate in the trust?
- 4.4 How do you see your role and responsibilities, and those of your department, changing in the context of open government and open data?
- 4.5 Do you think that recordkeepers need any additional skills to work in and manage an open government environment, for example, an increased technical knowledge to manage datasets and dissemination portals?
- 4.6 And lastly, what would you like to see in the future, in terms of open government, in the NHS?

Thank you very much for your time today.

Interview Schedule Two

Corporate Records Manager and Assistant Corporate Records Manager – Case Study

NHS Hospital Trust

Wada and as G. Island 2016

Wednesday 6 July 2016

Thank you for taking part in this research. The central aim of the project is to examine the role of the Records Manager within the NHS and the extent to which this is changing in the new context of an Open Government environment.

1. Role, Responsibilities and Context

- 1.1 What are your main responsibilities in your role as Corporate Records Manager?
- 1.2 Please can you give an overview of your current role and briefly explain your professional background and qualifications?
- 1.3 Given that this Trust does not proactively publish data other than that specified in the publication scheme and requested under the Freedom of Information Act, would you say that the 'open' initiatives influence your current role in any way?
- 1.4 Do you feel any pressures from either within, or outside of, the trust with regards to Open Government and Open Data?

2. Policies

Records Management and Freedom of Information

- 2.1 What are the main policies and guidance documents supporting your work in RM and FOI?
- 2.2 Would you say that these documents support you and staff in the Trust effectively in ensuring that information created, captured and managed is authentic, reliable and trustworthy and not in breach of sensitivity requirements?
- 2.3 The publication scheme of your Trust outlines what information is publically available. How was it decided what would be included in this and who is the intended audience for this information?
- 2.4 Do you think the existing publication scheme would form the basis for open government policy documents? Is there other information that could be opened other than that specified in the publication scheme?

Open government

2.5 Do the policies that you have mentioned reflect the open government data and transparency agendas within NHS England?

- 2.6 The Open Government Data initiative is not currently underpinned by any legislation. If this changed, where within the Trust would responsibility for ensuring compliance lie?
- 2.7 The NHS Records Management Code of Practice is supported by the Information Governance Toolkit – do you think it would be necessary for NHS England to create similar resources to support the proactive publication of Open Data?
- 2.8 Within your Trust, who would be responsible for the creation of guidance materials for professionals detailing how to manage open government data within the trust?

3. Practice

Records Management and Freedom of Information

- 3.1 Is there a standardised process for creating and applying metadata to records created within the Trust? If so, what descriptive/metadata standards are currently used? Are these processes different for different kinds of records, for example, health or patient records?
- 3.2 Do you think, or would you say, that the experience of Records Management and information governance in this Trust is typical of the NHS more generally?
- 3.3 How many FOI requests do you get each month?
- 3.4 Do you think public awareness of the open initiatives has impacted on the number of Freedom of Information requests received? Can you see this changing in a legislated open government data environment, if so, how?
- 3.5 The Trust Annual Report gives an overview of the most frequent themes for Freedom of Information requests. Could you explain the process of logging these requests? Is this data used for anything else, for example, informing the development of the publication scheme?

Additional questions about Health Records

- 3.6 What are the main differences between the management of health and corporate records?
- 3.7 Do you think the management of sensitive and personal records will alter in an open government environment?
- 3.8 Do you see open government and Open Data as a privacy threat, particularly in terms of health records?
- 3.9 A number of articles in the media have suggested that the public availability of health data is important for research that can be used to improve patient care and save the NHS money. Would you agree with this and why/why not?

Open Government

- 3.10Can you comment on why the Trust would or would not want to proactively publish datasets?
- 3.11What do you see as the main challenges for you and your team in proactively publishing data?
- 3.12Do you see the management of Open Government data as the responsibility of an existing or professional, or do you think it will require the creation of new roles?
- 3.13 Who do you think the intended audience of this initiative will be?
- 3.14Who would decide what data is published, and how would they do this?

4. Future and Professional Outlook

- 4.1 Is the proactive publishing of data something that you feel the Trust is prepared to do if it were to be legislated in the coming years?
- 4.2 Do you think that approaches to Open Government across the NHS will amount to a collaborative response or will each trust work separately?
- 4.3 Open Government data can serve many purposes, such as social accountability, increasing citizen engagement and encouraging innovation and economic development. What do you think the rationale will be for the Open Government initiative in this Trust? And how do you think the benefits of Open Government will translate in the trust?
- 4.4 How do you see your role and responsibilities, and those of your department, changing in the context of open government and open data?
- 4.5 Do you think that recordkeepers need any additional skills to work in and manage an Open Government environment, for example, an increased technical knowledge to manage datasets and dissemination portals?
- 4.6 What would you like to see in the future, in terms of open government, in the NHS?

Thank you very much for your time today.

Appendix E – Detailed Summary Transcriptions of Interviews

<u>Interview One – Detailed Summary Transcription</u>
<u>Information Governance Manager – NHS Trust in the South East of England</u>
Thursday 30 June 2016

Time	Question	Summary	Keywords
00:33	1.1	IG team works over whole of the trust to answer	Role;
		any requests or queries 'around IG in general'	responsibilities
		from both staff and the public. Responsible for	
		providing training and guidance for staff to 'make	
		sure staff know what their responsibilities are' in	
		terms of legislation affecting IG. Responsible for	
		overseeing implementation of systems which	
		process personal or confidential information.	
		Work closely with the Caldicott Guardian and the	
		information security side of ICT. Deals with 'IG	
		related incidents' – including cyber security, data	
		breaches and missing files etc. IG Manager also	
		line manages the Corporate Records team.	
02:40	1.2	Became a Data Quality Manager c.2002. Worked	Professional
		on Data Accreditation – Standards to measure	background;
		how data was being managed within the Trust. IG	qualifications
		Toolkit replaced Data Accreditation and IG	
		Manager appointed. IG workers tend to come	
		from different backgrounds – 'there are those	
		like me who come from the health records/data	
		quality side, and then there are those who come	
		from the ICT sideyou can tell the difference	
		because those from the IT side are more into the	
		IT security side than perhaps we are.' Has done	
		DP course and OU module in Information	
		Security.	
06:38	1.3	With regards to current proactive publication 'at	Publication
		the moment all we do is what's on the	scheme
		publication scheme.'	
06:54	1.4	'It does to an extent' particularly with regards to	Concerns;
		research in the R&D part of the trust. 'it's just	challenges;
		trying to work out what can be published, what	practicalities;
		can be asked for, so we are starting to get more	users
		requests now for anonymised data from	
		researchers who now know what they can do.'	
		Internally, requests for data have also increased –	
		'we know the data's on our system – how can we	
		access it for research?so at the moment it's	
		more from an internal point of view than	
		external.' 'it's obviously something that as a trust	
		we do need to sit down and consider, but at the	
		moment there are more pressing things.' The	
		trust is also awaiting the publication of the third	
		Caldicott Review – 'so again, depending on what	

	1		Γ
		that says, because there is a likelihood that that will say, yes you've got to start to publish all this data, then of course we will start to do it, but until thenand then it's a case of whether it's of any benefit. It's fine for people to say this, but we've still got to find people to actually do the work, and obviously if it's going to be public we've got to make sure there's no personal identifiable information there, so someone has to check it, and then, you know, if we did make a mistake we'd probably get fined by the ICO, so it's not just a case of 'yes we've got it on the systems' and then just click a button and it suddenly appears on the websitewe do have to do things.' Resources, in both manpower and monetary terms seen as a barrier to the proactive publication of data: 'the way the NHS is at the moment, and we're not obviously the only public authority that's suffering – the money's not there, the resource is not there, we're all doing more for less, and it's getting that balance right. We have got far more pressing priorities than releasing data for third parties to make money out of. And that is the realitywhatever the government might be saying about Open Government, that is what will happenthe general public aren't interestedit will be students doing dissertationsor it'll be third parties who want to use it to make money. And is that a good use of our time? But obviously we do what the government will tell us.'	
10:53	2.1	The main one is the DPA - new EU Directive will have an impact, but in light of the UK EU Referendum, it is uncertain how long for, under the new directive 'there will be emphasis on getting consent and not relying on complicit consent as we do at the moment'. Other changes are expected in the Third Calidcott report around information sharing. Internal trust policies come out of the DPA and are based on guidance from NHS England, the Information Governance Alliance, the IG Toolkit, ISO27001: Information Governance Policy Freedom of Information Policy Pata Protection Policy Records Management Policy (retention/destruction) Confidentiality Code of Conduct Healthcare Records Policy Information Security Policy Broadly, yes, the documents do support the	Policies; guidance; IG; Data Protection Act 1998; NHS RM Code of Practice
		i broadiv, ves, the documents do support the	rolicies; training

		,	<u></u>
		creation, capture and management of authentic,	
		reliable and trustworthy data within the trust but	
		it is also the responsibility of managers to ensure	
		that policies are adhered to – 'managers do come	
		to ussaying 'I need to do this, where's the	
		guidance in the policies', so people are aware of	
		it and they do use it as reference.' 'As a trust we	
		inform staff that the policies are out there but we	
		don't have any system in place, like some	
		organisations do, where you actually sign that	
		you've read them, basically you just sign in your	
		contract that you will abide and you will read the	
		policies, then it's down to you.' The IG team do	
		training across the trust which emphasises how	
		the policies can be used. Regarding the number	
		of policies, 'you could probably argue that we	
		might have too many'. It would be possible to	
		condense some smaller policies into a larger	
		document, but this would take time and is not	
		currently seen as a priority.	
15:56	2.3	The publication scheme follows guidance issued	Publication
		by ICO and has been mainly coordinated within	scheme; ICO
		the Corporate Records Management Team, with	
		input from IG Manager. Also went to Director of	
		Corporate Affairs. The scheme is updated to	
		reflect any changes made to ICO guidance. 'To be	
		honest with you, we do what we have to do, we	
		don't put on anything more than we have to put	
		on, but I know Corporate Records have spoken to	
		one or two of the teams who provide data to say	
		'it might be beneficial if you put it on – it might	
		cut down on some of your requests', but the	
		issue, and this is my personal opinion, obviously	
		not the Trust's opinion, just my personal opinion,	
		but I do consider the Publication Scheme to be a	
		complete waste of time. No one reads it, we're	
		expected to put it on, as far as I'm concerned It	
		should be one or the other – we should be told	
		by the Department of Health 'this is the data we	
		expect you to put on there, put it on, and then	
		get rid of the Publication Scheme and also get	
		tougher with FOIsit's too bureaucratic, it's not a	
		good use of our resource, and my personal	
		viewI see it as a complete waste of time and it	
		should be scrapped.'	
19:23	2.5	Internal policies are updated to reflect changes in	Policies; NHS
		national NHS agendas and policies – 'the	agenda
		guidance is that with our policies we tend to	
		review them every three years, unless obviously	
		there are other changes, major changes.'	
		Openness agendas affect different policies in	

	ı		
21:22	26.240	different ways. IG Manager is part of Trust Policy Committee, which is a helpful position to hold, 'it does actually help to find out about some things that are going on that you may not even have realised, so yes, it's beneficial. It also does help with some of the openness etc., people actually know, yes we do have to release that, or no we don't actually have to.'	Doon on silviliteis s
21:22	2.6, 3.10, 4.4	It is expected that Information Governance, within the Corporate Affairs directorate, would take responsibility for open government – 'I would see it coming to Corporate Affairs and the stuff that's around releasing data, IG and FOI would come our [IG's] way, but some of the stuff probably more about the policies, about how the trust runs itself would probably sit with the Trust Secretary. But because we're in the same department I think we would be working closely together.'	Responsibilities
23:20	2.7, 2.8, 4.4	The current financial position of the NHS means that the creation of new resources is very unlikely to happen – 'the answer is yes, there would be a need, but we wouldn't get it.' It is expected that staff would add any extra work generated by open government to their workloads 'and then just do it as we go along.' It is not expected that more staff would be taken on to deal with the increased responsibilities and workload of the department in an open government environment— 'I suppose at a push, as has happened in the past, maybe get a contractor in, to maybe do two or three months to get you into the position that you're meant to be in, but I would imagine it would be expected that a lot of it would be left for Corporate Records to deal with, and the Trust secretary.'	Guidance; challenges; responsibilities; staffing
24:49	3.1	The Corporate Records side is not considered to be typical of an NHS Trust as not many Trusts have Corporate Records Managers and Corporate Records Management Teams. Elsewhere, Corporate Records tend to be dealt with by either IG or the Trust Secretary, but 'as far as the Healthcare Records side goes, yes.' The problems of storing records is being approached in different ways by different Trusts — a mixture of scanning and offsite storage with 'the idea [being] to go as paperless as possiblewe're mainly using offsite storage, there is some scanning going on and there is a discussion about whether to do scanning of our main healthcare records.'	Responsibilities; staffing; records storage

	ı		
29:24	3.2, 3.3	'To sum up IG and what we try to do in just a few words, I assume it would be to ensure that we handle personal identifiable information securely and efficiently.' There is an IG committee that meets every two months and the IG Manager has an annual work plan of what the department wants to achieve each year but there is no formal 'strategy' – 'I don't think there needs to be, I think most strategies tend to be bureaucraticobviously you have to have a long term plan about where you want to get to, but I think doing work plans and adjusting them each year, that is a much better way of doing it. And particularly with IG things change so quickly what we're asked to do, I just think a strategy doesn't really help.'	Information Governance; strategy
32:31	3.4	Teams are in place on all the main sites of the Trust to assist with the management of health records. The participant made distinctions between active and inactive records – 'health care records is much more about active records as well as archive records, whereas corporate records is about archiving.' Information Governance offers advice to staff about 'how they should be looking after their records, retention periods and those sorts of things.'	Health records; records life-cycle
35:37	3.6, 3.7	As more records are electronic it is possible that Open Government and Open Data could be considered a privacy threat – 'we do have this clash where one person is saying 'yes that is to be totally anonymised data' and someone else says 'well actually if I have this field and that field I can match it up". In some cases, such as with rare diseases, it is possible to work out who data refers to even if individuals are not named in the records – 'there are big concerns about that. The question with open data is how is it going to be published. When we say it's going to be 'open', does that mean it's just going to be for those researchers who are asking for it and they do their reports around it, or are we actually saying yes, this is open data that we're going to stick onto our website that anyone can come onto and have a look at. That obviously worries me much more. If you're using dates, sites, gender, ethnicity, which of course is personal data, people can start to work it out who you are. Depending on what data goes alongside that, it might not be an issue.' There is also a concern that insurance companies and employers might use open data in the wrong ways – 'my	Security; Data Protection; Data Protection Act 1998; risks; trust; research; definitions; care.data

		understanding is that with openness it is about	
		bulk openness, not about individual records, but	
		there is still that concern.'	
		Particularly in terms of patient records, there are	
		concerns over what information gets out to the	
		public, 'once it's out there, it's out there. It is	
		about responsibility as well.' Many issues about	
		patient access and rights over records exist.	
		'Going back to the data itself, my personal	
		opinion is that I have no problem with it being	
		shared for research, but I do have concerns about	
		where it will go, and I do know that HSCIC did	
		obviously send data on to people that they	
		shouldn't have been, it's about having those	
		safeguards in place, and it's about getting the	
		trust of the public. With bodies like the HSCIC	
		losing that trust that does have a knock on effect	
		to us. We do have people saying 'I want you to	
		remove my data', but we can't, it's on the	
		electronic record, it has to stay. The trust has	
		been lost, and we've got to regain that. Obviously	
		with the care.data stuff that was just a mess.'	
45:14	4.3, 3.9	It is felt that the proactive publishing of data	Challenges; citizen
45.14	4.5, 5.5	could have social benefits – 'particularly with the	engagement;
		sort of population we serve, a lot of work could	benefits; data
		be done, but maybe by letting that data out to	sharing; trust
		other people could be of benefit.'	Silaring, trust
		With regards to disparities in wealth and	
		mixtures of ethnicity which exist within the	
		communities the Trust serves, the participant is	
		of the opinion that work could be done to	
		improve services, to find out 'who are the people	
		using our services, if they're not then why aren't	
		they using it, are we getting the public health	
		messages out there, are we understanding the cultures properly.' Open Data 'would be of great	
		benefit' to research. 'I <i>do</i> think that's the one	
		thing they really should be pushing is the research, not just about finding cures, but also	
		about preventionmaybe with using this data,	
		particularly with maybe third parties using it,	
		they might have access to software or experience	
		that we don't have access to.' Open Data would	
		allow for multiple points of view to be taken from	
		different organisations, the NHS has one point of	
		view, 'ours is obviously mainly about curing or	
		doing what we can for the patient, but there are	
		other things around prevention etc. that maybe	
		other people would be looking at, maybe the	
		social cultural side that they're more interested	
		in than perhaps we are, or have got time to be.'	

		The participant sees the benefits of Open	
		Government and open data but is also aware of	
		the difficulties presented by it – 'there are all	
		those benefits and I just think that they need to	
		be pushed, particularly with care.data, the	
		argument was lost quite early on. The Daily Mail	
		and the Guardian in particular were pushing	
		about this being bad and about consent and I	
		don't think the NHS in particular stood up to that	
		in the way it should have done. My personal	
		opinion is, particularly for the research, we	
		should be doing it, we have got this data, these	
		days we've got such a source of data and it being	
		electronic now, it is easier to analyse, it is easier	
		to do things with and to set up software	
		programmes etc. But because of the dangers of	
		the third parties and the way that HSCIC have	
		handled the data in the past we have lost that	
		trust and we have got to do a lot to regain it.'	
50:57	3.9, 4.2,	The lack of a dissemination portal is not seen as a	Freedom of
	4.4	great challenge – 'to me it is more about getting	Information;
		the message out there and about how to do it	Freedom of
		safely, getting the trust because in theory for	Information Act
		most of our data we have got the technology to	2000; challenges;
		publish that datain theory, anyone could put in	costs; technology;
		a Freedom of Information request and ask for a	research; trust;
		lot of this data. I think the resource is there, I	HSCIC; data
		think we do need to look at what the demand will	quality; accuracy;
		be, about whether we should go to something	users
		like a portal.' There are questions about where and how data would be published – 'when we	
		talk about portals, are we looking at local	
		portals? Or do we keep feeding our data into	
		HSCIC and then that's where everyone goes to.	
		That could be way forward, but people have got	
		issues with sending the data to HSCIC in the first	
		placeyou could argue that if you're getting the	
		data ready to send to the HSCIC can't we just	
		publish it and miss them out. The discussion	
		needs to be had. You do need to talk to the	
		researchers, to the third parties about what do	
		they want, what is beneficial? Is it beneficial for	
		us to do it locally or are we just wasting our time.	
		We're getting it ready for the HSCIC, it's more or	
		less ready, we would just need whatever the	
		technology is to get the portal, but again	
		obviously that would be a cost.' The participant	
		feels that there are a lot of unanswered	
		questions about the practicalities of publishing	
		data – 'I'm not particularly involved in that side of	
		things but you just get the feeling that there's not	

	I	T	
		really been the proper discussions about that,	
		that someone somewhere will just make up their	
		mind and that's what we'll get told to do. I do	
		think they should be looking at pilots, at working	
		with the researchers and the third partiesis it	
		that we just have portal for raw data, we just	
		stick raw data on then we leave it entirely down	
		to you to do your analysis, filtering etc. or do you	
		want filters already. It's all these sorts of things	
		that need to be discussed. The main thing is	
		making sure that it's properly anonymised. And	
		of course what's useful for researchers will be	
		different to probably what third parties need,	
		particularly if, for some of the public health stuff,	
		if you're trying to find trends you don't need as	
		much information perhaps as obviously the	
		researchers looking into specific cancer, for	
		example, because they definitely do need much	
		more detail.' There are also concerns about the	
		resources that proactive publishing would	
		consume – 'the resource implication needs to be	
		looked into. If we're going to be putting it out	
		there for free, like with the FOI etc. we still have	
		to do the work, we're all short staffed as it is. I'm	
		sure the politicians do just think it's the click of a	
		button, but it's not. Is it taking them away from	
		their own work, as a trust we've still got to	
		analyse our data, and then the other issue is of	
		course data quality itself, is it actually good	
		enough. There's the danger that yes, we're	
		publishing all this data but has it gone through	
		the right checks to make sure it's actually	
		accurateI'm not sure how that will work.'	
		Simply publishing the data is not the same as	
		being able to ensure that it is accurate, complete	
		and authentic. There is a feeling that there are	
		many unanswered questions – 'I don't think	
F7:30	4.5	there's been enough proper discussion about it.'	Hoolth reserve
57:30	4.5	IT skills are already assumed for everyday	Health records;
		working but the need for more specialist skills	skills; staffing
		'depends really how much we would be looking	
		at the electronic records, how much we'd be	
		going in there to do data quality and analysis.' For Corporate Records, 'how much more complicated	
		it would get, I'm not too sureit probably would	
		depend on the system you're using and the software, how much is automated, or how much	
		you have to write your own programmes.' The	
		participant felt that 'there would be less staff as	
		we go electronic. There'd be less time spent	
		trying to find records, there'd be a saving there. I	
	<u> </u>	trying to find records, there a be a saving there. I	

think like everything there will be more emphasis on electronic skillsthere definitely will be a change about how we do things, that's inevitable, but it's whether we get the point where we get rid of paper!'
--

Interview Two – Detailed Summary Transcription
Corporate Records Manager and Assistant Corporate Records Manager – NHS Trust in the
South East of England
Wednesday 6 July 2016

NB: At the request of the participants the Corporate Records Manager and the Assistant Corporate Records Manager were interviewed at the same time. Individual responses are identified using the following acronyms: CRM (Corporate Records Manager) and ACRM (Assistant Corporate Records Manager).

Time	Question	Summary	Keywords
00:40	1.1	CRM: Corporate Records is responsible for	Role;
		corporate and health records which fall outside	responsibilities
		of the core health records in both digital and hard	
		copy format, also responsible for Freedom of	
		Information on behalf of the Trust.	
		ACRM: No further comments.	
01:39	1.2	ACRM: Has held current position since November	Professional
		2012 upon qualifying from an Archives and	background;
		Records Management course. Wide range of	qualifications
		professional Records Management experience.	
		CRM: Has held current position since 2013.	
		Extensive experience in both a variety of Archive	
		and Records Management roles.	
04:13	1.3	CRM: 'I think probably not at the moment. I think	NHS agenda
		at this exact moment in time its not something	
		that the Trust is that interested in and I don't	
		think it has the capability to do it either at the	
		moment.'	
		ACRM: As a regular attendee at the NHS IG	
		Forum in London, the prominence of the 'open'	
		initiatives within the NHS more widely is	
		questioned – 'Open Government and Open Data	
		hasn't really been mentioned there either, so	
		how much it's on the NHS as a whole's agenda,	
		I'm not sure.'	
05:08	1.4	CRM: There is a move towards increased	Publishing
		publishing of information, but this is not	information;
		necessarily attributed to pressures of Open	definitions;
		Government – 'I think it's a case that we would	EDRMS
		probably see it or interpret it in another way	
		rather than strictly open government or open	
		data if you will. I think there is, as with archives, a	
		need now to publish an awful lot more of what	
		we hold on the internet - and that's true of us as	
		well.' The Corporate Records team is pursuing a	
		project around an EDRMS at the moment which it	
		is believed would make publishing large amounts	
		of material online much easier – 'the other side	
		of the problem for us is a technical one as well.'	
		ACRM: No further comments.	

06:18	Definitions of open government and open data	ACRM: Open Government and Open Data defined as 'getting information in the public domain because we are a public service.' Within Corporate Records there is an appetite for more proactive publishing of data — 'it would be good if the organisation was doing a bit more and publishing stuff proactively rather than us just responding to requests.' CRM: No further comments.	Definitions
06:57	2.1	 ACRM: Policies referred to: Trust Retention and Disposal Policy Information Governance Policy NHS Code of Practice on Records Management (under revision) Freedom of Information Policy Data Protection Policy ISO sector-specific standards Guidance from ICO website Both CRM and ACRM are active members of the recordkeeping community and are members of professional bodies such as the Archives and Records Association and the Information and Records	Policies; ICO; NHS RM Code of Practice; professional bodies; strategy
09:04	Impact of any future open government legislation on FOI	ACRM: Any Open Government legislation would sit alongside the FOIA – many of the FOI requests received ask for specific information, which might not be provided online. This is a feeling shared by others in the recordkeeping sector – 'I have heard other people in the profession talking about 'even if we publish more the requests we get will just get even more specific' because people look at the data that's on there and then they'll use FOI to get down even further into that information.' CRM: No further comments.	Freedom of Information Act 2000; Freedom of Information; legislation
10:11	2.2	CRM: There are guidelines and safeguards in place detailing how records are to be transferred to the records centre — 'there are certain safeguards in place to prevent the tampering of information and records once it comes to us.' ACRM: One of the main annual pieces of work for Corporate Records is a records audit, from which it is possible to identify departments that create a	Authenticity; reliability; security; training; Data Protection Act 1998; Data Protection

		lot of records - 'we would go and ask them about their recordkeeping and their information	
		their recordkeeping and their information	
	I		
		governance so that would be another safeguard	
		so that we can influence the way records are	
		created, ensuring that they are created in the	
		correct way and identify any problems.' Everyone	
		in the Trust must carry out mandatory training	
		every year in Information Governance to	
		maintain an awareness of the need to manage	
		confidential and sensitive information	
		responsibly. This is also emphasised in the	
		records audit, with departments being advised by	
		Corporate Records on the storage and security of	
		their information. Data Protection remains at the	
		forefront of employee's minds as they manage	
		records in their day-to-day roles - 'People are	
		quite responsive to the elements around	
		personal data because that's been drilled into	
		people ever since they've been in the NHS.'	
13:26	2.3	ACRM: The Publication Scheme is based on	Publication
		guidance published on the ICO's website. The	scheme;
		Corporate Records team then finds out where	classification
		that information is held within the organisation	scheme
		and lists it on the publication scheme.	
		CRM: In addition to this, the Corporate Records	
		team are working on a Business Classification	
		Scheme that will go online. It will 'set out which	
		parts of the organisation creates which types of	
		records, which isn't really the case now. So	
		people will be able to see the breadth of the	
		organisation, the types of records that are	
		created in each kind of areas etc.'	
14:48	2.4	CRM: 'The ICO view is that it wants to push the	ICO; Freedom of
		proactive publishing of information rather than	Information Act
		responding to it per se, so more emphasis on	<i>2000</i> ; Freedom
		actually actively publishing record series that are	of Information;
		routinely asked for, such as workforce data and	accountability;
		patient treatment data – these are the things	transparency
		that we deal an awful lot with under FOI but if we	
		got to the point where we could publish every six	
		months data sets covering certain areas then we	
		could legitimately say 'we're not going to deal	
		with your request because it will be published	
		already, or it will be available in no more than six	
		months time etc.'	
		'There is probably quite a lot that should be	
		thought of for being published' – examples given	
		include meeting agendas and minutes which are	
		public records but which aren't all currently	
	1	1 '	
		published. 'I think in terms of accountability and	
		personal data because that's been drilled into people ever since they've been in the NHS.' ACRM: The Publication Scheme is based on guidance published on the ICO's website. The Corporate Records team then finds out where that information is held within the organisation and lists it on the publication scheme. CRM: In addition to this, the Corporate Records team are working on a Business Classification Scheme that will go online. It will 'set out which parts of the organisation creates which types of records, which isn't really the case now. So people will be able to see the breadth of the organisation, the types of records that are created in each kind of areas etc.' CRM: 'The ICO view is that it wants to push the proactive publishing of information rather than responding to it per se, so more emphasis on actually actively publishing record series that are routinely asked for, such as workforce data and patient treatment data – these are the things that we deal an awful lot with under FOI but if we got to the point where we could publish every six months data sets covering certain areas then we could legitimately say 'we're not going to deal with your request because it will be published already, or it will be available in no more than six months time etc.' 'There is probably quite a lot that should be thought of for being published' – examples given include meeting agendas and minutes which are public records but which aren't all currently	ICO; Freedom Information of Information accountability

- 1			
		series of records which could be deemed to be of	
		interest, such as patient leaflets, policies of the	
		organisation etc., a lot more could be made	
		available than what is currently done at the	
		moment.'	
		ACRM: No further comments.	
17:34	2.5	CRM: The impression is that 'the culture is more	NHS culture;
		around publishing as little as possible'. This is	technicalities;
		expected to the similar across the NHS – 'I think	transparency
		that's partly around the culture, part of it's	
		probably around a lack of awareness and also	
		partly around, I suspect, the technical capability.	
		Very few Trusts are actually going to employ	
		either records managers potentially, or IG people	
		who would actually push the concept of	
		transparency being around the publishing of	
		record series etc.'	
		ACRM: No further comments.	
18:43	2.6, 3.12	ACRM: Corporate Affairs, the same directorate	Role;
		that Information Governance (and therefore	responsibilities;
		Corporate Records) would most likely take	staffing
		responsibility for open government – 'Whether it	
		would sit within Information Governance or	
		within Communications I'm not sure but ideally I	
		think it would be better placed within a similar	
		sort of remit to where FOI is.'	
		The creation of new roles is not seen as	
		necessary, instead 'what would be needed would	
		be to have a higher level of support to drive it	
		through.'	
		CRM: No further comments.	
20:05	2.7	CRM: 'I think they're trying to use the toolkit to	IG Toolkit;
		drive changes in the NHS's approach to the	guidance;
		handling of information. I think that the intention	support; policies
		is that The National Archives will have something	
		in future toolkits around the review of records'	
		whereby to reach a certain 'level' you would have	
		to undertake a review of all records which were	
		of a certain age. If data had to be opened in order	
		to reach a certain level, that would assist in	
		driving the 'open' initiatives forwards.'	
		ACRM: With regards to written policy or guidance	
		documents, 'there would be a requirement for	
		something more formal, that would probably be	
		Language the transfer of the second s	
		something that we could produce.'	
		CRM: There would be a need for formal policy	
		CRM: There would be a need for formal policy documents to ensure compliance – 'there were	
		CRM: There would be a need for formal policy documents to ensure compliance – 'there were have to be some stipulation exactly what the	
		CRM: There would be a need for formal policy documents to ensure compliance – 'there were	
		CRM: There would be a need for formal policy documents to ensure compliance – 'there were have to be some stipulation exactly what the	

		committee that the Trust has, 'we want their	
		agenda minutes, policies and patient literature	
		published online' then that would be perhaps a	
		good place to start and say that 'this is the	
		minimum'.	
23:03	2.8	ACRM: Guidance materials would be produced by	Freedom of
		the Corporate Records team -' it's quite similar	Information Act
		to Freedom of Information and we've got the	<i>2000</i> ; Freedom
		expertise in our directorate.'	of Information;
		CRM: 'We have editing rights to the website at	web publishing
		the moment to publish on there, so it would be	,
		kind of an extension of that.'	
23:50	4.4	ACRM: The challenge of implementing open	Role;
		government across the Trust is seen to be greater	responsibilities
		than that of dealing with it on a day-to-day basis.	responsibilities
		CRM: No further comments.	
24:32	3.1	CRM: There are no formal metadata standards	Metadata;
27.32	J.1	within the Trust. For electronic records available	EDRMS; health
		metadata is that generated and captured by	records
		computer programmes. Further information is	records
		captured on the transfer forms that accompany	
		records from creator to the records centre and	
		includes 'who is doing the transferring and where	
		do they come from within the organisation and	
		the surrounding information which we input onto	
		a database to manage those records.'	
		ARCM: The implementation of an EDRMS would	
		increase the amount and consistency of	
		metadata held for electronic records.	
		CRM: Regarding the management of health and	
		corporate records, 'we don't treat them any	
		differently, the processes are the same. But we	
		might apply different parameters for example,	
		treatment records, if they were going to be	
		requested more frequently then we'd need more	
		information on the contents than generalised	
		information so that we can find them a lot more	
		easily.'	
27:58	3.2	ACRM: The experience of the case study Trust is	Staffing
		not seen to be typical, not least in terms of	
		staffing – 'I don't think there are many archivists	
		and records managers that are employed across	
		the NHS.'	
		CRM: No further comments.	
28:28	3.3	CRM: The team receive around 75 FOI requests	Freedom of
		per month. 'It used to be more like 50 per month,	Information Act
		but there has been quite a big upswing this year,	2000
		we're probably talking a change from about 700	
		last year to about 800 this year.	
		ACRM: No further comments.	
30:04	3.4		Freedom of
5U:U4	3.4	CRM: An increase in FOI requests attributed to	Freedom of

			T
		the media – 'because the media have used Freedom of Information to uncover wrongdoing, such as MPs expenses and things, people realise that they do have quite a lot of ability to actually request information from organisations, be that Data Subject requests or Freedom of Information requests. There is quite a groundswell in the public wanting to know more about an organisation.' ACRM: No further comments.	Information Act 2000; Freedom of Information; transparency; accountability
31:18	3.5	ACRM: The process of logging FOI requests:	Freedom of
		 Request is acknowledged upon receipt using template responses. The request will then be allocated to the correct department who have ten days to respond. The CR team then check the information for any exemptions or Data Protection issues before a response is sent out. Often requests require authorisation from directors of departments for the information to be released. Response is sent out. CRM: 'The secondary uses [of the FOI request log] might be around the generation of reports, either for the Trust annual report or for departments, to tell them how many requests they've had, the nature of them and how quickly they were dealt with etc. But certainly we wouldn't envisage that information being used for other purposes within the organisation.' FOI requests influence the strategy – 'if we have a lot of requests about specific things then we should try and get datasets for those types of requests and then put them on the website so that's still work in progress at the moment, but we do use anonymised information from that to influence 	Information Act 2000
		how we should approach things in the future.'	
35:30	3.7	CRM: Questions around what constitutes a 'health record' can complicate their management — 'It's multi-layered to an extent - quite often we're asked to disclose information which can come close to that. There's also an issue around data subjects.' ACRM: No further comments.	Health records
37:20	3.8	ACRM: Dealing with any personal information requires following strict procedures, however, 'there is a drive towards being more open towards more data sharing, not necessarily to do with open government but there are more moves to see that Data Protection shouldn't be a barrier,	Data sharing; Data Protection Act 1998; Data Protection

		it's very important that you have all the procedures in place, but just the fact that the Data Protection Act exists in the first place shouldn't be seen as a barrier to information going out, so long as things are carefully checked and redacted as necessary.' CRM: No further comments.	
38:49	3.9	CRM: There are risks of data-sharing – 'I think there is an element of danger in some of this', such as who this information should be made available to – health professionals, insurance companies, employers – 'some of these are very potentially troublesome areas. It's obviously getting that balance right between what is an appropriate use and access to information and what isn't. So that's a whole big question that is out there at the moment.' ACRM: 'There's also the risk as well that even if information is anonymised whether it can be placed with other information to make it identifiable.'	Data sharing; risks
41:47	3.10	CRM: 'There is still probably a reluctance among quite a lot of the civil service to accept public scrutiny of the work that is done.' Local Authorities suspected to be further ahead in releasing information. An example is given of Registry of Interest Gifts and Hospitality, which did not used to be published by the NHS but are now. This is probably partly to do with the new ICO Publication Scheme which says 'you will publish these registers because we regard this as a transparency record.' You shouldn't just deal with it when you get a request, you should put it online, and if anyone asks you say it's there and that would be it really.' ACRM: No further comments.	Local government; Freedom of Information; transparency
44:55	3.11	CRM: The 'right' technology could allow for automatic processes for publishing data online and would allow for more productivity – 'of course that can't be the same for everything because you would need to check to see whether things can be published or need to be redacted. But obviously the technology is an important aspect. Given the quantity of records produced by the Trust, the task would be fairly significant.' ACRM: No further comments.	Technology; challenges
46:42	4.1	ACRM: 'If it was legislated then there would be a requirement to, we would have to do it.' CRM: No further comments.	Legislation
47:12	4.2, 4.4	ACRM: 'I imagine it would be like the FOIs which are dealt with on a trust by trust basis. An open	Freedom of Information Act

		government thing would be a bit different, if it	<i>2000</i> ; Freedom
		was stipulated what data needed to be published	of Information;
		and it was going to be hosted on our central website then that might be one way of	practicalities
		persuading people to do it.' CRM: No further comments.	
40.44	4.2		NAli-
48:14	4.3	ACRM: Having more open data about the Trust in	Media;
		the public eye would allow the public to see how	accountability; citizen
		concerns addressed in the media are being	
		addressed and 'it could help with accountability	engagement
		and demonstrate where things are improving or	
		perhaps not improving. Sometimes it might be	
		interesting to see numbers in comparisons as	
		well because there's a lot of press about the cost	
		of people from overseas using the NHS but if you	
		compare that to other things that the NHS is	
		spending its money on then perhaps it would be	
		framed in a different way.' On whether Open	
		Data would increase engagement – 'people already have other streams of being engaged	
		,	
		with the Trust. I think those things maybe have	
		more of an effect but I think open government would be more likely to have a positive effect	
		than not.'	
		CRM: No further comments.	
50:50	4.5		Guidance; skills;
30.30	4.5	ACRM: 'I think it's always helpful to have some sort of formal guide but a lot of the skills involved	EDRMS
		in open government are a lot of the same sort of	EDVIAIS
		skills needed for dealing with FOI requests.'	
		CRM: Computer skills, EDRMS and web publishing	
		skills emphasised. The team has computer	
		knowledge but this is not to be assumed across	
		the trust, 'there is some work that needs to be	
		done around that and as well as the use of	
		EDRMS systems too.'	
		ACRM: 'In regards to the principles, they are very	
		much in line with what we've been taught on the	
		[Archives and Records Management] course.'	
52:31	4.6	ACRM: Would like to see Open Government 'a bit	Challenges
52.51		higher on the agenda - but that would have to	5.14.1511863
		come from within the NHS itself rather than	
		within Information Governance. I think we're	
		limited with how much we can promote it as	
		records managers and archivists ourselves within	
		the organisation.'	
		CRM: Would like to see a clear outline of	
		requirements for open government 'so that there	
		isn't really any wriggle-room by the management	
		of the organisation to say 'we can just interpret it	
		as we like.' Then it is crystal clear for people	
		exactly what is expected of them to meet the	
		chacity what is expected of them to meet the	l

		requirements etc.'	
53:43	Are you worried by the idea of open	CRM: 'We're not worried but I expect the management are!' ACRM: 'As long as things are done properly with regards to Data Protection and as long as it's	Data Protection Act 1998; public engagement
	government ?	handled properly, I don't have a problem with the concept.' CRM: 'It would be safe to say that probably there is a difference of opinion over what we would regard as publishable and what the management would think but certainly the Trust has faced considerable scrutiny from both outside and within its sector, so stuff that has been published, or should we say unofficially published, has ended up in the newspapers for better or worse. The information has been used to identify areas which require attention but hadn't been noticed internally and it was only actually by someone writing a newspaper story that it was actually resolved which sounds bizarre but in many ways it was a very good example of the public engaging with records, and then obviously once it was highlighted action was taken to resolve it. Certainly it's an area which will only increase and be a requirement.'	

Appendix F - Survey Results and Analysis

Total number of survey responses: 12 (NB: Not all respondents answered all questions .The number of responses for each question is noted below)

1. Role, Responsibilities and Context

1.1 Profile of survey respondents: Place of work

Answer	Responses
Local Government	3
Educational Institution	2
Archive	1
NHS	2
Other	4
Total respondents: 12	

1.2 Profile of survey respondents: Main responsibilities at work (NB: Respondents were asked to select all that apply)

Answer	Responses
Corporate Records Management	6
Health Records Management	1
Dealing with Freedom of Information requests	4
Information Governance	7
Other*	8
Total respondents: 12	
Total comments: 7	

^{*}Respondents listed the following responsibilities under 'Other':

- Policies, standard operating procedures, risk register
- Data Protection requests and general historical research requests
- Cataloguing project involving medical records
- Archives and research data management
- Subject Access Requests under the Data Protection Act 1998
- Archives (x2)
- 1.3 Profile of survey respondents: Involvement in managing sensitive (personal or medical) records

Answer	Responses
Yes	12
No	0
Total respondents: 12	

1.3.1 Guidance: Currently available guidance and support for managing sensitive records effectively

Answer	Responses
Yes	7
No	2
I have some guidance	3
Total respondents: 12	

1.4 Open Government and Open Data: pressures from either within, or outside of, organisations

Answer	Responses
Yes	5
No	7
Total respondents: 12	

2. Open Government and Open Data – Policy and Practice

2.1 Open Government and Open Data: Existing proactive publication within organisations (NB: Respondents were asked to state where responsibility for Open Government and Open Data lies within their organisation, see below for responses)

Answer	Responses
Yes	6
No	2
Total respondents: 8	
Total comments: 6	

Respondents listed the following individuals and departments as being responsible for Open Government and Open Data:

- Information Governance team
- Freedom of Information and Communications Department
- Research Data Manager
- Corporate Governance Officer
- Information Security Officer
- Not held by anyone specifically
- 2.2 Guidance: Currently available guidance and support for managing Open Data (NB: Respondents were asked to provide details of any policies and/or guidance notes)

Answer	Responses
See comments below	N/A
Total respondents: 5	

Total comments: 5

Respondents listed the following guidance and support methods:

- Records Management Policy (x2)
- Information Governance training sessions
- Websites (internal and external)
- Information Governance Policy (x2)
- 2.3 Open Government and Open Data: Rationale for proactive publishing within respondent's organisations (NB: Respondents were asked to select all that apply)

Answer	Responses
Demonstrating transparency	4
Demonstrating accountability	3
Increasing trust	1
Increasing efficiency of services	1
Allowing simple and easy public access to data	4
Increasing public participation in your organisation	4
Other*	2
Total respondents: 6	
Total comments: 2	

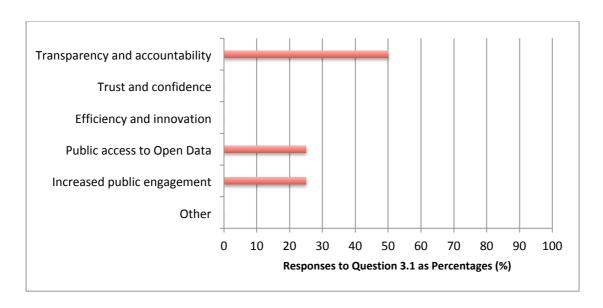
^{*}Respondents listed the following reasons under 'Other':

- Research funder requirements
- Education

3. Open Government and Open Data – Benefits and Barriers

3.1 Open Government and Open Data: Benefits (NB: Respondents were asked to select <u>one</u> answer)

Answer	Responses
The demonstration of the transparency and accountability of actions and	4
decisions taken and made by organisations	
Increased trust and confidence in organisations	0
Increased efficiency and enhanced innovation within organisations	0
The opportunity for public access to Open Data	2
The possibility of increased public engagement with data and participation	2
in public organisations	
Other	0
Total respondents: 8	
Total comments: 0	



3.2 Open Government and Open Data: Barriers (NB: Respondents were asked to select one answer)

Answer	Responses
Lack of knowledge and expertise in what to publish and how to do it	0
Lack of resources (including lack of a portal to disseminate Open Data)	3
Lack on any legislation mandating the publishing of data	0
Lack of information/accuracy of information suitable for publishing	0
Organisational fears about publishing data	5
Questions over whether/how published data will be used	0
Other	0
Total respondents: 8	
Total comments: 0	

