A Critical Analysis of the Guarantee Mechanism of the United Kingdom and Australian Health Sector on Open Data

Daka Steven and Prof. Gao Tianpeng

University of Electronic Science and Technology of China

Abstract: The Government is a custodian of large amounts of data, thus opening government data has various important benefits such as: ensuring there is efficiency and effectiveness in the public sector, innovation in service delivery, participatory governance, accountability and transparency. In particular, health open data benefits expand beyond the aforementioned significance's. It is critical in strengthening healthcare systems by connecting patients to providers, and providing essential data for health research.

That being the case, there has been a considerable body of research bordering on open data organisational readiness, implementation and maturity models to mention but a few. The 2014 and 2018 works by the World Wide Web Foundation and the New York University Government Governance Lab results in an open data common framework which highlights the three components that will help the success of public management in implementing open health data. The framework underpins that; Management, Legal and Leadership factors are paramount to the effective implementation of open health data. However, there is a paucity of research conducted to examine the concrete examples in two similar political entities to see the real state in the three fields above, for guaranteeing the open data implementation in the health sector.

Considering the gap in theoretical and practical knowledge of open health data guarantee mechanism, this study examines the United Kingdom and Australia, top ranked countries in open data implementation, and try to build a common knowledge framework for implementing open health data successfully. The 2014 and 2018 common framework is abstract and lacks the detailed practical success factors.

Based on literature analysis, the study first analyses the open data common framework to examine the real state in the three fields, namely, Management, Legal and Leadership aspects for the guarantee of open data implementation in health sector. Thereafter, the induction approach is utilized to explore the two cases and sum up the detailed knowledge to show the common practical knowledge and measures to shape an overall open data Guarantee Mechanism.

For both academics and practitioners, this thesis provides a practical and detailed common framework to implement open data. The common knowledge framework proposed in this thesis emerged from a comparative analysis of the practical evidence from the two high ranked countries in open health data implementation. Additionally, there is no common framework that has been suggested so far that is grounded by empirical research; this is one of the cornerstone achievement of this study. The deductive analysis of the qualitative data revealed the similarities between the two countries.

Keywords: Open health data, Management, Legal and Policy, Leadership, Health Sector

Chapter 1 Introduction

1.1 Background of the Study

The fundamental value of opening government data has far much reaching vital benefits such as; more efficient use of public resources, improved service delivery, participatory governance, accountability, transparency, innovation and economic growth. However, from the health sector perspective, open data can help strengthen healthcare systems by connecting patients to providers, improving governance by exposing and preventing mismanagement and corruption, provision of essential data to research work which may have high value on healthcare quality as well as cost. Open data is also a critical tool for fighting infectious diseases, combining clinic reports with social, demographic, geospatial and other data to predict and prevent outbreaks and track and combat diseases. This, in turn, does promote the well-being of the general citizenry by detecting epidemics in their early stages, compile diagnostics, analyze prescription drug use and improve access to medications at the right time and in the right place (Joel Gurin 2015)[1] cited by World Bank.

There has been much interest recently in the concept of open data and its relevance in the health sector. Research and speculation on open data adoption, data governance, and big data analytics are growing at a fast rate. In recent years the study of open data has focused on data quality measures and accessibility, guarantee mechanism, data governance as well as utilization models. Additionally, government open data has gained greater visibility and relevance in the attainment of the United Nations vision 2030 sustainable development goals across the globe.

United Nations (2016), [2] underpinned that government open data is key to policy integration and institutional collaboration in policy making, design as well as service delivery. Adding that, data are the lifeblood for decision making, fuel to innovation and the pillar for accountability. Additionally, open data is key in strengthening resilience and sustainability to various challenges that may hinder the attainment of vision 2030 sustainable development goals. Further, open data provides an enabling environment to empower people, institutions as well as societies with resources and knowledge capacities to minimize, absorb, forecast and adapt to dynamic present-day and forthcoming challenges in the quest of Vision 2030. Through open data, governments transversely can provide innovative public services to everyone on social basic needs such as health which is of ultimate importance in refining the quality of life as well as a precondition to productivity (UN E-government Survey 2018)[3].

However, since the launch of Data.gov in 2009 by the Obama administration in the United States of America, various countries have adopted government open data initiatives at various levels of government in different fields. Open data is open if it can be reused, and redistributed by anyone, for any purposes, including commercial reuse, free of charge and without any restrictions (United Nations Public Administration Program 2017) [4].

Previously, renowned institutions such the World Wide Web Foundation and the New York University Government Governance Lab in 2014 and 2018 developed an open data common framework which indicated that Management, Legal and Leadership are critical factors in guaranteeing open data. Wang, H.J., & Lo, J., (2015) [5], used Technology Organization and Environment (TOE) framework and the four factors that are fundamental to open data adoption resolutions: perceived benefits, perceived barriers, organizational readiness, and outside forces to assess open data adoption among government agencies. Findings showed a significant positive relationship among perceived benefits, organizational readiness, and outside forces and the adoption of OGD. Additionally, Zuiderwijk, A., et al (2015) [6], employed the unified theory to study acceptance and use predictors of open data technologies adoption. Yupan and Bo (2018) [7] applied resource theory to explore open data capacity of government agencies. The study revealed that resources, technical capacity as well as organizational processes are related to open data capacity of government agencies. Additionally, when it comes to the relationship between organizational structures and power distance, the study showed that power distance is a critical moderating factor. Ahmadi Zeleti et al. (2016) [8], explored the economic value of open data.

There is now a considerable body of research which suggests that open data guarantee mechanism is of great significance and must be properly studied. Most researchers in the field agree that management, legal and leadership are essential factors to ensure the rationality of open data is achieved. Furthermore, recent studies by Vanessa (2019) [9] and Whitford (2013) [10] have shown that it is of great importance to understand how management, leadership and organization structures affect government open data. Periera, G et al (2017) [11], found that through a critical analysis of open data management, one might understand: decision-making processes and how the government makes the judgment of public interests as they are publishing various health data sets. That is to say, how key principles like transparency, accountability, and participation are reflected in the process.

Surprisingly, very few works of literature have been published on open data guarantee mechanism. The recently published article by Vanessa (2019) [9] focused on what china can learn from Australia. The limitation in all the present work is that, there are no studies that have been done to examine the concrete examples in two similar political entities to see the real state in the three field, namely; Management, Legal and Leadership aspects for guaranteeing the open data implementation in health sector.

The literature on open data has concentrated principally on adoption factors, accessibility, and use as well as data governance and data privacy issues. Additionally, most of the data that can be found on open data in the literature hardly addresses the guarantee mechanism on health open data more specifically from a comparative perspective of the United Kingdom and Australia. These two countries share a number of similarities in their political systems and are among the top three countries with the highest open data rank in the world. The United Kingdom ranked number two, Australia number three (Open Data Barometer 2017) [12]. The Global Report (3rd Edition 2016) [13] ranked Australia third in the open data execution dimension.

Would an analyst of open data bear out their ears to the open data guarantee mechanism on the health sector of these two successful countries? Rather this matter in question calls for further empirical understanding. But the question remains; what management, leadership and legal mechanism is in place in the U.K and Australian health sector on open data? How does the management, leadership and regulatory process (mechanism) intervene and assure open data rationality in the U.K and Australian health sector? And what recommendations can be made in order to successfully implement health open data based on the U.K and Australian best common practices and experiences?

By doing comparative research, you can also find out the similarities and differences in these two countries in each aspects, especially the similarities shows you the common knowledge and measures to shape the overall open data guarantee mechanism.

Significantly, it goes noticed that the 2014 and 2018 works by the World Wide Web Foundation[14] and the New York University Government Governance Lab merit an open data common framework. However, this common framework deserves a critical analysis from a comparative perspective of two successful countries. The first reason for this is that, there is need to examine the concrete examples in two similar political entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guarantee the open data implementation in health sector. Secondly, to find out the real case in these three aspects, which will present evidence to show these aspects are really important to the success of public management and to the success of open data implementation. Further, as earlier mentioned, this is important to establish empirical similarities to show common knowledge and measures to shape the overall implementation of open data. Additionally, this knowledge can be used as a metric to evaluate what happened in other country's open data plans or projects and offer advices.

This has the potential to achieve economy in the health sector through less expenditure on huge costs of research. Secondly greater efficiency is maximized through the maximum output of valuable open health data on various health government services. Additionally, findings on the guarantee mechanism could aid in realizing accountability, transparency, citizen participatory on health surveillance, best management, legal and leadership Practices in the overall open data implementation in the health sector.

Therefore the object of this thesis is to look critically at the Guarantee Mechanism of the United Kingdom and Australia health sector on open data. The rest of the paper is organized as follows: problem statement, research objectives, and research questions, significance of the study, conceptual framework, and research delimitation, and innovation, limitation of the study, literature review, research methodology, findings, discussion and conclusion. Finally, recommendations and future research directions are conveyed.

1.2 Problem Statement

The 2014 and 2018 works by the World Wide Web Foundation [14] and the New York University Government Governance Lab results in an open data common framework which highlights the three components that will help the success of public management. The framework underpins that; Management, Legal and Leadership factors are fundamental to the effective implementation of open data. Nevertheless, there are no studies that have been published to examine the concrete examples in two similar political entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guaranteeing the open data implementation in health sector.

The problem is important because, it is essential to find out the real case in these three aspects, which will present evidence to show these aspects are really important to the success of public management and to the success of open data implementation. Further, through comparative research, you can also find out the similarities and differences in these two countries in each aspects, especially the similarities will show you the common knowledge and measures to shape the overall open data Guarantee Mechanism. Additionally, this knowledge can be used as a metric to evaluate what happened in other country's health sector open data plans or projects, and finally to put forward advices.

Given the rationality of open data in the health sector, optimization of on open data or adoption of more-effective Management, Legal and Leadership practices in the health sector is crucial for its continued development. Therefore, the aim of this study, is to critically analyze the Guarantee Mechanism of the United Kingdom and Australia health sector on open data.

1.3 Research Objectives and Research Questions

1.3.1 Research Objectives

a) To establish and explore the Management, Legal and Leadership Mechanism in the U.K and Australian health sector on open data
b) To critically analyze the Management, Leadership and Legal open data mechanism in the U.K and Australia health sector. And to further highlight significant differences and similarities
c) To establish how the Management, Leadership and Regulatory process (mechanism) intervene and assure open data rationality in the U.K and Australia health sector
d) To ascertain what recommendations can be made to other country's health sector for successful open government data implementation

1.3.2 Research Questions

a) What Management, Leadership and Legal Mechanism is in place in the U.K and Australian health sector on open data?
b) What are the significant differences and similarities for guarantee mechanism between the U.K and Australia health sector on open data?
c) How does the Management, Leadership and Regulatory Process (Mechanism) intervene and assure open data rationality in the U.K and Australian Health Sector?
d) What advises can be made to other country's health sector to provide a framework for successful open government data implementation?

1.4 Significance of the Study

At present, there is continued growth and recognition of the relevance of open data in the health sector in the current and future digital and globalized world. Consequently, in 2014 and 2018, the World Wide Web foundation established a common framework for the successful implementation of open data in public management. The aforementioned, point to the need to examine practical examples of similar open data top-performing countries from a comparative methodology to add more evidences for the original public management framework. This is important as it will show how imperative the three aspects namely; Management, Leadership and Legal are to the overall implementation of open data guarantee mechanism. Further, it will establish common knowledge and measures to evaluate what happened in other country's health sector on open data and ultimately offer advises for a successful framework on the implementation of open health data.

The first contribution of this study is that it provides more evidences for the original public management framework, and secondly, provides a framework for successful open government data implementation. Assuredly, the study will be beneficial to various stakeholders such us policy makers and leaders on health open data in the least performing countries.

Effective implementation of open data will enable the public to benefit from the speedy availability of accurate health data and information, quality data-driven public and administrative decisions. Secondly, harness data to build resilient societies in attaining vision 2030 SDGs through proper health care systems capable of detecting epidemics at their infancy, provide diagnostic and improve citizen accessibility to effective medication. Thirdly, enhance public value in the health sector through improved and innovative delivery of healthcare services and treatment.

1.5 Conceptual Framework

A conceptual framework is important as it represents the researcher's synthesis of previous research and provides a clear road map of investigation and viewpoint. Thus after a comprehensive literature analysis of and other relevant publications. A conceptual framework has been developed illustrating the key variables and constructs that makeup open government data Guarantee mechanism (Management, Legal and Leadership).
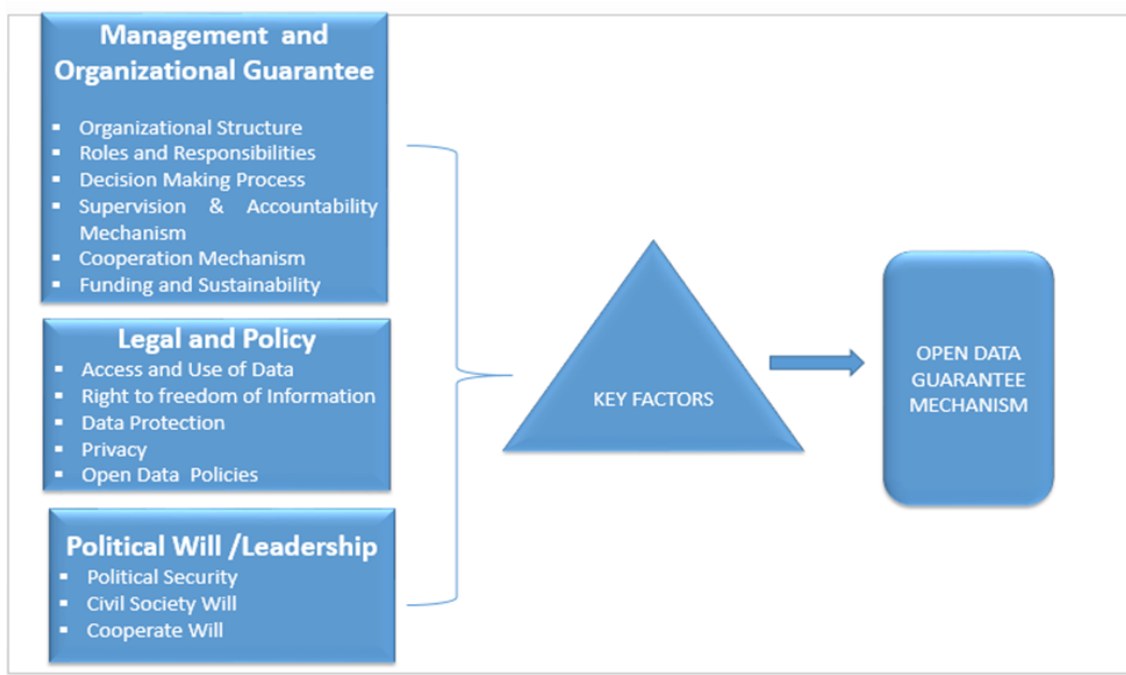
Figure 1-1 Open Government Data Guarantee Mechanism Conceptual Framework

1.6 Research Delimitation and Innovation

1.6.1 Research Delimitation

There are several other problems in the research arena of open data such as; privacy issues, quality measures and data governance. However, the researcher principally opted to research the Guarantee Mechanism of open data which includes

Management, Leadership, and Legal Mechanism. The first reason for this is that this area is of ultimate significance both from the knowledge of the researcher and the World Wide Web Foundation and the University of New York Government Governance Lab; the developers of the common framework on open data. There is a necessity to explore this unexplored research area as it holds the fundamental elements to flourish the effective application of open data in the health sector. Further, this sector is of specific interest to the researcher because it deals with critical mattes to the growth of any country. Like a common saying goes 'health is wealth', it is barely impossible to achieve any sufficient levels of productivity if the wellbeing to citizens is not enhanced

Additionally, the methodology utilized in this study provides a perfect setting to show more evidence for the importance of open data common framework from the experiences of the top-ranked open data performing Countries. Secondly, to offer a successful framework for the evaluation and implementation of open data projects and plans in other countries that are still struggling. Furthermore, the researcher opted for Australia and United Kingdom because the two countries have similar political systems and ranked top on open data with Australia ranked 3rd on the execution dimension of Open Data (Global Report 3rd edition 2016) [13]. These characteristics necessity a comparative empirical understanding to show evidence for the successful, fundamental elements of open data in public management. Therefore the Object of this thesis is to critically analyze the Guarantee Mechanism in the United Kingdom and Australia health sector on open data.

1.6.2 Research Innovation

This study is a step forward in the development of scientific knowledge in the field of Open Data. Ideally, the methods of data collection adopted when conducting research must eventually bring forth innovative theoretical approaches. As earlier stated, the 2014 and 2018 World Wide Web foundation contribution on the common framework for open data implementation in public management remains unexplored. In this study, the researcher argues that in the current works on Open Data, there are no studies that have been done to examine the concrete examples in two similar political entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guaranteeing the open data implementation in health sector. Further, to establish the

common knowledge and measures to shape an overall open data Guarantee Mechanism.

The researcher recognizes the need to go beyond mare local Open Data frequencies and cross-tabulations by adopting a critical comparative approach on fundamental elements of open data which remains unexplored. It is hoped that through this study more creativity on communication and explanations on open data key elements (Management, Legal and Leadership) will be achieved.

Fundamentally speaking, this study is not about rehashing or reformulating previously known results. Rather is paramount in realizing potential benefits of achieving economy, efficiency, and effectiveness in the Health Sector in public management and the developing world afforded by empirical evidence and a framework for successful open government data implementation. Reinforcing this view, Block, M. (1997) [15], underpinned that, international comparisons are vital in policy diffusion innovation given the high cost of research.

1.7 Limitation of the Study

The Limitation associated with this study firstly lies in its qualitative methodology which offers problems such as validity and reliability in that it is difficult to replicate qualitative studies. That is to say, the methodology and design such as phenomenology come with some limitations in which the researcher holds little control.

Chapter 2 Literature Review

2.1 Core Concepts

2.1.1 Health Sector

The Health Sector is a sector in the economy which consists of various government and non-government companies and stakeholders that provide a wide range of medical services such as; drugs, equipment's, medical insurance and other related healthcare services (Kenton, W. 2017) [20].In the United States of America, the healthcare sector is one of the largest and the most complex and accounts for about a fifth of the overall Gross Domestic Product.

2.1.2 Open Data

Government open data is tremendously changing economic sector outlooks of various countries including the health sector. The concept open government data has increasingly been defined by various scholars around the globe in the recent past decade. However, there is no universal definition. Logically, the concept open data appears to be self-explanatory, in its general sense, open data is an umbrella term to refer to all data that is free to the public. One of the widely used definitions of open data is that it is data that is free for everyone to use, can be modified, and shared by anyone for any purpose (Open Definition 2017) [16].

Health open data has sparked an escalating research trend to study the shared medical data sets. There is also more data-driven research been carried out in a bid to improve healthcare service systems in different countries in the United Kingdom as an example. As earlier established, health open data comes with opportunities such as establishing causes of diseases and effects of treatment at the same time enabling analysis bespoke to an individual's features, known as personalized or stratified medicine. Additionally, developments, such as crowdsourcing, participatory surveillance and data sharing using mobile phones among citizens' have great potential to contribute to our knowledge of the disease, improving diagnostics, and delivery of -healthcare and treatment (Holzinger, A. et al 2015)[17].

Organization for Economic Cooperation and Development (OECD 2018) [18], add more insight to the aforementioned definition by stating that, open government data (OGD) is a philosophy and increasingly a set of policies that ensure there is transparency, accountability and value creation in all government undertakings. Government organizations by virtue of their various functions turn to produce and store a large amount of data arising from people, projects, weather, health to mention but a few. In recent times, it has been generally been recognized by various governments world over that, releasing such kind of data to the public is key to attain transparency and accountability to citizens as well as business creation and innovation. Governments everywhere in the world are creating policies to improve data openness through providing comprehensive descriptions of how data relating to public welfare should be managed (DaGostino, M. et al 2018) [19].

2.1.3 Guarantee Mechanism

Just like a credit trading platform must be able to guarantee payment, delivery of credits, and timely clearing and settlement on every trade. In a similar manner, for open data initiatives to be effective, there is a need for a guarantee mechanism. With this logic, the World Wide Web foundation common framework July 2018 established that; Management, Leadership and Legal factors are critical to the effective implementation of open data initiatives.

Although research on guarantee mechanism on open health data implementation is scarce at present, the field of public administration has had several researchers who have extensively studied guarantee mechanisms on various public management factors such as accountability, corruption to mention a few. Guarantee mechanism schemes have been long recognised as a good policy implementation strategy. Hakeem Owolabi conducted a study on public accountability using a case study method to investigate government guarantee scheme in Public Private Partnership Projects in UK. In his study he carefully looked at process based accountability mechanism, outcome based accountability mechanism, ethics based accountability mechanism to mention but a few. The findings revealed that they were five most important accountability mechanisms in public private partnership projects in UK and they include: risk management, value for money, competition, parliamentary scrutiny and social and political impact (Hakeem, O.2018) [86].

A 2016 study by Santos Leonel on the impact of non-operational mechanisms on the effectiveness of public technology governance shows that investment portfolio management has a direct impact on the effectiveness of public technology governance. Further, the study concludes that there is a paucity of research in public administration that empirically examines which mechanisms are of relevance in ensuring public organisations are effective in service delivery in Brazil (Santos, L. 2017) [87]. In this line of logic, Vanessa contributed to the field of open data by carrying out a research in 2019 on the guarantee mechanism of the Australian local government open data. She employed the pluralistic view of public administration to establish the security mechanism of open data in general. Recommendations were given in 3 mainstream: management, politics and law. Research is yet to gain depth on health open health data implementation guarantee mechanism, and this research is a commendable contribution to this field (Vanessa. M, 2019) [9].

2.2 Theoretical Basis

This Section will discuss the theoretical grounding for the study. The following is the order of the discussion; New Public Management Theory, Transformational Leadership Theory, a theoretical review of Comparative Research Theory in Public Administration, Management, Leadership and Legal approach to Public Administration. Finally, the Institutional Approach to Public Administration respectively.

2.2.1 New Public Management Theory

In 1970 and 80's global public administration scholars reinforced the necessity that the public sector ought to become more efficient and effective in its service delivery. Arising from the insufficiencies the bureaucracy theory has, the field of public management borrowed several organizational principles from private management. With the advancement of society, there is great necessity to adapt efficient management methods. Since the past decades, the application of New Public Management principles is been done in several sectors including health in response to concerns on the increasing health care expenditure, catalyzed by new technologies as well as medical advances in treatment.

According to Ani and Antonieb (2014) [21], (Hughes, 1998, Strathern, 2000) [22], [23], New Public Management theory primarily focuses on results and underpins the need to evaluate performances on objectives-achieved scale. The logic here is that organizations ought to perform to achieve great results as well as prove to be efficient. The parameters of public management reforms instigated by NPM include the following (Matei, 2006) [24]:

- A transference from politics to management
- A transference from process-based kind of administration to focusing on results based administration
- A transference from hierarchical frameworks for decision making to dichotomy between basic activities as well as adopted operational services.
- Cost reduction
- A transference from state ownership to state management
- A transference from collective social services delivery, to a more flexible delivery of particular services.
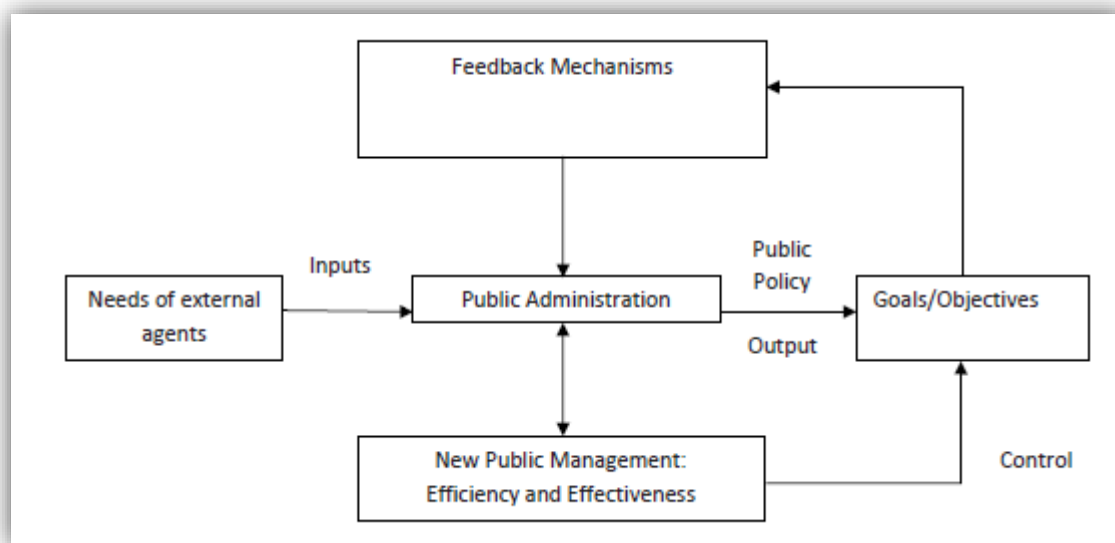
Figure 1-2 the NPM in complexity Model.

Source: Ani Mateia, and Cătălina Antonieb 2014[21],

From the figure above, Public Administration theatres a serious role, its actions on the needs of the citizens ought to be the solutions to the problems, which should translate into goals and objectives.

2.2.2 Transformational Leadership Theory

The modern health sector settings, demands more effective leadership to ensure there is high quality health care system that can consistently provide safe as well as efficient healthcare services to citizens. That said it is then imperative for various professionals in this critical sector to develop leadership styles that enables them to grow their skills and turn into better leaders and lead junior employees effectively. Additionally, ensure good employment relations with employees at diverse levels (Chin Nurs Res. 2017; 4:155-157) [25].

Transformational leadership theory is paramount in this scenario. Originally, the notion of transformational leadership was propagated by an outstanding leadership expert James McGregor Burns. Burns argued that, transformational leadership can be conceptualized as a liaison amid followers and the leaders which translates into motivation, the end result being a value system understanding between the follower and the leader. However, additional works by Bernard M. Bass alluded that a solid vision and character are shared traits among transformational leaders. Bass further opined that these type of leaders will usually motivate followers so as to adjust expectations, opinions as well as inspirations to work towards common established goals (Bass BM 1985) [26].

Four critical factors were identified according to Bass that are quite central in transformational leadership, namely; strong motivation, intellectual stimulation, ideal impact as well as personal consideration. Scientific evidence in the past years has shown that, transformational leadership greatly affects follower's satisfaction and commitment to an organization. Additionally, these type of leaders are seen as change agents capable of sing their qualities and personality to motivate followers and achieve goals. This achieved through inspiration, fairness, effective communication and building trust with followers (Bass BM 1985) [26].

2.2.3 Management, Legal and Politics Approach of American Public Administration.

David Rosenbloom currently the chair professor of Public Management at the City University of Hong Kong is commonly known for his approach to understanding the underpinning background fundamentals of American Public Administration from three perspectives: Politics, Law and Management. Rosenbloom argued that, the management foundation is key to organizational performance so that they can be successful. The political approach looks at how political officials oversee and supervise various

administrative decisions. He further holds that the legal approach is the most crucial approach in that it is essential to orderliness and spells out what ought to be done and how it must be executed. Therefore public administrators are supposed to be very competent in their legal obligations. To suffice, it is not enough for one to use one approach only, all approaches should be employed simultaneously (Rosenbloom, D. 2008) [27]. Based on this background Public Administration involves the use of Management, Political and legal theories and processes to provide valuable services to the people across different societies in different countries.

Similarly to analyze and understand government open data one must not only look at technical issues but Management, Leadership, and Legal mechanisms are imperative. World Web foundation in 2018 recognizes this fact in its common framework. The framework holds that, Legal and Regulatory mechanism is cardinal in facilitating access to and use of data, organizational mechanism defines various roles played by individuals, teams, and units in open data policy program and political will and leadership are essential to understand how to cooperate, political and civil society will, supports the application of open government data policy at different levels.

2.2.4 Institutional Approach to Public Administration

The fundamental focus of this approach in public administration is in the detailed study of structures, rules and regulations, and functioning of various government organizations. In other words, the approach holds that to study institutionalism the structural approach should be integrated as well. Generally, academicians and researchers that opt to use this approach view public management from an apolitical function perspective. This perspective sorely falls under policy implementation.

Some of the classical scholars in public administration that concentrated their quality effort to study structures and rules and regulations include Luther Gulick and Woodrow Wilson the father of public administration. Wilson defined public administration as the systematic and detailed application of the law. At present, the concept institutions refer to all rules, regulations, and policies that govern and guide how organizations function as well as structures. It can, therefore, be argued that an institutional perspective study is paramount to archive efficiency and effectiveness in public organizations. However, traditionally much focus was given in understanding the interplay between law and history. Complementary, modern institutional approach is deemed to focus on organization structure, goals and objectives, rules and regulations as opposed to paying more attention to delegation, coordination, and control as well as bureaucratic structures whilst neglecting roles, goals, and objectives (Juneja, P. 2019) [28]. Open data institutional enablers are critical if we are to avoid ineffective open data implementation in the health sector.

In this light, this study will investigate and critically analyze various open government data policies and structures, responsibilities and roles as well as objectives in the Australian and U.K health sector to add more evidences and importance for the original public management framework established by world wide web foundation for the effective application of public management, and provide a framework for successful open government data implementation.

2.3 Open Data Mechanism Research

2.3.1 Management and Organization Guarantee

It is of great significance to understand how management and organization structures affect government Open data. The organizational leadership structure is a sort of administrative resource which can affect the excellence of managerial decisions, which ultimately affect organizational performance (Hansen, Perry, & Reese, 2004; Lee & Whitford, 2013) [29], [10]. Data Management Association (2014) [30], defined data management as an overreaching concept that describes the process used to plan, specify, enable, create, acquire maintain, use, retrieve and purge data. Data governance is the oversight of all data management.

Data Management Association established that there are six elements which make up the environment for Data Management these are: organization and culture, this includes critical success factors, management metrics, reporting structures, values, and beliefs, expectations, styles, preferences symbols and heritage. The second environmental factor is roles and responsibilities, which include organizational and individual roles, I.T roles, skills, and qualifications. Practices and Techniques, these include, recognized best practices, common approaches, and alternative techniques. Process activities is another critical element, this involves phases and steps, and sequence and flow. Deliverables yield into account input and output, documents, information, and databases. The final element is tools, this includes standards and protocols, selecting criteria and learning curves. At the center of these

elements are goals and principles. Here we focus on specific objectives, strategic goals and guiding principles (Data Management Association 2014) [30] (Wijnohoven, F. et al 2014) [31].

However, the limitation in this work is that no studies have examined the concrete examples in two similar political entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guarantee the open data implementation in health sector. I argue that by taking a critical analysis of the practical open data management, leadership and legal of top performing countries, we will show more evidence on the importance of these key aspects and offer advises on a successful framework for the implementation of open data in the health sector.

Literature pointed out that understanding the key structures and their roles and responsibilities are important as it helps to ascertain who makes what decision and what procedures govern the decision-making process, who are the data holders and what kind of health data do they publish? Further, who is in charge of ensuring the data is of good quality according to the established standards and regulations, and finally who controls the publication (Sadiq, S., and Indulska, M. (2017) [32]. There must be development and creation of organizational structure and management system with clear rights and responsibilities. Danny added that funding and sustainability are of great prominence if we are to attain effective open data management. Funding is cardinal to booster employee innovations and establishes effective open data operations (Yupan, Z. and Fan, B. 2018) [33], (Lammerhirt 2017) [34]. To date, there is no research that has been done to critically analyze the similarities and differences in top countries in each aspects, especially the similarities to show the common knowledge and measures to shape an overall open data Guarantee Mechanism.

Vanessa. M, (2019) [9] added that cross-sector cooperation is paramount as it provides great opportunities for greater open data collaborations among various agencies and stakeholders in the health sector to enhance public value in service delivery. These cooperation's do not just imply government to government cooperation's rather it extends to non-governmental and civil society organizations as well. Supervision and accountability structures in any organizational set up are keen to ensure policies are implemented effectively. This is to say, Open data Management structures ought to have leadership structures executing the aforementioned functions. Through this study different supervision, accountability collaborations structures will be critically analyzed as a basis of which provides a framework for successful open government data implementation in the health sector.

2.3.2 Legal and Policy

Research has shown that for open data initiatives to be successful governments must first promote the construction of laws and regulations on data governance. Additionally, sincere efforts must be dedicated to establishing a good environment for law and Policy. Effective laws form the basis for any good data management and use. Successful countries have invested a quality amount of time, resources and effort to create comprehensive and complete legal and regulatory systems with laws covering, information management, information security, privacy and protection, information disclosure, freedom of information and data openness to mention a few. Wang opined that the pace of government informatization in the modern data-driven societies has accelerated, but the construction of laws and regulations has lagged behind. Therefore, there is a need to respond to current data demands in a timely manner in order to harness the optimal benefits of data (Wang, X. and Zheng, L. 2019) [35]. However, no research has been carried out which establishes an empirical grounded framework for fruitful open government data application in the health sector.

Furthermore, to guarantee the availability of open data for extended periods of time and attain relevant impact, ODC Global report 3rd edition 2016 guided that, clear policy frameworks, coupled with consistent global data management approaches must be the basis of all course of actions.

There exist a correlation between law and open data policy frameworks. Legal frameworks can enable, compliment, or perimeter the coverage of open data. For instance, information and freedom of expression structures bring to attention questions on how the legal environment affects the conduct and day to day decision-making on open data application of legal regulations and guidelines. Understanding the law environment effects is essential in analyzing government decentralization through devolution. Ana points out that, open data governance ought to cover all the government hierarchs to unleash data from the entire administrative units of the state (Ana Brandusescu et al 2017) [36].

In public health, Dagostino suggested that disease outbreaks such as Cholera, Ebola, and Zika virus epidemics that the world has experienced their damaging effects

are indicative and reveal the urgent need for government's world over to create and develop legal frameworks that will provide guidance for the management of public health data. Such a framework should ensure that data

collected during public health emergencies are accessible to the appropriate authorities and public in a form that can help with timely decision-making during such public health crises (Dagostino, M et al (2018) [19].

2.3.3 Political will and Leadership

One of the key barriers encountered by countries in implementing open government data initiatives effectively is the ability to sustain the political will to keep open data a priority amidst changing government leadership. To achieve effective open government data calls for governments' unwavering commitment, courageous leadership, creativity, innovation as well as strong capacities and adequate means of implementation. (United Nations 2016) [2]. Open data can be hugely be motivated and influenced by the political leadership and will to improve information flow. Sincere and genuine political will to ensure accountability and transparency is another critical driver.

ODC Global report of 2016 reported that a number of countries in Africa are still ranked at the bottom a clear indication that there is need for strong leadership and more efforts. It was clear that no country in Africa demonstrated clear leadership apart from Rwanda which remained stable in the past three edition of Open Data Barometer.

Additionally, an increase in accountability is not only related to the betterment of citizen to government relationship but also is important to strengthen central government by providing accurate information on the local communities, districts, and provincial undertakings. This helps in better policy making, citizen participation and improvement in social and environmental health benefits. If increased accountability, transparency and innovation are conceptualized among the key drivers of open data by the leadership, the result is effective implementation of open data laws and policies. To present, there is no research that has been done to critically analyze management, leadership and legal factors in similar political set ups to show practical evidence on the importance of these factors and how they have influenced open data implementation in top performing countries such as the U.K and Australia. Common knowledge and measures obtained from this study can be used as a metric to evaluate what happened in other country's Open Data plan or projects.

Research literature has shown that, despite senior political leadership being key to keep open data as a priority, front line champions in government organizations are important to drive open data vision implementation from bottom to up. Additionally, external support to sustain political will and drive continued demand for open data can also be derived from civil society organizations, media, academia to mention a few. This can further act as a platform for ongoing learning and dialogue. Chile is one of the countries cited to have been implementing this tactic (Ellen et al 2015) [37].

Another commonly cited challenge is a lack of understanding of open data within government departments and leadership. In Chile, survey literature revealed that some leaders did not understand clearly what open data is, this greatly impede open data policy development. Further, it was also noted that potential open data collaborators and some parts of the community simply did not know what data the government holds. It takes great leadership to influence public organizations to be transparent about their data holdings. This is important as it allows and stimulates the public to engage with the government since they know the types of data held by public organizations (Ellen et al 2015) [37]. However, there are no studies that have been done with primary focus on critical elements of open data namely; management, leadership and legal to reveal their significant in the practical set up. Ellen work is a mere description of the challenges and experience of Chile. It does not establish a successful framework which can be used as a metric to evaluate and offer advices on the overall implementation of open data in Health sector.

Chapter 3 Methodology of the Study

3.1 Research Design

The study will adopt both induction and deduction qualitative approaches using a comparative study design. The deduction approach will be employed to give a basic analysis of the open data common framework to examine the concrete examples in two similar political entities (the UK and Australia) to see the real state in the three field, namely, Management, Legal and Leadership aspects for the guarantee of open data implementation in health sector. Through literature interpretive analysis of the Open Data Guarantee Mechanism on the Health Sector. This approach is useful to explain similarities and differences in the experiences of the UK and Australia. Comparative research of particular country experiences is of great significance as it helps to focus on the design

as well as specific mechanisms.

Further, the induction approach will be utilized to explore the two cases and sum up the detailed knowledge. This approach will be especially important to establish the similarities to show the common knowledge and measures to shape an overall open data Guarantee Mechanism. In addition, can be used as a metric to evaluate and put forward advices in other country's open data plans or projects. In other words, this stands a great deal of potential to lead to an ideal type abstracting of institutional arrangements and process from the existing systems to deduce a model unconstrained by political, cultural or social setups of any existing nation.

The criteria for selecting the U.K and Australia is based on open data performance as established by the Global Open Data Index, Open Data Barometer, 2016 Global report 3rd Edition published by World Wide Web foundation in which the two countries are among the top performers with Australia ranked number 3 in open data execution dimension. Secondly, the two countries have a complete legal and regulatory system on data and information policies. Furthermore, the two countries have similar political systems. Australia adopted its political system from the UK, they are both constitutional monarchs and utilizes a federal system of government to mention but a few. The aforementioned factors warrant a comparative and intriguing empirical understanding.

However, in order to show the historical development of the last decade, I will collect data for the aforementioned countries from past to present. This research will use the International Social Survey Program (ISSP) guidelines which are widely and fairly regarded as a conscientious, rigorous and successful model for the cross-national social survey.

3.2 Methods and Techniques

I will adopt mixed approaches to explore and establish the most important factors in Open Data Guarantee mechanism whilst paying attention to different context and approaches as well as the wider impact. This study will compare case studies from the Historical perspective, using particularistic comparison and ideal types by means of exemplars. Some of the advantages of using the particularistic approach are that detailed attention can be given to country policies using local categories. Additionally, case studies turn to be valuable even before any comparison is made. The particularistic approach reveals common conditions that make the mechanism politically feasible and establish the significant political actors behind them.

Furthermore, the historical approach will be applied to analyze the U.K and Australia Open Data mechanism long –term development, identifying as well as contrasting critical factors and successful reforms. This is important as it helps to understand how various policies related to the epidemiological, changing political and economic contexts and processes. Suffice to say, this is crucial to identify country-specific changes which may account for their top performance on Open Data. The methodological framework for the collection and assessment of the Survey's data on Open Data is based on a holistic institutional view of open data that incorporates three important dimensions; Management and Organization, Law and Policy, and Politics and Leadership factors.

3.3 Data Type and Sources

This research will be based on qualitative pooled Country-level data and not Individual health departments or sections. In order to establish a good understanding of how specific experiences relate to each other, historical trends theoretical constructs, enable the discovery of trends and process. A framework of minimum data -set must be established to facilitate a meaningful comparison and explanation of systems structure, functions, and transformation. Therefore in this study, a minimum data set has been proposed on the basis of an extensive literature review to the comparability of Health Open Data Guarantee Mechanism. These include the current Open Data Mechanism, Its Background and Context, the rationale, specific proposals, political and administrative actors, processes, limitations and achievements and finally the wider impact.

The data sources for the study will be a critical analysis of the literature survey of government publications, open data reports, media articles, peer-reviewed research papers, open data policies, and laws. Next, I will examine publications from official national open data portals and websites of the ministry or department of health to understand practical insights other materials may not provide. According to https://www.opendatasoft.com/ 2019 [38] updated list for all open data portals around the world. Australia has a total of 67 open data portals and the U.K has 157 open data portals. A comprehensive literature search and analysis will be done for a total of 224 open data portals.

3.4 Data Analysis

The methodology for the analytical part of the survey will be based on a literature review and a qualitative analysis of the secondary data. Qualitative analysis can be more instructive to understand and analyze specific contexts as it allows the researcher to directly study the communicated text (Neuman, W.L. 2007) [39]. As earlier established, this study will use cross national aggregate level contextual national data than isolated data. Secondly, I will not interpret detailed local knowledge I know nothing about for example; social structure, history, and culture. The least that will be done is to describe. Finally, the analytical framework for this study includes; Open Data Management, Legal and Leadership guarantee mechanism factors as indicated in the conceptual framework of the study.

Chapter 4 Analysis of the Findings

This chapter presents findings from the comparative analysis of the guarantee mechanism of the United Kingdom and Australian Health Sector on open health data. In seeking to analyze and investigate the guarantee mechanism in the two countries it may be useful to begin by looking at a brief background of open health data in respectful countries with the view of understanding the historical progress and present status of open health data development. Nevertheless, this chapter is structured into four parts. The first part explores the open data guarantee mechanism in the U.K and Australian health sector, in terms of Management, Legal and Political security. The second part addresses the comparative analysis in terms of similarities and differences in the open health data guarantee mechanism between the two countries. While the third part presents an analysis of how the guarantee mechanism in the two countries intervene and assure open health data rationality in the health sector. Finally, the last part presents a common knowledge framework for successful open health data implementation.

The thesis aimed to explore the World Wide Web Foundation and New York University governance lab 2014 and 2018 common framework, by examining the concrete examples in two similar political entities to see the real state in the three fields namely, Management, Legal and Leadership aspects for guaranteeing the open health data implementation in the health sector. The problem is essential as it presents evidence to show that these aspects are important to the success of public management and open data implementation as well as to establish common knowledge and measures to shape the overall open data guarantee mechanism.

4.1 The United Kingdom Open Health Data Guarantee Mechanism

4.1.1 United Kingdom Healthcare System Overview

The United Kingdom is a country that is located off the north-western coast of Europe with a population of about 66.44 million people. In terms of composition, U.K is made up of England, Wales, Scotland, and Northern Ireland. Further, whereas public healthcare is concerned, the United Kingdom government is charged with the responsibility of providing healthcare to all permanent residents who are estimated to be around 58 million. Generally, healthcare is funded by taxation and is free of charge at a point of need. Administrative-wise, the National Health Service (NHS) founded in the year 1946 is in charge for providing healthcare in the United Kingdom. Prior to that healthcare was mainly accessed by wealthy individuals until the introduction of the National Insurance Act in 1911.Around 1948 the cornerstone belief of the NHS was the principle that good health must be inclusive to all, with access based on the clinical need and not the ability of the person to pay. Henceforth, there has been a number of reforms that have taken place since the time of Blair government such as lowering medical costs and patient's waiting time, dissolving NHS management structure to encourage privatization of the healthcare industry in 2014 among others. It is, however, crucial to also note that, healthcare in the U.K is devolved implying all the four countries have their own systems (Josh Chang et al 2010) [40].

1. Information Evidence and Research in NHS

Throughout its day to day activities, NHS produces billion pieces of information. The organisation believes that effective collection and use of information is quite central in rendering public services to the citizens. Thus the NHS constitution underpins the rights patients have towards information. Given the large number of

organisations which provides healthcare in the United Kingdom, NHS stresses the need to have a focal point to ensure collection, linking and publication of information is done effectively. Additionally, NHS also emphasizes the significance of research in improving health outcomes.

Quite notably in Northern Ireland health and asocial care is designed in a manner that brings together the market as well as bureaucratic leavers. This implies the executive still returns control of health and social services. Whereas in Scotland, the director charged with health and social care assumes the responsibility for health policy with local authorities and NHS boards returning the power to decide which services can be integrated (Research Service National Assemble Wales 2014) [41].

2. National Health Service and Open Data

United Kingdom is among the top countries in the world that has championed the new movement of opening up the vast amounts of data that are held by different government organisations as well as agencies. The National Health Service has over the years continued to innovate and come up with initiatives that have registered some significant impact on healthcare choice, patient education, healthcare costs as well patient outcomes. According to NHS, the value preposition of opening data on healthcare includes; Accountability; this is so to ensure organisations that are providing healthcare are held accountable for treatment outcomes. Secondly, Choice; NHS believes open health data helps patients to make informed choices on the healthcare alternatives that are made available to them. The third value preposition is efficiency in terms of cost-effectiveness of the healthcare that is been delivered to the people. Further, improving outcomes of treatment to ensure transparency among various healthcare organisation. Finally, NHS believes open health data makes patients satisfied and organisations that are providing healthcare more responsive. Additionally, innovation that comes with open data is fuel to new healthcare organisations which ultimately boosts economic growth (Stefaan Verhulst et al 2014) [42]. The figure below shows the value of open health data.
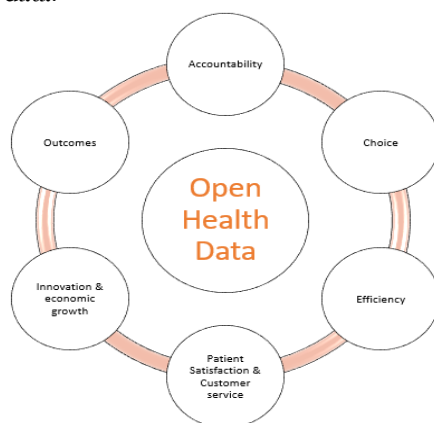

Figure 4-2 NHS 6 Value Preposition of Health Open Data

There are 3 key objectives at the core of National Health Service and they include the following: Transparency, NHS believes that safe sharing of information as well as data between the public, patients and clinicians is critical. Secondly, Participation is aimed at supporting patients and citizens to have more control of their own health care as well as to get them involved in the design of local services as opposed to them being spectators and receivers of the service only. Finally, Interoperability, this involves the creation of seamless digital data across all settings on grounds of open standards.

Beginning the year 2013, the National Health Service developed a number of initiatives to ensure that these objectives are met. Some of these initiatives include the launch of care. Data in 2014. This initiative was aimed at tackling the gaps in the

Information which was held by National Health Service and to seamless data flows across all the departments. The other initiatives were the publication of comparative provider outcomes as well as the introduction of the "Friends and Family test" which was basically a measure of the satisfaction of patients based on hospital inpatient recommendations made to friends and family members (Stefaan Verhulst et al 2014) [42].

3. Open Data Learning Environment in NHS

In a bid to improve how NHS opens data and provides real-time data, quite recently NHS resorted to making an open data education setting that syndicates the use of inventive technology platforms, close corporation with the research community, and wide consultation with stakeholders. A number of recommendations were suggested to achieve the aforementioned some of them include; building open health data learning capacity and culture within the National Health Service like creating open health data academy. Additionally, it was recommended to develop a common assessment framework, staying flexible as well as adaptive in measuring impact to mention a few (Stefaan Verhulst et al 2014) [42].

4. How to Open Health Data is classified under NHS

Open Health Data has been broadly categorized into three categories under NHS and they include the following; open health data, this is the data that is released under the open government license on the website Data.gov.uk, and gov.uk public health England, etc. The second category is Restricted Data: this is data that may carry personal or rather identifying information. Thus it has to be anonym zed so that researchers can request access after meeting the criterion established by NHS. The last category is Published Health Data: This kind of Data is prepared in an interactive format to take for instance pdf but the original data files are not published together with this kind of data. For example, surveys that have been conducted on patient satisfaction. Current Status on NHS and Open Data

As earlier mentioned, the U.K is among global leaders that have put up a lot of effort into opening data governance in healthcare. As quite evident, the 2012 government white paper begins with a critical emphasis, stressing that Data is the 21st century new raw material in holding governments accountable as well as improving the provision of government services. Since time immemorial, the U.K government identified the Health Sector as well and NHS as key priorities for data initiatives. As a matter of fact, the activities of the methodical Data collection under NHS date back to the period 1980s. This was way before even the interest on open data and big data spurred spontaneously. In the 1990s a more robust framework for data collection was established. However, the rationale for such developments was not necessarily motivated by transparency but rather by economic efficiencies and the desire to open markets. These concerted efforts were as a result of the efforts of the government in the application of the principles of New Public Management. Around the period 2000, there were even more efforts directed at collecting data on the waiting time of patients, performance evaluation to mention a few.

The past decade has witnessed how NHS has revitalized its commitment to collecting and publishing open health data below is a brief outline of some of the key milestones that NHS has gone through to achieve greater heights of open health data.

- 2005- National Health Service Information Center was created. Its mandate was to be an authoritative repository of the information under NHS. Its major achievements where that, it facilitated a wide range of data availability among researchers, patients as well as providers.

- 2007-In a bid to empower patients in making decisions and choices on their healthcare based on comparative data on hospitals, NHS choices was established. This provided a platform where users could share information and experiences on using NHS services. Current statistics show that this site attracts about 35 million visits in a month.

- From 2010 the coalition government placed much attention on transparency. A good example is the 2012 white paper that was released on open data

- 2011- David Cameroon, who was prime minister then pledged his commitment to open Data on the speech delivered at a pharmaceutical and Biotechnology conference.

- In 2012, an act was passed called the Health and Social Act. At the center of its strategy was a key emphasis on transparency and open data. The act mandated Health and Social care Information center to release all the data it held in custody in anonymized form. The record has it that about 83 data sets were published.

- Additionally, in 2012 there was an IT strategy that was published with the ten years plan requesting hospitals and other providers to release data to patients in a safe and secure manner.

- Care Connect Pilot was later launched by NHS in 2013, this phone web services created a platform on which citizens would interact with NHS and acquire relevant information and provide real-time data using feedback mechanisms.

Generally, open data initiatives in the United Kingdom have yielded a number of benefits. In the year 2014, a memorandum of understanding was signed between the United States Department of Health and Human Services and the secretary of Health for NHS England. This was in an effort to allow the two countries to learn from each other's experiences. The following chapters will highlight in detail other current development in the U.K (Stefaan Verhulst et al 2014) [42].

4.1.2 Management and Organizational Factors

1. Organization Structures

Findings on organizational structures revealed that there is a number of structures that play different significant roles in ensuring open health data is harnessed and implemented effectively. One of them is the Information Commission Office. The proceeding paragraphs outline the core business of this office.

1. Information Commission office

This office is charged with the mandate of upholding information rights in the public interest as well as promoting transparency in public bodies and ensuring data privacy for the Citizens of the United Kingdom. Some of its goals include: to see to it that public and private organizations that collect and use information do so in a secure, fair and responsible manner. It is further concerned with ensuring citizens are aware of their legal information rights and are confident using them and capable of protecting themselves from any possible misuse. This office has been influential and has to itself a couple of achievements such as taking part in the security and investigatory power bill, implementing information technology projects. It is interesting also to note that in the year 2014 /2015 this office attended to 15, 015 concerns of data protection from a total of 15,718 that were reported (Information Commission Office 2015) [43]. The figure below shows a sector distribution on generating most self-reporting incident.
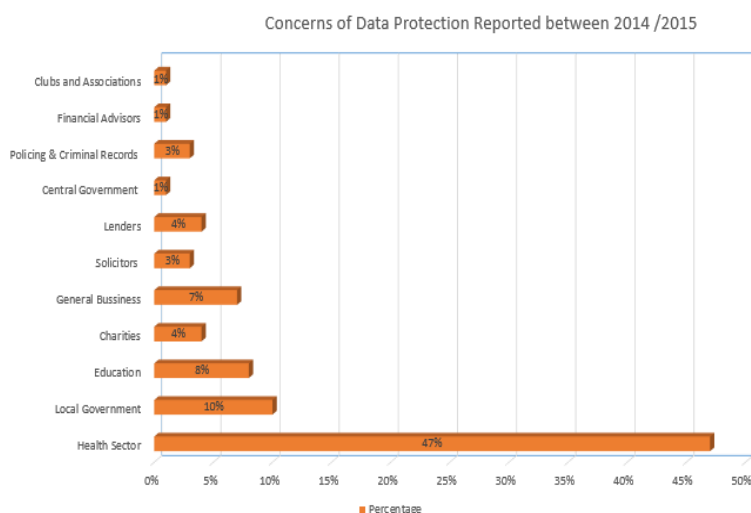

Figure 4-3 Sector Distribution on generating most Self-reporting Incidents

Furthermore, this office has made a huge impact on improving standards of information rights practices by ensuring there are clear inspiration, engagements, and influence. For example in 2017-2018 the commissioner delivered speeches regarding information rights including other aspects of law and policy (Information Commission Office 2017) [44]. The office has done major work implementing General Data Protection Regulation (GDPR) and Data Protection Act (DPA) 2018, freedom of information, collaboration as well as facilitating

innovation and resourcing.

The practitioner honor for brilliance with regards to Data Protection is one example that has been prominent in the United Kingdom to ensure key principles of GDPR and DPA are well embedded in all the organizations. (Information Commission Office 2018) [45].

In terms of regulation, the office of Information Commissioner Overseas and regulate the following.

- The Freedom of Information Act 2000(FOIA)
- The Privacy and Electronic Communication Regulations 2003 (PECR)
- The Data Protection Act 1998 (DPA)
- The Environment Information Regulation 2004 (EIR)
- The Infrastructure for Spatial Information in the European Community Regulations 2009
- The Data Retention Regulations 2014 (DRR)
- The Re-use of Public Sector Information Regulation 2015 (RPSI)

2. Roles and Responsibilities

The National Health Service identifies and places information as to its lifeblood: alluding to the fact that it is an important asset in ensuring clinical management of patients and individuals is efficient as well as the entire service provision in the health sector. Findings show that there are various roles and responsibilities that various structures play under NHS. The following are some of the examples within NHS England. The Chief Data Officers Team an administrative structure within NHS England is charged with the responsibility of developing and delivering a strategy regarding the use of Data at every level of the organization. There are basically 3 units within the Chief Data Office namely: The data policy unit, data project unit and data sharing and privacy unity. Below is a brief detail of the responsibilities of these structures. It is important to note that these units work hand in hand to see to it that there is a proper understanding of data requirements at the same time making sure that there is strict adherence to the legal framework (National Health Service 2016) [46].

1. Data Policy Unit

This unit works closely with commissioners as well as other various stakeholders such as researchers, Clinicians, and patients in order to establish needs and requirements regarding information standards, open health data governance, and transparency among others. Additionally, this unit pays close attention to peer-reviewed literature as well as adopting best international practices regarding the use of data as well as data policy. Thereafter the unit later submits specific requirements to the data project unit. At present, the policy on data primarily includes; open health data and information standards. Information standards are quite essential in ensuring effective publishing of the right health data to the right people in a timely manner. With more advancement in information systems in the health sector, NHS believes information sharing must be standardized to ensure consistency. In the same regard, patient's safety, as well as confidentiality, forms the core of information standards (National Health Service 2016) [46].

2. Data projects unit

This unit implements the requirements as established by the data policy unit. Its major focus is on benefits realization. To ensure NHS England meets the information commissioner requirements, it has a principal partner called NHS Digital. Basically,

NHS Digital plays a crucial role in providing information to support better care by ensuring there is high-quality data Collection, analysis as well as storage services, information governance as well as working in partnership with the Board for National Information to provide leadership.

Other structures include; Data and Services Panel charged with the responsibility for communication and resolving any strategic delivery issues with NHS Digital. Data Coordination groups receive requests across NHS and commissioning groups as well as Commissioning support groups. Then there is also a Service Coordination group, this one provides an environment in which National Health Service could identify opportunities to upgrade

and improve services that are provided by NHS Digital.

3. Data Sharing and Privacy Unit (DSPU)

This unit exists to provide guidance regarding privacy, data sharing as well as managing information governance strategic risks. Further, this office collaborates and works closely with Information Governance Alliance (IGA) as well as NHS corporate information governance (National Health Service 2016) [46].

3. Decision-Making Processes

Various legislation such as Freedom of Information Act 2000 (FOIA), General Data Protection Regulation (GDPR) as well as Data Protection Act 2018 (DPA) empowers citizens to access information held by public bodies and agencies. Thus decisions regarding access, data protection, use, confidentiality, and complaints are hugely guided by the aforementioned laws and other applying legislations. For example regarding how to make a complaint, the freedom of information Act 2000 holds that it must be put in writing within 40 working days after which it may not be considered. The aforementioned law also gives citizens the power to express their displeasure regarding how information or complaint was handled. (Locum Information Governance 2018)[47].Additionally, there are principles that public bodies try to employ when dealing with complaints procedures. For example, a complaint must be acknowledged within 3 days of receipt and the complainant must be informed of the target date for determining the complaint the list goes on.

4. Supervision and Accountability

Findings show that in the year 2016 the information Commission Office undertook a different approach to ensure there is obedience with the Freedom of Information Act. The agency took greater account of matters to do with intelligence coming from casework and made more use of tasking as well as groups charged with the responsibility of coordination. The end result has been an increase in informal monitoring as well as giving organizations the much-needed support to improve in its performance and delivery of services. The office of Information commission still carries out formal monitoring in all government agencies and departments, councils as well as the police force. For example, in Northern Ireland, all government departments were asked to submit their current freedom of Information performance statistics. This gave the office an opportunity to asses' compliance levels and further establish long outstanding requests in order to get them sorted out (Information Commission Office 2015) [43].

5. Cooperation Mechanism

As noted in the preceding findings, there are a lot of local and international cooperation and collaborations in NHS. For example in 2014, there was a memorandum of understanding that was signed between the United States Department of Health and Human Services and National Health Service England. The signing of this bilateral agreement regarding the use as well as sharing of health information, technology, tool, and services, was part and parcel of the commitment by President Obama in ensuring openness in governance. Particularly this MoU centered on open data initiatives and to learn from one another. A possible benefit to NHS is that it stands a great deal to benefit from the first initiators of publishing public health data (Stefaan Verhulst et al 2014)[42]

Information Commission Office also jointly led the 3rd Global Privacy Enforcement Network privacy sweep. The outcome of such a joint saw 29 data protection regulators addressing about 1494 websites which targeted children. It was reported that about 67% of those apps actually collected personal information and only 31% accounted for those that had effective controls in place (Information Commission Office 2015) [43]. Additionally, in March ICO hosted an Annual International Enforcement event which was attended by more 30 delegates representing over 20 organisations in the world. The event was characterized with workshops and discussions with the main intent of helping practitioners understand how to make international enforcement cooperation successful in the privacy regulatory community. International collaboration plays a critical role in learning best practices as well as lessons learn in health data governance. Research on international collaboration revealed that it

is especially needed for guidance in implementing projects, support and evaluate national legal framework for the protection of health information, and to ensure there is sufficient agreed international standards for data coding and interoperability (OECD 2015) [48].

6. Funding and Sustainability

NHS is mainly funded by tax augmented by national insurance contributions. Generally, taxes usually incur low administrative costs, thus they are usually an efficient way of raising money. It is also important to note that, while NHS is said to be free there some services such as medication that requires some contribution. However, the relative contribution of these sources of finance has fractured large and by for instance private insurance accounts for 10.6% of the entire population (Helen McKenna et al 2017) [49]. On another hand the Information Commissioner financial performance revealed that the institution has continued to be funded by grant in aid. In 2015, grant in aid was about £ 3750k. With regards to data protection activities, they are funded by fees collected from data controllers. The Data protection Act requires that all data controllers need to notify their processing of personal data. The cost of the fee is £35 per year, basically this fee was introduced in 2000 and has since remained unchanged to date. However, it is key to note that £35 only applies to charities and small organisations with about 250 employees .Larger data controllers defined as those who make £25.9 million and above and have a total size of the work force above 250 employees are required to pay £500 as of 2009 going forward. The same applies to public organisations employing more than 250 people. The period (2014-2015), a total of £17,519 k was collected. Further Information Commissioner office undertook the initiative of checking up which sectors were underrepresented bringing an additional of 2750 to 3000 additional data controllers in the same year (Information Commission Office 2015)[43].

Whereas sources of funding are not just limited to tax, fees and grants. Health Data Research United Kingdom took it open themselves to fund master's program in health data science at the University of Exeter. This newly funded program is aimed at equipping health professionals with skills to use big data in NHS. Apart from Exeter University, there are 5 more universities that won funding from Health Data Research U.K. The funding is especially designed to curb the shortage of big data skills in United Kingdom. (University of Exeter 2019)[51].

4.1.3 Legal and Policy Factors

Generally the legislative landscape of open health data in United Kingdom can be seen from legal instruments that govern confidentiality and treatment of medical health records, and the legal framework regulating open data. There are four acts of parliament that govern medical data these include Public Records 1958, Data Protection Act 1998, Access to medical Reports Act 1988 and Access to Medical Records Act 1990. (Stefaan Verhulst. et al 2014)[42].

The Legal framework that governs how personal information is used is complex in the UK. There are various legal instruments that primarily underline how confidential information is to be utilized. Among them is NHS act 2006, Data Protection Act, Human Rights Act, and Health and Social Care Act 2012. The aforementioned laws allows personal data to be shared between service providers and patients whilst ensuring confidentiality is maintained without compromise when data is been used for other purposes such us research. The purpose for secondary data use is to research what treatments works, commissioning clinical services, planning public health services, and improving the quality of care provided. Findings revealed that, besides the aforementioned laws there are other materials that support information governance in the U.K health sector. Below is a quick outline of information governance support materials (National Health Service 2016) [46].

Invoice Validation; through the secretary of the state for health, an approval was given to NHS England for an extension under regulation 5 of the health service of 2002. This approval allows commissioning groups to process confidential data. Risky stratification; NHS England gained approval in 2013 from the secretary of the state regarding the disclosure of the secondary use services. Fair Processing; according to European Union General Data Protection Regulation, it is required that all data controllers provide information to people whose information is been held or used. This is mainly done through a privacy notice. In terms of content, a privacy notice contains the following information; who the data controller is, contact information for its data protection officer, the purpose for collecting and using personal information, how will the data be used or disclosed, the legal basis that the controller has for processing the data and how long will the data be kept. The legal framework gives

citizens' rights to personal health information, among them include the following; right to access personal information, request correction of personal data, Request to erasure of personal data,

Request restriction of processing personal data to mention but a few (National Health Service 2016)[46].

1. Access and use of Data

According to Information Commissioners Office, /20152016 annual report, findings showed that there are several law tools that control matters to do with accessing and using information in NHS. The proceeding paragraphs highlights some of the key laws in detail (Information Commissioner's office 2015) [43].

- The Data Protection Act 1998 (DPA) - This particular act is crucial as it gives citizens the entitlement to be informed on what kind of information public agencies hold. Secondly, it also gives them the right to correct any error in the information being held. It was basically enacted with the mandate of protecting the wellbeing of the people by ensuring that the organisations that manage information do so effectively. On the hand, The Freedom of information Act of 2000 (FIOA) guarantees the general right to access information there by promoting a nation of directness and answerability throughout the public sector.
- 2003 Privacy and Electronic Regulations (PECR) - This piece of legislation is important as it plays key role by supporting the Data Protection Act in regulating electronic communications regarding unsolicited marketing to individuals as well as organisations.
- The Environmental Information Regulations 2004 (EIR) - This legislation provides supplementary means of ensuring people can access information relating to protecting the environmental. It covers nearly all firms, the business sector inclusive.
- The Infrastructure for Spatial Information in the EU Community Regulations 2009 (INSPIRE) – This regulation empowers the office of the information commission with power to the proactive provision of geographical information by public organisations.
- The Data Retention Regulations 2014 (DRR) - Is essential as it delivers the information commissioner a limited superintendent role according to the Data Retention and Investigatory powers Act 2014. The DRR enforce responsibilities and tasks regarding the entire communication endowment, organisations whose work is retentive communications data regarding third party inquiry tenacities in in instances where they ought to comply with the notice bearing the authority of the secretary of the state.
- The Re-use of Public Sector Information Regulations 2015 (RPSI) - This act gives the citizens the legal entitlement to ask for the re-use of government information. Further, it also gives a guideline on how public organisations should charge for re-use as well as license information. The body that is charged with the responsibility of handling complains that borders on how public bodies' deals request to use information is the Information Commissioner Office (Information Commissioners Office 2015) [43].

Besides the acts of parliaments, research findings show that there are several policies that play important roles according to different regions. For example Public Health England has an HIV and STI data sharing policy. The primary purpose of Public Health England is to protect and improve the general wellbeing of citizens through world class science knowledge, intelligence, advocacy and partnerships in service delivery. A policy was created with respect of sharing, storing and accessing patient level aggregated HIV and STI data (Public Health England 2015) [50].

1. Key Data Governance Mechanism on Health Open Data

Findings show that the Advisory panel of experts on health information infrastructure recommended the following key factors in order to ensure open health data work effectively (OECD, 2015)[48].

a) There should be a health information system that supports the monitoring as well improvement of healthcare quality and system performance. This should be coupled with innovations that could bring about better health care outcomes.
b) There should be both primary and secondary processing of data for public health research as well as statistical purposes. This should be subjected to safeguards enshrined in the legal framework for data protection.

c) There should be public Consultation, as well as dissemination of information regarding how health data is collected and used.

d) There should be certification for processing health data for statistics and research.

e) There must be justice and transparency as well as the decision making process ought to reinforced by a multidisciplinary and independent project review body.

f) Organisations must adopt best practices as far as data de-identification is concerned to protect patient data privacy.

g) Best data security and management practices must be adopted to mitigate problems of re-identification as well as breach risks.

h) There must be international review of governance mechanisms to harness social benefits and perils as novel information sources and technologies are being introduced

2. Right to freedom of information

1. NHS Constitution

Findings reveal that that the NHS constitution plays a critical role in establishing rights to patients, public and staff. The Secretary of the State for Health and all NHS organisations , voluntary groups, local authorities are mandated by law to see to it that they exercise their functions in accordance with the law. Generally, NHS is guided by a number of principles, among them includes excellence and professionalism, partnership in the interest of patients and the wider community, creating the best value out of taxpayers money to mention a few (National Health Service 2015) [52].

2. Equality Act 2010

Another important piece of legislation is the Equality Act 2010. This particular law mandates government establishments to eradicate illegal discrimination, harassment or victimisation of any form as they exercise their functions. The idea is to advance equality between people as well as ensure good relations (National Health Service England 2016) [53]. For example is there is a digital platform in Buenos Aires which is aimed at ensuring inclusiveness in accessibility to reproductive health services. This platform enables disadvantaged nationals to access geo-referenced good health information and bring forth issues regarding the quality of care provided (Open Government Partnership 2019) [54].

3. Information Rights Strategic Plan 2017-2021

The recent strategic plan is centered on upholding information rights for the United Kingdom citizens in the digital age. The vision behind this rationale is to increase confidence of the people in the public organisations and agencies handling and managing their personal information. Some of the strategic approaches adopted by the information commissioner's office includes the commitment to lead the implementation and effective oversight of the General Data Protection Regulation as well as other protection reforms. Secondly, to explore the technological agile ways protecting privacy. In the quest of the aforementioned, ICO set out key strategic priorities, below is a brief outline;

Leadership, the key emphasis here is to scan the horizon for new technologies as well as risks to information rights. Additionally, provide excellent guidance on the regulatory framework. The other key area is that of advising and influencing government on data protection policy makers in Scotland, Wales and Northern Ireland. Last but not the least, ensure partnership with key public, private and third sector stakeholders in the whole U.K in improving information standards (Informational Commissioners Office 2018) [45].

4. Freedom of Information Act 2000

Public Health bodies in Northern Ireland, England, Scotland and Wales are mandated to publish information to the citizens under their publication scheme for re-use. The FIOA 2000 ensures that government bodies provide the requested information unless it has been fully established that the information in question is not appropriate for release. The datasets code of practice requires that government agencies releases the data sets for re use under

open government License. Section 15 of the FIOA defines what is meant by dataset. The information Commission Office provides the guidance on dataset provision in FIOA 2000 Act of what is meant by "not appropriate" and "capable of re-use". (Health Bodies England 2014)[56].

As earlier established a publication scheme required by FIOA 200 plays a critical role in guiding information provision. The following is a summary of what information is requested by the publication scheme.

Publication Scheme

- **Who we are and what we do**
  The following information is requested under here; organisational information, structures and contacts. The information under this heading must be current only.
- **How we fit into the NHS structure**
  Given the complexity of NHS it is mandated that information be given regarding how the organisation fits into the local structures or national is provided. This includes the role and responsibilities of the authority.
- **Organisation Structure**
  Information on cooperate governance such as details of the governing board members and other key personal's must be provided. This should be accompanied by an explanation of internal structures and how the structure relates to the roles and responsibilities. Also information on key partnerships that the organisation has including meetings with pharmaceutical companies and medical suppliers.
- **What we spend and how we spend it**
  The information provided here relates to financial expenditure, contracts, audits and procurement. Other details that must be provided includes staff pay grading structures including endowment funds if any. Additionally, information on procurement and tendering procedures must be provided including current tender contracts.
- **What our priorities are and how we are doing**
  The following information is requested here; strategic plans, projects performance indicators, financial reviews, and assessments. Basically under this section, the information released covers annual reports, annual plans, targets, aims and objectives, performance against key performance framework, reports by regulatory bodies like care quality commission as well as NHS, Privacy impact assessment, service user surveys and many others.
- **How we make decisions**
  This section involves information on decision making processes and the records previously made decisions. Information should also cover patient and public engagement strategy, public consultations, internal communications and criteria that is deployed in decision making , manuals , Board papers like agendas to mention a few.
- **Our policies and procedures**
  The following information must be provided here, current written protocols, procedures as well as policies for delivering services. Information relating to health and safety, policies and procedures on human resources, employment, equality and diversity, codes of practices, memorandum of understanding, Data protection, information management and other similar information must be provided.

3. Data Protection

Data Protection is one of the major priorities for NHS. Findings reveal that there are several data security and requirements mandated by law to ensure public organisations meet the expected standards as they release information. According to the Digital, Data and Primarily care, Data security and protection requirements as well National Health Service and department of social healthcare there are certain requirements and standard that public bodies must meet and below is the outline (Department of Health and Social care 2017)[57].

- 2017/18 Data Security and protection requirements: This document stipulate the steps that must be followed by all health and care organisations to ensure the ten data security standards are effectively implemented. It also sets out the assurance framework. However, from 2018 the Information

Governance Toolkit (IG Toolkit) was replaced by the Data Security and protection toolkit (DSP Toolkit)

- Thus when it comes to monitoring, the Care Quality Commission (CQC) pays critical attention on how public agencies are assuring themselves in implementing data standards. In 2017/2018 NHS established three leadership obligations that NHS organisations must adhere to in ensuring the data security standards are met and they include the following:
- People: Assets that there must be a high-ranking administrative leadership to oversee cyber and data security in all government wings. Secondly, it is required that all the staff complete the needed annual training on data security and protection, as earlier noted the Information Governance training was replaced by the Data security and protection training whilst retaining the key elements. These trainings are also available online.
- Processes: All organisations must have continuity planning responding to data security as well as cyber incidents. Further, such planning must also include disaster recovery and near misses. There must also be a primary contact person responsible for receiving and coordinating careCERT advisories.
- Technology: All organisations are obligated to identify unsupported systems (this includes hardware and software applications) and replace them or rather mitigate the risks that could be associated with such unsupported systems. Additionally, NHS Digital at times requests organisations to do on-site cyber and data security assessment if need arises. It is a must that organisations act on the assessment outcomes and recommendations.

There is also a mandate for organisations to check the supplier certification; any supplier of IT systems to health and care organisations must meet the standards below. The supplier must hold a current ISO/IEC2 certificate issued by UKAS. UKAS is an accredited certifying body which looks at all the core activities in delivering services to organisations. Other certification include Cyber Essentials (CE) issued by CE certification body, Cyber Essentials Plus (CE+) and many other applicable (Department of Health and Social care 2017).

Findings also show that the United Kingdom adopted some key principles for data governance which effect all practices of data governance as well as ensure trustworthiness in how data is managed and used. The most underlying principle is the elevation of human prosperous which guides data governance system. Under this principle exists other core principles as follows: Data management and use; the key elements under this principle are: to safeguard citizens' legal privileges and interests, ensuring that tradeoffs affected by data management are done in a transparent manner. Further, good practices must be sort out and learning anchored from both success and failure. It is expected that the data governance framework should anticipate, monitor and evaluate, build practices and standards, and clarify, enforce and remedy. Additionally, data governance should ensure and facilitate citizen participation and enhance existing democratic governance systems through transparency and accountability (British Academy 2017) [58].

4. Privacy
1. Anonymisation code of practice of 2012

The need for privacy whilst publishing health datasets is critical in United Kingdom. The Anonymisation code of practice of 2012 plays a serious part in elaborating implications of anonymysing individual data and disclosing the data that has been anonymized in harmony to the Data Protection Act of 1998 requirements. Basically this code provides advices on good practices to all public organisation intending to anonymize individual data. A number of issues under data Anonymisation stems from the context of freedom of information act 200 and freedom of information act 2002 (Scotland). Further this code contains details explaining the exemptions of the Data Protection Act regarding research and the underlying significance. The intended purpose of this code is to show that effective Anonymisation of personal data is possible, desirable and stands a great deal in ensuring the availability of rich data through open health data initiatives. Some of the benefits of this code include, greater confidence when dealing with transparency agenda imperatives regarding any publication of information. Secondly, developing public trust by ensuring legal safeguards are in place, reducing questions complaints and disputes. Thirdly, furthering statistical and research that depends on information obtained from personal data. (Information Commissioner's Office 2012)[59].

For example in February 2005, ProLife Alliance made a freedom of Information Act request to Department of Health to give a detailed statistical information regarding the abortions carried out in 2003. The scenes of this request are that at first department of health declined the request on grounds of freedom information exemptions

from disclosure and section 40 regarding personal data. Later a complaint was made to the Information commissioner and an appeal to the Information tribunal. Far along, the matter was head in court of law with the key consideration of DPA. In the end the Department of Health was made to effectively anonymize the information and made it available as requested (Information Commissioner's Office 2012) [59].

2. Code of Conduct for Data –Driven Health and Care Technology

It is recognised that, at present there are a number of data-driven innovation, apps, and clinical decision support tools as well as advancements in artificial intelligence. However, data sharing across NHS is guided by a code of conduct which clearly spells out the expected behaviours by all those developing, deploying and using data-driven technologies. Some of the key guiding principles include respect for persons, accounting for decisions, participation and respect for human rights. This code of conduct handles various challenges regarding ethics in NHS and the wider health and care system. This cause is also supported by Center for Data Ethics and Innovation to ensure latest best practices. Additionally the whole health community is engaged in addressing couple issues that may arise. Other principles include; to understand user needs and the context; that is to say it must be established who exactly the intended beneficially of the innovation is and the problems aimed at. Secondly the outcome must be defined and how the technology contributes to it. Others include, the use of open

Standards, fairness and transparency to mention a few (Department of Health and Social Care 2019) [60].

3. Policy Initiatives to Support and Influence Open Health Data in NHS

A summary of policy initiatives 2013 to 2018

- 2013- The Caldicott Independent Review of Information Governance in the Health and Care System. Caldicott was chosen as the paramount constitutional National Data Protector for healthcare in 2014.
- 15 Academic Health Science Networks (AHSN) were established to improve health outcomes as well as innovation and economic growth with a funding of £39 million through the Office of Life of Science.
- 2014-Five Year Forward View: National Health Service England together with other national bodies created the FYFV with the focus on new models regarding three gaps namely, health and wellbeing, care and quality and funding and efficiency. This also included the ambition to harness the information uprising and clinically IT solutions. This development brought about new inputs to digital transformation with an additional investment of £4.2 billion from treasury. Later the National Information Board (NIB) published personalized health and care 2020 which is a framework set to support digital transformation in the health sector.
- 2015- National Advisory Group (NAG) on Health Information Technology was established by NHSE and DHSC. National Health Digital released a strategy called Information and technology care strategy 2015-2020, the core purpose of this strategy was to revolutionize the way technology, data and information are used in ensuring effective service delivery. Its main aims was to ensure every citizens data is protected as well as establish information standards and architectures to support all the health organisations harness the best from technology and data. Finally, to ensure health and care information is put to better use.
- 2016- The National Data Guardian Review of Data Security, Consent and Opt-outs was published. The main purpose for this was to build trust as well as assurance on information sharing and a consolidated cross system approach to patient consent. Thus from January 2016 there is been much collaborations between social care organisations as well much funding. For example £45 million multi-year program for online consultation, general practice forward view£ 2.4 billion to support new digital technologies to mention a few.
- 2017-Building Digital Ready Workforce (BDRW):The National Information Board established NHS Digital Academy to accelerate the development of 300 senior NHS Digital learners using a mixture of online , residential as well as work based learning. Thenceforth, there have been a couple of efforts in addressing the digital gap to ensure staffs and patients are supported in their own digital literacy (Deloitte Center for Health Solutions 2019) [61].

4.1.4 Political will/Leadership Factors

1. Civil Society Will

Active participation by the community and civil society organisations is critical in ensuring wider consultation on a various issues and service delivery at large. In this regard, findings revealed that, The Health and Social Care Act 2012 established a statutory duty for all Health and Wellbeing boards to ensure continuous commitment with local societies throughout processes. This in the end provides a vehicle to capture detailed knowledge that voluntary organisations and the community have regarding the needs of the several publics they serve (Manchester City Council 2019) [62]. Furthermore, the Department of Health annual stakeholder survey 2013, showed that many stakeholders had a positive attitude regarding doing business with Department of Health. The percentages were 78% in 2013 progressively, from 57% in 2009. Stakeholders added that the department is very professional, has a good work ethic and is committed (Cabinet Office 2014) [63].

2. Political will

Findings on the various legislative frameworks in the united kingdom regarding Open Health Data reflects and constitute great visionary leadership at various levels of governance. This kind of leadership is transformational as can be noticed in various laws, reports and policies that are long term in nature. Below are some of the administration stratagems and plans that shapes the vision of open health data in a great a sense.

1. Department of Health: The power of Information Strategy 2013

This strategy is quite important in the United Kingdom as it embraces change and marks a shift in how information ought to spearhead better health care and support in improving experience, quality of health whilst putting people at the heart of care. The strategy plays a crucial role as it set the ambition, clear direction and actions that ought to be conducted in a bid to transform health care services, needs and expectations at the moment and future. In a nutshell, the strategy has a ten year framework aimed at harnessing information and new technologies. It is underpinned by the Health and Social Care Act 2012. The thoroughfare plot of transformation outlined in this strategy focuses on transforming how information is gathered and used with a sturdy importance that the necessities of patients, providers, users and citizens are the key drivers for change. Basically, the strategy supports information from a broader perspective, including the support needed by people to navigate and understand available information (Department of Health 2012) [64].

2. United Kingdom Action Plan 2019-2021

The UK government to present remains committed to principles of transparence and openness of government. The adoption of this Fourth National Action Plan for open government symbolizes the country's political will to increase answerability as well the perceptibility of government institutions and services. The rationale for this National Action plan is centered on harnessing Innovative technology to erode public trust in state institutions, strengthening democracy and curbing irresponsible use of private information. The United Kingdom is a founding associate of the open government partnership which has been vital in creating new forms of accountability and shining light on developmental issues like corruption and fraud. Key commitments enshrined in the National Action plan includes opening up policy making, transparency and improvement to quality and quantity of data that the government publishes (Open Government Partnership 2019) [65].

4.1.5 Challenges

Despite the success of the United Kingdom in open heath data, it has also a several challenges. The challenges experienced can be categorized in 4 as shown below.
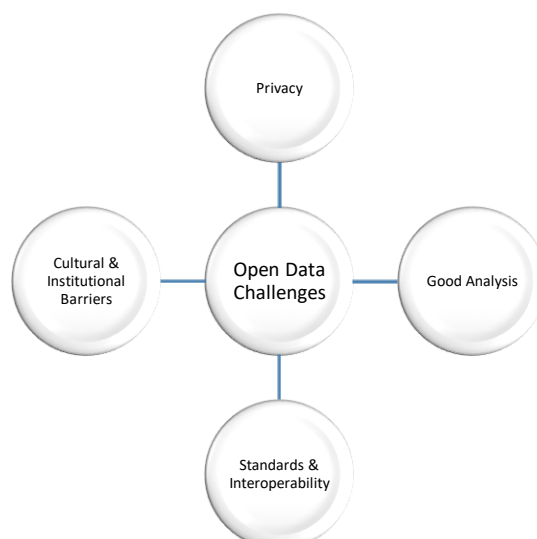
Figure 4-4 Challenges in Implementing Open Health Data

It is recognised that bureaucratic, Institutional as well as cultural resistance are among the top notable challenges that data transparency face. It was acknowledged that not all resistance can be attributed to bureaucracy but other cultural factors like vested interest also can be challenging. Vested interest may be as a result of fear of losing authority or being exposed or put simply fear of the unknown. To achieve potential open data in healthcare sector calls for a change in culture. This implies patients, providers as well as administrators ought to adapt to new ways of collecting and using data and this is not easy(Stefean Verhulst. et al 2014) [42]. British Academy, (2017)[58] puts it, as data collection activities continue to evolve rapidly the analytic techniques equally will need to adapt and eventually become sophisticated and this in its own sense will affect individuals and the community in unexpected ways. Additionally, there is a critical requirement for extra training, education, mentoring as well as general human capacity building as they are key factors to increase data transparency today.

Other challenges are that there is no discovery mechanism for health data, that is to say a user ought to know what data they are looking for, who is charged with the responsibility to publish such data, and where it is published. Findings indicate that health data is shared on ad-hoc basis responding to either an organisation or an individual, this has a potential of leading inconsistences in reporting and it is time consuming. Furthermore, data published in pdf formats or in web applications is not easy to process for analysis purposes. There are often poor data maintenance and standardization techniques in place. Last but not the least, HSE has a huge quantity of health data which has not been published yet. This hinders harnessing the benefits of Open health data (Office of CIO 2016) [66].

4.1.6 Summary

This section explored the Management, Legal, and Leadership factors that guarantees open health data in the United Kingdom. The following is a summary around the theoretical framework of this study.

1. Management and Organisational Factors

Under management factors, findings revealed that there are several structures that play crucial roles in open health data and they include the following: National Health Service (NHS) established in the year 1946 to provide health care. Secondly, The Information Commission office: This office is tasked with the directive of upholding information rights in the public interest as well as promoting transparency in public bodies and ensuring data privacy for the Citizens. Additionally, it sees to it that citizens are aware of their lawful information entitlements and are confident using them and capable of protecting themselves from any possible misuse. Furthermore, this office overs the legal framework concerned with information in the U.K the following are some of laws under its jurisdiction: The Freedom of Information Act 2000(FOIA), The Privacy and Electronic Communication

Regulations 2003 (PECR) The Data Protection Act 1998 (DPA), The Data Retention Regulations 2014 (DRR), The Re-use of Public Sector Information Regulation 2015 (RPSI) and other legislations concerned with information.

Other structures include: The Chief Data Officers Team an administrative structure within NHS charged with the responsibility of developing and delivering a strategy regarding the use of data at every level of the organization. Secondly, the Data Policy Unit which works closely with commissioners as well as other various stakeholders such as researchers, Clinicians, and patients in order to establish needs and requirements regarding information standards, and open health data governance. Then the Data projects unit implements the requirements as established by the data policy unit with focus on benefits realization. On the other hand, the Data Sharing and Privacy Unit (DSPU) provide guidance regarding privacy, data sharing as well as managing information governance strategic risks.

In order to ensure NHS meets the information commissioner needs, it has a principal partner called NHS Digital. Basically, NHS Digital plays a crucial role in providing information to support better care by ensuring there is high-quality data Collection, analysis as well as storage services, information governance as well as working in partnership with the Board for National Information to provide leadership.

1. Decision-Making Processes

All decision making process regarding access, data protection, use, confidentiality, and complaints are governed by the legal framework in the U.K. Freedom of Information Act 2000 (FOIA), General Data Protection Regulation (GDPR) as well as Data Protection Act 2018 (DPA) and other relevant legislations empowers citizens to access information held by public bodies and agencies and set the procedural measures .

2. Supervision & Accountability

The office of Information Commission Office ensures there is compliance with the Freedom of Information Act. The agency takes greater account of matters to do with intelligence coming from casework and makes more use of tasking as well as groups charged with the responsibility of coordination. This is mainly done through formal monitoring of all government agencies and departments, councils as well as the police force to obtain current freedom of Information performance statistics and act accordingly.

3. Cooperation Mechanism

There are a lot of local and international cooperation and collaborations in NHS that impacts open health data greatly. An example is the 2014, memorandum of understanding that was signed between the United States Department of Health and Human Services and National Health Service England Research on international collaboration for guidance in implementing projects, support and evaluate national legal framework for the protection of health information, and to ensure there is sufficient agreed international standards for data coding and interoperability.

4. Funding and Sustainability

The NHS is mainly funded by tax augmented by national insurance contributions, grant in aid. Additionally, The Data protection Act requires that all data controllers are mandated to notify their dispensation of private data at a fee of 35 pounds per year. Though the size of the organisation can impact the fee.

2. Legal and Policy Factors

The legislative landscape of open health data in United Kingdom can be seen from legal instruments that govern confidentiality and treatment of medical health records, and the legal framework regulating open data. There are four acts of parliament that govern medical data these include Public Records 1958, Data Protection Act 1998,

Access to medical Reports Act 1988 and Access to Medical Records Act 1990 (Stefaan Verhulst. et al 2014)[50].The aforementioned laws allows personal data to be shared between service providers and patients whilst ensuring confidentiality is maintained without compromise. Other materials that support information governance in the U.K health sector Include: Fair Processing: according to European Union General Data Protection Regulation, it is required that all data controllers provide information to people whose information is been held or used. This is mainly done through a privacy notice. In terms of content, a privacy notice contains the following information; who the data controller is, contact information for its data protection officer, the purpose for collecting and using personal information, how will the data be used or disclosed, the legal basis that the controller has for processing the data and how long will the data be kept. Additionally, NHS constitution plays a critical role in establishing rights to patients, public and staff. Meanwhile, the Equality Act 2010 mandates public establishments to eradicate illegal discrimination, harassment of any form be it employment, access to information etc.

Another important factor is that a publication scheme required by FIOA 200 plays a critical role in guiding information provision: in terms of content a publication contains the following: Who we are and what we do, how we fit into the NHS structure, Organisation Structure, What we spend and how we spend it, What our priorities are and how we are doing, How we make decisions, and Our policies and procedures.

1. Data Protection

Findings disclose that there are several data security and requirements mandated by law to ensure public organisations meet the expected standards as they release information. According to the Digital, Data and Primarily care, Data security and protection requirements as well National Health Service and department of social healthcare there are certain requirements and standard that public bodies must meet. In 2017/2018 NHS established three leadership obligations that NHS organisations must adhere to in ensuring the data security standards are met: People: Asserts that there must be a high-ranking administrative leaders to be accountable for cyber and data security in the organisation, Processes: All organisations must have continuity planning responding to data security as well as cyber incidents, Technology: All organisations are obligated to identify unsupported systems and replace. There is also a mandate for organisations to check the supplier certification; any supplier of IT systems to health and care organisations must meet the standards. For example ISO/IEC2 certificate issued by UKAS. Other certification include Cyber Essentials (CE) issued by CE certification body, Cyber Essentials Plus (CE+) and many others applicable.

Further the Anonymisation code of practice of 2012 plays a critical role in elaborating implications of anonymysing personal data and disclosing the data that has been anonymized in harmony with the Data Protection Act of 1998 requirements in United Kingdom. Basically this code provides advices on good practices to all public organisation intending to anonymize personal data.

On the other hand the Data –Driven Health and Care Technology code of conduct handles various challenges regarding ethics in NHS and the wider health and care system. This cause is also supported by Center for Data Ethics and Innovation to ensure latest best practices.

Findings further revealed that there are policy initiatives to support and influence open health data in NHS from 2013 to 2018. Among them include: The Caldicott Independent Review of Information Governance in the Health and Care System, National Advisory Group (NAG) 2015 on Health Information Technology was established by NHSE and DHSC, and Building Digital Ready Workforce (BDRW) 2017 to mention a few.

3. Political will/Leadership Factors

1. Civil Society Will

The Health and Social Care Act 2012 establishes a statutory duty for all Health and Wellbeing boards to ensure continuous engagement with local communities throughout processes to capture detailed knowledge that voluntary organisations and the community have regarding the needs of the various communities they serve.

2. Political will

The various legislative frameworks in the united kingdom regarding Open Health Data reflects and constitute

great visionary leadership at various levels of governance. Department of Health: The power of Information Strategy 2013 strategy is quite important in the United Kingdom as it embraces change and marks a shift in how information ought to spearhead better health care and support in improving experience, quality of health whilst putting people at the heart of care. The strategy plays a crucial role as it set the ambition, clear direction and actions that ought to be carried out in order to transform health care services, needs and expectations now and in the future. Another critical factor is the United Kingdom Action Plan 2019-2021. The UK government to present, remains committed to principles of transparency and openness of government. The adoption of this Fourth National Action Plan for open government symbolizes the country's political will to increase answerability as well the reflectiveness of public organizations and services.

4.2 The Australia Open Health Data Guarantee Mechanism

4.2.1 Management and organizational Factors

1. Organization Structures

Findings show that there exist several organisational structures that plays crucial roles in ensuring open health data is effectively implemented in Australia. Below is outline of the critical structures;

1. Office of the Australian Information Commissioner

This is an independent agency that lies under the jurisdiction of the Attorney General portfolio. Its major mandate is promoting and safeguarding confidentiality, liberty of information as well as government information policy. Thus it conducts investigations, decision reviews, complaint handling and providing guidance and advice. This office has regulatory powers and responsibilities in harmony with the Liberty of Information Act 1982, and the confidentiality act 1988. The information commissioner makes use of various sources to acquire information on issues like stakeholder cooperation, Rulings of the federal court of Australia and the High court of Australia , freedom of information statistics to mention a few. (Office of the Australian Information Commissioner 2018 OL)[67].

2. Bureau of Health Information

According to the Bureau of Health Information (2019), at present there is legislation which facilitate the right to information produced by NSAW, Bureau of Health Information (BHI) as well government agencies. Additionally, the government Information Public Access Act of 2009 (GIPA Act) is there to see to it that openness and accountability are realized. Further, to encourage proactive publication of information in harmony with the dictates of the law (Bureau of Health Information 2019) [68].

Bureau of Health Information is mandated to provide independent information regarding how the Healthcare system is performing; it was created in the year 2009 with the sole purpose of realizing accountability and provision of detailed information of the healthcare system to the citizens, healthcare experts and the government at large. The rationale behind this is to ensure improvement and establish opportunities for improving the general healthcare system. Furthermore, Bureau for Health Information collects its rich data from a various sources including patient survey program to see to it that there is effective analysis for reporting trends, benchmarks at the state level, district and hospital level. Year in and out patients are accorded an opportunity to give feedback of the experiences they have had in hospitals and clinics throughout New South Wales Australian State (NSW) (Bureau of Health Information 2019)[68].

3. Australian Institute of Health and Welfare

The Australian Institute of Health and Welfare is a major agency in the country; it was established by an act of law called Australian Institute of Health and Welfare Act of 1987. It is basically a statutory body charged with the responsibility of providing reliable, regular as well as relevant information on Australian health and welfare. Its major works is critical in supporting healthcare policy and programs at the same time a valuable source of

research data .This information agency hugely depends on strong data governance in carrying out its mandates effectively as well maintains a good reputation amongst its data providers, recipients and stakeholders. It is founded on a framework that recognizes legislation, policies, roles and practices, technology to be fundamental tools to deliver operative data governance at AIHW (The Australian Institute of Health and Welfare 2014)[69].

According to the AIHW Act 1987 , the institute is mandated to carry out the following functions gather and release data regarding health and welfare, consolidate and give sustenance in data gathered and created by other organisations or persons, conduct an promote research about the health of Australian persons and services provided to the public . Last but not the least to establish and make recommendations to the minister regarding prevention as well as treatment of diseases, improvement and promoting health awareness to the Australian citizenry. (Australian Institute of Health and Welfare 2018)[70].

4. The Department of the Premier Cabinet (DPC)

This departmental structure is mandated with the accountability of delivering technology, cyber security as well as digital leadership for South Australian Government including citizens and the industry at large. Its major function is assisting government agencies through the provision of ICT, Digital and security policies, standards, guidelines and toolkits (The Government of South Australia, Department of the Premier Cabinet 2019)[71]. In terms of technology this department provides the whole of government services including ICT infrastructure for South Australian Government. Additionally, it safeguards the states infrastructure, information against cyber-attacks and puts in emergency plans. It is also there to take key leadership in digital innovation and online services to mention a few. The SA.GOV.AU website provides single accesses to all sort of information citizens need on various topics. Below is an example of the New South Wales state of Australia data governance Structure.
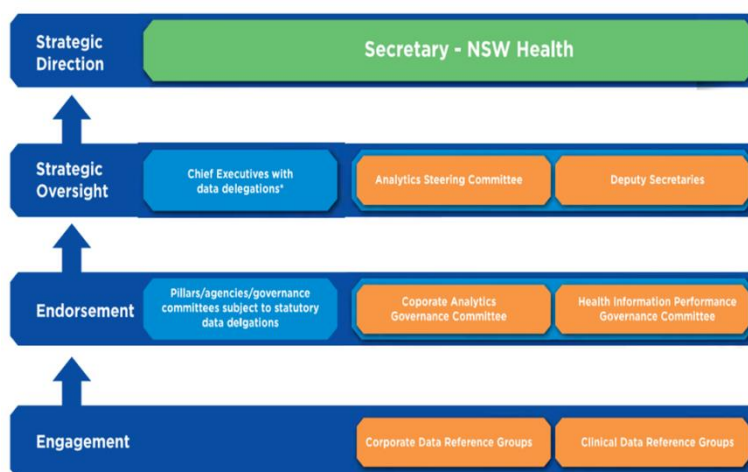

Figure 4-5 NSW Health Data Governance Framework.

Source: NSW Health Data Governance Framework (2019) [72].

2. Roles and Responsibilities

The AIHW is an agency made up of various structures which play varying roles in open health data governance. According to findings some of its key structures and responsibilities include the following:

- AIHW Board
    The AIHW Act under section 4 established the board which is subject to the minister. Section 8 of the aforementioned act clearly details the membership composition. Furthermore, section 5 of the AIHW spells out the key functions that are supposed to be carried out by the board and the include the following; assemblage and creation of all the health and welfare information, discussion with the Australian Bureau of statistics on specialized standards that are significant to health and welfare services, and enabling researchers to access health statistics in line with section 29 confidentiality guidelines (The Australian Institute of Health and Welfare 2014)[69].

1. Ethics Committee

Another structure that plays a central role in the AIHW is the Ethics Committee, findings indicate that, this structure was a result of the Ethics Committee regulations of 1989 which establishes its membership and functions in data governance. The key functions of this committee involves forming an opinion on ethical standings about the acceptability of projects as well as imposing conditions that it sees fit and appropriate on a range of activities like release of identifiable data by the AIHW for research purposes. This is done with regard to highly significant ethical principles as well as standards established by the National Health and Medical Research Council. Findings further revealed that it's not only identifiable data that is subjected to the Ethics Committee but also the use and release of any data held by the AIHW, changes to existing surveys and any work that requires data linkages to mention a few.

2. Australian Institute of Health and Welfare Director

According to Section 18(1) of the act, the AIHW Director is given powers which include managing affairs of the institute, subjected to the guidance and policies of the Board. From Data governance Perspective the director is charged with the responsibility of providing leadership in policy, data security, protecting confidentiality on privacy in line with the established legislation and ethical standards across the scope of AIHW.

3. Data Governance Committee

The Data Governance committee is responsible for activities like approving new data policies and guidelines. Further, it has the oversight of reviewing the data governance framework in 12 months operation. Its membership comprises of senior executives and 3 unit head level staff. Other structures include Audit and Finance Committee, Executive committee, Data Custodians and Security. (The Australian Institute of Health and Welfare 2014)[69].

4. Australia National Data Service

Australia National Data service is a partnership which is spearheaded by Monash University in conjunction with the Australian National University and the Commonwealth Industrial Scientific Organisation. It is financed by the government through the National collaborative Research Infrastructure Strategy. Its major mandate is to ensure to ensure Australia's Data is much more valuable to the research community and the nation at large. In carrying out the mission, ANDS makes use of data management plans.

Additionally, findings show that a data management plan is significant to ensure improvements to efficiency, protection, quality as well as exposure. Typically adopting last minute data management methods that come to mind is more prone to errors and often time consuming in a worst scenarios, it may lead to data loss or violation of privacy. In this resonance, the Australian Research Council and National Health Medical Research Council mandates having a data management plan as a requirement. Below is an example of what a data management plan should cover according to (Australia National Data Service 2017) [73].

Table 4-1 Elements of a Data Management Plan

The following list of topics can be treated as a check-list: Backups	This is essential. You ought to have a reliable backup stratagem of steady backups, and ensure compliance. It is advisable to also have an off-site backup in case of calamity.
Survey of existing data	What current data ought to be managed?
Data to be created	What data will your project create?
Data owners & stakeholders	Who will own the data created, and who would be interested in it?

File formats	What file formats will you use for your data?
Metadata	What metadata will you keep? What format or standard will you follow?
Access and security	Who will have access to your data? If the data is sensitive, how will you protect it from unauthorised access?
Data organisation	How will you name your data files? How will you organize your data into folders? How will you manage transfers and synchronization of data between different machines? How will you manage collaborative writing with your colleagues?

3. Decision Making Processes

The Australian Institute for Health and Welfare has a number of guidelines, procedures and principles to ensure there is total obedience to the legal and supervisory setting on data. In the same vain, international standards and classifications do have a role they play including ethical obligations on both internal, external governance agreements as well as contracts. All the aforementioned are to be followed sanctity by all the members of staff as they carry out their roles and make clear decision making regarding data. From a more useful perspective, findings indicate that AIHW encourages to consider its policies, procedures and guidelines more in line with the data lifecycle; acquisition, use; (access, storage , management and release). Finally, archiving, destruction and return (The Australian Institute of Health and Welfare 2014) [69].

1. Data Acquisition

On data acquisition the following guidelines applies:
a) Information may only be collected and held for the purpose of AIHW activities as contained in the act of law.
b) The institute's Ethics Committee should make the approval before any identifiable information could be collected and stored. This includes all the research involving identifying information. In an event where consent has not been sort, the use of information in a certain perspective of interest , will require the Ethics committee to consider regulations and practices that have been documented
c) The information collected is also limited to the direct significant aims and objectives of the approved project. There is also a data catalogue to ensure of data governance of the information acquired.

2. Dealing with complaints

Findings show that, there are two important documents that provides a clear road map on how complaints regarding privacy, and the role of the AIHW's Privacy officer. These include; AIHW Privacy Policy and the two brochures Safeguarding your privacy. As per custom and easy accessibility these documents are made available on <www.aihw.gov.au>. The Commonwealth Privacy Commissioner is the one charged with appropriate management of complaints on privacy matters. The procedure is that, those applicants who are dissatisfied with the refusal to access data by AIHW under the freedom of Information request, have the right to request for another review of the decision by the AIHW or alternatively can approach The Commonwealth Freedom of Information. On the other hand findings revealed that, the Charter of Corporate Governance provides guidance as well as management of Complaints about Board Members. Further, the Ethics Committee Background and practice document provides details on how complaints made in respect of the committees functions are supposed to be managed. Additionally, all Bi-lateral data sharing agreements by the AIHW are guided by a dispute resolution procedure to ensure prompt remedies to any maters of concern that may come forth (The Australian Institute of Health and Welfare 2014)[69].

4. Supervision and Accountability

The office of Australian Information Commissioner (OAIC) is conferred with the following powers which it exercises in maintaining supervision and accountability regarding information across all government organisations in Australia. The OAIC has power to monitor agencies compliance with freedom of information act, review Freedom of Information decisions of agencies, Investigate complaints, Issues guidelines according to section 93 of the freedom of information act, oversee the information publication scheme by assisting agencies to publish information in accordance with the scheme, and review, monitor as well as investigate compliance.

5. Cooperation Mechanism

The AIHW has since time immemorial adopted a strong collaborative approach in ensuring networking relationships with Australian, state, territory governments including the education as well as private sector. This is not just in practice but is also echoed in the formal arrangements with other collaborating organisations, national data settlements as well as the active participation of AIHW in various national committees. The rationale of informational agreements lies in supporting the availability of nationally-consistent, high-quality data. Additionally, to promote efficient, confidential as well as timely use of data shared among collaborative organisations. The national information agreements are also a critical tool in establishing information infrastructures, processes for data creation, sharing and provision of the National Minimum Data sets to the agency (AIHW). The following are National information Agreements at present (The Australian Institute of Health and Welfare 2014) [69].

a) National Health Information Agreement (NHIA) 2013- This agreement allows the commonwealth, states and territories to come up with programs that could advance, uphold and disseminate national healthcare information.
b) National Community Services Information Infrastructure Agreement. This settles and assists national infrastructure including the procedures desirable to assimilate, strategize and organize the development of reliable national civic services information.
c) National Information Agreement on Early Childhood Education and Care (NIAECEC) - This is targeted at ensuring the availability of national information base regarding early childhood policies, programs as well as reporting requirements.
d) National Housing and Homelessness Information and Infrastructure agreement (NIAHILA)-This is intended at having coordinated and consistent national housing homelessness information.

However, when AIHW is undertaking bi-lateral or multilateral agreements there are a couple of considerations that must met. For example, changes in focus regarding data collection activities, Commonwealth, state and territory legislation that applies to particular types of data. Additionally, memorandum of understandings, contracts that spell out the conditions for data use, disclosure and release are rigorously consulted for better understanding (The Australian Institute of Health and Welfare 2014)[69].

Furthermore, Australian Researchers regularly participate in International collaborative research works and many of the major funders of research mandates data sharing. Some of the collaborative partners include; Well come Trust in the UK, Medical Research Council in the UK, National Institutes of Health (NIH) in the USA, Bill and Melinda Gates Foundation in the USA and National Science Foundation in the USA (Office of the Australian Commissioner 2019)[74] .

6. Funding and Sustainability

1. Funders Guidelines that Support Data Sharing

Research findings indicate that there are funder's guidelines in Australia that has over the time increasing supported data sharing. Below is a quick Outline (Australian National Data Service 2018) [75].

a) National Health and Medical Research Council (NHMRC) Open Access Policy- This policy recognizes the significance of making data publicly available. It strongly promotes sharing research outputs from NHMRC supported Research.

b) National Statement on Ethical Conduct in Human Research – This covers any research on human beings and strong encourages sharing data for future research.
c) Australian Code for Responsible Conduct of Research – This code makes it mandatory for organisations to provide access to facilities where research data is stored safely, and records managed appropriately.
d) The Australian Research Council (ARC) Funding Rules 2016- This too strongly encourages deposition of data into institutional repositories that are publicly accessible.

2. International funders

According to findings, Australian Researchers regularly participate in International collaborative research works and many of the major funders of research mandates data sharing. Below is a list of some of the collaborative partners.

- Well come Trust in the UK
- Medical Research Council in the UK
- National Institutes of Health (NIH) in the USA
- Bill and Melinda Gates Foundation in the USA
- National Science Foundation in the USA

4.2.2 Legal and Policy Factors

1. Access and use of Data

1. Health Data Governance Framework

Findings reveal that health open data in Australia is hugely influenced and facilitated by the health data governance framework. There are about 8 principles in total that provide the foundation for ensuring effective data governance in the health sector and they include the following; Data governance is strategic and well planned, Data quality is described and fit for purpose, Data is protected and secured, data is discoverable and accessible, data is standardized, Data is stored to maximise its value, data is leveraged to support good decision making and finally data is integrated and interoperable (New South Wales Australian State 2019)[72].

Basically the data governance framework is key in ensuring there is shared direction and governance maturity. Its major mandate is to provide agencies with platform to effectively govern their data sets consistently and in a coordinated manner. Additionally, to advice on best practices model for building data governance maturity in various government agencies in that the framework underpins: key principles of good data governance, data governance organisations, data governance components, roles and responsibilities. Last but not the least recommended implementation activities that ought to be carried out. The framework does not prescribe a one size fits all approach on data governance. It is basically a model that sets out good practices that could be adopted by various agencies in order to improve their data governance.

By law good data governance is more than just a mare requirement in NSW government, rather it is mandatory and aligned with government statues, regulations as well policies relating to data governance and they include the following: (New South Wales Australian State 2019) [72].

- Privacy and Personal Information Protection Act 1998
- State Records Act 1998
- Health Records and Information Privacy Act 2002
- Government Information (Public Access)Act 2009
- Data Sharing (Government Sector) Act 2015
- NSW information Management Framework 2018
- NSW Digital Information Security Policy

Furthermore, findings indicated that, it is mandated that each department have a clearly defined data governance structure. At minimum the structure is suppose have the following key individuals and bodies;

- The Secretary or Chief Executive- This office should set the strategic direction and must invest in data governance initiates.
- Chief Executives, Steering Committees etc. – Must be responsible for strategic oversight of data governance activities
- Agencies and Government Committees- Are responsible for endorsement and providing input on data governance activities,
- Working Groups –Should be engaged in addressing specific data needs

This Kind of structure is critical in establishing decision making authority at all levels. Illustrated below is the NSW Health Overarching data governance structure.

2. Open Health Data Legislation

Findings indicate that are a number of laws, standards, manuals and policies that are put in place to regulate and safeguard access and use of open health data. The Table shows some of the key legal instruments and a proceeding paragraphs will lay out a summative outline of a selected few (The Australian Institute of Health and Welfare 2014)[69].

Table 4-2 Open Health Data Legislation

Freedom of Information Act 1982
The Archives Act 1983
The Australian Institute of Health and Welfare Act 1987
Privacy Act 1988
The Australian Institute of Health and Welfare Ethics Committee Regulation 1989
Australian Government Information Security Manual
Australian Government Protective Security Policy Framework
High Level principles for Data Integration (Cross Portfolio statistical integration Committee)

3. Australian Institute of Health and Welfare Policies and Guidelines

Table 4-3 AIHW Corporate Documents Policies and Guidelines

AIHW Ethics Committee Background and Practice document
Charter of Corporate Governance
Data Collection Management Principles
Data Custodianship Delegations
Data Linkage and Protecting Privacy Policy
Data Quality Statements Policy and Guidelines
Guidelines to Collaborating Units on Secure use, handling and storage of AIHW data
Guidelines for the Custody of AIHW data
Guidelines for Preparation of Submissions for Ethical Clearance
Information Security and Privacy Policy and Procedures
Physical Security Policy
Policy on reporting to manage confidentiality and Reliability
Publications Review Policy

	Secure use of ICT systems procedures
	Secure Messaging user guide and procedures
	Security Risk Management Policy

4. Access

When it comes to data management, Australian Institute for Health and Welfare have procedures beginning from access, storage until release of data. To ensure secure use of ICT systems, the first level of data access management involves procedures which include passwords and access to computer room. Furthermore, there is a signed confidentiality undertaking that must be lodged before any member of staff can be given access to any part of the Institute Computer system. Basically, AIHW's has information security and privacy policy and procedural guidelines which must be principally followed when it comes to accessing data. Additionally, there are requirements for access and specific data sharing agreements which must be followed at all cost according to the legal dictates. The office of Data Custodians is the one responsible for approving access to data, how it is used and the data collection for which they are entrusted with delegated authority. Their greater responsibilities spans across internal and external request access of the data held by the agency. Research purposed data requires prior approval by Australian Institute for Health and Welfare Ethics Committee (New South Wales Australian State 2019) [72].

5. Storage and security

On storage and Security AIHW has a high security for the data it holds both logically and physically. For one have access to data they are subjected to multiple levels of approval. Access is further audited and logged as well as permissions are revoked from individuals who no longer need access. AIHW provides and ICT based security, virus detection secure messaging and an ICT security page of the intranet. The Agency has risk management policies which details the approach to managing risks, delegating security related roles as required by the Australian Government protective policies, Agency Security Advisor as well as IT Security advisor. The aforementioned structures impose a number of requirements regarding compliance with directions issued by management, data providers as well as Ethics committee. They also see to it that data custodians are protected from unauthorised access, alteration or loss. Finally, they also task ICT units maintain a safe electronic environment, handle classified information properly including any photocopying of paper based information (New South Wales Australian State 2019) [72].

2. Privacy

There are a number of AIHW policies and procedures which reflects the obligations of the 1998 Privacy Act. Particularly, AIHW privacy policy, two broachers on safeguarding your privacy are available on the website of the agency. These documents outline the agency's approach to privacy, matters provide details on complaints handling procedures and contact details for the privacy officer of AIHW.

1. Data linkage

The Australian Institute of Health and Welfare is among the two integrating authorities that is accredited by the commonwealth data in Australia for high risk research projects. Over the years the agency has maintained its accreditation through following a stringent criteria which involves project governance, data management, capability as well as privacy and confidentiality. The other institution besides AIHW is the National Statistical Service (NSS) which applies integrating best standard protocols. Which is quite critical regarding best practices in data linking and management that secures privacy by separation of identifying data and content data.

2. Quality

Regarding quality management, the ICT strategic Plan for 2011-2014 which is anchored on consolidation and implementing a single source of truth for AIHW data collections analysis and outputs, underpins the agency's approach to quality. There basically 3 aspects on quality is managed namely ; working towards maximising the currency and quality of data, ensuring appropriate use of data given their quality and reporting on data quality. In practice, AIHW works hand in hand with data providers to maximise the currency as well as the quality of the data collection. To achieve this AIHW has in place an Online data receipt and validation product, ValidataTM, which is designed to improve the quality and timeliness of the data that is been supplied based on jurisdiction as well as from Non-Governmental Organisations. Basically what ValidataTM does is to check the data submission process and then notify data providers of potential errors suspected in the data supplied ((New South Wales Australian State 2019) [72].

1. Data Release

The AIHW data custodians bears the responsibility of ensuring decision making regarding release of data to third parties are done effectively. There exists a number consideration which must be met before the data is released. For instance, all functions are detailed in the AIHW work in the public domain policy statement, there are also policies and procedures on confidentiality of data which must be handled effectively at the same time maximising the amount of data released publicly.

3. Right to freedom of information
1. Freedom of Information Act 1982

This piece of legislation was established and enacted to give the public rights to access official documents in the care of the government and the commonwealth including its agencies. From inception, there are three main objectives that the act aimed at achieving; firstly to give the Australian citizens access to information as already stated. By this mandate all government bodies are required to release information and provide the rights of access. The Second objective was to enable parliament to promote representative democracy by increasing citizen involvement throughout government undertakings with the idea of promoting informed decision making, secondly to increase scrutiny and review of government activities. The third objective was to increase recognition that all information held in government bodies is managed for public purposes and is a national resource (Office of Parliamentary Counsel, Canberra 2019) [76].

Furthermore, the FOI Act does not just provide access to one personal data, but grants them rights correct it if inaccurate, outdated, incomplete or misleading. This can be done through the FOI request to the agency which holds your information through a formal process as outlined in the FOI act. (Office of the Australian Commissioner 2019)[74].

4. Data Protection
1. Privacy Act 1988

This is another essential act, according to findings the privacy act establishes obligations which are by mandate supposed to be followed by both the public and private sector organisations that collect, use or intend to disclose personal information. In this regard, the AIHW is guided by both the privacy act and the confidentiality and privacy requirements as established in the AIHW act section 29. Quite significantly, both aforementioned acts recognizes the significance of making available personal data for research purposes with the goal of benefiting local communities and the Nation at large. As clearly underpinned in section 95 of the Privacy Act, any release of personal information other than for medical research is a breach of privacy. Additionally Section 29 of the act further re affirms that any release of heath related information contrary to the AIHW act is prohibited (The Australian Institute of Health and Welfare 2014)[69].

The following are permitted health situations in relation to the collection, use or disclosure of health information.

2. Data Collection

- Collection for the provision of a health service – A health organisation is allowed to collect personal information if they are to provide a health service to the individual or if the Australian law other than this act authorised the collection for example Com Law Authoritative Act C2014C00757.
- Collection for Research- A health organisation is permitted to collect the information if its research relevant to public health or public safety, analysis is important to public health, and or it's for the management, funding, or monitoring of a health service.
- Other considerations include; if it's practically impossible to get an individual's consent or the information is collected according to the established competent health organisations charged with dealing professional confidentiality approved by the dictates of section 95 of the Act.

3. Data use or Disclosure for Research

A health organisation is permitted to use or disclose health information about the individual if it's for relevant research or statistical analysis for public health. Secondly the disclosure must be done according to established guidelines under section 95 A. Further the organisation can disclose if it reasonably believe beyond any reasonable doubt that the receiver of the health information will at no point disclose personal information that could be derived from the health information provided. Other Circumstances are that, if the organisation believes the release or use of the information is to avoid or preclude a severe risk of life, well-being or protection of an individual who is a blood relative of the firs individual (The Australian Institute of Health and Welfare 2014)[69].

However, findings emphasize that the Australian Privacy Principles are based on the law. That is to say any organisation can tailor their personal information handling practices to suite its setting and the characteristics of the people it serves. Additionally, the privacy principles are technology neutral making it easy to adapt new inventions of technology that would come in the future Office of the (Australian Information Commissioner 2019) [78].

4. Compliance, Breaches and Sanctions
Compliance

In order to ensure there is compliance regarding data management standards and security arrangements, The AIHW undertakes regular monitoring. For instance the Governance unit undertakes half –yearly validation of the data catalogue through the office of Data Custodians. This is done to see to it that all the current holdings listed in their data custodian is up to date. Furthermore, the Ethics Committee also undertakes monitoring of all the approved projects annually and a report is documented as evidence of the monitoring process (The Australian Institute of Health and Welfare 2014)[69].

Breaches and Sanctions

Research findings reveal that there exists rigorous controls and protocols to ensure information security, confidentiality and privacy at The AIHW. It is the agency custom to show transparency in mitigating or preventing possible risks. The Guidelines for Data Custody at AIHW provides the details for reporting processes as well as sanctions that follows if a breach of confidentiality or privacy is committed. Below is a summative outline.

- Firstly, the Australian Public Service Code of Conduct and The AIHW makes it a requirement for all the members of staff to exercise diligence in breaching information security.
- According to section 29 of the AIHW Act breaching confidentiality is an offence and there is a laid out process of reporting such a case. At inception, immediately a breach is noted it must be reported to the Director of the agency through the management channels established. Thereafter, it is within the rights of

the Director appoint a person to investigate the suspected breach. In an event, the breach has been proven legal or disciplinary action may be initiated according to the dictates of the law.

Health Identifiers Act 2010

This act was enacted with the purpose of providing a way of ensuring health organisations are correctly matched to individuals receiving healthcare services with regards to the health information that is created with the due process. This is done by assigning a number to the health care provider and the individual. This Act is important in that it facilitates using healthcare identifiers to communicate and manage health information about the healthcare recipient under strict rules (Office of Parliamentary Counsel, Canberra 2019) [79]. Additionally, the Healthcare Identifiers Regulations 2010 attention is on amenability duties of overall undertakings, private hospitals and healthcare experts. This is done through imposing penalties for any unlawful acts contrary to the dictates of The Health Identifiers Act, as well as impose data quality and data security obligations.

The role of the office of the Australian Information Commissioner is to oversee private healthcare provider's compliance with both The Health Identifiers Act and the established regulations as any breach of the aforementioned acts is tantamount to the breach of the Privacy ACT 1988 (Office of the Australian Commissioner 2014)[80].

4.2.3 Political will/Leadership

1. Civil Society Will

There are several communities that plays important roles in supporting research, information exchange, best practices and problem solving. Australian Vocabulary Special Interest Group, ANDS developers, Community Development Interest Group , Data Librarians Community , Data Services interest group, Health and Medical data Community , Research data management community and Data Provenance Interest groups to mention a few (Australian National Data Service 2019)[73].

2. Political Will

Leaders in health and welfare data in Australia engage nationally and internationally with credible authorities in ensuring there is quality standards, curating and connecting health and welfare data as well as quality schemes for statistics assemblage and dispensation. Over the past years AIHW has demonstrated strong foundations of delivering quality evidence on health care with more than 100 data holdings. The leadership has demonstrated commitment on developing catalysts of information enhancement through recognizing gaps and opportunities in various sources of health data possessions. Its support to collaborating associates to cultivate and obtain the desirable data to enlighten domestic top priorities has shown the governmental will to realize and improve capabilities in the health and welfare areas to change data and information into knowledge and intellect for the nation and the societies they serve (Australian Institute of Health and Welfare 2017)[81].

Findings reveal that the Australian administration has been influential in developing a strong data to ensure data sharing and systematic release and enhanced. Thus it was mandated that all agencies should adopt the following best practices; Have strong, explicit and ongoing data commitment from all levels of leadership, support should be rendered in the utmost sense to enable data sharing, data use and analytics should be belt as organisational strategies and finally there must be deliberate initiatives to encourage data skills and awareness at all levels in the organisation. Additionally, all agency policies should openly commit to regular data release and updates or alternatively create applications for high value data release. It was mandated that any grant provision to both private and public sector organisations must include data publishing as part of the service delivery agreement. Further, agencies are encouraged to have data champion networks across organisations as well use social media to engage with the public in identifying open data needs. Finally there are privacy trainings that must conducted for parties working with data as well as decision makers (New South Wales Government 2019) [82].

Furthermore the Australian government has demonstrated political leadership through the government adoption of the 2011 National Digital Economy Strategy (NDES 2011). The vision was lead Australia to become a leading digital economy by 2020 and a world leader in broadband connectivity and use of digital technologies. The government sought to see to it that Australians have the skills required as the digital world unfolds. In the

same vain the National archives introduced interim pathway targets in supporting agencies information staff development to deal with the dynamics that comes with the digital environment. Support is rendered to continuous skill acquisition and individuals have the opportunity to join professional associations to gain exposure to the frontiers of data management. Additionally, by 31 December 2019, all senior officers, chief information governance officers charged with the responsibility of information governance were expected to join professional association (Department of Broadband, Communications and the Digital Economy Australia 2013) [83].

4.2.4 Challenges

Australia health System is far fragmented. Findings show that the Australia health system is very large and complex as it comprises a network of service providers, recipients, organisational structures provided by both the private and public sector. The problem is that all these stakeholders collect and hold information. For example Public state hospitals, and federal government capture healthcare provider clinical data (My Health Record). On the other hand federal state, insurers and the private sector capture administrative claims and cost data. This fragmented approach creates challenges with regards to data sharing and coordination. Thirdly collection of individual's data is piecemeal in that Australia Medical association remains unsupportive of My Health Record. Additionally, the My Health Record is not automatically updated which makes it obsolete fast. The second challenge is that of government agencies having issues with capacity, capability and cost, this is mainly in terms of technology and managing risks form hackers'. Additionally, the proposed amendments to the privacy act 1988 may present technological and compliance challenges. In 2016 the office of the attorney general introduced a bill that prohibits re-identifying anonymized data .The challenge by policy makers is mainly in finding a balance between openness and data security (Racheal, G 2016) [85].

4.2.5 Summary

This section explored the Management, Legal, and Leadership factors that guarantees open health data in Australia. The following is a summary around the theoretical framework of this study.

1. Management and Organisational Factors

There are several structures that play crucial roles in open health data in Australia and they include the following: Office of the Australian Information Commissioner, the mandate of this independent agency is to promote and safeguard privacy, freedom of information and government information policy. Thus it conducts investigations, decision reviews, complaint handling and providing guidance and advice. This office has regulatory powers and responsibilities under the Freedom of Information Act 1982, and the privacy act 1988.

Secondly, Bureau of Health Information which is mandated to provide independent information regarding how the Healthcare system is performing, it was created in the year 2009 with the sole purpose of realizing accountability and provision of detailed information of the healthcare system to the citizens, healthcare experts and the government at large.

Thirdly, Australian Institute of Health and Welfare established by an act of law called Australian Institute of Health and Welfare Act of 1987. This is a statutory body mandated with the duty of delivering dependable, steady as well as relevant information on Australian health and welfare. Its major works is critical in supporting healthcare policy and programs at the same time a valuable source of research data.

The other structure is that of the Department of the Premier Cabinet (DPC) .This departmental structure is mandated with the duty of delivering technology, cyber security as well as digital leadership for South Australian Government including citizens and the industry at large. Its major function is assisting government agencies through the provision of ICT, Digital and security policies, standards, guidelines and toolkits.

In terms of roles and responsibilities, the AIHW Board is responsible for collecting and producing all the health and welfare information, consultation with the Australian Bureau of statistics on specialized standards that are significant to health and welfare services, and enabling researchers to access health statistics in line with section 29 confidentiality guidelines.

Further, the Ethics Committee plays key functions in forming an opinion on ethical standings about the acceptability and imposing conditions that it sees fit and appropriate on a range of activities like release of identifiable data by the AIHW for research purposes. This is done through highly significant ethical principles and standards established by the National Health and Medical Research Council. On the other hand, the AIHW

Director is charged with the responsibility of providing leadership in policy, data security, protecting confidentiality on privacy in line with the established legislation and ethical standards across the scope of AIHW. Additionally, the Data Governance committee is responsible for activities like approving new data policies and guidelines and has the oversight of reviewing the data governance framework annually.

Last but not the least, Australia National Data service a partnership which is spearheaded by Monash University in conjunction with the Australian National University and the Commonwealth Industrial Scientific Organisation. Its major function is to ensure Australia's Data is much more valuable to the research community and the nation at large.

Regarding decision making processes, The Australian Institute for Health and Welfare is guided by policies, guidelines and procedures to ensure there is total compliance with the legal and regulatory environment on data. This also take in consideration of international standards and classifications, and ethical obligations on both internal, external governance agreements and contracts. AIHW policies, procedures and guidelines are in line with data lifecycle: acquisition, use; (access, storage, management and release). Finally, archiving, destruction and return. For example on data acquisition: Information may only be collected and held for the purpose of AIHW activities as contained in the act of law. Additionally, the institute's Ethics Committee makes the approval before any identifiable information could be collected and stored. The information collected is limited to the direct significant aims and objectives of the approved project.

On complaints handling procedures, findings show that, there are two important documents that provides guidance on how complaints regarding privacy are handled, and the role of the AIHW's Privacy officer. These include: AIHW Privacy Policy and the two brochures safeguarding your privacy. The Commonwealth Privacy Commissioner is the one charged with appropriate management of complaints on privacy matters. While the Charter of Corporate Governance provides guidance as well as management of Complaints about Board Members. The Ethics Committee Background and practice document provides details on how complaints made in respect of the committees functions are supposed to be managed. Additionally, all Bi-lateral data sharing agreements by the AIHW are guided by a dispute resolution procedure to ensure prompt remedies to any maters of concern that may come forth.

On supervision and accountability, the OAIC has power to monitor agencies compliance with freedom of information act, review Freedom of Information decisions of agencies, Investigate complaints, Issues guidelines according to section 93 of the freedom of information act, oversee the information publication scheme by assisting agencies to publish information in accordance with the publication scheme, and review, monitor as well as investigate compliance.

Regarding collaboration, the AIHW has since time immemorial adopted a strong collaborative approach in ensuring networking relationships with Australian, state, territory governments including the education as well as private sector. There are formal arrangements with other collaborating organisations, national information agreements that play key roles in ensuring effective collaboration. For example, National Health Information Agreement (NHIA) 2013 allows the commonwealth, states and territories to come up with schemes that might advance, uphold and disseminate domestic health statistics. The National Community Services Information Infrastructure Agreement settles and assists the country's infrastructure plus the procedures desirable to assimilate, strategize and organize the formation of reliable domestic civic services information. Others include: National Information Agreement on Early Childhood Education and Care (NIAECEC) and National Housing and Homelessness Information and Infrastructure agreement (NIAHILA) to mention a few.

Furthermore, Australian Researchers regularly participate in International collaborative research works and many of the major funders of research mandates data sharing. Some of the collaborative partners include; Wellcome Trust in the UK, Medical Research Council in the UK, National Institutes of Health (NIH) in the USA, Bill and Melinda Gates Foundation in the USA and National Science Foundation in the USA.

On funding and sustainability, research findings indicate that there are funder's guidelines in Australia that has over the time increasing supported data sharing. For example, National Health and Medical Research Council (NHMRC) Open Access Policy strongly promotes sharing research outputs from NHMRC supported Research. Others include Australian Code for Responsible Conduct of Research, and the Australian Research Council (ARC) Funding Rules 2016. On the International scale, collaborating partners such as Wellcome Trust in the UK, Medical Research Council in the UK, National Institutes of Health (NIH) in the USA, Bill and Melinda Gates Foundation in the USA and National Science Foundation in the USA requires publication of all the funded research projects.

2. Legal and Policy Factors

Findings reveal that health open data in Australia is hugely influenced and facilitated by the health data governance framework. Basically the data governance framework is key in ensuring there is shared direction and governance maturity. Its major mandate is to provide agencies with platform to effectively govern their data sets consistently and in a coordinated manner. Additionally, to advice on best practices model for building data governance maturity in various government agencies.

By law good data governance is more than just a mare requirement in NSW government, rather it is mandatory and aligned with government statues, regulations as well policies Privacy and Personal Information Protection Act 1998, State Records Act 1998, Health Records and Information Privacy Act 2002, Government Information (Public Access) Act 2009, Data Sharing (Government Sector) Act 2015, NSW information Management Framework 2018 and NSW Digital Information Security Policy.

Findings indicate that they are a number of laws, standards, manuals and policies that are put in place to regulate and safeguard access and use of open health data. Freedom of Information Act 1982, The Archives Act 1983,The Australian Institute of Health and Welfare Act 1987, Privacy Act 1988,The Australian Institute of Health and Welfare Ethics Committee Regulation 1989,Australian Government Information Security Manual, Australian Government Protective, Security Policy Framework, High Level principles for Data Integration (Cross Portfolio statistical integration Committee) . Policies include: AIHW Ethics Committee Background and Practice document Charter of Corporate Governance, Data Collection Management Principles, Data Custodianship Delegations, Data Linkage and Protecting Privacy Policy, Data Quality Statements Policy and Guidelines to mention a few.

Basically, AIHW's has information security and privacy policy and procedural guidelines which must be principally followed when it comes to accessing data. These procedures are applied throughout the whole life cycle of information that is from creation, Storage to disposal. For example on security and Security, AIHW has a high security for the data it holds both logically and physically. For one to have access to data they are subjected to multiple levels of approval. The Agency has risk management policies which details the approach to managing risks, delegating security related roles as required by the Australian Government protective policies.

The Freedom of Information Act 1982 was established and enacted to give the public rights to access official documents in the custody of the government and the commonwealth including its agencies. It has three main objectives namely: to give the Australian community access to information, enable parliament to promote representative democracy by increasing public participation throughout government processes, and to increase recognition that all information held in government bodies is managed for public purposes and is a national resource.

The Privacy act 1988, the AIHW is guided by both the privacy act and the confidentiality and privacy requirements as established in the AIHW act section 29. Both acts recognizes the significance of making available private data for research tenacities with the goal of benefiting local communities and the Nation at large. As clearly underpinned in section 95 of the Privacy Act, any release of personal information other than for medical research is a breach of privacy. Further, the Australian Public Service Code of Conduct and The AIHW makes it a requirement for all the members of staff to exercise diligence in breaching information security. According to section 29 of the AIHW Act breaching confidentiality is an offence and there is a laid out process of reporting such a case

3. Political will/Leadership Factors

Regarding the civil societies will, findings show that there are several communities that plays important roles in supporting research, information exchange, best practices and problem solving. Australian Vocabulary Special Interest Group, ANDS developers, Community Development Interest Group , Data Librarians Community , Data Services interest group, Health and Medical data Community , Research data management community and Data Provenance Interest groups to mention a few.

Political Will

Leaders in health and welfare data in Australia engage nationally and internationally with credible authorities in

ensuring there is quality standards, curating and linking health and welfare data as well as quality systems for data collection and processing. The leadership has demonstrated commitment developing catalysts of data enhancement through recognizing gaps and opportunities in several sources of health data possessions. Its support to cooperating associates to grow and obtain the desirable data to inform domestic priorities has confirmed governments will to realize and improve competences in the health and welfare areas to change data and information into knowledge and intellect for the nation and the societies they serve. Thus all agencies adopted best practices; strong, explicit and ongoing data commitment from all levels of leadership, support the utmost sense to enable data sharing, data use and analytics is belt as organisational strategies and finally there are deliberate initiatives to encourage data skills and awareness at all levels in the organisation.

Furthermore the Australian government has demonstrated political leadership through the government adoption of the 2011 National Digital Economy Strategy (NDES 2011). The vision is leading Australia to become a leading digital economy by 2020 and a world leader in broadband connectivity and use of digital technologies.

4.3 Similarities and Differences between the U.K and Australia Open Health Data Guarantee Mechanism

4.3.1 Similarities between United Kingdom and Australia Guarantee Mechanism

Table 4-4 Similarities between the U.K and Australia on Health Open Data Guarantee Mechanism.

Management & Organisational Factors	Countries	**United Kingdom & Australia**
	Organisation Structures	• Information Commission Agency • Public & Private Stakeholders • Ethics Structures on Health Data • National Heath Data Bodies (NHS & ANDS)
	Decision Making Processes	• All decisions are guided by the legal framework & Policy • International standards and classifications, and ethical obligations on both internal, external governance agreements and contracts are consulted
	Roles & Responsibilities	• The Information Commission Office promotes information rights, safeguards privacy, conduct investigations, complaint handling, offer guidance & exercise regulatory powers. • There are structures that look at best international practices and policies on data
	Supervision & Accountability	• The office of Information Commission Office ensures there is compliance with the Freedom of Information Act and other related regulations through monitoring, reviews & investigation
	Cooperation Mechanism	• There are International, Local, and Regional open health data cooperation's (Both countries have collaborations between them, and with USA)
	Funding and Sustainability	• Taxation and Health Insurance
Legal and Policy Factors		• Health Data Governance Framework • Freedom of Information Act • Public Records Act • Data Protection Act • Data Access Act • Privacy Act • Publication Scheme required by FIOA • Codes of Conduct • Data Anonymisation Guidelines • Data Security Procedures • Information Standards & Manuals
Political	Civil Society will	• Several Communities, Voluntary organisations, and

Will/Leadership Factors		Associations participate & play important roles in supporting research and information exchange
	Political will	• The leadership has been kin on building drivers of data improvement by identifying gaps and opportunities in multisource of health data holdings. • The leadership has demonstrated commitment in developing catalysts of data enhancement through recognizing gaps and opportunities in several sources of health data possessions through the legal instruments established • The Leadership demonstrated commitment to transparency and accountability through the adoption of long term information strategic plans.

Table 4-4 shows the similarities between the United Kingdom and Australia in terms of the open health data guarantee mechanism in three dimensions namely: management and organisational factors, legal and policy factors and leadership factors. Under management and organisational factors the two countries were found have an information commission agency charged with the responsibility of information legislation and regulation. On legal factors both countries were found to have freedom of information act, public records act, data protection act among others. Furthermore, the leadership in both countries were found to have demonstrated commitment to transparency and accountability through the adoption of long term information strategic plans. The rest can be deduced from the table.

4.3.2 Differences between United Kingdom and Australia Guarantee Mechanism

Table 4-5 Differences between the U.K and Australia on Health Open Data Guarantee Mechanism.

	United Kingdom	Australia
Management & Organisational Factors	• The Chief Data Officers Team an administrative structure within NHS • Data Policy Unit • Data Sharing and Privacy Unit (DSPU) • The Data protection Act requires that all data controllers need to notify their processing of personal data at a fee of 35 pounds per year	• Bureau of Health Information which is mandated to provide independent information regarding how the Healthcare system is performing • Australian Institute of Health and Welfare (established by law) • Department of the Premier Cabinet (DPC) • The Commonwealth Privacy Commissioner is the one charged with appropriate management of complaints on privacy matters • Charter of Corporate Governance provides guidance as well as management of Complaints about Board Members • The Ethics Committee Background and practice document provides details on how complaints made in respect of the committees functions are supposed to be managed. • National information agreements that play key roles in ensuring effective collaboration • Has funder's guidelines
Legal & Policy Factors	• Information governance in the U.K health sector has a Fair Processing requirement done through a privacy notice • Equality Act • There is a mandate for organisations to check the supplier certification	• By law good data governance is more than just a mare requirement in NSW government, rather it is mandatory • Security Policy Framework • High Level principles for Data Integration • Data Linkage and Protecting Privacy Policy • Data Quality Statements Policy

		• Risk management policies • The Freedom of Information Act 1982 purpose is more than ensuring access to information but includes: to promote representative democracy and to increase recognition that all information held in government bodies is managed for public purposes and is a national resource.
Political Will/ Leadership Factors	• The Health and Social Care Act 2012 establishes a statutory duty for all Health and Wellbeing boards to ensure continuous engagement with local communities	• Health and Medical data Community, Research data management community and Data Provenance Interest groups

Table 4-5 shows the differences between the United Kingdom and Australia in terms of the open health data guarantee mechanism in three dimensions namely: management and organisational factors, legal and policy factors and leadership factors. On management and organisation factors Australia was found to have the bureau of health information which is mandated to provide independent information regarding how the healthcare system is performing while the United Kingdom did not have. With regards to legal and policy factors, in Australia good data governance is more than just a mare requirement, rather it is mandatory. This is different as compared to the United Kingdom where good data governance is just a requirement. Additionally, an analysis on leadership factors revealed that the UK had the health and social care act which establishes a statutory duty for all health and wellbeing boards to ensure continuous engagement with local communities while Australia on the other hand did not have. The rest can be deduced from the table.

4.4 Comparative Analysis of How the Guarantee Mechanism Intervene and Assure Heath Open Data Rationality

4.4.1 United Kingdom

1. Management & Organisational factors

Research findings show that there exists several management and organisational factors that intervene and assure that health open data rationality is achieved. In terms of structures the Information Commission office intervene by upholding information rights in the public interest as well as promoting transparency in public bodies and ensuring data privacy for the Citizens. This guarantees and enables citizen's access to open health data at the same time protecting the data privacy. Furthermore, citizens are made aware of their legal information rights which boosts their confidence in using them where need arises. Additionally, the creation of the agency to oversee all information related legislations plays an important role by specializing on the frontiers of information needs in the digital error. There is also a level of efficiency and effectiveness that is retained when it comes to monitoring, evaluation and implementation of information related projects.

The specialization within National Health Service that is: The chief data officers roles, the Data Policy Unit, The Data projects, and the Data Sharing Privacy Unit assures the rationality of open health data through efficiency and effectiveness in the execution of the roles assigned. For example, Chief Data officers sorely focuses on developing and delivering a strategy regarding the use of Data at every level of the organization. The Data Policy Unit works closely with commissioners and various stakeholders such as researchers, Clinicians, and patients in order to establish needs and requirements regarding information standards, and open health data governance. Then the Data projects unit implements the requirements as established by the data policy unit with focus on benefits realization. Finally, the Data Sharing and Privacy Unit (DSPU) provides guidance regarding privacy, data sharing as well as managing information governance strategic risks.

Furthermore, the partnership of NHS with NHS Digital assure the rationality of Open Health Data in that NHS Digital plays a significant role in providing information to support better care by ensuring there is high-quality data Collection, analysis as well as storage services, information governance and leadership. Additionally, the private and public participation makes data collection robust, dynamic and rich in content.

The Legal framework in the U.K is the bedrock and basis of all decision making processes regarding open health data. This assures consistency and transparency in decision making. Furthermore, the supervision by the Information Commission office done through formal monitoring of all government agencies and departments, councils as well as the police force to obtain current freedom of Information performance statistics assure open health data by ensuring compliance .On the other hand, the Local and international collaborations that exist in UK allows the health sector and the nation at large to greatly benefit from international good practices on open health data. When it comes to funding and sustainability, taxation and 35 pounds yearly processing fee for all data controllers guarantees and assure funding for open health data.

2. Legal and Policy Factors

The legal framework is robust and comprehensive as it govern, access to data, confidentiality and treatment of medical health records, basically the entire information cycle is enshrined in law and policy. Data protection and other related legal instruments intervene and assure the rationality of open health data by allowing personal data to be shared between service providers and patients whilst ensuring confidentiality is maintained without compromise.

3. Political Will/Leadership Factors

The political will and commitment reflected in the various legal instruments on health open data assures open health development in United Kingdom. Additionally, the Health and Social Care Act 2012 places a statutory duty for all Health and Wellbeing boards to ensure continuous engagement with local communities throughout processes to capture detailed knowledge that voluntary organisations and the community have regarding the needs of the various communities they serve. This assures the collective drive in establishing needs of all sort of communities in delivering open health data.

4.4.2 Australia

1. Management & Organisational Factors

According to findings there are various organisational structures that play important roles in assuring the rationality of open health data. The Office of the Australian Information Commissioner, assures the rationality of open data by promoting and safeguarding privacy, freedom of information and government information policy. It conducts investigations, decision reviews, complaint handling and providing guidance and advice. Furthermore, the Bureau of Health Information provides independent information regarding how the Healthcare system is performing with the view of achieving accountability and provision of detailed information. Having an independent information agency brings about lack of bias in the daily operation. Additionally, autonomy and stability is realized in that, this kind of agency is not staffed by political appointments which may impede with unbiased provision of health open data to all the stakeholders.

The Australian Institute of Health and Welfare assures the rationality of open health data by supporting healthcare policy and programs at the same time a valuable source of research data. On the other hand, the Department of the Premier Cabinet (DPC) delivers technology, cyber security and digital leadership. The department assures the rationality of open health data by assisting government agencies through the provision of ICT, Digital and security policies, standards, guidelines and toolkits. Further, the Ethics Committee forms the essential ethical standards and principles on health open data.

The existing legal landscape in Australia such as the AIHW Privacy Policy, the Charter of Corporate Governance assures the rationality of Open Health Data by providing guidance on how complaints regarding privacy are handled. This makes the decision making process guaranteed, transparent, and consistent. Furthermore, in assuring supervision and accountability of open health data the OIAC monitors agencies compliance with freedom of information act, review Freedom of Information decisions of agencies, Investigate complaints, Issues guidelines, and oversee the information publication scheme by assisting agencies to publish information in accordance with the publication scheme.

With regards to collaborations, formal arrangements with other collaborating organisations and national information agreements assures the rationality of open health data by ensuring effective collaborations that allows the commonwealth, states and territories to develop programs that could improve, maintain and share national

health information. In addition, funder's guidelines in Australia assures the rationality of open health data by mandating that all findings from funded research are made available to the public by default. This has over the time increasing supported data sharing.

2. Legal & Policy Factors

The legal environment in Australia plays critical roles in assuring the rationality of open health data as follows: The health data governance framework ensures there is shared direction and governance maturity by providing agencies with platform to effectively govern their data sets consistently and in a coordinated manner. Additionally, to advice on best practices model for building data governance maturity in various government agencies. Furthermore, making good data governance mandatory provides the security needed for open health data to thrive.

That being so, standards, manuals and policies, government statues, regulations such as Privacy and Personal Information Protection Act 1998, State Records Act 1998, Health Records and Information Privacy Act 2002, Government Information (Public Access) Act 2009, Data Sharing (Government Sector) Act 2015 to mention a few. Are all applied throughout the whole life cycle of information that is from creation, Storage to disposal. On that account, open data rationality is assured through the comprehensive guidance enshrined in the legal instruments. For example the freedom of information act gives the Australian community access to information, enable parliament to promote representative democracy by increasing public participation throughout government processes, and increases recognition that that all information held in government bodies is managed for public purposes and is a national resource.

3. Political Will/Leadership Factors

The political will demonstrated by the Australian leaders in health and welfare data, assures open data rationality through engaging nationally and internationally with credible authorities in ensuring there is quality standards, curating and linking health and welfare data as well as quality systems for data collection and processing. Whence, the leadership has been kin on building drivers of data improvement by identifying gaps and opportunities in multisource of health data holdings. Its support to collaborating partners to develop and capture the needed data to inform national priorities.

4.5 Common Knowledge Framework for Successful Health Open Data Implementation

Table 4-6 Common Knowledge Framework for Successful Health Open Data Implementation.

Common Knowledge Framework for Successful Health Open Data Implementation		
Management & Organisational Factors	Organisation Structures	• Information Commission Agency • Public & Private Stakeholders • Ethics Structures on Health Data • National Heath Data Bodies
	Decision Making Processes	• All decisions should be guided by the legal framework & Policy • International standards and classifications, and ethical obligations on both internal, external governance agreements and contracts should be consulted
	Roles & Responsibilities	• The Information Commission Office should promote information rights, safeguards privacy, conduct investigations, complaint handling, offer guidance & exercise regulatory powers. • There should be structures that look at best international practices and policies on open data
	Supervision & Accountability	• The office of Information Commission Office should ensures there is compliance with the Freedom of Information Act and other related regulations through monitoring, reviews & investigations

	Cooperation Mechanism	• There should be International, Local, and Regional open health data cooperation's • There should be national information agreements
	Funding and Sustainability	• All funded research findings should be made public • Taxation and Health Insurance • Data Controllers should be charged data processing fee
Legal & Policy Factors		• Health Data Governance Framework • Freedom of Information Act • Public Records Act • Data Protection Act • Data Access Act • Privacy Act • Publication Scheme required by FIOA • Codes of Conduct • Data Anonymisation Guidelines • Data Security Procedures • Information Standards & Manuals
Political Will/Leadership Factors	Civil Society will	• Several Communities, Voluntary organisations, and Associations should participate & play important roles in supporting research and information exchange • There should be a law that deliberately mandates civil society participation.
	Political will	• The Leadership should been kin on building drivers of data improvement by identifying gaps and opportunities in multisource of health data holdings. • The leadership should demonstrate commitment in developing catalysts of data enhancement through recognizing gaps and opportunities in several sources of health data possessions through the legal instruments established. • The Leadership should demonstrate commitment to transparency and accountability through the adoption of long term information strategic plans.

Chapter 5 Discussion and Recommendation

5.1 Discussion

This study aimed at examining the concrete examples in two similar political entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guaranteeing the open data implementation in health sector. Specifically to find out the similarities and differences in these two countries in each aspects, especially the similarities to show the common knowledge and measures to shape the overall open data guarantee Mechanism. This study is therefore a timely response to the paucity of relevant research on open health data guarantee mechanism. Since the focus is on practical evidence of the 2014 and 2018 works by the World Wide Web Foundation and the New York University Government Governance Lab which merits an open data common framework for the successful implementation. The study also offers practical implications for government practitioners who implement health open data initiatives. For both academics and practitioners, this thesis provides a practical and detailed common framework to implement open data. Thus, this chapter addresses implications regarding theory, research and practice as well as limitations of the thesis.

5.1.1 Implication for theory

This thesis makes some contribution to theory, the theoretical contribution of this paper is attributed to its

uniqueness. There are no studies that have been done to examine the concrete examples in two similar entities to see the real state in the three field, namely, Management, Legal and Leadership aspects for guaranteeing the open data implementation in health sector. The common knowledge framework proposed in this thesis emerged from a comparative analysis of the practical evidence from the two high ranked countries in open health data implementation. The deductive analysis of the qualitative data revealed the similarities between two countries. For example on management and organisational factors, both countries were found to have an Information Commission Agency, Public & Private Stakeholders, Ethics Structures on Health Data, and National Heath Data Bodies. The common knowledge framework proposed in this study reflects the practical experiences of the two countries. So far, there is no common knowledge framework of open health data implementation that has been suggested through an empirical grounded study. If anything, the 2014 and 2018 common framework by the World Wide Web Foundation and the New York University Government Governance Lab is quiet conceptual and abstract. In reality, there exist detailed and practical knowledge which offers practical insights and guidance regarding open health data implementation. Further, this approach is a great deal of potential to lead to an ideal type abstracting institutional arrangements and process from the existing systems to deduce a model unconstrained by political, cultural or social setups of any existing nation.

Another unique contribution of this thesis is the deductive analysis to see the real state in the three field, namely, Management, Legal and Leadership aspects for the guarantee of open data implementation in health sector. Thus, this thesis refines and elaborate the practical understanding of enabling as well inhibiting factors in open health data implementation. On the hand, gives a basic analysis of the common framework. In this way the study is both inductive by suggesting new theoretical insights founded on experiences as well as practices. It is deductive by testing the existing claims as propagated by the WWW Foundation and the New York University Government Governance Lab common framework.

Generally, this study brings about a new practical understanding of the guarantee mechanism for implementing open health data. Open data guarantee mechanism is of great significance to ensure the rationality of open data is achieved. Furthermore, recent studies by Vanessa (2019) [9] and Whitford (2013) [10] have shown that it is of great importance to understand how management, leadership and organization structures affect government open data. Periera, G et al (2017) [11], found that through a critical analysis of open data management, one might understand: decision-making processes and how the government makes the judgment of public interests as they are publishing various health data sets. Thus this study provides a theoretical basis for research initiatives to make open health data implementation effective.

Furthermore, this thesis puts forth practical common framework and principles that can be shared: for example, on legal and policy factors practitioners must ensure there is data protection act, data access act, privacy act, publication scheme required by FIOA, codes of conduct and data anonymization guidelines to mention a few.

5.1.2 Implications for research

This study is based on the common knowledge framework established by the WWW Foundation and the New York University Governance Lab. Nevertheless, the study brings out practical elements or rather success factors as effective means for the implementation of health open data. For example, on roles and responsibilities the Information Commission Office should promote information rights, safeguards privacy, conduct investigations, complaint handling, offer guidance & exercise regulatory powers. In addition, there should be structures that look at best international practices and policies on open data in order for the country to harness important knowledge regarding open health data. Furthermore, the findings of this study suggest the success factors that are related to public management: for example on political will: The leadership should demonstrate commitment developing catalysts of data enhancement through recognizing gaps and opportunities in several sources of health data possessions through the legal instruments established. Additionally, The Leadership should be kin on building drivers of data improvement by identifying gaps and opportunities in multi source of health data holdings. In this way this thesis offers open health data guarantee mechanism as a new research theme in public management.

Concerning the possibility of new research direction, this study can be understood as a fundamental study on key factors needed for successfully implementing health open data. These factors include Management and Organisational factors, Legal and policy, and Political will /Leadership. However, while this thesis offers a comprehensive view of open data guarantee Mechanism, for deeper analysis one factor could be analyzed with a more specified theoretical perspective. Further, future work should address other countries with varying conditions other than federal countries. This can deepen understanding of open health data guarantee mechanism.

This study limits its scope to open health data guarantee mechanism. Nonetheless, both academic and

practical implications related to open health data can be extended to other sectors of government. Additionally, the validity of the factors summed up from the inductive analysis can further be examined. For example a quantitative study can be carried out to examine and establish which factors are more important. In this regard, theoretical constructs and measures for each factor and challenge can be established.

5.1.3 Implications for Practitioners

This thesis mainly concentrated on practical guarantee mechanism for implementing open health data. In this sense, the findings as well as the common framework put forth appeals to open health data practitioners, in that it may explain core aspects of implementing open health data successfully. The direct benefit of this study can be offered to government agencies and organisations charged with open health data implementation. Further, this work is also useful to countries that are preparing to launch open health data and those struggling with the implementation. This study shows how and why and what factors are important to implement open health data. Thus government practitioners are challenged to think how they can improve the frameworks they are using to implement open health data rather than just copying what others are doing.

5.1.4 Limitations of the study

The first major limitation of the study is that, the management, legal and political factors derived in this study are literature based and as such there could be a difference in context in reality. Thus the institutional factors may be considered to influence the open health data implementation in other ways not revealed in this study. Interviews with policy makers and other top officials could elaborate more details, and the established success factors could be explored further.

Secondly, the study utilized multiple cases to examine the open health data guarantee mechanism in a definable framework. Nonetheless, an in-depth concentration on a single case could possibly reveal more in-depth content of the success factors established in this study. Additionally, just like other qualitative studies replicating of this study may be difficult.

5.2 Recommendations to Successful Health Open Data Implementation

Having established the outcomes of this study, the following are the practical recommendations:

Practical recommendation 1: establish adequate information organisational structures

- Information Agency

Create an agency to specialize on information regulation

- Public & Private Stakeholders

Institutionalize a governing body to coordinate and manage collaborations between public and private organisations.

- Ethics Structures on Health Data

At every level of organisation there must be structures that focus on ethical conduct.

- National Heath Data Bodies

There must be National Health Bodies to provide health data leadership.

Practical recommendation 2: ensure that all decision making process are guided by the legal framework and policy. The existing legal instruments should be the basis for all decision making. Furthermore, International standards and classifications, and ethical obligations on both internal, external governance agreements and contracts should be consulted.

Practical recommendation 3: ensure you engage in International, Local, and Regional open health data cooperation's. Further, Cooperation's should be clearly defined by agreements and contracts.

Practical recommendation 4: find a smart way to manage budgetary constraints.

Limited funding is often a challenge when it comes to open data implementation. Among other ways, you may adapt to least costly technology. Further, you can ensure that all funded research findings are made public, revenue from taxation and health insurance can be supplemented by annual data controllers processing fee charged according to the size of the organisation.

Practical recommendation 5: ensure you have an adequate information legal framework and always scan for new challenges and opportunities. There must be enough regulations to cover: freedom of information data protection, data access, privacy, codes of conduct, data anonymization, data security procedures, information

standards & manuals etc.

Practical recommendation 6: the Leadership should be kin on building drivers of data improvement by identifying gaps and opportunities in multisource of health data holdings.

5.3 Conclusion

Open health data is the fuel of innovation in the 21stcentrury in the government health sector. It is a critical tool in fighting infectious diseases, strengthening healthcare systems by connecting patients to providers, improving governance by exposing and preventing mismanagement and corruption, provision of essential data to research work which may have high value on healthcare quality as well as cost. To successfully implement open data demands a clear understanding and application of the guarantee mechanism, which comprises of management and organisational factors, legal and policy factors, and the political security.

However, research is yet to tackle in depth on how the open health data guarantee mechanism can be leveraged to ensure there is effective and efficient implementation of open health data in various countries with different capabilities. Given the relevance of health data today, it is crucial that researchers recognize the significance and role of comparative studies in this field. Thus filling the various research gaps in open health data remains paramount in the field of public administration.

Using both the deductive and inductive research logic this study examined the open health data guarantee mechanism of two successful countries: the U.K and Australia. Key findings revealed the practical common success factors which are divided into management and organisational factors, Legal and policy factors, and political will/leadership factors.

Going forward, this study provides some implications for both researchers as well as practitioners. It suggests future research directions to facilitate further understanding of open health data guarantee mechanism.

Acknowledgments

References

[1]   Gurin, J., Manley, L. and Ariss, A. Sustainable Development Goals and Open Data [OL].2015 http://blogs.worldbank.org/ic4d/sustainable-development-goals

[2]   United Nations, E-government Survey: E-government in Support of Sustainable Development [R]. New York: 2016.

[3]   United Nations E-Government Survey: Gearing E-Government to Support Transformation towards

Sustainable and Resilient Societies[R]. New York: 2018

[4] United Nations Public Administration Program [OL].What is Open Data.2017 https://publicadministration.un.org/en/ogd.

[5] Wang, H.-J., & Lo, J. Adoption of Open Government Data among Government Agencies [J]. Government Information Quarterly xxx (2015) xxx–xxx http://dx.doi.org/10.1016/j.giq.2015.11.004.

[6] Zuiderwijk, A., et al. Acceptance and use Predictors of Open Data Technologies: Drawing upon the Unified Theory of Acceptance and use of Technology [J]. Government Information Quarterly (2015), http://dx.doi.org/10.1016/j.giq.2015.09.005.

[7] Yupan Zhao, Bo Fan. Exploring Open Government Data Capacity of Government Agency: Based on the Resource-based Theory [J]. Government Information Quarterly 2018. https://doi.org/10.1016/j.giq.2018.01.002

[8] Ahmadi Zeleti et al. Exploring the Economic Value of Open Government Data [J]. Government Information Quarterly 33 (2016) 535–551.

[9] Vanessa -Mae. Research on the Guarantee Mechanism of Australian Local Government. Open Data [J]. E-government think: Information Theory and Practice 2019.

[10] Lee, S, and Whitford, A. Assessing the Effects of Organizational Resources on Public Agency Performance: Evidence from the US Federal Government [J]. Journal of Public Administration Research and Theory, Volume 23, Issue 3, July 2013, 687–712, https://doi.org/10.1093/jopart/mus050

[11] Periera, G., et al. Delivering Public Value through Open Government Data Initiatives in a Smart City context [OL].2017 https://link.springer.com/article/10.1007/s

[13] World Wide Web Foundation. Open Data Barometer Global report 3rd edition [R]. 2016

[14] World Wide Web Foundation. Towards Common Methods for Assessing Open Data: Workshop Report & Draft Framework[R]. New York: New York University. May 8th and 9th 2014.

[15] Block, M. Comparative Research and Analysis Methods for Shared Learning from Health System Reforms [J]. Health Policy, International Clearinghouse of Health System Reform Initiati6es (ICHSRI), Mexican Health Foundation 1997 – Elsevier.

[16] Open Definition. Definition of Open Data. [OL] http://opendefinition.org/.

[17] Holzinger, A. et al. Smart Health Open Problems and Future Challenges [D].2015

[18] Organization for Economic Cooperation and Development [OL]. Open Data definition.

[19] D'Agostino M, et al. Open Data and Public Health [J]. Pan American Journal of Public Health 2018 https://doi.org/10.26633/RPSP.2018.66.

[20] Kenton, W. Fundamental Analysis: Healthcare Sector [OL].2017 Investopedia https://www.investopedia.com/ters/h/health

[21] Ani Mateia and Cătălina Antonieb .The New Public Management within the Complexity Model [C].2nd World Conference on Business, Economics and Management -WCBEM 2013. © 2014 Published by Elsevier Ltd. Selection and peer review under responsibility of Organizing Committee of BEM 2013.

[22] Hughes, O. E. Public Management & Administration [M].1998 Basingstoke: Macmillan.

[23] Strathern, M. Audit Cultures [M].2000 London: Routledge.

[24] Matei, A. Performanța Serviciilor Publice [J]. Modele Sistemice și Abordări calitative, Revista Transilvană de Științe Administrative 2004 3(12), 114-120.

[25] Xu J-H. Leadership Theory in Clinical Practice. Chin Nurs Res. 2017 4:155-157. https://doi.org/10.1016/j.cnre.2017.10.001.

[26] Bass, B.M. Leadership and Performance beyond Expectations [M].1985 New York: The Free Press.

[27] Rosenbloom, D. Public Administration: Understanding Management, Politics, and Law in the Public Sector, Seventh Edition. [M]. NY: McGraw Hill, April 2008, 580.

[28] Juneja, P. Institutional Approach to Public Administration. Reviewed by Management Study Guide [OL].2019 https://www.managementstudyguide.com

[29] Hansen, Perry, & Reese. A Bayesian operationalization of the resource-based view [J]. Strategic Management Journal. 2004 https://doi.org/10.1002/smj.432

[30] Data Management Association. International's Guide to the Data Management Body of Knowledge (DAMA-DMBOK Guide).[OM] 2014 DOI:10.1016/j.giq.2018.01.002.

[31] Wijnohoven, F. et al. Open Government Objectives and Participation Motivations [J]. Government Information Quarterly 32 (2015) 30–42

[32] Sadiq, S., and Indulska, M. Open data: Quality over quantity [J]. International Journal of Information Management 2017.

[33] Yupan and Bo. Exploring Open Government Data capacity of Government Agency: Based on the Resource-Based Theory [J]. Government Information Quarterly 2018.

[34] Lammerhirt. Mapping Open Data Governance Models: Who Makes Decisions About Government Data and How [OL]? 2019 https://blog.okfn.org/2019/02/20/open-data-governance-and-opengovernance- interplay-or-disconnect/.

[35] Wang, X., and Zheng, L. Local Government Data Governance for Data Opening: Problems and Paths. [J]. E-Government, 2019(02): 27-33

[36] Ana Brandusescu et al. Open Data Governance and Open Governance: Interplay or Disconnect [OL]. 2017 Open Knowledge International https://okfn.org

[37] Ellen Broad et al. Open Data in Government How to Bring About Change. Open Data Institute [OL].2015 http://theodi.org/

[38] Open Data Soft. (2019). A List of all Open Data Portals around the World [OL]. https://www.opendatasoft.com/a-comprehensive-list

[39] Neuman, W.L. Basics of Social Research Qualitative and Quantitative Approaches [OL]. 2007Allyn and Bacon, Boston.

[40] Josh Chang et al. The UK Health Care System [OL]. Columbia University: 2010 http:// assets.ce.columbia.edu

[41] Research Service National Assemble Wales. The Organisation of the NHS in the UK: Comparing structures in four countries [OL]. 2014 National Assembly Wales Commission Blog: assemblyinbrief.wordpress.com.

[42] Stefaan Verhulst et al, GOVLAB: The Open Data Era in Health and Social Care[R]. 2014.

[43] Information Commission Office. Information Commissioner's Annual Report and Financial Statements 2015/16[R]. Wycliffe House: House of Commons, 2015.

[44] Information Commission Office. Information Commissioner's Annual Report and Financial Statements 2017-18 [R]. Wycliffe House: House of Commons, 2017.

[45] Information Commission Office. Information Commissioner's Annual Report and Financial Statements 2018-19 [R]. Wycliffe House: House of Commons, 2018.

[46] National Health Service. Data and Information [OL]. 2016 http://www.nhs.uk/your-nhs-data-matters/

[47] Locum Information Governance. Information Rights Complaint Procedure [OL]. 2018 www. manchester.gov.uk

[48] OECD, Health Data Governance: Privacy, Monitoring and Research, OECD Health Policy Studies [OL]. 2015 OECD Publishing, Paris. http://dx.doi.org/10.1787/9789264244566-en

[49] Helen McKenna et al. How Health Care is Funded [OL]. 2017   https://www.kingsfund.org.uk/

[50] Public Health England. PHE HIV and STI Data Sharing Policy [OL]. 2015 www.gov.uk/government/publications/hiv-and-sti-data-sharing-policy

[51] University of Exeter. Health Data Research UK to fund Exeter Masters Programme in Health Data Science [OL]. 2019 https://www.exeter.ac.uk/

[52] National Health Service. The NHS Constitution [OL]. 2015 Department of Health www.orderline.dh.gov.uk

[53] National Health Service England. NHS England response to the specific duties of the Equality Act: Equality information relating to public facing functions [R].Peninsula House, Equality and Health Inequality Unit, Commissioning Strategy 2016.

[54] Open Government Partnership. Health Fact Sheet: Making Access to Reproductive Health Services Inclusive [OL].2019   https://www.opengovpartnership.org/wp-content/uploads/2019/05/Health

[55] Informational Commissioners Office. Information Rights Strategic Plan 2017-2021[OL] 2018 http://ico.org.uk

[56] Health Bodies England. Freedom of Information Act 2000[OL]. 2014 http://ico.org.uk

[57] Department of Health and Social Care. 2017/18 Data Security and Protection   Requirements [OL]. 2017 www.gov.uk/dh

[58] British Academy. Data management and use: Governance in the 21st century a joint report by the British Academy and the Royal Society [R]. London, British Academy 2017.

[59] Information Commissioner's Office. Draft Anonymisation Code of Practice [OL]. 2012 http://ico.org.uk

[60]   Department of Health and Social Care. Code of conduct for Data-driven Health   and   Care Technology [OL]. 2019 https://www.gov.uk/

[61]   Deloitte Center for Health Solutions. Closing the Digital Gap Shaping the Future of U.K Healthcare [R]. Deloitte UK Centre for Health Solutions 2019.

[62]   Manchester City Council. Health and Wellbeing: Involvement of the voluntary and Community Sector [OL].   2019 https://secure.manchester.gov.uk/info/200048/health_and_wellbeing

[63]   Cabinet Office. Departmental Improvement Plan: Civil Service Reform [OL].2014

[64]   Department of Health. The power of information: Putting all of us in control of the health and care information we need [OL]. 2012 http://ww.gov.uk

[65]   Open Government Partnership. United Kingdom Action Plan 2019-2021[OL]. 2019 https://www.opengovpartnership.org/

[66]   Office of CIO. Open Health Data Governance Strategy [OL].2016 http://www.cio.co.uk

[67]   Office of the Australian Information Commissioner .About us [OL].2018 http://www.oaic.au

[68]   Bureau of Health Information. How we work [OL]. 2019 http://www.bhi.nsw.gov.au/

[69]   The Australian Institute of Health and Welfare. Data Governance Framework [OL]. 2014 https://www.aihw.gov.au/

[70]   Australian Institute of Health and Welfare. Australian Institute of Health and Welfare Act 1987[OL]. 2018 Office of Parliamentary Counsel, Canberra

[71]   The Government of South Australia, Department of the Premier Cabinet. About ICT, digital and cyber security [OL]. 2019 https://dpc.sa.gov.au/

[72]   New South Wales Australian State. NSW Data Governance Framework [OL]. 2019 https://www1.health.nsw.gov.au/pds/Active

[73]   Australia National Data Service.Data Management Plans [OL] 2017 https://www.ands.org.au/

[74]   Office of the Australian Commissioner. Australian Privacy Principles [OL].2019 https://www.oaic.gov.au/privacy/australian-privacy-principles/.

[75]   Australian National Data Service. Data sharing considerations for Human Research Ethics Committees [OL]. 2018 www.ands.org.au/guides/data-sharing-considerations-for-hrecs

[76]   Office of Parliamentary Counsel, Canberra. Freedom of Information Act 1982 [OL]. 2019 Office of Parliamentary Counsel, Canberra.

[77]   Office of the Australian Commissioner. Access information under FOI [OL]. 2019 https://www.oaic.gov.au/freedom-of-information/

[78]   Australian Information Commissioner. Australian Privacy Principles [OL]. 2019 https://www.oaic.gov.au/privacy/australian-privacy-principles/

[79]   Office of Parliamentary Counsel, Canberra. Healthcare Identifiers Act 2010 [OL]. 2019 Office of Parliamentary Counsel, Canberra

[80]   Office of the Australian Commissioner. The Healthcare Identifiers Act and Regulations [OL] .2014 https://www.oaic.gov.au/

[81]   Australian Institute of Health and Welfare. Strategic directions 2017–2021: Stronger Evidence, Better Decisions, Improved Health and Welfare [OL]. 2017 www.aihw.gov.au

[82]   New South Wales Government. Building a strong data culture [OL].2019 https://data.nsw.gov.au/

[83]   Department of Broadband, Communications and the Digital Economy Australia. Advancing Australia as a digital economy: an update to the national digital economy strategy [OL]. 2013 https://apo.org.au/node/227751

[84]   Australian National Data Service. Partners and Communities [OL] 2019 https://www.ands.org.au/partners-and-communities

[85]   Racheal, G .Big Data Big possibilities: How Australia can use big data for better healthcare. The Mckel Institute. 2016

[86]   Hakeem, O. Public Accountability: The Case of Government Guarantee Scheme in PFI/PPP projects. University of West England. 2016 [OL]

[87] Santos, L. A study on the Impact of Non-operational Mechanisms on the Effectiveness of Public Technology Governance. Science Direct .2018 [J]