Role of Data in Improving Care within a Health System
A Case Study of the Australian Health System

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Abstract

**Background** - Health information technology (HIT) has been an emerging solution to reducing some gaps in care. Several nations have implemented expensive, large-scale, HIT projects; most have struggled with poor uptake, interoperability, and low sharing and reuse of data. Lack of understanding of complex “multilevel tensions” was a common reason for failure.

**Objective** - This study aims to understand how organizational context and interfaces affect the collection, management, and use of data for care improvement (CI).

**Methods** - The case study consisted of 33 hour-long semi-structured interviews with 38 informants from 27 organizations from 2 states. Primary data collected using snowball sampling in 2007-08 and elicited information on the use of data for improving quality of colorectal cancer care. Data were supplemented using publicly available organizational information. Data analysis included coding to identify themes and converting data into thematic matrices to enable the detection of patterns and comparative analysis.

**Results** - CI activities centered around the “patient-provider-hospital” relationship. Commonwealth and state entities exhibited higher levels of diversity in CI projects compared to local entities. Funding was a key driver of CI; bulk of CI activities occurred either in response to or in anticipation of funding. Some successful CI caused negative system feedbacks like further weakening of stressed systems and generated perverse incentives to shift costs. The NGO sector was a valuable government ally in CI due to their ability to: 1) influence the “patient-provider-hospital” relationships; 2) focus on diverse and niche areas of care; 3) contribute to CI knowledge base; 4) mitigate governmental conflicts of interest, and 5) act as a policy counterbalance. There were four fundamental uses of data within the health system – operations, CI, reporting, and knowledge generation. Data flow (sharing) occurred in response to funding and five distinct patterns of data-funding flows were identified within the health system. Existing data resources were largely underutilized due to various reasons like suboptimal data quality, failure to meet stakeholder needs, high administrative burden of linking and using data, privacy laws, and unwillingness to allow secondary uses of data. Data flow was hindered due to fragmentations including those arising from sovereignty, specificity, or philosophical issues.
1 Executive Summary

1.1 Background

The last two decades have seen a plethora of evidence highlighting major gaps in healthcare access [1] [2], quality [3] [4] [5] [6], affordability [7] [8] [9], and outcomes [10] [11] [12] in the U.S. [7] [13] and other developed nations [8]. These gaps in care are associated with higher rates of mortality, disability, lost earning potential, higher rates of adverse events, lower levels of health-related quality of life and patient satisfaction with care [7]. In most cases, this burden is disproportionately high in vulnerable groups such as the poor, minorities, groups, children and the elderly [7]. Several efforts are underway to reduce these gaps. Researchers have touted the promise of “big data” analytics to identify and manage high risk and/or high-cost patients [14], to support personalized medicine [15] for predicting emergency department visits [16] [17] developing actionable models to improve confidence in decision making [18], improving value by limiting the overuse of high value resources [19], improving care [20] and improving safety [21].

Several developed nations have invested hundreds of millions of dollars to implement large-scale HIT projects designed to facilitate the collection, management, analysis, and use of data in healthcare. Nearly all such countries (except U.S. which is still implementing) have already experienced major hurdles in their implementation of HIT systems, with some abandoning (e.g., UK, Germany, France) their programs temporarily before re-attempting again, incurring losses from $0.8-14 billion of tax payer money in the process. A review of several post-implementation lessons from US [29], UK [30], and Australia [33] indicate that most countries underestimated the complexity of their health systems. HIT deployment is usually studied with a focus on technological requirements at individual organizational levels rather than wider issues of data flow(s) that need to be achieved for optimal use and reuse of data within a health system. This indicates a need to step back further to understand the complexities underlying care improvement decisions and the role of data within CI.

1.2 Study Objectives

This case study uses a multilevel framework to categorize stakeholders at various levels within the Australian health system. This helps understand how organizational context and interfaces affect the setup, collection, management, use and sharing of data and data systems to improve care, thereby setting the stage for targeted interventions and policies for systemic change. This research will be of interest to high level policy making bodies (e.g., Office of the National Coordinator for Health Information Technology) and to administrators of private, public and non-governmental organizations. This research is motivated by the desire to provide insights on how public, private, and non-governmental healthcare organizations can work together to leverage current and future data systems to meet their care improvement goals.
To examine these issues, this study posed the following research questions:

1. What is the role and place of data (and HIT systems) in improving the delivery of care from the perspective of various stakeholders?
2. What are the perceived barriers and facilitators to the collection, management, analysis and use of data to drive improvement?
3. How do the results from question 1 and 2 vary across and within levels of the healthcare system?

1.3 Methods

This study used a case study methodology to examine the role and place of data in activities designed to improve the delivery of care within a health system. This study examined the case of the Australian health system to better understand how data and data systems are used within and across various levels of the health system.

1.3.1 Case identification

For the purposes of this research, an ideal case was a modern, multilevel, and sophisticated health system with an extensive data collection and sharing infrastructure. The Australian health system fulfilled all these criteria while remaining amenable to being studied easily. Colorectal cancer was chosen as the clinical condition on which the interviews would be focused after considering a few high priority cancer types, namely – breast, colorectal, lung, prostate, and skin cancer. Each type of cancer was assessed and ranked on the following dimensions: age-standardized incidence risk, total potential years of life lost, gender prominence, risk in indigenous vs. general populations, variations in current quality programs, and the availability of performance measures. Colorectal cancer was selected following this ranking and was also preferred because a review of clinical pathways indicated that colorectal cancer had prevention, screening, diagnosis, and treatment options that were spread across multiple settings (inpatient, outpatient, community clinic) and organizational sectors (government and non-government) within the Australian health system, thus offering an excellent opportunity to explore the role of data across settings and health system levels.

1.3.2 Sample generation and data collection

An initial sample of approximately 30 individuals was targeted, and snowball sampling was used to identify any additional informants who operated within this “universe” of cancer care in two Australian states until themes were fully delineated. The use of snowball sampling was appropriate because the key informants were a fairly “rare” group of high level decision makers who were in a position to recommend other potential informants who operated within the area of cancer control.

Data were collected in 2008 via semi-structured interviews with key informants. The initial list of informants was identified through conversation with the first informant who happened to be a very high
level official within the Australian cancer care ecosystem with extensive knowledge of the system. The list of informants targeted included high level decision makers (and administrators) within leading Australian organizations, in the government and non-government sectors, in roles pertaining to cancer care, specifically, clinical colorectal cancer care. A wide range of organizations from various levels of the Australian system were sampled including the Commonwealth/federal, states, local (area health services, general practice divisions, private and public hospital administrators), and clinical microsystem levels including primary and specialty care practitioners including surgeons. The interviews were conducted in person and lasted between 45-90 minutes. Interviews adhered to a predetermined protocol and included topics such as quality improvement, performance measurement, incentives and disincentives for quality improvement, and organizational relationships among key players in the healthcare system.

1.3.3 Sample characteristics

The original sample consisted of 35 interviews from 43 informants from 29 unique healthcare organizations in Australia. The final sample used in this dissertation consisted of 33 interviews from 27 unique organizations and 38 informants. One interview was excluded due to poor recording quality and another for being a high influence outlier organization within the health system.

1.4 Results

First, CI activities centered around the “patient-provider-hospital” relationship. CI efforts could be classified into 6 major categories: 1) patient focused; 2) provider focused; 3) institution focused; 4) provider-patient interface focused; 5) provider-healthcare institution focused; and 6) health ecosystem focused. Examples of each type of CI activity are noted in Table 1-1.

Table 1-1 Types of CI within a health system

<table>
<thead>
<tr>
<th>Focus</th>
<th>Example</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>1) Spreading awareness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2) Providing patient and caregiver resources to seek appropriate and timely care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) Giving them a voice in public policy and advocacy</td>
<td>May occur at any level</td>
</tr>
<tr>
<td>Provider</td>
<td>1) Education</td>
<td>Credentialing and clinical guidance occur closer to the commonwealth while education and training occur at local levels.</td>
</tr>
<tr>
<td></td>
<td>2) Credentialing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) Training</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4) Clinical guidance</td>
<td></td>
</tr>
<tr>
<td>Focus</td>
<td>Example</td>
<td>Notes</td>
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<td>---------------------------</td>
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<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Healthcare institutions</td>
<td>1) Accreditation</td>
<td>Can occur at commonwealth, state, and local levels; both sectors</td>
</tr>
<tr>
<td></td>
<td>2) Payer contracting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) Risk mitigation</td>
<td></td>
</tr>
<tr>
<td>Provider-patient interface</td>
<td>1) Communication training</td>
<td>Both can occur at any level</td>
</tr>
<tr>
<td></td>
<td>2) E-Health portals</td>
<td></td>
</tr>
<tr>
<td>Provider-healthcare</td>
<td>1) Peer credentialing</td>
<td>Can occur in either sector but at the local and individual levels</td>
</tr>
<tr>
<td>institution interface</td>
<td>2) Incentive payments</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) Feedback</td>
<td></td>
</tr>
<tr>
<td>Health ecosystem</td>
<td>1) Patient advocacy (e.g., allowing terminally ill patients access to</td>
<td>Generally, occurs in the NGO sector and aimed at governments</td>
</tr>
<tr>
<td></td>
<td>retirement funds earlier</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2) Professional advocacy (e.g., better pay for clinical work and hours</td>
<td></td>
</tr>
<tr>
<td></td>
<td>for nurses)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3) Institutional advocacy (e.g., streamlining of reporting requirements)</td>
<td></td>
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</tbody>
</table>

There and there was two-way communication between these entities with the health system within they operated which occurred through a set of intermediary organizations, which were usually NGO organizations.

Second, the NGO sector was a valuable government ally in CI due to their ability to: 1) influence the “patient-provider-hospital” relationships; 2) focus on diverse and niche areas of care; 3) contribute to CI knowledge base; 4) mitigate governmental conflicts of interest, and 5) act as a policy counterbalance. NGOs come in many shape and forms, allowing them to connect with individual professionals and patients across a variety of issues (e.g., support, advocacy). Governments on the other hand, even in their most powerful role as a payer, were not successful in connecting with individuals at this level. Informants consistently pointed out that providers tended to be independent spirited and resisted attempts to be directly controlled by the government, there by necessitating NGOs stepping in to serve as the intermediary in care improvement endeavors such as awareness generation, training, and support. Similarly, almost all the informants from government organizations indicated engaging in CI activities that were broad based in nature and not specific to any one therapeutic area due to the limited resources. Care improvement activities that were focused on specific therapeutic areas and/or groups of people/professionals were conducted through the NGO sector, which could be very diverse (disease specific, people specific, purpose specific) in its nature and purpose. Moreover, a bulk of the research knowledge (and data) were generated and disseminated through the non-government sector. NGOs
served additional purposes like enforcement of standards for individuals like credentialing and for organizations through accreditation thereby allowing the government(s) to keep an arm’s distance from enforcement roles where there might be conflicts of interest (e.g., where the government owned hospitals and was also responsible for enforcing standards). Finally, influential or well-respected NGOs were valued for their ability to critique government policy making or take a position that may be critical but unpopular. Their outsider perspective acted a counterbalance to government policy making efforts. Government agencies generally tended to contract with NGO around resource intense CI activities (e.g., curriculum revisions, large research projects), whereas less resource intense activities (e.g., patient awareness brochures, smaller research projects) may be done using private funding from NGOs alone.

Third, commonwealth and state entities exhibited higher levels of diversity in CI projects compared to local entities. The data indicate that organizations at higher levels of the health system played greater number of roles in improving care and this pattern stayed consistent across both government and non-government sectors. Similarly, higher levels of the health system not only greater number of roles in improving care but also had a more diverse range of interventions that were aimed at a wider range of targets including physicians, patients, healthcare organizations, and health system, whereas local level organizations largely focused on targeting only two or so targets per sector.

Fourth, funding was a key driver of CI; the bulk of CI activities occurred either in response to or in anticipation of funding. The non-clinical reasons for improving care highlight the fact that healthcare is as much a business as it is about doing good. Improving care or even the appearance of improving care can serve as business value proposition for healthcare organizations, which is used to attract more patients and better clinical talent. Thus, improving care can be good for business and the bottom line. For example, in certain circumstances, clinicians can make more revenue, if they provided the guideline recommended services through routine follow ups than they would if they disregarded the guidelines. Similarly, improved care can reduce risks (e.g., of falls or infections) and bolster the profitability due to fewer malpractice suits. Governments improve care to improve their financial accountability by investing in services that are efficient and high performing. They also improve care to reflect the broader societal values like equity by investing in reduction of care (e.g., by improving access) and outcomes disparities (e.g., sub groups with worse outcomes compared to the general population). The money driven nature of CI means that most individual clinicians are not in a position to drive CI. The clinicians reported being too busy providing care to engage in any continuous CI projects. Individual clinicians also reported working in resource stressed environments that did not provide the support needed to undertake and sustain CI efforts.

Fifth, while engaging in CI is a laudable goal, it is not possible to engage in CI within certain resource strained places of the health system where the struggle to offer basic services is so real that improving care is the last priority. This can be particularly true in rural areas with low density of care providers (general and specialty) or organizations where the demand for services far exceeds the staffing or
funding available to provide those services. Due to the connected nature of the healthcare system, in resource, strained situations like these, successful CI efforts in one area might result in a system feedback that stresses the overall healthcare system in other ways. For example, a population health screening program if truly effective could direct large number of people into the screening and then onto treatment that may or may not enough infrastructure or availability of trained staff (e.g., shortage of staff trained staff to perform colonoscopies) to handle this increased flow of patients. Thus, providing better care or even more efficient systems may fall apart just by virtue of the limitations of the inherent healthcare provisioning infrastructure within a health system. Moreover, pursuits of CI require detection of problems prior to fixing. In certain cases, detection of problems alone can have a deleterious effect on staff morale. As one informant explained the more people dig into the data looking for problems with care delivery, the more likely people are to detect problems with care. Thus, CI attempts can suddenly make a health system appear to be worse on paper than it might be in real life, triggering a negative feedback cycle. Additionally, in a joint public-private payer system, there is considerable incentive for the cash-strapped public sector to reduce its obligations to the public. There are two ways to achieve this: 1) by providing less than acceptable levels of care in certain areas, and/or 2) through reorganizations of care delivery such that all (or part) of the care is now delivered in a different setting. This can result in a shift in public use towards the organizations that are more heavily invested in CI, thereby reducing some of the obligations of the public sector. In a fragmented multi-payer system, this is a way to shift costs from the one payer to another, relieving some of the stress. Similar cost shifting can occur across any natural fragmentations (e.g., shifting costs from medical benefits to pharmaceutical benefits by reducing hospital stay and sending patients home while on expensive drugs) in a health system.

Sixth, data remain a key necessity for CI within the health system. Using inductive analysis, this analysis found seven different categories of data use for doing care improvement work – 1) operations, 2) reporting, 3) monitoring, 4) identification, 5) intervention selection, 6) providing feedback/program evaluation, and 7) knowledge generation. A closer examination of these categories indicated a hierarchical connection between some of these categories. This analysis indicated that the seven categories of data use can be reduced to four primary end goals – operational use, reporting, knowledge generation, and CI (Figure 7-3). These end goals are freestanding and one or more categories can be mixed and matched to create any desired action. For example, an organization that has no need to improve care can simply use data for operational purposes or use data for CI with or without any reporting requirements.

The use of data to serve and improve the day-to-day operations of an organization include the use of data to for reimbursement, uphold regulatory standards, offer incentives, and to aid decision-making about service provisioning and resource allocation. Operations data are used for CI and were most commonly used by administrators. The commonest type of operations data was reported by organizations that are payers (public or private) or those that routinely interface with payers (e.g., healthcare organizations).
Data use for CI purposes included the subcategories of monitoring, problem identification, intervention support, feedback, and program evaluation. Data used to generate knowledge like use of comparative effectiveness evidence or any studies to support the choice of intervention may or may not be used within this context. The last major category of data use within a health system was for the purposes of reporting. Periodic performance reporting is a common requirement within the highly regulated and increasingly held accountable field of healthcare. This use of data can be further classified into four sub-categories based on the intended consumer of the reports: 1) oversight bodies (internal/external), 2) subordinate bodies, 3) clinical teams, and 4) the public.

Seventh, like CI, data flow (sharing) mostly occurred in response to funding and five distinct patterns – 1) accountability; 2) direct CI; 3) indirect CI; 4) regulatory approval; and 5) transparency - of data-funding flows were identified within the health system. The accountability (or “I give you money, you give me data”) flow was characterized by the one-way flow of funding and a one-way flow of data in the opposite direction. These relationships can be seen across all levels, but are more prominently seen within the government sector. The reporting of data to the payer entity and generally constituted the fulfillment of an accountability relationship. This relationship is also characterized by a lack of knowledge of how the data shared were subsequently used by the recipient of the data. The direct care improvement (or “I give you money, you give me data, I give you feedback) relationship was characterized by a two-way flow of data and a one-way flow of money between two entities. The data feedback loop made a huge difference in the impact of this relationship. The data that were being fed back to the sender, usually was designed to evaluate the sender’s performance in a domain of care (e.g., rate of immunization) and this feedback could be used to the sender to promote CI efforts in the recipient entity. These kinds of relationships occurred both in the private and the public sector, especially at the state and local levels, which were closer to clinical care provisioning.

Indirect care improvement (or “I give you money and feedback, and you provide a service”) was the third major data-funding relationship. This is characterized by one way across sector flow of data and money; these flows can be seen at all levels of the health system. There are two variants within this category. While the pattern of money and data flows remained the same in both cases, the purpose was different. In the first case, money and data flowed from government institutions to non-government support organizations. This kind of pattern indicated the presence of CI contracts that were implementation oriented. For example, government agencies rolling out new population screening programs would enlist the help of physician support bodies to spread awareness about the program and to train physicians around the clinical and administrative changes resulting from the program. In the second pattern funding and data flowed from government institutions to non-government research and voluntary health organizations. This kind of pattern indicated the presence of CI contracts that were designed to generate and disseminate knowledge. Non-government organizations relied heavily on government funds but also raised their own funds to generate all the knowledge that is available within a health system.
The regulatory approval (or "I give you data and money, you give me feedback") flow was characterized by a two-way flow of data but flow of money is reversed from that seen in "direct improvement" in that the payer entity, instead of giving feedback, is also receiving feedback. These kinds of relationships generally occur between providers or healthcare organization and regulatory bodies. For example, hospitals must submit performance data and pay a fee to undergo accreditation by a regulatory body. Similarly, physicians have to pay a fee and take provide competency data to be credentialled by professional standard setting organizations. The final data-funding flow pattern was the transparency (or “I give you data, you give me nothing”) was characterized by a one-way flow of data in the absence of any overt flow of money. This does not mean that money did not flow to the other organization. For example, government agencies provide performance reports and other kinds of health data in the public domain. These are undertaken for transparency and accountability purposes because the public is the true owner of the data that were generated using public tax monies.

Eighth, existing data resources were largely underutilized due to various reasons like suboptimal data quality, failure to meet stakeholder needs, high administrative burden of linking and using data, privacy laws, and unwillingness to allow secondary uses of data. Suboptimal data quality resulted from three issues: inconsistency, incompleteness, and inaccuracy. Inconsistency had to do with variances in the data collection process which hamper both the data quality of at the lowest unit level but also the ability to compare across units. For example, informants reported that local cancer registries shared few or no common data points, making any other local comparisons or health outcomes nearly impossible. Incompleteness of data refers to completion of only a subset of the required data points. For example, commonwealth government officials responsible for population health programs noted that physicians participating in the screening program did not return all complete all the data fields requested, resulting in high levels of missing data. Inaccuracy related issues were around errors in the value of the data. Several informants reported an error in a commonwealth report which erroneously switched the fractions of colorectal cancer care conducted within the public and private health sectors, resulting in confusion when used for planning and resource allocation purposes. Together these three issues erode stakeholder confidence in data and prevent its use for CI decision-making purposes.

The second problem occurs when primary data are being collected but the data are such that they do not serve the needs of all the key stakeholders. This could be due to couple of reasons: 1) the relevant data variables are missing in the data set, or 2) the level of granularity or response options are inadequate. In the former case, occurs when databases fail to evolve in response to changing needs. The latter problem involves levels of data aggregation (e.g., state level when local levels are needed to intervene) that is inappropriate for meaningful use by another stakeholder or lack of meaningful codes that will enable differentiation and subsequent intervention. This problem tends to occur when large organizations collaborate on a complex care improvement project and the dataset designers overlooked input from key stakeholders or failed to account for organizational data sharing agreements with other entities. Problems
like this can result in “data dumps” and underuse of data (even when data are shared) and inefficient use of existing resources.

The third barrier to data was the high administrative burden of linking or using data. Several informants indicated their willingness to use data to improve care but noted too high a burden associated with data use and reporting. This was especially problematic for informants at the frontline of care giving, who are either too busy to engage in additional administrative duties or did not have the resources required to set up automated systems to facilitate data collection, management, and reporting. Another type of burden arose in situations where informants had access to multiple complementary databases (e.g., inpatient visits, inpatient billing data) but the datasets could not be linked due to technological or political/legal restrictions. In such cases, there was a frustration associated with the knowledge that data were available but with significant barriers to their use. The fourth and final barrier resulted from privacy laws, often resulting in strict organizational interpretations of data use. While privacy laws were designed to protect illegal dissemination of patient information, these were often interpreted too stringently by entities that are not in favor of data sharing. Organizations, such as those designed to promote population health, often have broad data sharing powers granted by legislations, however, they might choose a stricter interpretation to not share or not link the data to other datasets, thereby reducing preventing a fuller picture from developing. Similarly, certain older population based datasets were originally developed for very limited purposes (e.g., understanding disease epidemiology) and organizations might be hesitant to use that data for other purposes (e.g., to inform the development of population based interventions).

Funding, adequate staffing, and automated systems are the most mentioned facilitators in the use of data in CI.

Data flow within the health system was hindered due to fragmentations including those arising from one or more of these three issues: 1) sovereignty, 2) specificity/breadth, or 3) philosophical differences. The first kind of fragmentation hampered data flow due to data ownership (e.g., commonwealth vs. state or public vs. private sectors), and subsequent sharing related issues. This fragmentation could be thought of as a power struggle resulting in a tug-of-war between two or more somewhat similarly motivated (e.g., both interested in public health issues) entities. The second kind of fragmentation hampered data flow due to fundamentally different data needs of each stakeholder (e.g., primary vs. specialty care or inpatient vs. outpatient), making it extremely difficult to reconcile in one dataset. This kind of fragmentation is likely to produce irrelevant data from the perspective of one or more of the stakeholders. The last kind of fragmentation - philosophical - directly hampered data collection and indirectly impeded data flow by challenging the very need for data due to core differences in their belief sets. This was a fragmentation of perspectives about the nature (standardized vs. individualized) of healthcare. Standardized care lends itself to routine collection and use of data to inform decision-making processes, in ways individualized care does not. Individualized care, by definition, treated healthcare on a case-by-case basis and makes it harder to evaluate performance of individual providers. Thus, individual willingness, to invest in routine
data collection, management, or reporting systems, or to believe in the validity of performance metrics can be driven by perspective of healthcare processes. This fragmentation is one of the issues at the heart of disagreements around performance measurement. Performance measurement requires agreement around the “healthcare can be standardized” school of thought, whereas physicians that believe in the “healthcare is individualized” school of thought do not think performance measurement can be good reflection of their true merits as a physician.

1.5 Policy Recommendations

This research was one of the first attempts, to the best of our knowledge, at examining the role of data in CI within a developed health system. By not focusing on the role of data from a narrow post-HIT-implementation perspective, this study also provides an “outside, looking in” view which is different from what is obtained by the traditional evaluations conducted post failure of HIT projects.

1.5.1 Payers are the leaders in CI

Regarding CI, the first important thing to note is the payer-driven nature of CI. By virtue of being a payer-driven enterprise, CI is also a top down process, which can be understood once we understand the high demand for accountability faced by payers. Payers wish to demonstrate their accountability, financial and performance, by investing in high performing projects. As attractive as it sounds, CI is not suited to be a physician-driven process because physicians are too many in number with too few controls to aggregate and monitor and coordinate efforts at an individual level. Moreover, most health systems are resource strained and physicians lacked the extra time to conduct CI work on top of their clinical and administrative duties. There is just not enough financial bandwidth for individual clinicians to invest in CI. Additionally, if you wish to understand the driver of CI within a health system, all that is needed to identify the biggest payer within the health system. The organization and sector that covers the largest proportion of expenses would be the leader. All other payers will likely follow the lead, in a publicly funded system, that payer is the government and that is when the government gets to lead CI. Currently most existing data resources are used for operations and reporting purposes. More data need to be used for the purposes of CI related knowledge generation and care improvement. As indicated by our findings, a lot of CI efforts are collaborative in nature and are undertaken by the NGO sector. In order to scale up knowledge generation and CI use of data, funders need to work with the NGO sector to provide required funding assistance.

1.5.2 The value of data is not politics free

While data are considered neutral in nature, data use is inherently political. When governments (as major payers) lead CI efforts, it is important to remember that it is nearly impossible to untangle CI from politics. All decisions are political at multiple levels – organizational, state and national. For example, at the organizational level, nearly all informants that worked closely with providers or were providers themselves
indicated that most providers believed that they provided good care, even the absence of any objective evidence. What they meant is that doctors had a firm belief that they are doing the best they can under their particular operating circumstances and they hoped that would suffice. Use of data to measure performance amplifies that fear of being proven inadequate and feeds into of the desire to not look bad in front of peers. This fear of data can result in refusal to use data or to cooperate with other departments with the organization.

The impact of national and state politics is dependent on how the political system is set up (election cycles, health related positions held by political appointees). In such context, data are both power and also a problem. Data could provide the support to get people to rally around an idea, data could also be shunned as a way to avoid accountability that comes with knowledge of suboptimal performance. Thus, political will is key consideration when thinking about data, especially large-scale HIT projects, because such sweeping changes are often undertaken by government agencies. There is need to figure out beforehand how data will be fit within the political ethos of the health system because unless HIT implementation considers political environments, it will likely fail in fostering data utilization.

1.5.3 Data exhibit money-like characteristics

Data and HIT systems are expensive to collect, manage, and analyze, making it a valuable resource just like money. Once data have been collected, there is a sunk cost associated with it, which means that data, like money, offer the greatest benefits when shared or reused repeatedly. While some entities do not wish to share their data, there are other organizations which might wish to reap the greatest return on their investments by facilitating data sharing. Taking the money analogy and exploring how money gets used and reused by banks through the lending process, we can learn two lessons: 1) data sharing should have a transactional fee associated with it, and 2) data sharing should be accompanied by rules governing the sharing and use process. The need for a “transactional fee” to cover the cost of data has been demonstrated repeatedly in the data where money flows were essential for generating corresponding data flows within a health system. Similarly, data sharing should also be accompanied by rules, like loans have repayment dates or interest rates governing each agreement. Having a set of formalized rules along with incentives and penalties can help establish confidence in the data sharing process and deter misuse.

1.5.4 Effective data-driven CI requires improvement-oriented environments

The findings from this study indicated that many CI efforts are collaborations between two or more organizations. In healthcare, if data use were to be promoted, there is a need to provide an improvement-orient environment that is cognizant of the organizational challenges (e.g., post-data use care might seem worse compared to pre-data use periods) associated with data use as an organization adopts and then matures into the data-driven CI process. In a collaborative situation, this improvement-oriented environment has to exist across all participating organizations. This is especially needed when new HIT
systems are implemented, but should be available at all times within the system, albeit in different forms. Entities using data to improve care should be allowed to fail or underperform without fear of economic or public repercussion. This includes the responsibility of the media to not sensationalize any reports that might come from these data being made public. Media should make all efforts to report events in a sensible manner. Similarly, in a new data use environment, payers should consider gentler ways to promote better performance and build user confidence in the value of sharing performance data.

1.5.5 Fragmentations affecting data flows can be overcome

Sovereignty based fragmentations can be overcome through the judicious of monetary incentives to encourage data sharing and formalized relationships (e.g., memorandum of understanding or stronger legal recourse). Specificity and breadth based fragmentation can, perhaps, be overcome through provisions to link discrete datasets on a as needed basis to balance between irrelevance and creating large unwieldy datasets trying to incorporate multiple perspectives. Philosophical fragmentation may be overcome through awareness building and education in the topic of interest.
2 Introduction

2.1 There are major gaps in care within developed health systems

The last two decades has seen a plethora of scientific research highlighting major gaps in access [1] [2], quality [3] [4] [5] [6], affordability [7] [8] [9], and outcomes [10] [11] [12] in the U.S. [7] [13] and other developed nations [8]. In a Commonwealth Fund survey [8] of adults from 11 developed countries (Figure 2-1), only 25% of adults in the U.S. reported that the U.S. system worked well and only needed minor changes, compared to 40% (France) to 63% (U.K) of adults in the countries surveyed. U.S. also reported the most proportion of respondents who reported wanting their health system needed to be “completely rebuilt” compared to 4-5% (UK, Netherlands), 7-10% (Switzerland, Sweden, New Zealand, Canada, Australia, Germany), and 12% of adults in Norway.

Figure 2-1 Adults’ view of the health system in 11 developed countries


These gaps in care are associated with higher rates of mortality, disability, lost earning potential, higher rates of adverse events, lower levels of health-related quality of life and patient satisfaction with care [7]. In most cases, this burden is disproportionately high in the poor, minority groups, and the vulnerable like children and the elderly [7]. Several efforts are underway to reduce these gaps, however, progress has been slow uphill battle. Findings indicate that areas of care that were measured tended to improve more compared to areas that were not measured, highlighting the importance of data in improving care.
2.2 Data and HIT are one of many ways to address these gaps in care

The promise of data and the use of health information technology to facilitate the collection, management and use of data has one of the most promising ideas on the horizon. Researchers have touted the promise of “big data” driven analytics to identify and manage high risk and/or high-cost patients [14], for personalized medicine [15] for predicting emergency department visits [16] [17] developing actionable models to improve confidence in decision making [18], improving value by limiting the overuse of high value resources [19], improving care [20] and improving safety [21].

2.3 Investments in large-scale health information is increasing

Over the last decade, health care delivery systems have seen increasing public demands for quality, transparency, and accountability [22] [23]. Addressing each of these demands requires better decision-making by both organizations and individuals alike as they navigate the healthcare system in their various roles as patients, providers, administrators, insurers, researchers, and policy makers. The routine collection, management, and subsequent use of data in decision-making has been put forth as a key step towards achieving a health system that is continuously improving to respond to the changing needs of its stakeholders [24] [3] [25]. Hence, the collection, management and analysis of data are core functions of modern day healthcare systems and substantial investments have been made in developing infrastructure needed to promote these activities across several developed healthcare systems (Table 2-1).

Table 2-1 Large scale investments in health information and data around the world

<table>
<thead>
<tr>
<th>Country</th>
<th>Investment</th>
<th>Project Status</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>$30.0 billion</td>
<td>Ongoing</td>
<td>The 2009 American Recovery and Reinvestment Act legislation established the HITECH Act that seeks to improve patient care and make it patient-centric through the creation of a secure, interoperable nationwide health information network [26].</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>$6.1 billion (£4.2 billion)</td>
<td>Ongoing</td>
<td>Started in 2014, this project aims to make all patient and care records digital, real-time, interoperable and go paperless by 2020 and introduce a national collection of anonymous patient data to enable care improvement and intervention research. [27]</td>
</tr>
<tr>
<td>Country</td>
<td>Investment</td>
<td>Project Status</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>------------</td>
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<td>-------------</td>
</tr>
<tr>
<td>France</td>
<td>$0.3 billion (€0.3 billion)</td>
<td>Ongoing</td>
<td>Started in 2011, the Dossier Medical Personnel (DMP) is the national health care tool for sharing and exchanging information about individual patients. The system was set up to be entirely private with no secondary use of the data included within it, or at least in its first stage [28] [29].</td>
</tr>
<tr>
<td>Germany</td>
<td>$1.8 billion (€1.7 billion)</td>
<td>Ongoing</td>
<td>This 2016 law will create a “E-Health Card” to store administrative data, a photograph, and medical applications such as emergency information, medication plans, and cross-facility electronic health records. Other objectives include establishing the infrastructure to support the card and improvement of health information technology interoperability.</td>
</tr>
<tr>
<td>Australia</td>
<td>$0.4 billion ($0.5 billion)</td>
<td>In transition</td>
<td>Set up in 2005, National eHealth Transition Authority has been working to establish interoperable infrastructure to support communication across the health care system. The record supports prescription information, medical notes, referrals, and diagnostic imaging reports. [30]</td>
</tr>
<tr>
<td>China</td>
<td>$18.9 billion (CN¥130 billion)</td>
<td>Ongoing</td>
<td>The “3521” plan where 3 refers to a three-tiered (country, province, region) data platform with 5 applications including public health, medical services, rural insurance plan, basic drug plan, and general planning and management and consists of two systems, the EHR and the EMR, all contained on 1 specialized network. Aimed to be complete by 2020.</td>
</tr>
</tbody>
</table>

Note: Australian invest in Australian dollar; £; Great Britain pound; €; Euro; ¥, Chinese yen, EHR; Electronic health records; EMR; Electronic medical record. All cost estimates are in 2016 USD.

2.4 Data and HIT have failed to fulfill its promise

Even as healthcare spending keep increasing over time [31] investments in data collection and management systems have yet to demonstrate their full value in either clinical [26] or economic metrics [32] [33]. Just about every country (except U.S. which is still implementing) on this list has already struggled major hurdles in their implementation of the EHR systems and grappled with issue like low rates of uptake (France, Australia), low rates of data sharing (U.S., U.K.), and stakeholder resistance (Australia, U.K.). Some abandoned (e.g., U.K., Germany, France) their programs temporarily before re-attempting again. Preliminary data [26] indicate that the U.S. is headed in a similar direction.
Table 2-2 Outcomes of health information technology projects across the world

<table>
<thead>
<tr>
<th>Country</th>
<th>Sunk Investment</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>$28.0 billion</td>
<td>Several interim studies report lower than expected return on investment and failure to meet stakeholder needs.</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>$14.1 billion</td>
<td>The National Program for IT (NPfIT) was scrapped in 2011 after nearly a decade of trying to implement a centralized EHR for patient, provider, administrator, and public use. Project failed due to inability to adapt to the complexity of the NHS and failure to meet the needs of stakeholders. This program was replaced by the current effort. Case report noted that 60-80% of government health IT projects ended in failure. [27, 28]</td>
</tr>
<tr>
<td>France</td>
<td>Not available</td>
<td>Criticized for low uptake and high cost. Was abandoned once and was revamped in 2014. High cost remains a concern.</td>
</tr>
<tr>
<td>Australia</td>
<td>$0.8 billion</td>
<td>The Personally Controlled Electronically Health Record System (PCEHR) was criticized for being overly complicated and unusable. [34] [30]</td>
</tr>
</tbody>
</table>

Note: All cost estimates are in 2016 USD

2.5 HIT deployments ignored the complex, multi-stakeholder nature of health systems

A review of several post-implementation lessons from US [26], UK [32], and Australia [34] indicate that most countries underestimated the complexity of their health systems. Within this context, various other shortcomings like haste to implement, trying to achieve too much with limited skill and resources, and underestimation of cultural inertia have resulted in some very expensive experimentations, as seen in Table 2-1 and Table 2-2) in trying to solve some “wickedly” [34] complex challenges of healthcare improvement. However, it is important to note that these post-hoc evaluations only provide complexities from the implementation point of view (i.e., problems that arose once a project was implemented). There is a need to step back further because there is a need to understand the complexities underlying care improvement decisions and then the role of data within CI. The challenge is to find ways to create a system which collects, manages, and shares data effectively within a health system. This can occur if we can visualize how data and data systems function within larger context of a complex, multilevel healthcare system comprising of numerous moving parts [35] [36] [37]. Without a vision for our data and data systems we will have what we already observing today – highly fragmented data silos, often built to meet narrowly defined objectives of a few stakeholders [30] [34]. These systems fail to serve the needs of data in stakeholders upstream at the national, state, or even the local levels that are also responsible for the performance of our healthcare systems instead contribute an “additional layer of complexity to an already complex health delivery of healthcare…” [37]. Studying the health system within which data and data
systems are embedded can provide clarity and set the stage for predictable systemic improvement to help increase the efficacy and efficiency of efforts to strengthen the collection, management, sharing and the use of data within health systems [38] [39].

This case study will use a multilevel framework to categorize stakeholders at various levels within the Australian health system. This will help understand how organizational context and interfaces affect the setup, collection, management, use and sharing of data and data systems to improve care, thereby setting the stage for targeted interventions and policies for systemic change. This research will be of interest to high level policy making bodies (e.g., Office of the National Coordinator for Health Information Technology) and to administrators of private, public and non-governmental organizations.

For the purposes of this research, data has been defined very broadly to mean a slice of the bigger information stream that has been consciously given form by a user for use for a particular purpose. Data are also by definition storable and shareable. Similarly, HIT was used broadly to include a broad range of data collection, management, and analyses systems used in healthcare including, but not restricted to, electronic health records, clinical prescription and order entry tools, clinical decision support, and image storage and retrieval systems. It also includes public health databases like epidemiological and clinical registries and adverse event reporting systems. Care improvement was defined more broadly to include the “continuous” and “systematic” aspects of quality improvement [40] as well as other “non-continuous” and “nonsystematic” efforts to generally improve the delivery of care within a health system.

In order, to understand the problems, this study posed the following research questions:

1. What is the role and place of data (and HIT systems) in improving care from the perspective of various stakeholders?
2. What are the perceived barriers and facilitators to the collection, management, analysis and use of data to drive care improvement?
3. How do the results from question 1 and 2 vary across and within levels of the health system?

This dissertation will be in the form of a monograph. Chapter 1 will provide an executive summary. Chapters 2-3 will introduce the problem and provide a review of the literature on health systems, care improvement, and the role of data and HIT in healthcare. Chapter 4 will discuss the study methodology. Chapters 5-6 will discuss findings from individual cases and Chapter 7 will present a synthesis of these findings. Chapter 8 will discuss the implications of these results, provide policy guidance, and offer suggestions for future research.
3 Background

3.1 Understanding health systems

Health systems can be seen as a social system where multiple actors from different decision environments collaborate to produce desired social outcomes. In such social systems, each independent actor is constantly evolving and adapting in response to various stimuli within their environments [41] [42] [36]. The health system could be decomposed into three key components: 1) actors and social entities; 2) the role each actor and social entity perform; and 3) the relationships actors and social entities have to each other.

3.1.1 Purpose and goals

The goals of a social system were often multifaceted and sometimes contradictory. In a health system, the fundamental goal was twofold – to: (1) improve the health status of individuals through the delivery of care when they are ill; and (2) improve the health of a population by defending its people from threats to their health status (e.g., acts of bioterrorism). Other goals of an “ideal” healthcare system included equitable access to care and fairness in the financial contributions made to obtain care and providing people with a safety net against the financial risks associated with ill-health. Furthermore, healthcare delivery systems aimed to remain responsive to both the personal and healthcare needs of individuals by honoring their rights to dignity, autonomy and confidentiality while remaining prompt in attending to their health needs [25] [38] [43].

Health information systems were one of the six key features identified by the World Health Organization (WHO) as being crucial in helping any healthcare system achieve its goals. The other five factors were: 1) Leadership & governance, 2) Health financing, 3) Human resources for health, 4) Essential medical products and technologies, and 6) Service delivery systems [25].

It is not possible to understand the role of health information systems in improving care without considering the complexities like interconnectedness between various system components. In order to understand a health system, we need to focus on the major actors, the roles played, and understand the nature of the relationships with the system.

3.1.2 Actors and social entities

In a social system, the term “actors” refer to both individuals and social entities. Although social entities are composed of individuals; they are also independent actors. Social entities often outlast their original founders and often act in contradiction to at least some of the individuals that compose them. Although there are many alternative ways of classifying actors and social entities[44] [45], one study [46] identified six categories that appears to provide the most comprehensive and intuitive list. They include:
educators/researchers, suppliers, insurers, providers, payers and government organizations (Table 3-1). Most of the categories are self-explanatory, with the exception of “insurers” and “payers.” Insurers are organizations that contract with a policy holder to pay for services rendered by a healthcare provider to the policy holder. Payer specifically refers to what is usually known as a “third party administrator” which is neither the policy subscriber nor the insurer; these third-party administrators serve to process insurance claims and payments and help manage administrative aspects of insurance plans like recordkeeping, adjudications etc. There is some degree of overlap between both categories, but there are instances where these two actors can exist separately.

Table 3-1 Types of actors within a health system

<table>
<thead>
<tr>
<th>Education/Research</th>
<th>Suppliers</th>
<th>Insurers</th>
<th>Providers</th>
<th>3rd Party Payers</th>
<th>Government</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical schools</td>
<td>Pharma companies</td>
<td>Managed care plans</td>
<td>Health departments</td>
<td>Commercial insurers</td>
<td>Public insurance financing</td>
</tr>
<tr>
<td>Dental schools</td>
<td>Medical care suppliers</td>
<td>Commercial insurers</td>
<td>General practitioners</td>
<td>Employers</td>
<td>Health regulations</td>
</tr>
<tr>
<td>Nursing programs</td>
<td>Biotech companies</td>
<td>Self-insured employers</td>
<td>Specialty physicians</td>
<td>State agencies</td>
<td>Health policy</td>
</tr>
<tr>
<td>Allied health practitioner programs</td>
<td>Durable medical equipment companies</td>
<td>Public assistance programs</td>
<td>Dentists</td>
<td>3rd party administrators</td>
<td>Research funding</td>
</tr>
<tr>
<td>Research orgs</td>
<td>Public entitlement programs</td>
<td>Non-physician providers</td>
<td>Pharmacists</td>
<td>Public health</td>
<td></td>
</tr>
<tr>
<td>Private foundations</td>
<td>Veterans’ Health programs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public research agencies</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Professional associations</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Trade associations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data Source: [46]

3.1.3 Roles

For any social system to work, the actors and their roles must be connected [3]. The connectivity among actors and functions can be broken into two parts – namely roles and relationships. In this work, we refer to role as the function that one actor plays relative to another actor. In a social system, each actor performs at least one – but often more – roles that assist the system in achieving its overall goals. Thus, a
A single actor could play different roles when paired with different actors within a system. For example, an insurer played the role of a “collector” or “resource pooling” agent during its interaction with a subscriber and played the role of a “payer” during its interaction with a service provider. Like actors, these roles can be divided into categories [38] [43] [45] [46]. Harmonizing across categories included seven core functions: stewardship, regulation, service financing, service payment, service provisioning, and resource development. It is important to note that any actor/entity can take up one or more of these roles and these roles can occur either in the public sector or the private sector or be shared between the two sectors.

Table 3-2 Key roles within health systems

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Financing</td>
<td>The process of pooling and the subsequent redistribution of revenues for service provisioning activities. Activities include revenue collection, fund pooling, purchasing etc.</td>
</tr>
<tr>
<td>Service Payment</td>
<td>The process of determining how much is to be reimbursed to the service providers and in what ways. Payment strategies include fee for service, capitation, out of pocket etc.</td>
</tr>
<tr>
<td>Service provisioning or Service delivery</td>
<td>The process of providing both personal and non-personal care using financial and non-financial resources generated within the system. This occurs within both public and private sectors</td>
</tr>
<tr>
<td>Resource development*</td>
<td>This includes the generation of human (e.g., medical professionals) and physical resources (e.g., health IT, facilities, equipment, pharmaceuticals) required to support the production and delivery of healthcare services</td>
</tr>
<tr>
<td>Resource allocation</td>
<td>The process of planning, assigning and distributing available resources in an economic way</td>
</tr>
<tr>
<td>Stewardship</td>
<td>Stewardship goes beyond traditional idea of regulation and includes setting/monitoring/implementing rules; ensuring a level playing field for all actors; and providing strategic vision for the entire health system.</td>
</tr>
<tr>
<td>Regulation</td>
<td>These establish rules and regulations and provide oversight and ensure compliance to promote safety and quality.</td>
</tr>
</tbody>
</table>

Note: Resource development, resource allocation, stewardship/regulation are cross cutting

3.1.4 Relationships

Relationship is the connection (or “role interaction”) between the two actors in their respective roles. For example, two entities – one playing the role of a supervisor and the other playing the role of a supervisee – one possible relationship resulting from that interaction could be that of “oversight.” Each entity may be connected to itself and to others in a variety of tightly- or loosely-coupled inter-actor relationships. Examples include joint ventures and programs, trade associations, networks, consortia and alliances, interlocking directorates, and agency-sponsor linkages [47] [48]. In this section, we examine the known
relationships between the six actors/entities of a healthcare delivery system: government organizations, insurers/payers, provider, suppliers and educators/researchers [46].

3.1.2.1 The government(s)

While the exact nature of the role of national and state governments within a healthcare delivery system varied, there were some generally established roles played by governments in many modern-day health care delivery systems. Major roles played by national governments include priority setting, policy making, financing, resource allocation, and regulation [49] [46]. Roles commonly fulfilled by state governments include implementation and administration of federal programs, regulation of insurers and healthcare professionals, purchase of health care services, innovation in health care delivery, and setting state-specific policies [50] [51]. This kind of arrangement, while not necessarily efficient, allowed national governments to deal with issues that pertain to the health and welfare of entire populations, while allowing states to deal with issues that were more susceptible to local idiosyncratic preferences and value pluralisms [50].

Governments may have direct impact on health care delivery through health (and sometimes non-health) related policy making activities [52]. Health policies aimed at individuals were designed to promote healthy behaviors choices, protect rights, and serve the needs of vulnerable and needy populations. They used regulatory policies aimed at health organizations to influence standards of care, negotiate service fees, and promote quality and patient safety [53]. Health policies aimed at addressing public aspects of health included environmental, workplace safety, immunization, and drug safety regulations [52]. Subsequently, some or all of these policies achieved legal standing through government legislations, which provided legal support for policies by fleshing out roles, responsibilities, risks, and obligations of various public, private, and non-governmental entities. Policy making coupled with the legislative and judicial powers of the government allowed them to bring national health objectives to fruition [52].

National governments provide leadership, vision, and set the stage for improving healthcare delivery by setting healthcare goals and priorities (e.g. the US Healthy People 2020 or Australia’s Strengthening Cancer Care Report). These goals were then broken down into tasks and projects that are then assigned to (or chosen by) states for execution (e.g. cessation of tobacco smoking programs). For example, in an attempt to reduce tobacco consumption and associated improvements in birth outcomes, several US states enacted state level policies like higher taxes on cigarettes and banned smoking in public places. Data from 29 states indicated that these state-level policies were effective in prompting pregnant women to quit smoking [51]. States also served as the hotbed of innovation, thus allowing health systems to experiment with novel forms of health care delivery without disrupting the health care delivery of an entire nation [50]. There have been numerous debates [54] [55] trying to understand what roles governments should play in improving care. One study [50] developed a criteria based on social justice, procedural democracy, value pluralism, feasibility and economic sustainability for deciding which kinds of health care
initiatives should be undertaken by which level of government. It concluded that national governments were best suited to undertake large, financially intense projects (e.g., increasing health care coverage) that take advantage of its substantial economic might to improve the health of the population; another research [56] agreed with this assessment. On the other hand, state governments were better suited at tackling issues that are hinged on the value sets (e.g., drug policy) of specific populations due to their proximity to the general population.

**Government – Government:** National and state governments worked together through a combination of interagency or intergovernmental agreements that laid out roles and responsibilities of all parties [54]. However, the true power of national governments was wielded through financing arrangements with state governments. National governments, by default, had larger tax bases compared to state governments, making them more financially stable, and thus often wielded significant indirect control over state governments through stipulations attached to the disbursement of tax dollars to states [50]. While national governments were very powerful in shaping the health care priorities of the nation, state governments, with funding from national governments, were often tasked with when the implementation of these priorities [50]. Letting states guide the implementation of federal initiatives allowed for tailored solutions that were in sync with the values and realities of that geographic area.

Together, national and state governments played a considerable role in improving the delivery of care due to their unique role as both purchasers and regulators of healthcare [57] [54]. This allowed governments to exert significant control, either formally or through informal agreements, in improving standards of care. For example, governments could refuse to purchase services from providers/organizations that were not appropriately licensed/accredited or withhold a portion of the reimbursement, if specific care standards were not delivered. Thus, governments could not only influence the standards of care, as regulators, but could also effectively force organizations into adherence to these standards through extensive economic maneuverings as purchasers. Other ways of influencing care delivery included safety net arrangements to provide care to the poorest sections, and through policies (e.g., visas for foreign medical graduates) to develop and maintain the professional workforce [58] [59].

**Government-Non-provider organizations:** Governmental relationships with non-provider organizations like payers/insurers, suppliers, and the research/education organizations are discussed here. Governments, especially at the state level, were often directly responsible for regulation, price setting of insurance providers; they were also responsible for maintaining a desired level of coverage within targeted population (e.g., young children, pregnant women, elderly) and for negotiating the terms of state sponsored employee benefits plans (e.g., the Employee Retirement Income Security Act) [50] [60]. Insurance firms and many other health care suppliers (e.g., pharmaceuticals and medical devices), on the other hand, influenced government policies using a combination of up front negotiations and indirect advocacy to obtain a favorable business environment (e.g., getting a new/expensive medicine or medical or mandating insurance coverage). Advocacy groups used information (not always correctly) and
sometimes celebrity power to draw attention to issues and promote the development of policies and legislations in that area. Similarly, professional guilds used advocacy to negotiate better tangible (e.g., better pay rates) and intangible benefits (e.g., better working conditions, lesser work hours, stipulated breaks) for healthcare professionals. Thus, there is a complex two-way system of influence – one that was highly dependent on business, politics, and monetary transactions between governments and many suppliers of care.

**Government – Providers:** The influence of the government was felt directly on healthcare providers because of the highly regulated nature of the healthcare industry [46]. Public policy influenced providers throughout their careers, first, through policies which incentivized the “production” of specific kind of medical professionals, and second, through subsidies of medical education, and finally through licensing and service reimbursement policies [61] [62]. When it came to medical professionals, government policies played a huge role in the production and distribution of medical professionals. Historically, the medical workforce has cycled through periods of workforce “shortage” and “surplus” [63]. In response to shortages, government policies often provided additional financial incentives (e.g. scholarships, loan forgiveness) that enabled targeted areas to train more graduates in that field. Similarly, rural United States has a very low penetration of specialty medical care; government immigration policies have included easier access to permanent residency for foreign medical graduates, conditioned upon their availability to practice medicine for a stipulated time frame in a low provider density (often meaning rural) area [59] [61] [63]. The workforce shortage problem had a feedback loop that was directly connected to the compensation policies of major health care insurers. Significant differential in compensation between general and specialty care fields could result in an increasing number of medical graduates choosing more “profitable” medical specialties over less profitable ones. Finally, practicing care providers were often bound by numerous mandatory state-specific licensing requirements; these licensing requirements were bound to financial incentives or even punitive outcomes (e.g., revoking of license). These licensing requirements allowed governments to maintain a certain quality of providers. Thus, national and state governments played a huge role in managing the availability, distribution, a maintaining the quality of care providers throughout the nation through its financial, educational, and immigration policy levers [62].

### 3.1.2.2 Insurers/Third Party Payers

Even though payers are separate actors within a health system, there was a large overlap with insurers and it was fairly difficult to talk about payers without also talking about insurers. In this section, “insurer” and “payers” were used interchangeably. Depending on the kind of health system, the role of insurers differed significantly within a health system. In fact, health systems were often classified based on the type of actors and sectors that were involved in the financing and provisioning of care. Some of the more frequently encountered configurations (Table 3-3) in the Western world included the national health system (NHS or the Beveridge model), the national health insurance (NHI), and the social health insurance (SHI or the Bismarck model) systems. The out of pocket health system was common in many
parts of the developing world where healthcare delivery systems were not well defined and many of the five key functions (discussed in Section 3.1.1 Purpose and goals) considered central to the working of healthcare delivery systems were fulfilled by the market instead [64].

Table 3-3 Types of health care financing models within health systems

<table>
<thead>
<tr>
<th>Classification</th>
<th>Characteristics</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National Health Insurance</strong></td>
<td>Publicly funded through taxation; service delivered privately. e.g., Australia, Canada</td>
<td>[45] [46] [64]</td>
</tr>
<tr>
<td><strong>National Health System</strong></td>
<td>Publicly funded through taxation; mostly delivered publicly. e.g., UK, Italy, Spain. Also, known as the Beveridge model, social security, or universalist state.</td>
<td>[45] [46] [64] [65]</td>
</tr>
<tr>
<td><strong>Social Health Insurance</strong></td>
<td>Socially funded through premiums paid by employee/employers; service delivered by privately. e.g., Germany, France, Switzerland. Also, known as the Bismarck model or social insurance.</td>
<td>[45] [46] [64] [65]</td>
</tr>
<tr>
<td><strong>Private Insurance</strong></td>
<td>Predominantly privately funded; services delivered by private sector. e.g., USA</td>
<td>[45] [65] [66]</td>
</tr>
<tr>
<td><strong>Social Assistance/Minimum State</strong></td>
<td>Predominantly privately funded and delivered public focus on helping the needy and the vulnerable. e.g., USA, Chile</td>
<td>[66]</td>
</tr>
<tr>
<td><strong>Etatist Social Health Insurance</strong></td>
<td>Special case of Social Health Insurance. State regulated, socially financed, and privately delivered e.g., Czech Republic, Hungary, Poland</td>
<td>[45]</td>
</tr>
<tr>
<td><strong>Out of pocket</strong></td>
<td>Private out of pocket payment for care. Also, called market driven healthcare.</td>
<td>[64]</td>
</tr>
</tbody>
</table>

In certain health systems like NHI, NHS and SHI systems there was a high presence of governments in service financing, though the NHI and NHS were technically not funded through the traditional system of premiums and are instead financed through tax revenues. SHI and the Etatist SHI systems, on the other hand, functioned more like a national insurance. In such cases, governments took over the role of insurer, regulation and price setting of insurance providers; they were also responsible for maintaining a desired level of coverage within a targeted population. These roles were already covered in the section under governments. In many of these systems private insurers coexisted side by side to provide topped off coverage to some or all residents. In some health systems like Australia, all residents were covered by the NHI but they were also encouraged to buy private coverage to provide additional coverage [67]. In such markets, private insurers often function as luxury products. In contrast, health systems that were primarily dependent on private insurance for coverage, insurers stepped in as intermediaries in the
fulfillment of the service financing and service delivery functions. Thus, insurers acted as a buffer between the patients and providers. This often had the effect of distorting the consumer’s perception of the true cost of their care and dampened traditional economic cues that enabled consumers to judge the value and quality of their care [46].

**Payer- Providers/Provider Organizations:** Over the years, insurers have tried to contain costs through closer integration of the financing and delivery aspects of healthcare. While insurers yielded tremendous power over providers as payers for the care [68] this has traditionally led to a highly contentious relationship between payers and providers and a lack of trust [69]. However, as new health reforms brought about newer care delivery model in the form of Accountable Care Organizations (ACOs) payers and providers have been forced to rethink their relationship. Steps taken to improve payer-provider relationships included clinical, economic and administrative alignment strategies. Example of clinical alignment strategies include mutual agreement on the evidence base used to determine the appropriateness of care; economic alignment included payers giving providers a clear understanding of the parameters used to determine reimbursement in advance. Administrative alignment includes the use of technology and tools designed to reduce to overhead of administrative responsibilities on both sides [70].

**Payer – Governments:** This relationship is already discussed under 3.1.2.1 The government(s)

3.1.2.3 Providers

Healthcare providers, along with patients, form the core of any health system. Providers played multifaceted roles and may be involved in the diagnosis, treatment, prevention, management, and care coordination for disease and conditions. Physicians served as both leaders and supervisors in caring for the overall health of the patient. Apart from regulatory influences, major influences on providers included clinical peers, healthcare organizations, and professional support bodies.

**Provider-Provider:** In an environment of persistent workforce shortage, nurse-physician relationships have come under constant scrutiny because interactions between physicians and nurses seem to be directly related to the morale, satisfaction, and retention of nursing staff [71]. Good relationship between physicians and nurses was important because they worked closely to provide care to the patient; strained relationships between these two groups of providers ultimately affected the quality of care received by the patient. To that end, there had been several studies [72] [73] [74] exploring ways to strengthen ties between nurses and physicians.

**Provider – Provider Organizations:** Relationships between providers and provider organizations have been evolving in response to the market forces [75] [76] [77] and this led to both groups working out of sync with each other [78]. Specifically, this has led to strains on the relationship due to a shift from the traditional “expert culture” of physicians into a mutually dependent “affiliative” cultures promoted by modern organizations [76]; it also tended to intensify traditional areas of conflict (especially amongst
younger physicians) between physicians and provider organizations [77]. Strategies to improve hospital-physician relationships include trust building and aligning economic incentives [79] [77].

**Provider – Government:** This relationship is already discussed in Section 3.1.2.1 The government(s)

**Provider-Payer:** This relationship is already discussed in Section 3.1.2.2 Insurers/Third Party Payers

### 3.1.2.4 Suppliers

Major suppliers included manufacturers of pharmaceutical, biomedical devices and other durable equipments, among other products. Suppliers worked most closely with governments, payers, and providers. Suppliers came together to form trade organizations which lobbied governments for favorable contracts and preferences for their products.

**Supplier-Provide Organizations:** Provider organizations increasingly subscribed to group purchasing organizations (GPOs) and integrated delivery networks (IDNs). Participating in GPOs and IDNs allow private practice organizations and hospitals negotiate better contracts through collective bargaining with suppliers [80]. The supplier market underwent extensive changes which affected the traditional patterns of interactions between suppliers and providers. This was especially evident in interactions between physicians and the pharmaceutical suppliers; there is an increased awareness of the potential for conflicts of interest that did not serve public or patient interest. This has led to attempts at self-regulation by the suppliers before stricter legal requirements were implemented [81].

**Supplier-Government:** This relationship is already discussed in Section 3.1.2.1 The government(s)

### 3.1.2.5 Educators/Researchers

This category included researchers, educators, government and non-government voluntary health organizations (VHO), and trade/advocacy organizations that functioned within the arena of healthcare. These bodies tend to be mostly governed by government regulation including tax laws, accreditation requirements and compliance of research activities with healthcare laws like HIPAA, Common Rule, registration of clinical trials, and institutions review board (IRB) protections of human subjects [82]. Governments are also directly involved as major funders of research, innovation [56] and education and through providers of subsidies for medical education through state run institutions.

**Educator/Researchers – Government:** This relationship is already discussed in Section 3.1.2.1 The government(s)
3.1.5 Frameworks to understand health systems

Health systems have several moving parts and frameworks can be useful in providing succinct understanding of the key features of a health system. These frameworks can be used to understand one or more of the following: 1) components of health systems, at varying levels of granularity; 2) describe the workings of a health system, metaphorically, and 3) understand how specific activities occur within a system.

3.1.3.1 A framework for frameworks

Health systems specific frameworks are deeper diving versions of the healthcare delivery as a “system” idea discussed in the previous section.

Figure 3-2 Types of health systems frameworks from least to most resolution
A study [38] reviewed various health systems frameworks and noted that health systems frameworks could be classified based on the level of resolution. A framework with the least resolution provided the big picture view and the focused narrowed with higher resolution frameworks. Thus, health systems frameworks provided a big picture overview of a health system and its purpose was to describe and explain the health system in terms of its “its objectives, structural and organizational elements, functions and processes” [38]. Conceptual frameworks for strengthening healthcare systems took one or more components of the system and suggested ways to enhance (or strengthen) the specific functions of the health care system. Finally, operational health systems strengthening (HSS) frameworks provided detailed ways to both strengthen and coordinate these changes (e.g., through standardization of key elements) both within the system in which it is embedded and across partner systems [38]. For the purposes of this research, the use of the big picture health systems frameworks was appropriate because it provided the clearest understanding of how the various elements of the healthcare system. Shakarishvili (2010) [38] provided a good review of approximately 11 health systems model and they concluded that even though these models differed in their resolution and analysis, they seem to converge on the several important functional characteristics like goals, overarching principles, processes/control knobs and critical building blocks of a health care delivery system.

There are several frameworks that can guide our understanding of healthcare delivery systems. It is important to note that these frameworks were not necessarily mutually exclusive; on the contrary, these frameworks each add a dimension to our understanding of the health system. The frameworks that provide the least resolution and the biggest view were conceptual frameworks that have more to do with how to understand the field of healthcare delivery. These did not provide any information on about the goals, actors or the relationships between the various components of the system. Frameworks in this category generally presented a metaphor to illustrate the operating principles of the healthcare delivery system. Some of these frameworks (Table 3-4) described the early stages in the development of modern day healthcare systems (e.g., cottage industry) with the industrial revolution ushering the era of factory system of healthcare delivery [83] [84] [85].

The “Cottage industry” framework of health care emphasized the autonomy and dedication of individual physicians. Care received is customized and its quality was often highly variable; this kind of system did not lend itself to (or resisted) standardization which made the building of accountability and continuous learning systems challenging to implement [83].
Table 3-4 Key frameworks to understand the evolution of health systems over time

<table>
<thead>
<tr>
<th>Health system metaphor</th>
<th>Characteristics</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cottage industry</td>
<td>Service delivery – by individual provider at provider’s home; characterized by nonintegrated, dedicated artisans who eschew standardization.</td>
<td>[83] [84] [85]</td>
</tr>
<tr>
<td>Factory</td>
<td>Service delivery by individual provider in clinics and hospitals; characterized by increased use of technology, medical specialization and sharing of core medical infrastructure.</td>
<td>[3] [85]</td>
</tr>
<tr>
<td>System</td>
<td>Service delivery as teams in clinics and hospitals; characterized by the recognition of mutual interdependence and its impact on overall system performance.</td>
<td>[84]</td>
</tr>
<tr>
<td>Complex adaptive system</td>
<td>Builds on the “system” framework by attributing non-linear, dynamic, and self-organizing properties to each actor/entity. Also, known as the “complex organism” model.</td>
<td>[42] [86]</td>
</tr>
<tr>
<td>Multilevel systems approach</td>
<td>A special case of the complex adaptive systems approach.</td>
<td>[35]</td>
</tr>
</tbody>
</table>

The “Factory” framework was more appropriate in describing the state of healthcare as technology started making its presence felt in this industry. Lessons from other industries (e.g., aviation, manufacturing) were incorporated and technology was used to achieve standardization of routine business/administrative processes and the use of advanced technology to guide care; however, the processes of care remained largely customized. While both these frameworks did a great job of conceptualizing the healthcare industry, they took a provider-centric view to care provisioning and did not acknowledge the contribution of other actors in the delivery of care. Systems frameworks [84] highlighted the interdependencies between various actors within a healthcare system. Specifically, the complex adaptive systems (CAS) framework imbibed the largely static systems approach to healthcare with dynamic properties to better reflect the decision making and adaptive power of real life organizations. The CAS framework was particularly useful in that it identified certain key features of complex adaptive systems. For example, CAS could not be decomposed hierarchically which meant that it did not respond to the incentive structures of a traditional mechanistic or deterministic system [42] [86].
3.1.3.2 Multi-level health system frameworks

Of particular interest was a model that added a further layer of sophistication to the CAS through the addition of multiple "levels" within which the entire health system is embedded. This idea made sense because it was common to encounter natural (and artificial) hierarchies in our day-to-day lives. Two [84] [35] multilevel health systems framework provided a good understanding of the complexity, hierarchy, and the multitude of formal and informal relationships that influence each stakeholder in modern day healthcare setting. The multilevel frameworks used in health care improvement bore striking similarities to the ecological frameworks, commonly used in health promotion [87] and there were numerous versions of the multilevel framework [3] [35] [36]. Multi-level frameworks described a large collection of causal relationships, including the effects of regulatory and fiscal environments on organizations, societal/community effects, the effects of certain organizations on others, and internal workings of organizations. The term “multi-level” generally, referred to the idea of organizations lower in the hierarchy being nested within organizational structures that inhabit higher levels. The idea of studying multiple “levels” was motivated by the observation that our social and political structures tended to be organized in various kinds of hierarchical units with lower level units embedded or nested within the higher-level structures [88] and it was common to find numerous variations in the hierarchies within these models.

The push for multilevel thinking in healthcare delivery came as a result of two fundamental changes: 1) the shift from the reductionist approach to improving delivery [36], and 2) expansion from basic biological research to research on health systems [89]. The reductionist approach to improving health care delivery was based on the idea that improving one step in what was essentially a “multi-step” process to care delivery would translate in overall improvement [36]. However, keeping in mind the complex adaptive nature of the health care system, it is possible to get some insights in this matter. A small change that was only directed at one level of the health care system did not have the potential of getting “amplified” because it did not impact any other level and was thus limited by design. Furthermore, as researchers branched out from trying to understand causes of diseases to understanding how the health care delivery system worked, it became increasingly important to focus on the various entities, steps, and interfaces that led to the delivery of the care. While, the traditional single level approach to research had its rightful place in understanding certain kinds of health care problems, a multilevel approach would be needed to understand and improve the healthcare delivery system [89].

Using the example of a multilevel approach to improving care (Figure 3-3), the hierarchical design of the multilevel approach gave rise to boundaries (e.g., national, state, local, organization) that demarcate one level from the other. The place where one level ends and the other level begins is what can be thought of as a fracture point. This is the juncture where everything changes based on how we classify the levels of the system. Multi-level analysis can help understand the various levels through with changes to health care delivery mechanisms are produced and propagated (noted in the boxes on the side) thereby enabling us to design a portfolio of solutions [88]. One key study [35] suggested the multi-level (individual,
group/team, organization, and environment) approach to improving healthcare delivery as a potential way to achieve system wide changes. This framework proposed not only making changes at one level but to also considered how that change would impact and react to everything else that is occurring at other levels. Thus, while the primary goal might be practice change at the individual level, this framework expanded its focus to create a full arsenal of interventions that facilitated the uptake and promotion of this individual level change at other levels (group, organization, and environment) through suitable mechanisms of policy making, management directives, and participant incentives.

**Figure 3-3 The multilevel context of cancer care**

Healthcare data and HIT are perfect candidates for being studied using this approach due a few reasons. First, data pass through various layers of our healthcare system for various reasons including care provisioning, performance management, and financing. These data were exposed to a multitude of influences at each of these levels from various stakeholders. Theoretically, one could give the same data set to various stakeholders and each of them would hone in on different pieces of the dataset and use it differently to achieve fundamentally different healthcare goals. Taken together, these goals could have a synergistic effect (or not) on the performance of the entire healthcare system. The multilevel framework could help us explore these effects. Second, to the best of my knowledge, only one study [90] attempted to take a multilevel look at building healthcare information infrastructure; however, it was an observational study. Therefore, a systematic approach was [36] proposed.
study with no structured interview protocol to facilitate direct comparison of responses. Finally, while multi-level frameworks had been used to develop interventions for obesity [91], social disparities in asthma outcomes [92], trauma care [93], cancer care [94], infection control [95] [96], and EMR adoption [97], the potential to evaluate and refine this framework remained largely untapped [98] [99].

3.2 Importance of data and HIT within health systems

It is next to impossible to talk about data without talking about HIT because they are inextricably linked. HIT systems were so valued because of their ability to collect, manage and often analyze data for various entities within a health system. This study subscribed to the definition of HIT laid out by the U.S. government as, “…any equipment or interconnected system or subsystem of equipment that is used in the creation, conversion or duplication of data or information.” Data was defined as bits of information that have been extracted for a specific purpose [100].

There had been a huge push in numerous developed healthcare systems (e.g., U.K., Australia) to transition to a fully electronic system. This push had been driven by the recognition that it was near impossible to achieve a high functioning health care system without bringing in HIT or data [3] [25]. The 2001 “Crossing the Quality Chasm” report specifically noted,

“The committee believes information technology must play a central role in the redesign of the health system if substantial improvement in quality is to be achieved over the coming decade.” [3], p16

This recognition was echoed by numerous health systems frameworks that considered both the use of data and HIT systems as a “critical health system function” [38]. This “critical” function status is no exaggeration because within health systems data and HIT were used in activities that cut across numerous routine and project specific activities including health data and image archival, management of chronic diseases, care improvement activities, and patient safety [101].

In the decade following the publication of the 2001 IOM [3] report data collection, management and analysis were gradually came to be acknowledged as the “heart of healthcare delivery” [84] ironically, the same report noted that the U.S. health system lagged behind in the adoption of HIT, calling it practically “information technology starved” compared to other industries in spite of information being “the fundamental currency of healthcare” [84]. Other researchers noted that in spite of EHRs being in development for nearly 40 years, very few use of EHRs existed outside of billing and prescription order purposes [102].

Data/HIT played an important role in supporting each of the key functions of a healthcare system like service financing, service provisioning, resource development, stewardship, resource development and allocation [25]. For example, data/HIT systems support the stewardship/regulation functions within a health system which were highly dependent on the timely availability of trust-worthy data. Data generated
from HIT systems could be used for the purposes of public health surveillance [101], needs assessment, aligning incentives, monitoring resource generation, resource utilization, access to care and quality of services provisioned.

Table 3-5 Potential role of data and technology within a health system

<table>
<thead>
<tr>
<th>Health system role</th>
<th>Role of data</th>
<th>Role of information technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Financing</td>
<td>To determine risk, premiums, coverage, access, cost and projections</td>
<td>Financing uses mostly business information systems. Used for operations, reporting, and modeling the impact of alternative forms of financing.</td>
</tr>
<tr>
<td>Service Payment</td>
<td>To determine reimbursement schedules and payment strategies; track payments, identify fraud</td>
<td>Payment uses business IT systems (see service financing comments). Used for reporting and modeling the impact of alternative forms of payments.</td>
</tr>
<tr>
<td>Service provisioning or Service delivery</td>
<td>To provide appropriate care; understand progress. Develop public health programs, needs assessment, program management</td>
<td>HIT is used to store/retrieve/manipulate health and imaging data; order services; aid clinical decision making; manage chronic conditions; ensure patient safety and improve quality. Used for reporting.</td>
</tr>
<tr>
<td>Resource development</td>
<td>To educate/train medical professionals; drug discovery; technological discovery; operations</td>
<td>This category consists of a diverse range of production activities that may use IT; but the exact uses are difficult to pinpoint.</td>
</tr>
<tr>
<td>Resource allocation</td>
<td>Used to assess needs; develop business cases; develop policies</td>
<td>Both business IT and HIT systems may be used to provide ongoing data collection, monitoring, and reporting of key performance metrics</td>
</tr>
<tr>
<td>Stewardship/Regulation</td>
<td>Both performance and research data are used to monitor and evaluate programs; set policies to reduce disparities and protect patients and workers</td>
<td>Both business IT and HIT systems may be used to provide ongoing data collection, monitoring, and reporting of key performance metrics</td>
</tr>
</tbody>
</table>

Information technology (IT) and HIT systems were widely used to help support the six key functions; business/administrative IT systems were more widely entrenched compared to their HIT counterparts.
This could be attributed to a couple of different reasons: 1) it was easier to demonstrate the value of business IT in tangible terms; 2) there were fewer regulations around the transfer and sharing of financial/administrative data; and 3) the process of billing/administration could be standardized easily. The case for HIT on the other hand was: 1) harder to justify in dollar terms; 2) had numerous regulations/restrictions associated with it; 3) did not lend itself to standardization with ease; and 4) is dominated by professionals who constantly struggled with the trade-offs between the time spent handling HIT systems and the time spent caring for patients in need. It must be noted that HIT and business or administrative IT systems often did not interface directly with each other; this was mostly to protect sensitive health data. Finally, it was interesting to note that general frameworks for health systems (discussed earlier) did not explicitly include the role of data or HIT in it; these frameworks also did not depict the dynamic nature of data and information exchange within a health system, even though empirical research demonstrated such movement [103].

**Figure 3-4 Snapshot of data flow in a complex health care system, United States**

3.3 Importance of data and HIT in CI

Since, healthcare delivery consisted of so many moving parts and has multiple dimensions against which it could be evaluated; there were a multitude of ways to achieve some degree of improvement in any of these five dimensions of quality. Efforts to improve care generally fell under two non-mutually exclusive categories – efforts that proceed with a specific outcome in mind (e.g., achieving patient centeredness,
increasing timeliness) and efforts that focused on improving core processes within an effort using one or more care improvement frameworks (e.g., Lean thinking, Six Sigma). Actors could use one strategy or a portfolio of strategies included under both categories (e.g., improve patient centered using lean six sigma processes) to achieve their end goals. The six-dimensional quality framework first proposed by the Institute of Medicine (2001) [3] noted that good care should be efficient, effective, patient centered, timely, safety and equitable. Patient centeredness emphasized the role of the patient as the “source of all control” and patient care should be cognizant and respectful of the patient’s background, wishes, and needs. Timeliness meant that health care delivery should continuously strive to provide prompt care and reduce delays and wait times. Safety was a key feature and the model emphasizes that good quality care gives paramount importance to patient safety by building infrastructure and processes that did not threaten the patient’s safety. Finally, the idea of equity meant constant efforts to reduce disparities between the quality of care received by the rich and that received by the poor [104]. Data and HIT driven conditions promoting the delivery of high quality care includes the free flow of information and sharing of knowledge, and the use of evidence to drive the decision-making process (IOM, 2001). In this model, effective care is the kind that is proven to work by science delivered at appropriate levels that prevent both over- and under- utilization of service. Efficient care seeks to reduce wasteful use (or misuse) of healthcare resources.

Figure 3-5 Understanding the role of data in care improvement

Adapted from IOM, 2001 [3]
The use of data to drive care has been long held as one of the key ways to improving care through uses that include care improvement, demonstration of value, and furthering research and development [3] [105]. Care integration, investment in HIT systems, workforce development/capacity building, patient-centered care, and aligning provider payments and incentives represent some of the current approaches to improving care delivery [106]. It is generally agreed that any deliberate attempts to improve care delivery must be measurable and hence, data collection, management and analysis are standard components of most improvement models (e.g. Total Quality Management, Rapid Cycle Change) currently used in healthcare settings [105]. Types of data collected within healthcare settings include socioeconomic, environmental, biomedical, individual health status, individual health behaviors, individual genetics, care processes and associated health outcomes, resource utilization, and healthcare related expenditures [103] [107] [108]. These data, when analyzed at the appropriate level of aggregation and with appropriate techniques, can lead to various (e.g. clinical, business) kinds of insights regarding quality, access, cost, and performance [107].

Within clinical care, routinely collected data are commonly used to monitor situations, identify problems, and measure changes [105]. In addition to routine data, project specific data are used to guide choice of solutions, implementation, and for program evaluation, and as a way to influence others [108]. HIT systems contribute to patient safety by preventing clinical errors, facilitation faster response in case of an error, and by monitoring and providing feedback about such incidents [101].

While the different way the delivery of health care can be improved are listed in Figure 3-5, there are several ways to achieve these goals using a variety of care improvement pathways listed in Table 3-7.

### Table 3-6 Key CI models in healthcare

<table>
<thead>
<tr>
<th>CI framework</th>
<th>Description and role of data</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>TQM/CQI</td>
<td>Heavily reliant on rigorous data collection, management, and use of data for continuous monitoring and for measurement of change.</td>
<td>[109] [110] [111]</td>
</tr>
<tr>
<td>Rapid Cycle Change</td>
<td>Less emphasis on requirements for data collection compared to TQM/CQI. Requires the collection of just enough data (formal or informal) to make a rapid decision on whether the intervention is effective.</td>
<td>[112] [113]</td>
</tr>
<tr>
<td>Lean Thinking</td>
<td>There no explicit call for data use and the exact role of data is unclear. Data could be used to understand the “value” of or the “value added” by a step in a value stream.</td>
<td>[114] [115] [116]</td>
</tr>
</tbody>
</table>
**3.3.1 Experiences with health-system wide use of HIT in developed nations**

Numerous data driven efforts to improve care have been conducted in last many decades. While there have been incremental improvements in response to these efforts, it appears that improving the delivery of care has been a largely uphill battle. Researchers looking at the impact of various "well intentioned" improvement activities have concluded time and again that "major problems" still manifest in our care system and that "improving quality is proving to be very hard." The impacts of these interventions have been summarized as mostly "local rather than system-wide," "partially effective" "largely unsuccessful" and "sustained with difficulty" [35] [118] [119]. It can be argued that our attempts at improving care delivery through "narrow, single level programmatic changes" have been a “limited” or “moderate” success [35] [120] [121]. This lack of success at the levels desired can be partly explained by two fundamental issues: 1) Gaps in our data systems, and 2) Flaws in our approaches to understanding data and data driven CI.

Regarding the first problem, there are numerous issues plaguing our healthcare systems. The first has to do with collection – even though the healthcare industry has been lagging behind other business areas in the adoption of information technology, healthcare systems are now collecting enormous amounts of data (known as “Big Data”); the US healthcare system collects an estimated exabyte (or a billion gigabyte) of data each year [122] [123] [124] [125]. However, a lot of these data are collected in a non-systematic fashion with no one agency collecting key data elements consistently [103] [126]. Several studies reported that key data demographic elements like race/ethnicity data are often not collected or are collected in non-standard ways [103] [127] [128]. This patchwork of data collection efforts often lead to poor data quality and missing data. Barriers to data collection (and data quality) include lack of organizational policies and procedures promoting good quality data collection, lack of standardization of data categories, technological limitations, communication barriers, use of inadequately descriptive response choices, and privacy concerns [103] [127] [129]. The second problem has to do with fragmentation and silos within healthcare [122] [124]. Healthcare data are heavily regulated by privacy and security requirements. This has led to inter- (and intra-) organizational barriers to data flow, sharing, and access, resulting in duplication of data collection efforts [103] [124]. Political and organizational factors that can remedy some of these issues include the creation of a legal framework for data sharing and governance, good data collection practices including explaining data use to patients; inter/intra
organizational data sharing agreements, data standardization, integration of internal and external databases, and use of technology that can build actionable clinical and business intelligence from a giant pile of data [90] [127] [123] [130]. Addressing both these issues will help increase the usability of these data for a wider number of activities for a larger number of stakeholders.

Regarding the second issue, most of our understanding of the role of data comes from studies that provide a narrow glimpse of data instead of focusing on trying to understand how it works within the system within which it is embedded. Systematic reviews of our current efforts show that most interventions try to change one step of a multi-step process, and also focus mostly on changing provider behavior, when in fact a lot of other factors are ultimately responsible for the kind of care that is delivered by any provider or organization. A comprehensive multi-level approach is needed for any interventions to achieve its full impact; in fact, one might say that ignoring the complex nature of our health care systems might not have served us well in achieving the most out of our improvement efforts [131] [35] [132] [36] [133] [89] [134].

Investment in and the effective use of health information technology (HIT) has been long seen as a major step towards improving healthcare delivery [3] [35]. Amongst other things, HIT aims to improve care delivery by improving access to clinical information, providing timely clinical decision support, increasing adherence through reminders and alerts, reducing delays and prescribing errors using computerized ordering systems, instant sharing of clinical test results, and increasing patient engagement through access to personal clinical data and appointment scheduling via secured web portals [135]. This policy makes sense in the light of the generally positive impact of HIT in increasing the quality, efficacy, efficiency, and patient safety of healthcare delivery and in reducing utilization of care [135] [136] [137]. However, there is mixed evidence on if HIT results in improvements in a variety of care settings like hospitals, community clinics, and physician offices [135] [136] [137] [138].

Similar nationally efforts have been undertaken in other developed healthcare systems (e.g., UK, Australia) with varying degrees of success. Common reasons for the limited success in using HIT as envisioned include the inherent complexity of the health systems, the need for considerable capital investment, the need for numerous for a wide range of actors to change their behaviors; technical barriers include lack of interoperability, non-standardized data collection [3]; these findings were supported by a more recent systematic review [139] of 44 systematic reviews from the U.S. and Europe. In a systematic review [140] of 37 paper on the implementation of e-health, researchers noted five issues that got “relatively little” attention during the implementation process. Specifically, they found three cultural barriers and two technical barriers. The cultural barriers included failure to clearly establish the value of e-Health systems to users, not paying attention to factors that influence user engagement and participation, and inadequate considerations for the changes in workload or roles that resulted from the eHealth implementation. The review also found that organizations also engaged in little risk management planning.
to mitigate any fallout from use of eHealth technologies or made little attempts to figure out how individual users could use eHealth to generate knowledge that is meaningful at an individual level [140].

### Table 3-7 Key types of barriers to HIT implementation identified in the literature

<table>
<thead>
<tr>
<th>Barrier type</th>
<th>Description and examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structural</td>
<td>Complexity of health system (e.g., numerous stakeholders); no one person is responsible</td>
</tr>
<tr>
<td>Financial</td>
<td>High capital investment; few or no incentives to promote the use of HIT; ROI is hard to justify</td>
</tr>
<tr>
<td>Cultural</td>
<td>Requires many people to change their behaviors; fear of technology/data</td>
</tr>
<tr>
<td>Technical</td>
<td>Lack of interoperability; variations in data related standards; dependability and reliability of HIT</td>
</tr>
</tbody>
</table>

Source: [84]

However, one of the most interesting reasons can possibly be attributed to a failure to follow necessary steps before rolling out HIT as described by in this article on the common challenges,

“...countries too often skip a crucial first step: understanding what the end users of technology need and how they would use technology to address those needs.” [141], Pg.1

This statement describes partially the motivation for this study. There are too many ad hoc data systems that are designed to serve the need of only a few stakeholders. Some of these problems could be eliminated if actors had a better sense of who might be the other actors who might be in a position to leverage the data that are going to be collected. To achieve this, actors need a good way to identify other stakeholders who might share a common interest with them; especially when these other stakeholders may or may not operate in the exact same sphere.

#### 3.2.1.1 United States

The Health Information Technology for Economic and Clinical Health (HITECH) Act was enacted under the American Recovery and Reinvestment Act of 2009. The HITECH Act sought to reform American health system by promoting the use of EHRs, facilitating data sharing through improved interoperability, and using the subsequently generated data “meaningfully” for better personal and population health outcomes. The goal was to encourage providers and organizations to achieving increasingly higher levels of “meaningful use” of data over the years through use of incentive payments; 2021 is the last year during which participants can receive these incentive payments for demonstrating meaningful use.
Table 3-8 Criteria for assessing various stages of "meaningful use" under the HITECH Act

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronically capturing health information in a standardized format</td>
<td>More rigorous health information exchange (HIE)</td>
<td>Improving quality, safety, and efficiency, leading to improved health outcomes</td>
</tr>
<tr>
<td>Using that information to track key clinical conditions</td>
<td>Increased requirements for e-prescribing and incorporating lab results</td>
<td>Decision support for national high-priority conditions</td>
</tr>
<tr>
<td>Communicating that information for care coordination purposes</td>
<td>Electronic transmission of patient care summaries across multiple settings</td>
<td>Patient access to self-management tools</td>
</tr>
<tr>
<td>Initiating the reporting of clinical quality measures and public health information</td>
<td>More patient-controlled data</td>
<td>Access to comprehensive patient data through patient-center HIE</td>
</tr>
<tr>
<td>Using information to engage patients and their families in their care</td>
<td></td>
<td>Improving population health</td>
</tr>
</tbody>
</table>


An early cost benefit analysis [142] using Healthcare Information and Management Systems Society (HIMSS) Dorenfest survey data, estimated indicated supported the tremendous potential of the HITECH Act by estimating that the adoption of effective interoperable EHR’s could lead to savings of $81 billion per year between 2002-2016 due to improved safety and efficiency. Seven years after the publication of this research, an update [33] found that the empirical data on the impact of HER’s on the efficiency and safety were “mixed” and “disappointing.” This review noted that the optimistic prediction of savings by Hillestad et al. [142] and colleagues did not come to fruition not because of incorrect estimates, but due to the flaws with HITECH’s design, implementation, and the very health system within which the EHRs were deployed. Specifically, the study noted issues around slow uptake of EHR systems, unwillingness to devote the time and resources needed to gain facility with EHRs, and failure to successfully reorganize work processes to unlock and optimize HIT potential [33]. A five-year post implementation review [26] of the achievements and challenges produced a verdict of “mixed” success. The review concluded that HITECH Act had been effective in getting healthcare organizations to adopt EHRs and achieving higher degree of information sharing. This finding on increased rates of EHR adoption was also supported by data from a nationally representative survey of 3,180 physicians in 2011 [143]. However, the program still struggled to get participants to achieve more than the very first and basic levels of its meaningful use of data criteria [26]; a diffusion of innovation modeling study reported that the “meaningful use” incentives had very little influence on the EHR adoption curve [144]. The inability to promote meaningful use of data and the inability of meaningful use to promote EHR adoption is at the heart of the fundamental issue –
just having access to electronically available data is not sufficient to foster the use of these data for purposes other than personal care delivery.

Some critics [145] consider the investment into the HITECH Act as sunk cost and proposed cutting loses and redirecting the remaining funds to promote innovation instead of taking of functions like interoperability and standardization of HIT system, which are best left to industry. Proposed areas of innovation included ideas to make HIT systems affordable to small businesses and providing incentives that encourage data contribution to a common platform (something akin to Facebook’s model) by offering health insights of interest to multiple stakeholders [145].

3.2.1.2 United Kingdom

While the UK has launched multiple large scale health IT projects (Figure 3-6) over the years, the National Program for IT in the NHS (NPfIT), budgeted at £6 billion, was its biggest public sector health IT project [32] [102]. This program aimed to modernize NHS’ use of HIT through the introduction of EHRs, appointment scheduling systems, image retrieval, computerized referral and prescription medication ordering systems medication systems.

**Figure 3-6 Timeline of major NHS IT projects undertaken (1960-2020s)**

Adapted from Brennan, 2005 [146] and updated using data from Parkin, 2016 [27]. HISS, Hospital Informatics Support Systems; EPR, Electronic Patient Records; ERDIP, Electronic Record Development and Implementation Program; NHS, National Health Service; IT, Information Technology; NPfIT, National Program for Information Technology; PHC, Personalized Health and Care

The NPfIT program outlined four main groups of beneficiaries – patients, healthcare professionals, NHS program administrators, and the public. Patients would benefit from access to their own data, healthcare professionals would benefit from fast access to reliable patient information, program managers would
benefit from high-quality secondary data to understand gaps and allocate resources, and the public would benefit from comparative performance data for local hospitals and healthcare providers. This program ran in several issues including delays, opposition from key stakeholders, and implementation problems and was pulled in 2011. Despite being a failure, as were 60% of health IT projects undertaken (Figure 3-7) earlier in the UK [32], this project continued to incur significant costs to tax payers due to contract transitions and exit costs which continued to accrue well 2-3 years after NPfIT was formally dismantled [32].

A retrospective case history of the NPfIT was published in 2016 by the NHS [32]. This case report examined issues that negatively impacted the implementation of the NPfIT which are outlined in Table 3-9. This report indicated that according to a cost benefit analysis by National Accountability Office done in June 2013, the NPfIT, over 12 years, accrued cost £9.8 billion in costs and delivered £10.7 billion in benefits. However, the researchers dispute the methodology of this estimate by stating that the “success or failure of national elements that have already been delivered while ignoring the many regional elements remained undelivered cannot be used to measure the success of the NPfIT; moreover, these calculations did not account for contract exit costs and other litigation costs with vendors. Additionally, the lack of baseline measure of costs made it very difficult to measure program success [32].

**Table 3-9 Key themes from the failed implementation of NPfIT initiative in UK**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hasty deployment</td>
<td>Unrealistic timetable</td>
</tr>
<tr>
<td></td>
<td>Lack of time to engage with key stakeholders including users and privacy activists</td>
</tr>
<tr>
<td></td>
<td>Inadequate background setting work</td>
</tr>
<tr>
<td></td>
<td>Failure to measure progress against expectations</td>
</tr>
<tr>
<td></td>
<td>Failure to test IT systems</td>
</tr>
<tr>
<td>Poor program design</td>
<td>Failure to recognize the risks or limitations of big IT projects</td>
</tr>
<tr>
<td></td>
<td>Failure to recognize that the longer the project takes, the more likely it is to be overtaken by new technology</td>
</tr>
<tr>
<td></td>
<td>Over ambitiousness</td>
</tr>
<tr>
<td></td>
<td>Undertaking a project is too large for the leadership to manage competently</td>
</tr>
<tr>
<td></td>
<td>Patient confidentiality issues</td>
</tr>
<tr>
<td>Culture and skills</td>
<td>A lack of clear leadership</td>
</tr>
<tr>
<td></td>
<td>Not knowing, or continually changing, the aim of the project</td>
</tr>
<tr>
<td></td>
<td>Not committing necessary budget from the outset</td>
</tr>
<tr>
<td></td>
<td>Not providing training</td>
</tr>
<tr>
<td></td>
<td>A lack of concern for privacy issues</td>
</tr>
<tr>
<td>Theme</td>
<td>Sub themes</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>No exit plans and no alternatives</td>
<td></td>
</tr>
<tr>
<td>Lack of project management skills</td>
<td></td>
</tr>
<tr>
<td>Treasury emphasis on price over quality</td>
<td></td>
</tr>
<tr>
<td>IT suppliers depend on lowballing for contracts and charge heavily for variations to poorly written specifications</td>
<td></td>
</tr>
</tbody>
</table>

Source: Campion-Awwad, 2016 [32]

According to a UK House of Commons briefing paper [27], the current initiative was put forth in 2014 by NHS’s Five Year Forward View plan under the Personalized Health and Care 2020 Strategy. It was built around going “paperless” by making all patient records available in digital format with real-time access and interoperability. The goals of this project are to enable patients to make appropriate healthcare choices, allow professionals access to data, enable transparency through publication of comparative outcomes data, build and sustain public trust, foster innovation and growth, support data use for care giving, and ensure future healthcare investments can reduce cost and improve value. The implementation of this vision is to be carried out in phases with full access to own GP records by 2016, full access to records from all care providers by 2018, and physician access to patient lifesaving information available across practice and emergency care delivery units by 2019 [27].

### 3.2.1.3 Australia

Since the early 1990s, Australia has undergone at least two rounds of major healthcare information technology implementation projects and is currently in the process of undertaking its third initiative. The first two initiatives (HealthConnect and Personally Controlled Electronic Health Records, PCEHR) failed [34] [30] [102]. In 2016, The PCEHR project was modified and restarted under a new name, “My Health Record” and new administration to oversee the implementation [34]. A timeline outlining the key events in the evolution of the various electronic initiatives are outlined in Figure 3-8.

In the early 1990s, the HealthConnect initiative was an attempt to build a national health information network for all Australians; there was decade between project conception (1990s) and launch (2000). Between 2000-2004, the project was rolled out, however, by 2005 the national imperative was downgraded prior to being abandoned in 2005 in favor of a brand-new electronic health project [34]. The next project commenced in 2009 with the recommendation to develop a “personally controlled” electronic health record for all Australians with a proposed budget of AU$467 million. Three years later, the PCEHR project was live. By 2013, only 2.7% of the population had registered with very little interest from clinicians and consumers. Government review of the initiative in 2014-2015 recommended the restructuring the PCEHR project and replacing it with a new initiative called “My Health Record” [34].
After the failure of the PCEHR project, an introspective document by the National E-Health Transitional Authority (NEHTA) noted three major themes – 1) multilevel tensions complicating decision making; 2) organizational competence to do eHealth; and 3) cultural shifts – based on their experience [30]. This report noted that the presence of multilevel “tensions” that complicate decision making was one of the most commonly reported themes across the electronic health information technology implementation literature.

**Table 3-10 Key themes from the failed implementation of PCEHR initiative in Australia**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multilevel tensions that complicate decision-making</td>
<td>Technology-led vs. community-led</td>
</tr>
<tr>
<td></td>
<td>Centralized command and control vs. diffused power</td>
</tr>
<tr>
<td></td>
<td>Directed vs. open, community led development</td>
</tr>
<tr>
<td></td>
<td>Market intervention vs. free market</td>
</tr>
<tr>
<td></td>
<td>Participant vs. bystander</td>
</tr>
<tr>
<td>Organizational and system competencies</td>
<td>Presence and subsequent use of a strategy</td>
</tr>
<tr>
<td></td>
<td>Relationship building and collaboration</td>
</tr>
<tr>
<td></td>
<td>Capacity to evolve rapidly</td>
</tr>
</tbody>
</table>
In yet another review of the evolution of Australia’s electronic health initiatives, researchers [34] described the problem of electronic health record implementation as a “wicked problem” to highlight complexities in both problem identification and subsequent choice of solution(s). The article noted.

“[Wicked problems] emerge in complex environments in which many interacting and interdependent elements – human, social, cultural, technical and political – combine to create intractable dilemmas that can endure without resolution for decades” [34] pg. 368

Moreover, any solutions to these problems end up with unintended consequences which might result in future problems. According to the researchers [34], the implementation of NEHRS in Australia had ended up being a wicked problem, instead of being the solution to one due to several factors like the failure to recognize and understand complexity, using conventional approaches to manage risk and uncertainty, and due to the inability to reconcile divergent viewpoints and value sets. These findings are aligned with NEHTA’s evaluation of Australia’s failure, described earlier [30].

3.2.1.4 Rest of the world

The European eHealth Strategies study surveyed [147] the information and communication technologies infrastructure of 34 European states (27 EU states, UK, Iceland, Norway, Switzerland, and Turkey). The findings indicated that EHRs and the development of patient identifiers were the commonly pursued
agenda item for most member states. There appeared to be an increasing level of awareness towards the need for evaluation to enable greater control over the implementation process. At the time of the survey, 19 states reported being in the deployment stage, 5 in the implementation phase, 2 in the pilot phase, 7 in the routine use phase. In 2010, 15, 9, and 7 states reported eCapture, eTransfer, and eDispensation capabilities respectively [147], in the ePrescription technology. Vast majority reported not having any of these features.

Table 3-11 National level eHealth activities reported by 34 European countries in 2006 and 2010

<table>
<thead>
<tr>
<th>Reported eHealth activities</th>
<th>2006</th>
<th>2010</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>EHR Patient Summary</td>
<td>27</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>ePrescriptions</td>
<td>16</td>
<td>22</td>
<td>6</td>
</tr>
<tr>
<td>Telehealth</td>
<td>23</td>
<td>27</td>
<td>4</td>
</tr>
<tr>
<td>Electronic ID - Patients</td>
<td>24</td>
<td>26</td>
<td>2</td>
</tr>
<tr>
<td>Electronic ID - Professionals</td>
<td>13</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Electronic insurance cards - Citizens</td>
<td>22</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Electronic insurance cards - Professionals</td>
<td>7</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>Standards (technical/semantic)</td>
<td>19</td>
<td>27</td>
<td>8</td>
</tr>
<tr>
<td>Legal activities</td>
<td>14</td>
<td>22</td>
<td>8</td>
</tr>
<tr>
<td>Evaluation</td>
<td>5</td>
<td>21</td>
<td>16</td>
</tr>
</tbody>
</table>

Source: Stroetmann, 2011 [147]

Denmark has had a long history of the use of EHRs with online access to some patient records available as early as the late 1970s and detailed patient records were available since 2000s. Electronic prescription records were added in 2005 and e-consults were available since 2006 [29]. International perceptions of the Danish EHR system is largely positive [29] due to reports of successful use of EHR data for emailing consults and sending patient reminders, very little is publicly known about their system [29]. A recent publication [148] shed some light and noted that in spite of Denmark’s privileged position as a leader and inspiration to other EU nations in this arena, it was struggled with issues around data sharing and interoperability across public hospitals due to regional variances in care giving responsibilities that could not be handled by state level initiatives [148].

France started its first EHR project, Carte Vitale, in 1998 which was later expanded under the Dossier Medical Personnel (DMP) effort in 2004 [28]. The DMP is personal EHR, consisting of various documents like discharge summaries, laboratory and imaging results, that is accessible online and allows the patient to control both its content and physician access privileges. Unlike other many other EHR system (e.g., U.S., U.K., Denmark), this system was set up with no secondary use of EHR data use in mind. The implementation of ran into trouble and the project failed to meet its original operational date of 2007 due
to patient security issues [28]. Moreover, even at the cost of €210 million, the DMP has failed to garner sufficient patient uptake [29] and has in fact, lower levels of uptake 67% compared to the 69% in the U.S., which started its EHR implementation much later [28]. Efforts have been underway since to increase uptake of the DMP [29].

3.3.2 Towards achieving health information technology’s potential

In a perspective piece [149] exploring why HIT systems have failed to achieve their potential, one of the suggestions is to figure out what might be an adequate ROI measurement timeframe. HIT systems are susceptible to the “IT productivity paradox,” which described the relationship between rapidly increasing use of IT that was accompanied by a lowering in productivity. Experts noted that this paradox was noted with the advent of IT in the banking industry as well, mostly because initial IT systems tend to be clunky and are often accompanied by duplication of work processes and slower workflow processes redesign which negative affect productivity [149]. Experts have suggested waiting 7-8 years before HIT could start meeting some of the productivity expectations. This suggestion was back by another set of researchers [150] that also recommended evaluating longer-term impact of HIT such as economic benefit, reductions in healthcare resource usage, and impact on clinical efficiency and quality over interim measures such as rate of EHR adoption [150]. Yet another article recommended cognizance of how various entities and levels “integrate” and “intersect” while developing any HIT interventions within a multilevel health system [151].
4 Methods

This study used the case study methodology to examine the role and place of data in activities designed to improve care within a health system. Using secondary data from organizations at various levels and sectors of the Australian health system, this study examined how data and data systems were used within and across various levels of the health system. To compare within and across the four major levels of the health system (i.e., commonwealth, state, local, and individual), a framework was developed drawing from existing literature. New logical frameworks were created where there were none that matched the needs of this study.

4.1 Approaches to studying the problem

The first research question aims to examine the role and place of data in improving quality within organizations and finally within a health system. The second research question is geared towards understanding the facilitators and barriers to the use of data in doing quality improvement activities; the third and final question compares the results from the previous two questions within and across levels of the health system.

The role of data and HIT were not very well understood at levels beyond the organization. Thus, the question was both complex and the boundaries and the role of HIT was hard to separate from that of all the other CI activities that were going on within a health system or organization at any given point in time. This was going to be an exploratory study and it needed a deep dive within a health system in order to understand how data traversed within and across levels of a health system. Case studies were well suited to studying complex phenomena with fuzzy relationship boundaries [152] [153]. Thus, the use of a case study method was a straight forward choice. This question did not lend itself to being studied using either quasi-experimental or experimental methods because of two main reasons. First, there was no way to deliberately manipulate any one thing within a health system without triggering inadvertent changes in many other variables that may or may not be observable. Second, there was scant knowledge that adequately demonstrated how the various components of the healthcare system were linked together (i.e. we don’t know if the variables were related and if so, how?)

Table 4-1 Potential approaches to studying this problem

<table>
<thead>
<tr>
<th>Approach</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mail-in surveys</td>
<td>Can be used to reach many participants; inexpensive</td>
<td>Low rates of participation (without incentives)</td>
</tr>
<tr>
<td>In-person survey</td>
<td>Better coverage of responses and check quality of responses; some chance to provide elaborate responses</td>
<td>Expensive</td>
</tr>
<tr>
<td>Approach</td>
<td>Pros</td>
<td>Cons</td>
</tr>
<tr>
<td>---------------</td>
<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td>Observation</td>
<td>Ability to describe behavior fully and correctly</td>
<td>Hawthorne effect; very expensive due to need to observe across a variety of settings/situations for long periods of time</td>
</tr>
<tr>
<td>Focus group</td>
<td>People from various backgrounds all together; ability to study both verbal and nonverbal reactions to what is being discussed</td>
<td>Strong voiced participants might overpower the quieter ones; controlled environment might hinder natural reactions; scheduling meaningful groups might be tough</td>
</tr>
<tr>
<td>Interviews</td>
<td>Rich content; especially useful for exploring new ideas</td>
<td>Response bias</td>
</tr>
<tr>
<td>Archival records</td>
<td>Low cost, good accuracy, moderate validity</td>
<td>Chances of undetected systematic errors</td>
</tr>
</tbody>
</table>

4.2 The case study method

Morra and Friedlander (1999) [153] defined the case study method as,

> “a method of learning about a complex instance, based on a comprehensive understanding of that instance obtained through extensive description and analysis of that instance taken as a whole and in its context”

This research used the case of the Australian health system with the individual actors/organizations serving as the embedded sub unit of analysis. Within the case study method, there were many ways to collect data using techniques like surveys; naturalistic observations; the use of focus groups would have probably been good alternatives. Surveys are a cost-effective way of studying a healthcare system, but mailed surveys run the primary risk of eliciting rather limited responses. In the absence of any clear incentives for participation, there was an additional risk of very low participation rates and the depth and breadth of information would be limited. Both focus groups and observations were potentially viable option, but they were more useful in areas that had some degree of structure that could be imposed on them and both had very significant burden associated with it. However, interviews were often a great way to elicit a variety of rich information especially about topics where very little was directly known. Care improvement efforts within health systems were not well studied empirically and semi-structured interviews provided both structure and flexibility to explore additional relevant topics at the discretion of the interviewer which made it an appropriate method of studying this topic.
4.3 Case identification and case description

For the purposes of this research, an ideal case was a modern, multilevel, and sophisticated health system with an extensive data collection and sharing infrastructure. The Australian health system fulfilled all these criteria while remaining very amenable to being studied easily. According to a Commonwealth Fund study [154]; there were approximately 15 nations which can be considered to have developed health care systems. These nations are Australia, Canada, Denmark, France, Germany, Iceland, Italy, Japan, Netherlands, New Zealand, Norway, Sweden, Switzerland, UK, and the U.S. Organizational relationships within the Australian health system are described in the picture below taken from Healy (2006). Moreover, it shared some similarities with the US health system, but there were enough differences as well from which lessons could be learned.

Studying the Australian health care system had several advantages in this respect. There were similarities with the U.S. health care system in the governance (federal/state), legislative (bicameral Congress/Parliament), and judicial set up. Australia was also a developed nation with an advanced health care system that was often compared with other developed nations within the research literature [31]. Australia differed from the U.S. in that it offered its residents universal health care coverage but had similar tax-based financing mechanisms. One of the biggest advantages of the Australian system compared to many other large developed nations (e.g. Canada, France, and UK) was the ease with which the Australian health care system lend itself to being studied. While Australia has a large (~22.2 million in 2010) population, it had only 6 states (and 2 territories) and most of its population was concentrated along the coastal states; the rest of the country had extremely low population density. Thus, it was possible to study the impact of policies and procedures that impacted a significant fraction of Australia’s population by focusing on one or two high population density states like New South Wales or Victoria. To conduct a study like this in the U.S. would be extremely time-consuming and expensive to conduct because: 1) the U.S. had 50 states, each with unique systems and bureaucracies; 2) the U.S. health care system was very fragmented compared to the Australian system. Thus, any study aiming to do this kind of research would be incredibly complex with an exponential increase in the sample size required to be able to conduct any research that was generalizable to the population.

The choice of the study of cancer was meaningful from clinical, political, and service delivery perspectives. From a clinical perspective, cancer is a high impact condition within the Australian population. In 2008, there were 112,304 new cases of cancer diagnosed, with the five commonest cancer types (prostate, bowel, breast, skin, and lung cancer) accounting for 62% of all cases. While cancer is mostly considered a condition of the elderly, skin cancer (or melanoma) is the commonest type of cancer amongst the 15-29 year old group [155]. Thus, clinically, cancer was of concern to all Australians. A diagnosis of cancer was of importance not only at the individual level but for the Australian entire health care system [156]. The pervasive and highly visible impact of cancer on the Australian population also meant that cancer control related policies were highly likely to be discussed, debated, and promoted.
within the Australian political and legislative systems. This meant that cancer control would be a priority within the Australian health care system and would provide ample material for exploration. Finally, from the health care delivery perspective cancer was the kind of condition that required services that spanned across the entire continuum of care – from preventive, primary, specialty, diagnostics, long term, and palliative care [36]. Thus, focusing on cancer would provide the chance to study a variety of health care delivery organizations. Due to practical considerations, the example was limited to one condition – the original researcher chose colorectal cancer as the clinical condition where previous quality improvement work might affect ability to discern differences across the system. Colorectal cancer was chosen as the cancer on which the interviews were focused by rating and ranking across a few high priority cancer types, namely – breast, colorectal, lung, prostate, and skin cancer. Each type of cancer was assessed on the following dimensions: age-standardized incidence risk, total potential years of life lost, gender prominence, risk in indigenous vs. general populations, variations in current quality programs, and the availability of performance measures (Appendix A "Assessments for condition selection"). Gender prominence assessed if a specific cancer was gender specific or had disproportionately higher prevalence in any gender. Preference was given to conditions that were non-gender specific.

This data was a good fit for the case study because the interviews elicited information on the use of routinely generated clinical tracking reports (see sample used in Appendix D Sample performance measurement data) to drive performance improvement at the organizational level. This question led to other detailed discussions around data and HIT within the Australian system.

### 4.3.1 Actors, roles, and relationships within the Australian health system

Historically, the Australian health care system has been both a universal health insurer and has also been a privately financed health system. However, since 1984, Australia has been a national health care insurer (called Medicare) which provides universal coverage to citizens, permanent residents, and specific category of short term visitors with care using a combination of income taxes and income dependent Medicare levy and through private payments [46] [154]. The government acted primarily as a payer of medical services provided by private medical professionals. Medicare covered preventive, mental/behavioral, and long-term care. Medications were subsidized according to the Pharmaceutical Benefit Schedule (PBS). While inpatient care through public hospitals was fully covered by Medicare, outpatient/physician services were subsidized based on a fee schedule. On an average, Medicare reimbursed 75%-100% of the schedule fee for inpatient and outpatient care [154]. In addition to the National Health Insurance, 44.3% (as of 2011) of Australians used private plans for additional coverage to private inpatient facilities. Private insurance plans were regulated by the Private Health Insurance Administration council and any increase in policy rates needed prior approval by the Australian Department of Health and Aging (DoHA).
As a national payer (Figure 4-1), the Australian Government played a major role in setting the tone for the Australian health care system through policy making, goal setting, and resource allocation. Top federal (also known as the commonwealth) level healthcare bodies included the DoHA, the Council of Australian Governments, which served as the advisory and national agenda setting body, and the Australian Health Ministers conference. The federal/commonwealth bodies worked with the 6 states/2 territories to administer public hospitals, mental health services, and long-term care facilities using a combination of funding and interagency agreements [154]. Health care delivery improvements were guided by the Australian Commission on Safety and Quality in Health Care (ACSQHC) that set national standards, provided public reporting, policy input and implemented new approaches to improving care (e.g. through new types of accreditation policies). The Australian government provided incentives (e.g. the Practice Incentives Program) to individual providers and practitioners to encourage participation in maintaining quality standards through processes like accreditation using the quality standards set by the Royal College of General Practitioners. The exclusion of unaccredited hospitals and long term care facilities from the Medicare payment schedule served as a strong incentive to seek proper accreditation [46] [154] [67].

**Figure 4-1 Key actors and relationships within the Australian health system**
4.3.2 Cancer control within the Australian health system

Since the 1980s, Australia has recognized the far-reaching impact of cancer on morbidity and mortality in Australia and has made various organized efforts at cancer control at the national level [156]. Cancer control was defined as all actions that were aimed to reduce the burden of cancer and included prevention, early detection, treatment and palliative care. Both the government and the non-government sectors (e.g., Cancer councils, Cancer Voices New South Wales) participated in crafting the various national strategic recommendations that had been developed over time. At the time of the data collection in 2007, the latest cancer control strategy guiding the Australian healthcare system was entitled “Strengthening Cancer Care,” which included plans to not only improve cancer care but also support cancer survivors and care delivery professionals by providing better screening and prevention, care coordination, and greater funding for cancer research. The 2004-2005 national budget allocated AU$189.4 million towards this project over a five-year period. This funding was for training clinical and allied professionals (nurses, counsellors, GPs), enhancing screening, prevention, and awareness programs, providing support to survivors and their families, improved medical benefits for the pediatric population, supporting clinical trials and other cancer related research, and program evaluation at the end of the funding cycle [157]. While this provided the vision at the national level, states and territories also had their own cancer control initiatives. Victoria and New South Wales were front runners in this effort.

4.4 Data

This study was a secondary analysis with a specific emphasis on the role of data/technology of primary data materials collected as a part of a fellowship to Australia in 2007-08. The original data were collected with the aim of understanding current quality improvement efforts, identifying major themes related to incentives and disincentives for quality improvement and performance measurement at each level of the healthcare system. A summary description of the original study can be found in Appendix E “Description of the primary project.” The semi-structured interviews were designed to elicit questions about specific improvement initiatives, use of data related to performance improvement and relationships with other organizations. In order to answer the research questions fully, some gaps in the original interview data were supplemented and updated by the author by collecting additional, mostly organization related, data directly from publicly accessible websites of the organizations studied in the original interview.

4.4.1 Sample Generation

Data were collected in 2008, in the form of semi-structured interviews with key informants. The initial list of informants was identified through conversation with the first informant who happened to be a very high level official within the Australian cancer care ecosystem with extensive knowledge of the system. The list of informants targeted included high level decision makers (and administrators) within leading Australian organizations, in the government and non-government sectors, in roles pertaining to cancer care, specifically, clinical colorectal cancer care. A wide range of organizations from various levels of the
Australian system were sampled including the Commonwealth/federal, states, local (area health services, general practice divisions, private and public hospital administrators), and clinical microsystem levels including primary and specialty care practitioners including surgeons.

An initial sample of approximately 30 individuals was targeted, and snowball sampling was used to identify any additional informants who operated within this “universe” of cancer care in two Australian states until themes were fully delineated. The use of snowball sampling was appropriate because the key informants were a fairly “rare” group of high level decision makers who were in a position to recommend other potential informants who operated within the area of cancer control.

4.4.2 Data collection

Data were collected in the form of semi-structured interview. The interviews were conducted in person and lasted between 45-90 minutes. Interviews adhered to a predetermined protocol and included topics quality improvement, performance measurement, incentives and disincentives for quality improvement, and organizational relationships among key players in the healthcare system. The interviewer probed for clarifications and to learn more about a specific topic of interest. To ensure that the information obtained was concrete and actionable, the interviews focused on colorectal cancer and two discrete, evidence-based opportunities for quality improvement – ensuring that patients with positive bowel screens obtain appropriate follow-up, and incorporating routine screening for psychosocial distress. In cases, where the organization was not involved in activities around colorectal care, informants were given the option of discussing performance measure in other cancer areas or other CI related activity of their choice.

Every interview was recorded with the permission of the informant; informant confidentiality was assured using a master list to connect the interviews to the names of the informants. Interviews were stored on secure servers at the Veteran’s Administration (VA) health system to prevent unauthorized access. Recorded interviews were de-identified and transcribed into transcripts for the purposes of coding. This study requested and received official permission from the VA of Greater Los Angeles for access and use of the data for this research. A sample of the interview protocol can be found in Appendix B Interview protocol.

Additional data, mainly organizational in nature, were collected to supplement and verify information from the interviews. These data consisted of information gleaned from the websites and of sample documents found from various web archives. Examples of archival documents include samples of reports generated by an organization or promotional materials (e.g., flyers, brochures). These materials were primarily used to get a bigger sense of the purpose (e.g., organizational mission, vision, and values), its overall organizational structure (e.g., organizational charts), and its hierarchy within the Australian system than that covered in the interviews. These additional data were specific to organizations and not shared in this dissertation to protect the privacy the organizations and ultimately the informants. In cases where informant roles (e.g., manager of a specific department within an organization) or experiences were
unique (e.g., specific project names), the exact nature of these details were purposefully obfuscated to prevent identification.

4.4.3 Sample characteristics

The original sample consisted of 35 interviews from 43 informants from 29 unique healthcare organizations in Australia. There were more than one interviews from 4 organizations (2 Commonwealth and 2 State level). One data point (state level) was removed from the sample because the transcription quality was unreliable; another data point was removed because this organization was an outlier organization. The final sample used in this dissertation consisted of 33 interviews from 27 unique organizations and 38 informants. Majority of the interviews come from Commonwealth and State level organizations with a little over half of them from organizations from the government sector.

Table 4-2 Sample characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Government</th>
<th>Non-government</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of unique interviews</strong></td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Commonwealth</td>
<td>14 (42.42%)</td>
<td>8 (24.24%)</td>
</tr>
<tr>
<td>State</td>
<td>11 (33.33%)</td>
<td>7 (21.21%)</td>
</tr>
<tr>
<td>Local</td>
<td>3 (9.09%)</td>
<td>2 (6.06%)</td>
</tr>
<tr>
<td>Individual</td>
<td>5 (15.15%)</td>
<td>3 (9.09%)</td>
</tr>
<tr>
<td><strong>Number of unique entities</strong></td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Commonwealth</td>
<td>11 (40.74%)</td>
<td>5 (18.51%)</td>
</tr>
<tr>
<td>State</td>
<td>8 (29.62%)</td>
<td>4 (14.81%)</td>
</tr>
<tr>
<td>Local</td>
<td>3 (11.11%)</td>
<td>2 (7.40%)</td>
</tr>
<tr>
<td>Individual</td>
<td>5 (18.51%)</td>
<td>3 (11.11%)</td>
</tr>
<tr>
<td><strong>Number of informants</strong></td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Senior management</td>
<td>16 (42.10%)</td>
<td>8 (21.05%)</td>
</tr>
<tr>
<td>Middle management</td>
<td>12 (31.57%)</td>
<td>8 (21.05%)</td>
</tr>
<tr>
<td>Operational (including clinicians)</td>
<td>10 (26.31%)</td>
<td>5 (13.15%)</td>
</tr>
</tbody>
</table>

Note: All clinicians were defined as operational. Informants may have more than one role (e.g., clinicians with management responsibilities within a small unit, like a division head).

4.5 Data analysis

In order to facilitate within and across levels comparison, a framework was developed to help analyze the data. The framework was used using a combination of a priori codes (where available) and codes generated using grounded theory.
4.5.1 Data Analysis - Stage 1

The transcribed data documents were imported into Atlas.ti for ease of management, abstraction and coding. The dataset consisted of long narratives which were rich in detail. The aim of this analysis was to 1) establish a sense of the breadth of the responses for each of the research questions, and 2) identify recurring ideas and concepts. To answer research question 3, responses were compared across public and private sectors; similar comparisons were made across and within non-governmental organizations within various levels of the healthcare system. Since this study involved working with secondary data; an extra data processing step was undertaken before conducting the analyses. That step consisted of skimming through 1/3rd (~12) of the transcripts to assess how well the interviews adhered to the original interview protocol and to get a sense of the actual content of the interviews. Once the content areas of interest were established, a two stage “top down” approach was used to analyze the data.

The first stage of the analysis consisted of two steps. First, codebooks using the frameworks were developed for codes within four major content areas – organizations, data/HIT, quality improvement, and health systems. The codebook provided the name of the code, defined the code, provided an example and noted any exceptions to the code. Some codes were unique to the content area and some cut across. Codes that cut across content areas included: vision, priority, policy, facilitators and barriers. Aside from the analytical codes, a set of non-analytic codes (called “convenience codes”) were created that marked chunks of text that were especially suitable for use as quotations within each content area for ease of access while writing manuscripts. Second, the transcripts were coded to indicate every instance a specific idea of interest occurred within in the data using Atlas.ti. The coding in this stage was kept fairly broad within each code and content area.

At the end of the first round of coding, there were numerous quotations linked to each code. This was expected with the top down approach. So, the codes generated so far were reviewed a second time on Atlas.ti. Codes that have had too few quotes associated with it were re-examined and in some cases, were merged with other appropriate codes. For example, codes for data and HIT sections were merged because in many instances the presence of technology was implied through the discussion on data and hence was coded under sections on data. In other instances, informants invariably talked about data and technology in the same breath. No attempt was made to disentangle the nuances between the two codes.
in this stage. After this kind of housekeeping activity, the analysis proceeded to the next stage which involved taking a closer look at these codes.

Table 4-3 Theoretical frameworks used to guide the coding process in stage 1

<table>
<thead>
<tr>
<th>Reference</th>
<th>Description of the framework</th>
<th>Use in analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ferlie &amp; Shortell, (2001) [35]; IOM (2001) [3]</td>
<td>Postulates that any action taken within a health system needs to be understood in the context of the level which the action occurs and the levels that come before and after it</td>
<td>The Australian health system was studied and analyzed at 4 functional levels: Commonwealth, State, Local, Individual</td>
</tr>
<tr>
<td>Shakarishvili (2010) [38]</td>
<td>Reviews health systems frameworks and attempts to synthesize common elements within these frameworks</td>
<td>Used to code roles and responsibilities based on the critical functions of a healthcare system</td>
</tr>
<tr>
<td>Shi &amp; Singh (2004) [46]</td>
<td>Groups various actors within a healthcare system into six groups</td>
<td>Used this to classify organizations into one or more of these groups: Payers/Insurers, Suppliers, Education/Research, Providers, and Govt.</td>
</tr>
<tr>
<td>Leatherman &amp; Sutherland (2007) [39]</td>
<td>Taxonomy of quality improving activities</td>
<td>Used to code CI activities: patient focused regulatory, incentives, data/IT driven and organizational and sub categories.</td>
</tr>
</tbody>
</table>

The second stage of the analysis included numerous steps. First, all codes from Stage 1 were revisited and reclassified into sub codes that reflect finer nuances within that major code. For example, the code “Data Use” from stage 1 was reclassified into six sub codes reflecting the purposes associated with data use. These sub categories reflected the use of data to run day to day “operations”, data for “monitoring,” data used for “understanding problems,” data to “support interventions,” data for providing “feedback,” and data for “reporting.” This helped identify themes and sub-themes using an iterative pile sorting technique as described by Lincoln and Guba (1985) [158] and Ryan and Bernard (2003) [159]. Data were managed using ATLAS.ti (Scientific Software Development GmbH). A list of codes is enumerated in Table 4-4.
Table 4-4 List of key codes used in analysis Stage 1

<table>
<thead>
<tr>
<th>Code name</th>
<th>Description</th>
<th>Sub codes, if any</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roles</td>
<td>Indicated text describing either the institutional role or the informant's roles and responsibilities</td>
<td>--</td>
</tr>
<tr>
<td>Relationships</td>
<td>Reflected CI relationships between agencies. The code specifically noted the levels and/or the sectors of involved institutions/entities.</td>
<td>Levels -- CW-CW; CW-State; CW-Local; CW-Individual (all possible combinations) Sectors -- Within sector (e.g., Govt-Govt) and across sector (Govt – NGO)</td>
</tr>
<tr>
<td>CI</td>
<td>Indicates description of specific CI efforts</td>
<td>--</td>
</tr>
<tr>
<td>CI barriers</td>
<td>Indicated descriptions of barriers to CI activities</td>
<td>--</td>
</tr>
<tr>
<td>CI facilitators</td>
<td>Indicated descriptions of facilitators to CI activities</td>
<td>--</td>
</tr>
<tr>
<td>Data use</td>
<td>Indicated descriptions of how data or health information technology was used by the organization</td>
<td>Accountability; Feedback; Hypothetical; Intervention Support; Monitoring; Operations; Problem Identification; Reporting; Standards Development</td>
</tr>
<tr>
<td>Data barriers</td>
<td>Text indicating factors that were barrier or facilitators to data flow and data use for the informant and institution</td>
<td>--</td>
</tr>
<tr>
<td>Data Echo</td>
<td>Indicates text where one informant is referring to or validating a point made by another informant</td>
<td>--</td>
</tr>
<tr>
<td>Data flow</td>
<td>Indicated descriptions of sharing of data/information between two entities, at any level, with or without the use of HIT</td>
<td>--</td>
</tr>
<tr>
<td>Money flow</td>
<td>Indicated sources of funding or fund distribution of funding between entities</td>
<td>--</td>
</tr>
<tr>
<td>Fragmentation</td>
<td>Indicated descriptions of breaks in the system that prevented flow of information or other resources</td>
<td>--</td>
</tr>
<tr>
<td>Quote</td>
<td>Indicates interesting quotes for future reference</td>
<td>--</td>
</tr>
</tbody>
</table>
4.5.2 Data Analysis - Stage 2

In this stage, the coded data were abstracted to create a matrix in Excel. The matrix consisted of each organization in the rows and data from various themes and sub themes in the columns. A list of variables in the matrix can be seen in the Table 4-5 and Table 4-6 below.

Table 4-5 List of variables abstracted at the organizational level in Stage 2

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level and Sector</td>
<td>Identified positioning of the organization within the health system. Total possible options 8 (4 levels and 2 sectors)</td>
</tr>
<tr>
<td>Organizational ID</td>
<td>Identifier for the organization – Transcripts from multiple organizations were combined together to create one unified data set.</td>
</tr>
<tr>
<td>Health system function</td>
<td>Identifies the organizational role within the health system using the framework laid out in Shakarishvili (2010).</td>
</tr>
<tr>
<td>CI relationships</td>
<td>Indicated CI related partnerships of an organization with other organizations. Indicated using level/sector positioning of the partner organization.</td>
</tr>
</tbody>
</table>

Table 4-6 List of variables abstracted at the CI level within each organization in Stage 2

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level and Sector</td>
<td>Identified positioning of the organization within the health system. Total possible options 8 (4 levels and 2 sectors)</td>
</tr>
<tr>
<td>Organizational ID</td>
<td>Identifier for the organization – Transcripts from multiple organizations were combined together to create one unified data set.</td>
</tr>
<tr>
<td>CI target</td>
<td>Identifies the target of a CI intervention. Option included physician, patients, healthcare institutions, physician-patient relationship interface, the physician-healthcare institution interface, healthcare intermediaries, or the overall health system</td>
</tr>
<tr>
<td>CI activity type</td>
<td>Brief description of the CI activity</td>
</tr>
<tr>
<td>CI classification</td>
<td>Classified CI activity type using categories generated by the framework by Leatherman and Sutherland (2007). Any CI could be classified in up to 2 categories. There were 14 classification options.</td>
</tr>
<tr>
<td>CI funding source</td>
<td>Sector (Govt/NGO) from where the funding for a CI activity was generated</td>
</tr>
<tr>
<td>CI implementation</td>
<td>Sector (Govt/NGO) where a particular CI activity was carried out.</td>
</tr>
<tr>
<td>Variable name</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>CI motivator</td>
<td>Classified stated motivator for a CI effort using over 20 different categories</td>
</tr>
<tr>
<td>CI role</td>
<td>Identified role of the organization in a CI project using 9 option</td>
</tr>
<tr>
<td>CI relationships</td>
<td>Indicated CI related partnerships of an organization with other organizations. Indicated using level/sector positioning of the partner organization.</td>
</tr>
<tr>
<td>Data sources</td>
<td>Lists stated data sources.</td>
</tr>
<tr>
<td>Data-money relationships</td>
<td>Types of data and money flow relationships noted.</td>
</tr>
<tr>
<td>Data flow levels</td>
<td>Indicated if any data flow was noted across levels relative to the position of this organization within the health system.</td>
</tr>
<tr>
<td>Data flow sectors</td>
<td>Indicated if any data flow was noted across sector relative to the position of this organization within the health system.</td>
</tr>
<tr>
<td>Data reliance score</td>
<td>Indicates an evaluation of whether the informant(s) indicated low, moderate, or high organizational reliance on data to drive CI efforts. Higher scores indicated use of data across wider range of CI activities.</td>
</tr>
<tr>
<td>Data use</td>
<td>Lists the uses of data in the CI efforts mentioned by the informants using the sub codes in Stage 1.</td>
</tr>
<tr>
<td>Data barriers</td>
<td>Indicates barrier(s) to data use and data flow mentioned by the informants.</td>
</tr>
<tr>
<td>Data facilitators</td>
<td>Indicates facilitator(s) to data use and data flow mentioned by the informants.</td>
</tr>
</tbody>
</table>

Note: CI, Care improvement

### 4.5.3 Data Analysis - Stage 3

The matrix obtained in Stage 2 allowed for the systematic examination of core and peripheral aspects of various themes by sorting chunk of texts into typical and atypical piles. The examination of each theme and sub theme, classified by level (federal/state/local/individual) and sector (public/private) type allowed the description of the range, central tendency and distribution of themes within each thematic domain. The salience of each theme was evaluated based on the degree to which participants mentioned it. In some cases, extreme options that were less often reported were also noted to provide a sense of the range of sub themes. Once central themes and sub themes were delineated, they were compared across levels and sectors to identify any additional patterns.
4.6 Limitations

There are several limitations that need to be noted – some arise due to the methodological issues and others due to the secondary use (i.e., using this data for purposes other than for which it was originally intended to answer) of the data. First, this study might not be replicable in the true spirit of scientific research, by virtue of the human element (interviewers and interviewee). This does not make the findings irrelevant or invalid; it means that these findings are truly exploratory in nature and further confirmatory analyses should be conducted. Second, some of these insights only partially answer some of the questions posed in this study due to lack of control over the aspects what was asked and probed further. Third, there was no direct control over data quality; all efforts were made to validate the transcripts for a small sub-sample of interviews, however, the vast majority were used as received and transcribed. There could be errors in transcription that might have remained in the data. Finally, snowball sampling has inherent biases like non-randomness which could lead to inaccurate findings. These interviews were conducted only for departments deal with urban/near-urban populations and did not include the Australian indigenous health sector.
5 Actors, roles, and care improvement

This chapter will provide an overview of the organizations and informants including name, affiliation, funding sources, key partners, informant designation, and organizational missions of key organizations within the Australian Healthcare system. The intent of this chapter is to provide a glimpse of the range of organizational roles and concomitant care improvement activities that are undertaken by various organizations within the cancer care ecosystem in Australian healthcare. Organizations were placed based on their positioning on one of the 4 major levels – Commonwealth, State, Local, and Individual – of the health system and by the sector – Government or Non-Government – within which it operated.

5.1 Commonwealth

5.1.1 Government

5.1.1.1 CWG1

This organization is the commonwealth health department, a large entity with wide diversity in the roles and responsibilities of individual divisions within the agency. This sample consisted of three informants from two different divisions (or sub agencies). Sub-agency 1 was responsible for financing and managing programs to ensure the provisioning of ambulatory care within various settings. Sub agency 2 was responsible for managing public health programs including screening for various types of cancers.

Role in care improvement

Funder

Table 5-1 Overview of role and CI activities - CWG1

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service payment</td>
<td>Providers; Healthcare organizations</td>
<td>Appropriate payments</td>
</tr>
<tr>
<td>Service provisioning</td>
<td>Health system</td>
<td>Ensure service</td>
</tr>
<tr>
<td>Stewardship</td>
<td>Health system</td>
<td>Reducing disparities</td>
</tr>
</tbody>
</table>

Sub agency 1 identified itself primarily as an insurer paying for medical, pharmaceutical benefits under the national health scheme. They also subsidize private health insurance. Their second major role was stewardship of the overall functioning of the health sector even though they do not play a direct role in the provisioning of healthcare and do not employ any of the staff who "lay their hands on [the] patients."
As an informant described, “…with our main role being that of the insurer, we don’t – we tend not to know really what goes on in the consulting room…because we are not actually delivering services, we probably have a quite limited in direct quality improvement.”

As a public payer of primary care services, which is predominantly conducted in the private sector their efforts to improve care delivery were mainly in their capacity as “gate-keepers” to Medicare that allowed them to control what was covered. As gate-keepers they exert “control over inputs” that go into the production of healthcare services. This control over inputs included requiring doctors to have defined levels of training, competencies, and accreditation before they become eligible to claim all or some of the benefits offered by the government payment programs. In addition to payments to individual practitioners, the program also has additional payments that can be obtained at the “organization” (i.e. private practice) for meeting certain criteria like achieving certain immunization benchmarks or for staying open longer.

Sub agency 2 had a bigger role in improving care delivery, although it is limited in its focus on activities that are of interest in maintaining population health. Population health screening is a major activity within this agency. Screening requires a lot of entities, individuals (e.g., physicians) and agencies (laboratories, government agencies), to work together to make screening happen from beginning to end. Hence, this sub agency’s efforts to improve care delivery are focused around increasing multidisciplinary care in cancer and to working as teams.

Part of their efforts in improving quality seem to be through funding. For example, they funded the development of quality assurance frameworks for colonoscopy and performance indicators for cervical/gynecological cancer by the professional bodies (Royal Colleges). These efforts allow the government to influence delivery of care indirectly.

They have also put the data collected through their cancer registries to good use by using that data to develop performance indicators which was then tied up with accreditation requirements, which in turn were connected to Medicare’s payment mechanism. This tight connection of accreditation has affected the whole industry. The multidisciplinary nature of screening activities makes care improvements felt across a broad range of practices and “is the opportunity for the screening programs to affect practice more broadly.”

Care improvement relationships

Commonwealth Govt, Commonwealth NGO, State Govt, State NGO

Commonwealth: Sub agency 2 was part of several working groups by the national government cancer control and breast cancer control agencies, this relationship leveraged the deep knowledge (partly due to their unique data resources) about the cancer that members of this organization had around certain cancers. This sub agency also received semi-annual performance reports for the various programs from another commonwealth agency.
Sub agency 2 reported close relationships with the non-government sector organizations like the Cancer Council and Royal Colleges. This relationship benefited from the extensive resources this NGO could provide the government organization around cancer. This agency also served as a platform to put out views that a government agency cannot (or should not due to ethical concerns) discuss publicly. Sub agency 2 funded the Royal Colleges (non-government sector) to develop quality assurance frameworks for various cancers.

State: Nonhierarchical relationship with the state governments. Both organizations were closely tied to each other through funding relationships, however, state governments are “sovereign governments” and the commonwealth governments technically “can’t tell them what to do.”

Local: The divisions of general practice were key to implementing the care improvement efforts put forth by this agency. The divisions of general practice received funding to support general practitioners in their area.

5.1.1.2 CWG2

This organization was the peak cancer control body with the explicit mission of “reducing the impact of cancer on Australians” through improved coordination of cancer control activities within Australia.

This organization was responsible for identifying “opportunities where there might be some gaps that could be managed through particular mechanisms” and for developing some new policies options for consideration by “the government of the day.” They were also responsible for researching evidence, “reacting and responding” to official questions and concerns raised by high level decision makers, around cancer control policies. This organization was entirely funded by the Australian government and sat within department of health’s portfolio; however, they did not report to the them, bypassing them to connect directly with the Australian Health Ministers.

Role in care improvement

Funder; Leader; Coordinator

Table 5-2 Overview of role and CI activities - CWG2

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource development</td>
<td>Providers; Patients</td>
<td>Curriculum; Treatment Guides</td>
</tr>
<tr>
<td>Stewardship</td>
<td>Health system</td>
<td>Improving access to care</td>
</tr>
</tbody>
</table>

Improving the quality of cancer care was an integral part of the roles and responsibilities of this organization with a dedicated organizational team around this role. Cancer Australia’s flagship care improvement activity was aimed at improving inter-organizational linkages between service providers across the spectrum of cancer care to create regional and metropolitan comprehensive care networks.
This effort was geared to improve access and the timeliness of care received by patients. As an informant explained, “…if someone reasonably suspects they have cancer…there is a pathway that will link them as quickly and effectively as possible with the service that can map out the best possible care for them.”

Other efforts included supporting the development of a new curriculum aimed at increasing cancer related training curriculum to all future health care professionals and professional development programs. In addition, they met with a wide variety of groups to get a holistic view of what constituted good cancer and what were the expectations of care from various stakeholder perspectives – “What are the reasonable expectations of someone walking through the door of a cancer center, as to the care they should get? And, we’re going to be working with those consumers to articulate that clearly to service providers and to funders and clearly, psychosocial care is valued greatly in the people with whom we’re working.”

**Care improvement relationships**

**Commonwealth NGO; State Govt; Individuals**

Key stakeholder relationships included commonwealth and state health departments, state cancer control agencies, commonwealth voluntary health organizations, and peak patient and caregiver advocacy bodies.

Commonwealth: This organization had a close parallel within the non-government sector – the Cancer Council of Australia. Cancer Council predated this organization and was considered an influential figure in cancer control with access to reliable epidemiological data. Their feedback on cancer policies was sought out by various policy making bodies.

State: In order to facilitate their flagship project to improve timeliness of access to cancer care, Cancer Australia provided matching funding to the states, which allowed both levels of government to leverage their funding beyond what would have been possible by any of these agencies doing it alone. As an informant described their funding approach, “… has been quite an innovative use of the funding that we’ve had…by using it to add to, and combine with the states and territories, to increase the quantum of money, but also the quality of how it’s used to get more sustainable outcomes for improvements in cancer services, which will be monitored over time when they are established. And that’s the first that’s been done in this country in cancer.

Individual: This organization actively makes sure that consumer preferences are heard in policy making through consumer oriented surveys and focus groups.

5.1.1.3 CWG3

This organization was a cancer control government organization specific to gynecologic cancers. With the establishment of a centralized cancer control agency, there emerged a significant overlap in roles and responsibilities between the two organizations. At the time of the interview this organization was a
separate agency with different governance and leadership structures; the two organizations merged in 2011. This merger eliminated implicit competition due to “overlapping remits” between these two government agencies and harnessed existing synergies. This organization covered the entire spectrum - “covering risk through palliation” - of breast and ovarian cancer care.

This organization is funded primarily through the Commonwealth (upward of 90%); the rest of its funding came from charitable donations and corporate sponsors. The choice of corporate partnership was done in ways such that it avoided conflicts of interest and did not “compromise” their reputation. As a funder, the Commonwealth was a key stakeholder along with other government and non-government agencies. The group works closely with numerous stakeholders including commonwealth and state health departments, voluntary health organizations, media, and consumers to carry their mission around awareness building and education. This organization works closely with researchers to stay abreast of happenings. As one informant described the role of researchers, “we get sort of a prior warning of the things that are coming out around trials…”

**Role in care improvement**

**Generator; Implementer; Innovator**

**Table 5-3 Overview of role and CI activities - CWG3**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource development</td>
<td>Providers; Patients; Healthcare Organizations; Regulators; Provider-Patient</td>
<td>Curriculum; Treatment Guidelines; CI Toolkits; performance measures</td>
</tr>
</tbody>
</table>

This organization was engaged in a wide range of breast and activities including awareness raising, consumer and provider information, clinical practice guideline development, education, quality improvement, and breast and cancer related data monitoring. The interview revealed an extensive range of activities including the development, implementation, and testing of care improvement interventions. For example, this organization developed a quality improvement kit for hospital services treating women with breast cancer and participated in a randomized control trial to test the effectiveness of this intervention in approximately 20 hospitals in the state. Another example included the development of toolkits that aimed to improve adherence to guideline based breast cancer care and addressed a wide range outcome like increased use of reporting in pathology and patient-provider communication. This organization was notable in its involvement in the active implementation of its interventions by providing “supporting” tools and “guiding them [hospital staff] in how do that [audit].” To facilitate the implementation, process this organization worked at the “systems level” engaging with a wide range of stakeholders (e.g., hospital CEOs) to establish buy-in and to get access to the resources (e.g., staffing) and processes (e.g., auditing mechanisms) needed to support and study the implementation of the
project. Some of their interventions had been effective in improving processes and have demonstrated some sustainability. As the informant summed up the experience, “…in the majority of the places it [the intervention] continued to work well - the ones [hospitals] that had already found it hard to start out were just floundering at the end of that [study period].”

The organization was also a frontrunner in addressing new issues (e.g., psychosocial care, multidisciplinary care teams, holistic care) around cancer control. These kinds of less addressed issues often tended to be cross cutting in nature or belonged outside the traditional domain of physical health. This organization developed “a world first” in setting standards of psychosocial care for patients with breast (and ovarian) cancer throughout Australia. This was remarkable given that the data revealed a lag in psychosocial care in many organizations and domains of cancer care. Their guidelines were designed to promote a multidisciplinary holistic approach to care and were disseminated through the Cancer Councils to “rave feedback.”

Care improvement relationships

Commonwealth Govt; commonwealth NGO; State Govt; State NGO; Local Govt; Individual

Commonwealth: This organization worked with the federal department of health in an advisory capacity including helping them set their standards for the accreditation process for the breast cancer screening program.

In the non-government sector, this organization reported close ties with all the Royal Colleges (e.g., surgeons, physicians, radiologists, pathologists) that collaborated with this organization due to the multidisciplinary nature of cancer care. This organization participated in an audit, conducted by one of the Royal Colleges, that looked at outliers in the clinical care data reported by the surgeons and there was a feedback mechanism to individual physicians in place to ensure that standard of care is followed. Yet, another relationship with this sector included the industry advocacy groups for private hospitals, a member of this group serves as an advisor on the clinical performance measurement work undertaken by this organization.

The informant noted that they develop performance indicators for hospitals (public and private) and part of their dissemination strategy involves collaborating with the peak safety and quality body which is known for developing innovative models and working with other groups to take them up. Another key relationship was with a NGO regulatory body that is responsible for accrediting hospitals. Stakeholders from this regulatory body were part of the steering committee that was responsible for developing the breast cancer diagnostic services, with the anticipation that these standards would get incorporated into the accreditation standards upheld by this regulatory body, thereby effectively influencing the standard of care for all hospitals.
State: This organization worked with the state based cancer control groups around improving care delivery like communication training for doctors. In particular, these organizations act as the state level implementation and information dissemination arm for this commonwealth organization.

Similarly, state based consumer advocacy groups were a partner especially in efforts to improve public cancer awareness programs and also provide a way to get consumer representation in every effort undertaken by this organization.

Local: Research groups from local groups were another key partner in care improvement. These groups provided a “sort of a prior warning” of latest findings from clinical trials, so that that this organization advise people accordingly.

In yet another example, this organization implemented a care improvement project at several locals healthcare organizations; during the project, members of this organization worked with coordinators for each hospital. The coordinator led the program and provided support to the hospital staff under guidance from the experts from this organization.

Individual: This organization aimed to provide clinicians with tools to ensure they’re giving comprehensive care and to prompt them provide evidence based care. These efforts include improving communication between patient and providers by training doctors on a variety of sensitive topics like “breaking bad news to patients” and “transitioning to palliative care.”

5.1.1.4 CWG4

This organization was the peak national body around issues of safety and quality. They had an “all embracing remit” and were concerned with the safety of quality of all aspects of the Australian health system, whether public or private. Despite undergoing several changes in its set up and purpose since inception, the organization had established a name recognition and presence within the Australian healthcare system in its current avatar.

This organization reported directly to the Australian ministers (Parliament) and sats parallel to other Commonwealth level agencies like the health department and the cancer control organization. They coordinated the activities across the various state level equivalent safety and quality bodies.

Role in care improvement

Leader; Coordinator; Innovator

Table 5-4 Overview of role and CI activities - CWG4

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Health system; Healthcare organizations</td>
<td>Data operating principles and governance; accreditation models</td>
</tr>
</tbody>
</table>
The primary roles were around facilitating the propagation of standards of care in the areas of quality and safety and providing policy advice to the health ministers. Being a facilitator organization meant that this organization coordinated services and provided policy advice without direct involvement in the implementation of their strategies. Due to the absence of any “money to throw around” or legal authority “clout,” moral suasion was the chief mechanism of influence. This was achieved through personal contact with high level decision makers and stakeholders, which allowed them to find common ground with the goals, values and objectives of the other organizations and to leverage the general desire of individual decision-makers to improve safety and quality within their organizations. At the time of the interview, this organization had 9 priorities running, each of which focused on better services in cancer or a range of other modalities of specializations in Australia, from medication management, hygiene stuff, even dynamic stuff around patients with open wound closure, patient charter, etc.

The ability of this organization to improve care was highly dependent on the will of others to bring about change. Their advice to the health ministers is crafted in a way, “…things happen through the actions of others, not the Commission itself per se…”. Their work is highly innovative involving thinking differently about core concepts, like accreditation, that already exist within the healthcare system with the goal of meeting the needs of patients and providers.

They were involved in creating a new model of accreditation for health services. This accreditation process is expected to serve as the “vehicle” for national and state health standards to impact service provisioning. Along with this, they are development a structure whereby there would be mandatory reporting of assessed performance against national health standards across all settings of care.

They are involved in creating clear governance and operating standards for any future clinical registries such that these registries can be used for improving the quality of care. These standards will clarify agreements around data handling, data use, access privileges, and expectations in terms of data provided to advise government on improving care. The informant specifically notes that these data are not meant to look at the individual patient or provider but are meant to substantiate accountability by demonstrating that investments made are actually producing outcomes and showing improvements in care.

*Care improvement relationships*

**Commonwealth Govt; Commonwealth NGO; State Govt**

This agency worked through a network of relationships with state and territory health services, Commonwealth Department of Health and Aging, with the private sector, because “our remit is across the whole the Australian health system, it’s not just public hospitals, but an all-embracing remit.”
Commonwealth: Peak advocacy bodies for professionals (doctors, nurses, allied health) and the industry (e.g., hospitals, insurers, medical colleges). They also worked with government sector organizations responsible for the electronic side of healthcare on developing the health agenda to improve safety and quality along with the peak cancer control agency. Regulatory organizations looked up to this organization for guidance on raising the bar and the upcoming agenda in safety and quality.

State: This organization shared relationships with all state and territory health departments to help their role as a coordinating body for all state government safety and quality agencies.

5.1.1.5 CWG5

This organization was the national organization dealing with health data. It sat within the health department portfolio and received appropriations from the Australian Parliament. It reported directly to the Australian Parliament and had ongoing collaborative relationships with numerous commonwealth and state level government agencies that are primarily built around data collection and management agreements. This organization supplemented (and complemented where appropriate) the data collection and statistical analysis work done by the Australian Bureau of Statistics. Key relationships for this agency included state cancer registries as “data providers,” state health departments that provided data on hospital use. The commonwealth health department was a key stakeholder due to their funding relationship and Medicare Australia is a key provider of service data from the commonwealth. Voluntary health organizations in the NGO sector were users of the reports produced by this organizations.

Role in care improvement

Generator

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Patients; Policymakers; Researchers</td>
<td>Statistical analysis and reporting</td>
</tr>
</tbody>
</table>

This organization’s primary role was to provide statistical analysis support to other commonwealth and state level agencies. This agency was organized around six substantive areas of analysis looking at issues around aging, aged care, child welfare, prisoner health, disability, mental health, palliative care, indigenous health, homelessness and substance abuse. They also conducted epidemiological studies around several chronic conditions (e.g., cancer, diabetes) and on preventative measures that were taken through the Australia population health programs. One of the key cancer related activities included the compilation of the national cancer incidence dataset using data supplied by the state cancer registries. This dataset provided current and historical estimates of several epidemiological variables including survival, mortality and incidence going back to 1982. These data were made available to researchers for
epidemiological research aimed at establishing epidemiological connections between various cancer types and sub populations or to improve care by measuring cancer related health outcomes post treatment in a hospital setting]. AIHW provided routinely generated statistics and reports that provide a glimpse into the state of the health of the Australian people and the public health system.

Unlike many other advisory organizations, this organization’s influence came from their ability to facilitate access and improve understanding of various data that are available within the Australian health system. Their contribution to improving quality was indirect through their management and analysis of health care delivery data. They served a major role in improving the quality of data available through their data management and verification processes. Particularly relevant to the effort of improving quality was the work done by the hospitals classifications and performance group that developed performance indicators, comparing hospitals, and reported them to government agencies. Some of these performance reports eventually got published for consumers/patients.

**Care improvement relationships**

**Commonwealth Government; State Govt; Local Govt; Local NGO**

Commonwealth: This organization helped analyze and monitor the data in the bowel screening registry that was administered by another commonwealth agency.

State: This organization compiled incidence statistics from state and territory cancer registries into a cleaned national dataset that was used to calculate national cancer statistics. This partnership required that this organization had to abide by the rules that governed each state/territory registry. In yet another example of their relationship with state departments, this organization was contracted by the state screening departments to send monthly reports on the jointly funded screening programs to supplement their own data. These data were used to understand how the state’s participation in the screening program would impact the demand for health services (e.g., colonoscopies) and to understand how it is going to affect the state’s ability to deliver.

The Cancer Councils were major users of the data produced by this organization. They monitored new publications and used the data to update their statistics, which also served as a new opportunity to obtain more publicity for their cause. Other peak cancer bodies are also users of this organization’s data reports.

Local: Research groups connected with this agency to get approval to use the cancer registry data linked with other health outcomes data (e.g., cancer and mining data). This organization assisted researchers to evaluate how to improve care by measuring the impact of interventions on various hard outcomes (e.g., survival post hospitalization).
5.1.2 Non-Government

5.1.2.1 CWNG1

In the Australian health system, there are generally two types of bodies involved in the accreditation processes – 1) organizations that set the rules, and 2) organizations that use these rules to accredit facilities. For example, the peak professional body for general practitioners sets the rules for accreditation of general practices which are then enforced by another non-government agency. This served to keep the standard setting bodies at an arm’s length from the accreditation process itself and helps avoid direct conflicts of interest. Public hospitals were required to be accredited and private hospitals opt for accreditation to stay competitive and receive top dollar reimbursement from insurers.

This organization interviewed here was a hospital accreditation body in Australia. Their mission was to enable the pursuit of safety and quality goals of both providers and consumers of healthcare through accreditation. This was privately held organization that answered to its own board of advisors. It had some competitors, like the U.S. based the Joint Commission’s international arm - Joint Commission International, but remains a widely-recognized organization in the area of accreditation in Australia.

Role in care improvement

Regulator

Table 5-6 Overview of role and CI activities - CWNG1

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regulation</td>
<td>Healthcare organizations</td>
<td>Accreditation</td>
</tr>
</tbody>
</table>

Accreditation was a powerful lever to improve care because it was intimately tied up to the public funding mechanisms of the predominantly government funded Australian health system. Public providers were required to be accredited; private providers chose to undergo accreditation because it improved its ability to compete with the public sector and also receive the highest possible rates for its services from payers - public or private.

As an accreditation body, this organization was responsible for ensuring that Australian hospitals upheld a minimum set of prescribed standards. These standards underwent periodic reviews and restructuring to reflect changing priorities and values of the Australian healthcare system. The informant described how the standards had been drastically restructured in the prior years to reflect the organization’s decision to explicitly emphasize the clinical focus of the standards to include the provisioning of clinical services, the clinical leadership, and the governance processes established to support the delivery of clinical care.

Hospital accreditation was a multi-year and multi-step (5 steps of performance measurement – awareness, implementation, evaluation, performance levels 1 & 2) process during which this organization
and the hospital(s) work together closely to identify strengths, remedy weaknesses and develop a plan for continuous quality improvement processes to address gap. The informant made a very nuanced understanding of the process saying, "...accreditation is not an aim in itself...it’s a consequence of what is essentially a quality program." The purpose of accreditation is not about “pushing people [and organizations] across the line” but to serve a greater economic efficiency because poor quality care could be inefficient and cost payers a lot of money. At the time of the interviews, there was no national accreditation approach that was specific to cancer but at least one state cancer control agency, in conjunction with commonwealth cancer control bodies, was in the process of piloting one such a program.

Thus, this organization served to operationalize some of the innovative work done by the peak Australian safety and quality body. Accreditation agencies have tremendous influence in changing the “attitudes and systems” that are established within a healthcare provider organization and have “significant influence” on the ability to achieve national safety and quality priorities.

**Care improvement relationships**

**Commonwealth Govt; Commonwealth NGO; State Govt; Local Govt; Local NGO**

Commonwealth: One of the key relationship was with the peak safety and quality body, that served as a significant source of guidance to this organization, which incorporated some of its safety and quality priority areas into its accreditation standards.

Other major relationships at this level included peak professional (e.g., nurses, doctors, health service executives, medical administrators), industry (private hospitals, public hospitals) and consumer bodies. These relationships, though not fully described in the interview, made sense because all these stakeholders are directly impacted through the accreditation process.

State: All state and territory governments were represented in the board of this organization. This relationship was crucial because the state and territory governments were responsible for running the public hospital system in Australia and needed to be accredited.

Local: Local hospitals (public and private) were key partners in care improvement. Hospitals provided data, underwent assessments, and received feedback from this organization during the accreditation process (for a fee).

**5.1.2.2 CWNG2**

This was a professional support body with oversight and coordination responsibilities of state and (indirectly) local chapters (called divisions) of the body. This organization had a purpose that was separate from the professional standard and ethics setting bodies like the Royal Colleges or the professional unions which worked to protect the terms and conditions, roles and responsibilities of the profession. This organization was built around the idea that clinicians only listened to other clinicians and
specifically to those that worked in the same areas. Thus, this type of a support body was modelled after the concept of “divisions” found within the Australian hospitals and was designed to be a group of professionals who would normally “work together to support general practice and to produce health outcomes” within their local communities.

This organization served as the peak body for local and state level professional organizations for general practitioners; specialists had their local divisions. The lowest independent unit existed at the local level, called a “division of general practice.” At the time of the interviews, there were 119 such geographically based “divisions” within Australia. Each “division” was an incorporated, not-for-profit company owned by the local professional community and received its core funding from the commonwealth health department; this funding was topped off with a “range of contracts,” which varied on state and the setting of the division amongst other things, from both the Commonwealth and the States to deliver particular outcomes in a variety of areas like practice nursing, aged care, immunizations, rural palliative care, hospital avoidance, home health, and mental health. The local divisions were headed by a state level organization (covered in another interview) and were spearheaded by this organization at the national level.

Although, this organization was originally aimed at working with general practitioners, in recent years, with the shift in care provisioning from an individual to a team, the organization had expanded its role to include other kinds of health professionals that generally worked within the general practice setting like practice nurses, practice managers etc. For example, they made efforts to streamline the role of a nurse who works in a general practice setting and delineating roles and responsibilities with a general practice that can be undertaken by a practice nurse (e.g., routine management of chronic care).

Role in care improvement

Champion

Table 5-7 Overview of role and CI activities - CWNG2

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Providers</td>
<td>Policy advice; professional advocacy</td>
</tr>
</tbody>
</table>

The biggest contribution to improving care had been through its role as a high-level thought leader for advocacy purposes. They were connected to their local divisions and had a good understanding of the challenges faced by care providers at the front line of care; similarly, as an organization working at the highest level of the health system, they were aware of key systemic issues that plagued the Australian system. Thus, this organization worked at the highest level of policy making to improve the quality of care provided through guidance of system wide activities that impact the area of general practice in Australia. For example, they provided advice to Commonwealth government on policies involving general
practitioners, providing input on what all needed to happen for the initiative to be feasible, given their understanding of the ground level realities in Australia.

Second, they also advocated for changing payment policies that enable more effective use of payments and was a good reflection of current practice of medicine. For example, historically, practice nurses, or nurses who worked in a general practice setting, were not used to perform clinical duties. Only doctors performed clinical duties and were compensated by insurers; practice nurses were compensated by the practices. Over the years, sometime in the 1990s as the fee-for-service payment became increasingly inviable as a payment mechanism for managing chronic conditions, nurses stepped into clinical roles like monitoring blood glucose levels and educating patients about healthy diet. Most of these changes were taking place at the grassroots (or local) level within the member organizations. This organization helped by lobbying to change the old payment system to include new Medicare “item numbers,” thus opening a new funding stream for practice nurses that performed clinical duties.

Improving cancer care was not a direct area of interest for the general practice community because cancer care was traditionally considered to be in the domain of specialty care, except in matters of screening which often occurred in a general practice setting and required a general practitioner to trigger the hand off into specialty care.

Care improvement relationships

Commonwealth Govt; State Govt

Commonwealth: The commonwealth health department was a key partner for this organization because they were responsible for paying for primary care and general practitioners and this organization was the peak body for supporting general practitioners. So, the commonwealth government provided both core funding to cover operational expenses and topped it off with additional contracts to deliver improved outcomes in various areas like practice nursing, aged care, immunization, rural palliative care, and mental health.

State: The state health departments were another major care improvement partner that funded this organization to improve hospital avoidance rates. The state governments paid for hospital care and they are keen to keep people out of hospitals, if possible. Similar contracts were in place for an array of other conditions like medication use etc.

5.1.2.3 CWNG3

This organization was an example of a professional standard and ethics setting body for general practitioners. There are similar bodies for various other medical professionals (e.g., surgeons, physicians, dentists, psychiatrists, nurses). The mission of the organization was to support general practitioners, practice registrars, and medical students in their efforts to improve the health and wellbeing of all people.
This organization differs from other profession support body (covered earlier) in that it operates primarily in the standard setting space with no direct presence or involvement in implementation of its policies within the health system.

The organization is entirely funded through the subscriptions of its members and does not accept government funding unless contracted to undertake a specific project.

**Role in care improvement**

**Leader; Generator; Regulator**

Table 5-8 Overview of role and CI activities - CWNG3

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Providers</td>
<td>Policy advice</td>
</tr>
<tr>
<td>Resource Development</td>
<td>Providers</td>
<td>Curriculum; Training materials</td>
</tr>
<tr>
<td>Regulation</td>
<td>Providers</td>
<td>Credentialing</td>
</tr>
</tbody>
</table>

This organization improved care through resource development (e.g., curriculum and training materials for GPs), endorsing treatment guidelines, and through advocacy at a national level. It had produced several well authoritative physician support guides in the form of the “Red Book” and the “Green Book” among other resources. The “Red Book” provided guidelines for preventive activities for general practitioners and the “Green Book” complemented the “Red Book” by outlining steps required to fulfill the guidelines. These two books had been electronically incorporated in the health information systems most commonly used by general practitioner to provide immediate information and decision support in their day-to-day clinical practice. The preventive care guidelines incorporated in the Red Book were integrated with the Medicare payment scheme facilitating the use and practice of their care guidelines. In addition to its tie up with Medicare, the organization also wielded significant influence over the practice of general medicine through its linkage with another peak non-government regulatory agency operating in the area of accreditation of general practices. This tie up allowed the operationalization of the standards set by this organization through the accreditation process. Accreditation was necessary to receive the Medicare incentive payments (e.g., PIP, SIP) which, at the time of the interviews, could constitute approximately 20% of a practice’s total revenue.

Yet another important role was its credentialing program which certified new general practitioners; at the time of this interview this credentialing program had been in effect for around 10 years and it provided the only way for new general practice professionals to secure payments through Medicare. Professional credentialing was a direct component of care improvement by ensuring a minimum level of professional quality.
Nascent efforts included the development of an e-health approach and developing a patient driven healthcare agenda. The e-health project consisted of developing a clinical audit tool and the development of a data aggregation repository. The patient focused health agenda was geared at encouraging a shared physician-patient control of healthcare. This project was identified by a consumer representative to empower patients to proactively seek out guideline recommended care.

Care improvement relationships

Commonwealth Govt; Commonwealth NGO; Individual

Commonwealth: This organization had strong ties to the government health agencies. They represented the general practice perspective on policy making decisions. This relationship reflected the fact that general practitioners within the Australian healthcare system were directly reimbursed by the Commonwealth government through Medicare.

They also connected with peak regulatory agencies (for general practices) and peak credentialing agencies that oversaw the registries for general practitioners; both agencies helped uphold the professional standards set by this agency.

This organization also interfaced with peak voluntary health organizations for various health conditions (e.g., stroke, heart diseases, cancer) for advocacy and joint policy development and endorsement efforts.

Individual: Individual general practitioners and medical students formed the core subscription membership base for this agency. Individual general practitioners underwent professional credentialing at the end of their training, which gave them the privilege to practice medicine.

5.1.2.4 CWNG4

The role of the private payer in Australia could be understood using the example of this organization which was a commonwealth level private insurer. In Australia, private insurance was a “luxury product,” available in addition to the universal insurance provided by the government; thus, its role was additive and not substitutive in nature. The private sector funded services that were generally not covered by under the public insurance, Medicare. Claims were generally dominated by obstetrics, procedural medicine, and elective surgeries, with a bulk of the payments made for hospital care and any doctors’ (specialist) charges that are not covered by Medicare. The government provided both carrots and sticks to promote the uptake of private insurance; the carrot came in the form of a subsidy towards the purchase of insurance, the stick come in the form of an additional tax for those who deferred purchasing the subscriptions beyond a certain age.

Role in care improvement

Funder
Private insurers had access to one of the strongest levers to improving care - money. The strong influence of the payer in improving care has also been demonstrated from an international experience in improving care, “…the UK experience shows you that unless the payer wants to do it, it doesn’t get done and I think the American experience is the same....” and if care was not getting improved in certain areas it was because “the payer hasn’t ordered it.” However, payers took a business perspective of quality, which is very different from the clinical perspective, as the informant pointed out, “in the business world what you are selling is a construction of quality that partly overlaps that [quality of clinical care] but has other dimensions to it as well.” This multi-dimensional construction of quality includes not just clinical but organizational aspects of care.

Organizational components were improved by stipulating these terms in the service contracts; however, the language in these contracts tended to be broad and non-specific in nature, generally asking the contracting provider organizations to adhere to certain generic best practices (e.g., reporting clinical data to registries) subject to availability and applicability. The general strategy behind this broad strokes approach to improving care was to avoid the “micromanagement” of quality outcomes and instead focus on incentivizing participation in national level quality incentives. In cases where these conditions were applicable, contracting provides a great way to build in aspects of care improvement activities. However, enforcement of these practices was often done using the honor system with the head of each facility certifying that care improvement tasks was carried out as stipulated in the contract. The monetary lever at the disposal of the private insurance firms was better at addressing organizational components of care improvement than clinical ones, primarily because of a lack of direct relationship between the insurers and individual clinical providers. Of course, this lack of relationship between the clinicians and insurers was driven by two factors: 1) Individual clinicians were paid (monetary lever) by the Commonwealth government through Medicare; and 2) The private insurers liked this arm’s length distance. The first factor was a manifestation of the Australian constitution and the second factor was a manifestation of the Australian culture where insurers hesitated to tangle directly with clinicians and micromanage their production of clinical outcomes, preferring to provide “incentives and engaging with private hospitals to get them to engage with their clinicians” instead. Moreover, there was a feeling that hospitals and doctors are interrelated “organic functional entities” which gave the hospitals a “better idea of how the production of healthcare out to be done than an insurer will have.”

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Financing</td>
<td>Healthcare Organizations; Provider-Healthcare Org</td>
<td>Purchase of service contracts with CI clauses built in</td>
</tr>
<tr>
<td>Resource Allocation</td>
<td>Healthcare Organizations</td>
<td>Funding to do CI projects</td>
</tr>
</tbody>
</table>
The private insurance sector in Australia was indirectly and somewhat distantly active in improving the quality of clinical care; however, they did have a significant impact on organizational factors that improve the delivery of care. It is important to understand that within the Australian context, the private health insurer is only responsible for paying a small fraction of the health care cost incurred by all Australians and hence the private insurer could not serve as a “leader” in the area of care improvement; the informant noted that this leadership would have to come from the biggest payer – the Commonwealth government. However, if the Commonwealth did lead, the private sector would likely follow its lead.

Care improvement relationships

Commonwealth Govt; Local NGO

Commonwealth: The Commonwealth government had close relationships with the private insurance industry in its role as a regulator and provider of the insurance subsidy to individuals. The Commonwealth governed all private insurers by monitoring and controlling the lifetime community risk ratings and the premiums that could be charged.

Local: The strongest care improvement relationships were with the hospitals through their contracts to deliver more efficient production of healthcare (described earlier).

5.1.2.5 CWNG5

This organization was a large network of hospitals. At the time of the interview, they owned and operated several hospitals in Australia and an international presence in Europe and Asia. This organization is a publicly traded organization with roles and relationships in place that are both designed to reflect its business and humanitarian roles. The national corporate office connected with state level managers. Any further communication down the chain occurred between the state manager and the CEO and other high level clinical officers (e.g., Director of Clinical Services or the Chief of Medical Staff) of the local facility.

Each facility was locally run under the aegis of the CEO. The CEO was held accountable for the performance of the facility by the corporate office. The corporate office in turn provided each facility with the maximum reimbursement by negotiating with insurance companies collectively under their corporate banner. As a national level hospital chain, this gave them considerable bargaining power and enabled each individual facility to receive the best possible reimbursement for its services. The corporate relationship with each facility started and ended with the CEO; all relationships at the local level were managed by the CEO.

Role in care improvement

Generator; Regulator; Coordinator
At the corporate level, care improvement activities stemmed from two distinct yet broad based needs: 1) to establish and maintain public trust; and 2) to obtain the highest possible reimbursement for their services.

As a supplier of healthcare services, this organization needed their individual hospitals and clinics to be safe and trusted by regulators, patients, and investors. To that end, their care improvement activities included extensive monitoring of clinical safety events in each of their facilities. Similarly, as a publicly traded company they need to maintain the trust of their “shareholders” who were also “consumers” overlapped in one. Thus, their improvement activities are primarily geared towards the reduction of risks, directly clinical and indirectly financial, through improved safety and quality processes. Generally, high impact or high volume processes were prioritized due to high visibility and high level of financial burden associated with these procedures. The individual facilities maintained quality through provider credentialing, which involved verifications of physician qualification, references, and panel interviews with other hospital physicians to determine suitability to practice at the hospital.

The second motivator for improving quality is to obtain the best possible financial returns. As service providers, the corporate office negotiated collectively on behalf of their facilities, which afforded them significant leverage during their contractual negotiations with private insurers. They monitored various service utilization metrics like length of stay and other clinical metrics, to both maximize bundled payments, increase efficiencies, and also to control the risk of malpractice suits. The informant used an example of how they identified high levels of pain in patients undergoing knee surgery and failure to adequately manage it in their treatment plans was causing patients to fall off the clinical pathways. This finding was communicated to the facilities to get better outcomes for joint replacements.

*Care improvement relationships*

**Commonwealth Govt; State Govt; Local NGO**

Commonwealth: As a player within the highly-regulated healthcare industry this organization was subject to several kinds of safety and quality regulations and as a publicly traded entity it was also subject business/fiscal regulations. Thus, several commonwealth agencies, both government and non-government, were key relationships, including the peak safety and quality agency and hospital accreditation bodies.
State: As a player within the highly-regulated healthcare industry, it was subject to several kinds of safety and quality regulations, and as a publicly traded entity, it was also subject to business/fiscal regulations. This organization had strong relationships with the state government and was represented in their clinical risk and clinical governance-related policy-making committees.

Local: They connected with local hospitals through their state affiliates to pursue care improvement projects.

5.1.2.6 CWNG6

This organization was an example of a non-cancer specific voluntary health organization (VHO) that was dedicated to fighting depression. They were relevant to the cancer care ecosystem because cancer was associated with higher rates of depression. This organization was built with support and initiative from the federal government and one state government; since then, their funding support had increased to include all state and territory governments. Its mission was to raise awareness within the Australian community about issues of depression and anxiety and be the go-to resource on care, treatment, and latest research for a wide range of people including caregivers, consumers, families, and community agencies.

Role in care improvement

Generator; Funder

Table 5-11 Overview of role and CI activities - CWNG6

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
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</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Provider-Patient; Caregivers</td>
<td>Training materials</td>
</tr>
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</table>

The organization worked in five key areas: increasing community awareness, repealing stigmas associated with depression, consumer- and caregiver- engagement, and advocacy aimed at bringing the “lived experience of people” to policy makers, governments, and service providers in a collaborative way and bypasses the “shame and blame” approach that is often associated with mental health. More specifically, their organizational priority is around prevention and early intervention of depression.

Their first domain of work was improving care through clinician engagement - they worked closely with primary care providers who often served as the first point of contact for patients with anxiety and depression and yet some of these practitioners didn’t have the confidence” dealing with these patients. The organization provided training assistance to physicians so that they could present information in user-friendly manner and communicate the impact of psychological issues in patients, along with available treatment options.

This organization not only targeted the problem through physician training, they also adopted a second strategy towards improving care – consumer and community awareness building. It had been successful...
in achieving high levels (~70%) of awareness around anxiety, depression, and sources of information within the community. This enabled a larger proportion of patients to initiate the conversation around depression and anxiety using patient resources (e.g., depression checklists).

Finally, their third approach to improving care was through funding of psychosocial research that could be used to build the evidence base to support the future development of mental services within the Australian community. Traditionally, psychosocial research had been an underfunded area within the Australian health system. Their research funding served the dual purpose of building an evidence base along with increasing their organizational profile within the research community. Further, they had invested additional funds on developing treatment guidelines that incorporated psychosocial elements. For example, their collaboration on treatment guidelines for stroke ensured the inclusion of psychosocial aspects of stroke management including caring for depression in patients with stroke.

**Care improvement relationships**

**Commonwealth Govt; Commonwealth NGO; State Govt; Individual**

Commonwealth: The commonwealth government was a part of the board of directors and aligned priorities of the organization and received the latest knowledge of psychosocial care from the organization.

They also connected with several peak voluntary health organizations for several disease areas. Sometimes this organization would collaborate around the development of treatment guidelines when the VHOs themselves were too busy tackling the clinical aspects of the diseases and were often "reluctant to take on other factors, including psychosocial" that were also associated with the condition.

State: The state government(s) were a part of the board of directors and aligns priorities of the organization and received the latest knowledge of psychosocial care from the organization.

Individual: This organization was a direct source of resources that were explicitly geared for individual patients, providers, and caregivers.

**5.2 State**

**5.2.1 Government**

**5.2.1.1 SG1**

This organization was a branch within a state health department. State health departments had the responsibility for the provisioning, delivery of care and are jointly responsible for the funding of these services along with the Commonwealth government. The goal of the state department was to keep people healthy through the provisioning of high quality care. Their explicit commitment to quality care was
manifested can through their goals of providing appropriate, safe, efficient, equitable, and patient centered care.

Just like its Commonwealth counterpart, this health department was a behemoth organization with numerous branches; each branch was in turn sub divided into divisions. The informant indicated that the organization was so large that the branches tended to “siloded” within the department. This informant had knowledge of the performance improvement and quality of care initiatives within the state run health system.

Role in care improvement

Funder; Leader; Coordinator

Table 5-12 Overview of role and CI activities - SG1

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Hospitals</td>
<td>Reducing quality disparities</td>
</tr>
<tr>
<td>Service Provisioning</td>
<td>Providers</td>
<td>Standardizing medication charts</td>
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</tbody>
</table>

To improve care, the organization focused on supporting area health services that were responsible for the day-to-day administration of the hospitals by identifying “appropriate strategic paths to implementing change.” Moreover, state health departments set the vision for all care improvement within the state.

One example of a care improvement effort involved managing the state level efforts of a nationwide effort of a building a network wide medication chart. This project originated out of another Australian state which had developed this system. Over a span of 3 years, observational audits demonstrated that this effort provided benefits like improved compliance with prescribing practices and improved patient health outcomes, while reducing medication errors. This improvement effort was brought to the attention of the Australian health minister and plans were made to roll out this effort in all Australian states. This organization’s role included getting consensus from key state level officials, developing structural frameworks to support implementation such as setting up requirements for audits, data collection, and reporting, providing educational materials, and coordinating the activities across various sites. Once the effort was implemented, efforts were made to understand the impact of this national mandate on patient safety.

Yet another care improvement project aimed at the early identification of frail elderly within a community setting. Those identified were provided with rapid access to healthcare and diagnostics and home and community care support to help transition to their former state. If this didn’t work, they were transitioned to a residential aged care facility.
As with many government organizations, this department did not undertake any cancer specific care improvement efforts because they conducted under the aegis of the state cancer control agency (included in this case study). There were no formal (or informal) relationships in place with the Cancer Institute but the informant indicated possibilities in the future.

**Care improvement relationships**

**State Govt; Local Govt**

State: They collaborated with other state government agencies on aging, disability and homecare services. They also collaborated with another government agency (included in this case study) that was responsible for overseeing the clinical care improvement within the state due to their overlapping remits around quality.

Local: The area health services (or local health departments) were major partners for this organization because this organization’s role, among other things, was to support the local health department improve the care delivered by facilities under its jurisdiction.

Relationships with other agencies or other branches within the department tended to be driven by personal relationships leading to “informal collaborations,” with very few formal relationships in place. However, there was a gradual shift towards increased collaborations and formal relationship building across traditional lines of authority that were created due to the funding roles played by the State and the Commonwealth because “we are more and more required to play in each other’s space.”

5.2.1.2 SG2

This organization was an example of a state government cancer control agency. Some states had free standing cancer control agencies; several other states had these embedded within their state health departments. The study sample consisted of three informants with representation from the management team and general staff. Their mission was to eradicate the burden of cancer through reduction in the incidence of cancer, improvement in cancer survival; improvements in quality of care, and providing expert advice to policy makers and public. As the state cancer control agency, one of their key roles was to provide a strategic vision for cancer control, or more specifically “develop an infrastructure that would strategically influence cancer services.”

The organization was responsible for the planning and provisioning of these cancer control related activities - prevention, screening, treatment, research, and education. More specifically, the organization was responsible for the operational aspects of cancer related public health programs including screening for colorectal, breast, and cervical cancers in collaboration with commonwealth public health agencies. The organization was not responsible for the delivery of cancer care services; that responsibility lay with the state health department. This agency reported direct to the state minister of health.
Role in care improvement

Funder; Leader; Innovator; Generator

Table 5-13 Overview of role and CI activities - SG2

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
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</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Healthcare Org</td>
<td>Improving infrastructure and access</td>
</tr>
<tr>
<td>Service provisioning</td>
<td>Providers</td>
<td>Funding staff for cancer care</td>
</tr>
<tr>
<td>Resource Development</td>
<td>Providers</td>
<td>Care management pathways</td>
</tr>
</tbody>
</table>

This organization played numerous roles in the improvement of cancer care activities within the state. Their set up was parallel to that of the health department and while this allowed the organization to address complex issues in cancer care, it also added a layer of complexity by bringing in concerns of duplication of services, parallel control (authority) structures, and reductions in productivity as various state agencies with overlapping remits competed to carve out their jurisdictions within the cancer care spectrum.

This organization was heavily invested in the development of infrastructure and evidence generation activities. One of the primary sources of care improvement was through the funding of new or additional workforce. For example, this organization funded several positions like directors, a development managers, cancer information officers and additional funding to conduct multidisciplinary team meetings that facilitated the meeting of clinicians from different areas of cancer control. This allowed them to try out innovative cancer care delivery models. They partnered with the peak commonwealth cancer control organization and established a system of coordinated care for cancer where the “players would know each other” and “there would be some agreed referral patterns” along with information for both patients and providers.

One of their major projects was around building a system of clinical governance and accreditation for hospital based inpatient cancer care services. At the time of the interviews, this accreditation effort was undergoing piloting at several public and private hospitals. This accreditation effort was well known and well recognized amongst clinical and administrative staff in the cancer space at both state and commonwealth levels. Other informants that worked closely in the cancer care space mentioned efforts to “plug in” their set of psychosocial indicators into this accreditation program as an alternative to developing their own accreditation program themselves. This accreditation program does not apply to outpatient practice of oncologists because private practice is outside of state government control and funded by the commonwealth government through Medicare.

They were also interested in identifying best practices and promoting their uptake. To that end, they developed management pathways for psycho-oncology support in cancer patients, which included a
screening tool. These support resources were built using data from two large research projects which captured data from the psycho-oncology parameters and validated questionnaires using a touchscreen which has been embedded in 6 cancer centers throughout the state. However, the noted that that a lot of work still needed to be done in this area.

**Care improvement relationships**

**Commonwealth Govt; State Govt; Local Govt; Individual**

Commonwealth: This organization collaborated with the commonwealth cancer control agency on various care improvement projects that were of national and state interest (e.g., increasing timeliness of access to care). The commonwealth had co-funded care improvement projects with this agency. Other commonwealth government agencies shared national level cancer statistics with these organizations.

State: The state health department was another key relationship. There was some overlap within the care improvement remits and these two organizations worked closely to leverage knowledge, experience and resources. This was achieved by connections at various levels (management and staff) across both departments.

Local: This organization worked closely with the local health departments to pilot some of its care improvement initiatives. Most of their care improvement initiatives occurred within the hospital setting which were managed by the area health services.

This organization contracted with the local professional support divisions to roll out educational training modules to several thousand general practitioners in the area, in anticipation of a public health screening program.

Individual: Main stakeholders are individual practicing clinicians – doctors and nurses, because they were directly impacted by the various care improvement interventions. About 500 clinicians were estimated to be involved in various committees of this organization in advisory capacity.

5.2.1.3 SG3

This was a state government agency for safety and quality of clinical care. Its role was to improve the safety and quality of health through interventions that were aimed at increasing a patient’s recognition of good care and through improvements in workplace safety for healthcare professionals. The informant described their role as to not “preach at people” but to guide them to their strategic safety and quality objective. As the informant explained, “We don’t care which pathway you take, we’ll be beside you all the way, we’ll help you, and we’ll even guard your back to a more appropriate path if you get lost.” The leadership of this organization consisted of political appointees. The study sample consisted of two informants from this organization.
Role in care improvement

Leader; Generator

Table 5-14 Overview of role and CI activities - SG3

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Health system</td>
<td>Incidence reporting/safety</td>
</tr>
<tr>
<td>Resource Development</td>
<td>Providers; Patients; Healthcare Organizations</td>
<td>CI training for individuals and organizations</td>
</tr>
</tbody>
</table>

As a state government organization, the priorities of this organization were heavily driven by the state’s vision for safety and quality. Their choice of activities was described as a “political balancing act” between staying within their remit while addressing major issues and justifying the effective use of state funds. This meant that the organization focused on safety and quality issues in areas of care that were of interest to the state, namely inpatient and community care. Outpatient care was considered as commonwealth concern and was of less interest to state.

Like several government agencies, both informants noted that the organization did not engage in disease specific care improvement work choosing to focus on “…very broad brush generic exercises in safety and quality…” that is not linked with any specialty. The informants explained the reason for this broad strokes approach by stating, “It needs to be generic. It’s absolutely impossible…there will never be the resource to focus our work on individual discipline groups…so what we do is to provide activity that encompasses all discipline groups, whether they’re treating cancer or diabetes…”

In terms of choice of care improvement initiatives, the state was heavily focused on issues of safety. Focusing on patient safety allowed the state to demonstrate its ongoing commitment to upholding the public trust in state run facilities. One major achievement in improving care has been its efforts to convert “a non-reporting system to a reporting system” (adverse events) with help and motivation from the commonwealth safety and quality body. This effort included getting all states and territories to “face the same direction” on the reporting of eight sentinel events. The process of choosing the sentinel events was long and convincing the clinical stakeholders took over two years. This initiative had been a major step towards gaining a better understanding of the overall safety of the health system.

Other key safety initiatives included supporting local health departments around infection control (e.g. safe blood transfusion), preventing falls and injuries, medication safety, preventing patients from undergoing incorrect procedures, and investigating mortality from surgical procedures. All of these were areas that had been associated as drivers of increased inpatient/hospital healthcare utilization and decreased levels of public trust in the system.
In addition, the organization also served as a resource for improving care including training materials for improving clinical practice and tools for monitoring quality for the local health departments and resources to empower patients to make safer choices.

The informants noted that the organization was new (at the time of the interviews) and they were “playing on the edges to some extent,” with limited budget and manpower, and their influence is still fairly limited. As an organization interested in the clinical aspects of care improvement, one of the problems faced by this organization was “getting heard by individual clinical discipline groups.” As the informant described, “doctors tend to listen to doctors, nurses tend to listen to nurses, managers listen to nobody except other managers and their boss.” This problem was exacerbated by the fact that even within the clinical community there is a strong tendency to pay heed only to other clinicians who coexist in the very similar clinical space. As the informant explained, “…even though the principles and in fact, the actions, might be the same across all disciplines, to have it said by somebody who is not in your discipline means that it’s less valuable.” This specificity of messenger made it difficult to gain buy in from the various clinical stakeholders.

**Care improvement relationships**

**Commonwealth Govt; State Govt; Local Govt; Individual**

Commonwealth: The commonwealth safety and quality agency (included in the case study) is a key partner in the care improvement. It had an “overarching role” of coordinating state efforts ‘because all of our states have very separate…political aspirations for their health systems.”

State: The state health department was a key partner because they guided the choice of priorities and resources for care improvement.

Local: Most of their safety related work was to support local health departments.

Individual: The organization provided resources aimed at improving care for both individual practitioners and at empowering patients to make safe and informed choices.

**5.2.1.4 SG4**

This was a clinically focused care improvement body consisting of 20 clinical networks (e.g., diabetes, gyni-oncology). At the time of the interviews, it had a voluntary member base of between 3000-4000 specialist.

As the informant explained, this organization acted as a “source of advice, assistance, information, [and] a conduit to clinicians so that if people want to reach a group of clinicians in a discipline, they come to us.” Specifically, this organization provided key support services like clinical guidance around areas that were not addressed by existing state plans, identified major problem areas, and created proposals to solve each problem.
This organization’s primary mechanism of was indirect – they had to work extensively with a lot of stakeholders to get buy in to make any progress because of the voluntary nature of the effort. This organization operated in an area (clinical care improvement) that shared overlapping remits with several other public (state agencies on safety, quality, and innovation) and private organizations (e.g., professional divisions of practice). At the time of the interviews, this organization reported to both the state health ministry and the department of health.

**Role in care improvement**

**Generator; Implementer**

**Table 5-15 Overview of role and CI activities - SG4**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Providers</td>
<td>Support clinical network goals</td>
</tr>
</tbody>
</table>

This organization improved care in two ways: 1) By fostering clinical innovation and improvement across traditional lines of fragmentation (e.g., geography and sector) and 2) By bringing attention to issues that needed improvement to policymakers and providers. This organization provided a platform for health professionals and administrators from both the public and private sectors to collaborate within and across the entire state health system. At the time of the interview this organization was not officially a statewide service, but were “de facto in many areas;” however, it went on to establish a formalized statewide presence in subsequent years.

The role in fostering clinical innovation involved supporting Individual clinical networks implement their care improvement priorities. The types of implementation help provided by this organization included supporting the development of health information infrastructure like databases, information processing capabilities, and the assignment of a full-time health services manager to handle day to day management and reporting tasks.

An example of their policy related work was a study of the state’s workforce capacity to handle the demands of the commonwealth initiated and state executed bowel cancer screening program. This study defined existing capacity and pointed out workforce capacity related bottlenecks and gaps within the screening pathway. Specifically, they identified the lack of skilled people to handle colonoscopy related sedation as a bottleneck due to a shortage of anesthetists. This identification subsequently resulted in an agreement that allowed the use of non-anesthetists to provide these sedations. Moreover, practice change initiated by this organization, with the help of peak professional standard setting bodies, also had the potential to “flow on nationally” to achieve wider impact.

Overall, this organization’s role in improving care was indirect in that their work “puts on the table” “inefficiencies or deficiencies or inadequacies” but eventually, the onus of working on those suggestions
in a way that would bring about meaningful practical and clinical change rested with individual clinical networks and the state government agencies.

**Care improvement relationships**

**State Govt; Local Govt; Local NGO**

State: This organization provided the state health departments with policy advice on how to improve care delivery by addressing inefficiencies and inadequacies in the current health system. They also interacted with other state agencies when deal with clinical care improvement issues that were of interest (or within the remit) of other state organizations.

Local: This organization served as a guide and partner in care improvement to 20 local clinical care networks from both the public and private sectors. This was their most significant relationship.

**5.2.2 Non-Government**

5.2.2.1 SNG1

This was a healthcare research organization funded by the state health department; its goal was to increase the use of evidence and policy by serving as a "bridge" between the healthcare research community and policy makers.

When state government policy makers needed evidence to guide their policy making efforts, they worked with this organization. As a result, the bulk of this organization's research activities were developed as a reaction to the needs of the policy makers instead of through apriori internal prioritizing. This organization consisted of researchers from various research centers and universities with public health programs.

**Role in care improvement**

**Generator**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Healthcare Organizations</td>
<td>Scientific research to support interventions/policy</td>
</tr>
</tbody>
</table>

This organization's primary role was improving care through evidence building in various areas which identified policy need. As researchers, they did not have the required authority or scope to improve clinical care; however, they did initiate new research that can potentially help answer various unanswered questions about how the healthcare system functions to provide the care needed. Their primary work has been in characterizing cancer care and the workings of the health service system. For example, one of
their projects involved studying the flow of people through an emergency department; this study was done in response to interventions by the local health department to reduce the waiting times in emergency departments. This organization’s role was to examine routinely collected data and decide: 1) if the interventions had an effect on emergency department wait times; and 2) if successful, to initiate additional research into the changes that were part of the local health department’s intervention.

**Care improvement relationships**

**Commonwealth NGO; State Govt; Local Govt; Local NGO**

Commonwealth: The organization worked with several non-government voluntary health organizations in cancer, cardiovascular diseases, and mental health.

State: The state health department was the core care improvement partner for this organization and helped generate the agenda for research activities undertaken by this organization.

Local: This organization pair up with local research teams and local hospitals to conduct their research. Thus, local organizations, both public and private, were key partners in care improvement.

5.2.2.2 SNG2

This was a state level chapter of a cancer focused voluntary health organization. A peak Commonwealth level organization was responsible for managing and coordinating the activities of this organization and that of its other state level counterparts state. Their activities can be broadly classified into five major areas: Prevention, Support, Research, Advocacy, and Fundraising.

Prevention related activities included early detection programs and health promotion through education, evidence gathering, and awareness. Support activities were geared towards patients, caregivers and professionals. These included a network of local patient/caregiver support groups, professional education and the development of treatment guidelines. Research related activities included funding of innovative clinical, epidemiological, and behavioral research. Their advocacy activities included serving as the independent (non-government) voice of cancer control in Australia. Finally, fundraising allowed it to remain largely independent of government funding, except through projects conducted under government contracts (e.g., managing the state cancer registry or a public awareness campaign).

**Role in care improvement**

Champion; Generator; Funder

**Table 5-17 Overview of role and CI activities - SNG2**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Patients; Health system</td>
<td>Policy/Advocacy</td>
</tr>
<tr>
<td>Health System Role</td>
<td>CI Target</td>
<td>CI Details</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----------------</td>
<td>----------------------------------------------------------------</td>
</tr>
<tr>
<td>Resource Development</td>
<td>Patients; Providers</td>
<td>Funds scientific research to support interventions/policy</td>
</tr>
<tr>
<td>Health Information</td>
<td>Patients</td>
<td>Cancer registry data collection</td>
</tr>
</tbody>
</table>

This organization’s two-tiered structure, a national peak body with state level chapters, allowed this organization to advocate for important issues, both at the Commonwealth and at the State levels. This organization was in a unique position to be heard mainly because of two reasons: 1) they had an established track record as a legitimate source of cancer related information, and 2) as a non-government agency are free of obligations to be politically correct. Thus, this organization served as both a sounding board and as a purveyor of alternate viewpoints for the Australian government’s cancer control policy making.

This organization’s main mechanism of influence was through advocacy and through data collection. Their role in improving care was largely limited by their lack of direct authority over resources. However, they participated in advisory boards and took an active role in kick starting care improvement processes by collecting and presenting epidemiological and healthcare utilization data to clinicians associated with regional oncology care improvement groups. In its role as a data collection agency, one of the major improvement activities undertaken was non-clinical in nature; it involved efforts to improve the quality, completeness, and breadth of cancer data collected. This included efforts to understand what additional data would need to be collected to be useful from both clinical and service management perspectives and also conducting pilot projects exploring additional sources of cancer data like reporting of the patient experience and patient satisfaction with care.

*Care improvement relationships*

**State Govt; State NGO**

State: The state health department is a major partner in care improvement. This organization runs several cancer-related public awareness programs under contract from the state.

They also participated in the clinical care improvement efforts led by a state oncology care improvement group.

5.2.2.3 SNG3

This organization was a state consumer advocacy. They operated at both the national and state levels (e.g. this chapter). All state chapters of this organization across Australia operated on the same set of core objectives and worked together to address important issues. This organization was active in the following cancer areas: diagnosis, information, treatment, research, support, care, survivorship and
policy. Their primary role was to ensure patient perspectives were considered while making important decisions that impacted various aspects of cancer care (e.g., direct of cancer research).

To achieve their mission, they brought together consumers with decision maker at all levels of the government; they provided training programs to prepare volunteers for their roles as representatives in various committees (e.g., tumor based policy bodies). They served to put a human “face” to the disease by providing access to real life patients for public service announcements and media campaigns. In addition, this organization also provided services that matched various trained consumer representatives with openings on decision making boards looking for consumer representation.

**Role in care improvement**

**Champion; Generator; Coordinator**

**Table 5-18 Overview of role and CI activities - SNG3**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Patients; Health system</td>
<td>Policy/Advocacy</td>
</tr>
<tr>
<td>Resource Development</td>
<td>Patients</td>
<td>Treatment protocols; training patients to be effective consumer representatives</td>
</tr>
</tbody>
</table>

This organization had been involved in systemic care improvement efforts that were not always clinical in nature but, nevertheless, served the interests of cancer patients. For example, this organization worked with legal bodies on issues of tax law reform for the terminally ill. This bill (if passed) would help patients who were terminally ill with cancer to get access to their tax deferred saving before the designated age of 60 years.

This organization influenced care delivery indirectly by raising consumer awareness around expectations while undergoing cancer care, changing entrenched concepts, and by serving in advisory positions to local cancer specific government bodies. They were also involved in the development of consumer versions of various evidence based patient management frameworks in conjunction with government organizations. Among other things, these treatment protocols provided consumers (patients, families, and caregivers) information around available treatment options, familiarized them with various possible health outcomes (e.g., full or partial recovery), and treatment seeking decision guides.

**Care improvement relationships**

**Commonwealth Govt; Commonwealth NGO; State Govt; Local Govt; Individual**

Commonwealth – Consumer representatives from this organization participated in work groups and task forces conducted by both government (e.g., peak cancer control agency, national research groups) and
non-government organizations (e.g., professional standard organization in disciplines affiliated with cancer care).

State – Consumer representatives also participated in ministerial task forces of the state government.

Local - Consumer representatives served in advisory capacities in local government organizations that were aimed at improving issues around access, quality, and safety in the care delivered by public hospitals.

Individual – This organization trained and empowered consumers to better represent issues faced by patients, families, and caregivers.

5.2.2.4 SNG4

This organization was the state level peak body of a professional support organization. It was responsible for over thirty local divisions of practice within the state. This organization in turn was represented at the commonwealth level by a peak body (also included in this study). This organization’s core mission was to advance state health reform and strengthen the primary care infrastructure through leadership, representation, and advocacy of the field and its practitioners.

In its leadership role, this organization proactively sought out ways to increase the scope of their clinical practice, explore new systems of care delivery and payment that would enable effective service delivery in a changing healthcare arena.

This organization’s advocacy role included working to increase the visibility of the clinical discipline and practitioners and ensuring the participation of its member practitioners in various policy making activities within the state (most public health related issues). As a part of their advocacy work, the organization worked closely with the state and local health departments to support primary care, general practice and increase collaboration and integration between these related service areas.

Finally, program support is one of the most prominent role played by this organization; this role also came with a variety of Commonwealth and State government related funding streams attached to it. At the time of the interview, this organization held contracts with the Commonwealth that were aimed at preventing falls in elderly patients and developing educational modules for physicians and to help physicians manage patients with complex comorbidities. Similarly, they were also contracted by the State to raise awareness of physicians about screening programs through their partnerships with the local divisions. The organization was funded through a combination of member (local divisions) subscriptions and the contracts with the Commonwealth and the State governments.

Thus, the role of this organization was heavily focused on leveraging their statewide presence to support local divisions to implement various programs aimed at improving both the practice and practitioners.
Role in care improvement

Generator; Coordinator

Table 5-19 Overview of role and CI activities - SNG4

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Development</td>
<td>Providers</td>
<td>Program awareness and training</td>
</tr>
</tbody>
</table>

As a state level body their one of their primary roles was to work with the state run healthcare delivery infrastructure to integrate care between the state government run acute care and the privately run primary care sector. This role was especially important because the State ran the acute care hospitals and the community care facilities; neither of these facilities were traditionally served by general practitioners. General practitioners worked predominantly in a private practice setting which is funded by the commonwealth. Thus, continuity of care became a major issue as a patient transitioned between the privately run general practice and the government run hospitals to receive care. This break in continuity was especially relevant for cancer care where the screening and detection might occur through general practice but the treatment was overseen by a specialist, all this happened even as the GP remained responsible for managing the care of other existing or new health conditions. There was often little or no communication between the inpatient based specialist care and the outpatient based GP care. Many patients fell through these cracks in the system resulting in poorer health outcomes and inefficient use of available resources.

Yet another major role was to aid the State government roll out national level programs in ways that are tailored to meet the needs of their situation. In this role, this organization acted as a source of information and was responsible for educating leaders from individual divisions of general practice on latest practices such that they can spread the information to their local practitioners. In yet another example, this organization partnered with the state cancer control agency to develop educational materials that were focused on teaching aspects of the P-D-S-A quality improvement cycle for the bowel screening program. As we have seen with the national level peak body also covered in this study, this organization’s role in improving cancer care was limited to screening and detection related activities which often occurred under the aegis of public health.

At the time of the interviews, the organization was actively considering greater involvement in quality improvement at the practice level through direct involvement with a quality improvement collaborative to promote data driven quality improvement efforts amongst its member organizations. This organization played a key supportive role in promoting improvement of primary care delivery through increased awareness, education, and promotion of data driven efforts to improve care at the local and state levels and acted as a high-level resource for the local leaders who were the true leading forces behind care improvement in Australia.
Care improvement relationships

Commonwealth Govt; Commonwealth NGO; State Govt; Local Govt; Local NGO

Commonwealth: This organization held contracts to deliver around a variety of health outcomes with the commonwealth department of health.

They also connect with peak disease specific (e.g., heart disease, asthma, etc.) voluntary health organizations in a less formal fashion.

State: This organization held contracts to deliver around a variety of health outcomes with the state department of health. They also work with the state cancer control agency on a care improvement project and the state agency on quality and safety.

Local: This organization stepped in as consultants to the local departments of health to help them identify problem areas in their cancer care delivery pathway. The informant also mentioned relationships with some local university departments (primary healthcare research and evaluation department).

5.3 Local

5.3.1 Government

5.3.1.1 LG1

This organization was a local health department. While the state government co-funded service provisioning, the service delivery was decentralized by geographic catchment areas, called local health districts (or area health services). The number of LHDs had changed over time due to redistricting resulting in consolidation or separation, in order to adapt to population needs and other external stimuli.

Each LHD operated several facilities, a combination of hospital and community care facilities, to provide intensive care, general care, specialty care, mental health, and emergency services. Moreover, LHDs also acted as the local public health, disaster preparedness, and allied health agency. LHDs received a negotiated annual service funding contract from the state government to provide healthcare services within their geographic boundaries and served key functions including clinical and corporate governance, management (performance/program/financial), workforce planning, strategic planning, and providing information technology services to facilities under their jurisdiction.

Role in care improvement

Coordinator
LHD were hotbeds of improvement activity due to its extensive connections to provider organizations. They undertook and facilitated improvement activities by working with various organizations, government and non-government, to improve care. Sometimes, LHDs had dedicated care improvement units as a part of its organization. Care improvement activities undertaken by the LHDs were generally aimed at improving organizational performance or improving patient safety. However, interventions aimed at improving clinical care were not directly undertaken by LHDs, but facilitated through partnerships with other clinically focused agencies (e.g., local clinical care networks). The focus of care improvement was driven, in part, by the strategic vision at the state level. Several informants mentioned working with LHDs on a variety of care improvement projects including consulting to find bottlenecks in care and helping staff address those areas.

Care improvement relationships

State Govt; State NGO; Local Govt

State: State health departments collaborated to provide direct care improvement project support to various facilities.

State level professional support organizations collaborated to improve care within specialized disciplines of care.

Local: The LHDs worked directly with the hospitals and other community care facilities to provide feedback and resources to undertake care improvement activities.

5.3.1.2 LG2

This organization was a research unit affiliated with a large public university in Australia. This university housed several other research facilities and teams. This organization specialized in studies on living with disease, more specifically on issues around, risk management, diagnosis treatment, and supportive care. This organization was governed by the policies of both the university and the disciplinary school within which it was housed. The primary role of a researcher within this organization was to conduct research that would influence policy and ensure the uptake of the evidence into clinical practice.

Role in care improvement

Generator; Implementer
Table 5-21 Overview of role and CI activities - LG2

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Generation</td>
<td>Provider-Patient</td>
<td>Provider-patient communication</td>
</tr>
</tbody>
</table>

This organization conducted research related activities that contributed to improving psychosocial care for cancer, conducting large scale clinical trials, and improving patient-provider communication. Examples of their care improvement related work included understanding barriers and facilitators to the routine screening of psychosocial distress and understanding factors impacting the quality of patient-provider interactions. However, at the time of the interview the research agenda was gradually headed towards a more explicit quality improvement framework driven approach. In addition to the research, the researchers served as experts and advisors to guide the development of quality improvement related government policy making.

*Care improvement relationships*

**Commonwealth Govt; Commonwealth NGO; State Govt; Individual**

Commonwealth: This organization served in an advisory capacity on several government (cancer control organizations) and non-government bodies (professional standard setting bodies; cancer-specific groups and consumer bodies). The commonwealth is also the largest funder of their research.

State: This organization collaborated with the state cancer control agency around the development of performance indicators for measure psychosocial care.

Individuals: The researchers worked closely with individual practitioners to improve issues like patient-provider communication skills.

### 5.3.2 Non-Government

#### 5.3.2.1 LNG1

This organization was a stand-alone, not-for-profit, private hospital in a large Australian city. The hospital was governed by an executive body that reports to its board of directors; the hospital had no shareholders. This organization catered to a population that was relatively affluent, privately insured, and interested in getting elective care.

*Role in care improvement*

Regulator; Implementer; Doer
This organization played a direct and meaningful role in improving the quality of clinical service delivery. It started with their set up for peer accreditation which included a thorough review of clinicians requesting hospital practice privileges. This credentialing was especially important because it helped hospitals uphold a minimum standard of quality of their clinicians.

A large part of their care improvement occurred through their extensive case management system. This system tracked and supported patients in their journey through the care delivery process. The informant noted that while these systems can't always change the final outcomes but are geared to “actually change the course to its finality” by being more patient centered.

The informants stated that the historic push for quality improvement at this organization originated from two different directions: 1) through the adoption multidisciplinary care teams (MDT) for cancer care; and 2) through payer driven initiatives. Initially, the introduction of MDTs in cancer care made this organization an attractive place to practice medicine for clinicians. Eventually, this organization became “known for our [its] quality” in cancer care. This generated a feedback loop that prompted a quality improvement mindset, “where you start to look at what you are doing, you start to look at the gaps in service, and you look at what it is you need to be able to do for your patients.” Their efforts to improve on quality was established through repeated efforts made by the staff to use established, standardized, evidence based guidelines to drive benchmark their care processes and improve care delivery. For example, this organization introduction of the U.S.-based Millerman Care Guidelines, into their clinical pathways to manage length of stay, and guide their expectations from a patient recovering from surgery on a daily basis. The use of these guidelines helped focus the attention around the milestones that the patient needs to achieve before discharge was recommended. Similarly, they brought in the use of the National Comprehensive Care Network’s distress thermometer and introduced it in their breast cancer clinical pathway to enable the measurement of psychosocial distress. They have similarly used state and national cancer care guidelines to benchmark their treatment and care management efforts. Additionally, they participated in the state cancer control agency’s pilot accreditation program to identify areas within their cancer services that needed additional work and the informants stated their plans to address those issues unless they were faced with severe resource constraints.

The second push came from private payers. The informants used the example of case management, which was initially set up not for care improvement purposes but to keep track of the financial aspects of
health contracts. Thus, the earliest focus of case management was driven largely by cost considerations. However, in approximately 6 years since the start of this case management program, the focus had gradually shifted to “become a lot more quality than cost now.” As the focus gradually shifted from cost to quality, barriers between clinical and case management staff broke down and case managers were now an integral and accepted part of the cancer care teams in this organization.

Finally, this organization was amongst a small fraction of private hospitals that actively competed for state funded public grants for innovative pilot programs which allowed them to explore and push their boundaries without using existing hospital resources.

**Care improvement relationships**

**Commonwealth NGO; State Govt; Individual**

Commonwealth: This organization was accredited periodically by regulatory bodies. Private payers were also important connections.

State: This organization worked closely with the state cancer control agency’s care improvement efforts.

Individual: As a service provider organization, two of its major relationships were with patients and providers. This organization reported strong relationships with its patients and maintained connection through routine patient centric events that allowed patients to provide feedback and show mutual appreciation.

5.4 Individual

5.4.1 Government

5.4.1.1 ICAG1

This informant was a clinician with extensive experience in running facilities and performed administrative roles, in addition to clinical responsibilities.

**Role in care improvement**

Champion; Coordinator; Doer

**Table 5-23 Overview of role and CI activities - ICAG1**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Delivery</td>
<td>Provider-Patient; Provider</td>
<td>Multidisciplinary care teams</td>
</tr>
<tr>
<td>Resource generation</td>
<td>Provider</td>
<td>Clinical cancer registry data collection</td>
</tr>
</tbody>
</table>
As an administrator and clinician, this informant had an opportunity to improve the way cancer care was delivered in Australia. These changes included establishing partnerships within various oncology related sub disciplines (e.g., medical oncology, radiation oncology), employing cancer care nurses and integrating imaging services. Together, these changes enabled patients to receive all their care at a “one stop service” and made it possible to receive their diagnoses by the end of day. Some of these changes were first adopted locally and then adopted and implemented across other states with support from state level cancer control bodies.

In addition to clinical administration, this informant was also engaged in the development of guidelines (sponsoring agency is unclear) that identified the need for more real time guidelines to physicians because evidence changes with time. These guidelines emphasized the need to use monetary drivers to ensure that patients are guided to areas where they stand the highest chances of receiving the best evidence-based care. Similarly, another use of monetary incentives was to encourage physicians the make the right decisions and not be tempted by their ability to generate further revenue by prescribing additional services.

This administrator was a champion of the state cancer control organization’s vision of multidisciplinary cancer care and had facilitated the use of MDTs in all tumor groups and hired care coordinators to guide the patients in their journey through the healthcare system and to act as an interface with the multidisciplinary care teams. These changes met with resistance from senior clinicians who were reluctant to move to the newer team based approach to communicating and care provisioning. Part of getting this change to work was by highlighting the fact that multidisciplinary teams were not just about individual clinicians providing care but also served as learning environments for junior clinicians and to keep everyone in the loop. This care improvements went through in the face of some lingering resistance.

In another state government funded effort, this organization participated in piloting a cancer registry data collection program that aimed to collect more comprehensive set data on several tumors including crucial piece of data (e.g., staging at diagnosis) that had not been collected before. In yet another role as an administrator, this informant reported being a part of an initiative to build a new state of the art telehealth facility that would allow the healthcare teams in the hospital to communicate with rural areas, provide additional educational opportunities for patients and clinicians.

**Care improvement relationships**

**State Govt; Local Govt; Individual**

State: The state cancer control agency was a frequent partner in cancer care improvement efforts.

Local: The local health departments were also another key partner in care improvement.

Individual: The clinicians and care coordinators on multidisciplinary teams were key participants in the clinical care improvement efforts.
5.4.1.2 ICRG1

This informant was a gastroenterologist with a background in clinical research. This informant has been referred as a “leader” with extensive knowledge of area of care improvement by other informants.

**Role in care improvement**

Leader; Generator

**Table 5-24 Overview of role and CI activities - ICRG1**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource generation</td>
<td>Provider</td>
<td>Treatment Guidelines</td>
</tr>
</tbody>
</table>

As a clinician, this informant had firsthand experience of areas within the system where there were gaps in services and how patients fell through cracks in the system. As a researcher, this informant brought a deeper understanding of different political dynamics which fragmented the system and complicated care provisioning and set systems up for failure.

The informant was a part of several commonwealth government funded research teams and was involved in the development of guidelines for screening and detection for gastrointestinal cancers and was part of several committees dedicated to quality improvement. In addition to the clinical insights and real life experiences, perhaps, the biggest contribution by this informant was the leadership role played by this informant. This informant was described by another state government informant as, “the very top leaders in terms of academic and research ends.” This leadership and depth of knowledge facilitated a better understanding of the health system, its successes and failures, setting the stage for incremental work.

**Care improvement relationships**

**State Govt; State NGO; Local Govt**

State: This informant participated in several quality focused research groups conducted by state level organizations.

Local: As a specialty physician, this informant was strongly connected with a public hospital and was part of several multidisciplinary care teams. As a researcher, the ties extended to other education and research organizations (e.g., local universities).

5.4.1.3 ICSG1

This informant was the chief medical oncologist at a public hospital, located in a large city. In addition to clinical service, the informant managed an outreach clinic located in another part of the state, managed the active clinical trials research unit, and trained medical professionals in the medical college that is
affiliated with the hospital. The informant was also involved with state and national level cancer groups and professional bodies.

**Role in care improvement**

**Leader; Generator**

### Table 5-25 Overview of role and CI activities - ICSG1

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource Generation</td>
<td>Provider</td>
<td>Teaching/Training; Treatment Guidelines</td>
</tr>
</tbody>
</table>

The informant's role in care improvement was through teaching, training, research. As part of the state health department's efforts, this clinician was involved in local cancer care clinical networks (discussed in another case), formulating care guidelines, developing protocols for chemotherapy delivery, outcomes review, understand patterns of care outcomes and supported the state cancer control organization’s efforts to build an accreditation system for cancer care facilities.

As the chief of the active clinical trials research unit, the informant described how the clinical trials indirectly impacted the hospital’s care by providing an example of the value of protocol based management of care and the recognition and follow up of adverse events. These trials had inspired the hospital staff to incorporate some of these steps in their day-to-day clinical practice, replacing some of the vacuum around the lack of internal structures (e.g., no protocol for data audits) for clinical processes and the clinical inertia within the department. With the incorporation of some of the protocols around care delivery, the hospital MDTs met every fortnight to discuss all adverse events for feedback and peer review. In the absence of any internal forcing functions for improving care, most of the care improvement occurs either informally or due to external initiatives. An example of such an externally driven initiative would be the state cancer control organization’s mandate to have MDTs be a part of every cancer care team; this mandate pushed the hospital’s clinicians to form MDTs, however, there were still some clinicians who chose to not participate in the MDTs.

Part of the reason for the lack of internal interest in care improvement was driven by the heavy workload faced by the clinical staff. The informant noted that restructuring of area health service boundaries had resulted in larger share of burden falling on their department without a commensurate increase in additional resources. This lack of resources has resulted in understaffing which had left them with very little time to take the additional paperwork intense steps required to participate in other kinds of care improvement activities, including competing for external grants offered through competitive funding mechanism. The departments have identified staffing shortages in almost all clinical areas including doctors, nurses, allied health, social works, psychologists, bereavement counselors and the informant did
not seem to feel like the situation was going to improve stating, “I think we are not going to win – I know for a fact we’re not unique.” The informant also explained that as a result of the resource crunch, the states have increasingly shifted the costs, mostly to the Commonwealth government, or to the private sector. When the costs were shifted to the private sector, it was often able to bear the cost, but lacked both the infrastructure and the human capital that was needed to deliver in the face of increasing workload. Costs were shifted to the commonwealth through inclusion for payment under its medical and pharmaceutical benefits. However, this cost shifting came at the price of physician control over care delivery. The informant noted that once certain elements of care got subsumed under the Commonwealth’s schedule of benefits, it took away the local variations in care that were permissible when the states paid for it, thus becoming the de facto national standard of care because patients are more likely to accept treatments and drugs that are both covered under Medicare. Thus, cost shifting provided continued coverage of services at the expense of uncertain quality of infrastructure and reductions in a physician’s flexibility to choose the best treatments for their patients.

The clinician noted that trying to improve care in a resource strapped environment took its toll on clinicians, stating, “There’s a conscious attempt to do that [improve care] but physically it’s hard. Many times, through the year, I just feel like a ball in the pinball machine, and waiting to see what I going to bounce to next.”

**Care improvement relationships**

**State Govt**

State: The state cancer control organization was a major partner in care improvement.

**5.4.2 Non-Government**

**5.4.2.1 ICNG1**

This informant was general practitioner and part owner of a community practice in an Australian city. As an independent practitioner, the informant reported two major stakeholders – the patient and the other practitioners who work in the same practice.

**Role in care improvement**

**Doer**

**Table 5-26 Overview of role and CI activities - ICNG1**

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Delivery</td>
<td>Provider (self)</td>
<td>Clinical care audits</td>
</tr>
</tbody>
</table>

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Four findings about efforts to improve care stand out from this interview: 1) efforts were sporadic; 2) efforts were driven by external forces; 3) efforts were isolated; and 4) efforts remained undocumented. Primary care practices in Australia could choose to remain unaccredited, albeit at significant cost to the bottom-line. In cases, where the practice was unaccredited, clinical registration (or the state licensing) of individual professionals was the primary driver of clinical care improvement efforts; practice level accreditation was more associated with ensuring a basic level of quality of the infrastructure and the operational processes. The informant indicated that continuing medical education requirements served as a motivator to seek training on improving cancer related communication skills. The informant also conducted “self-audits,” but these audits were one off events that coincided with the time for clinical registration renewal (i.e., every 3 years). Efforts are not only sporadic but also done informally and often in a methodological vacuum. As the informant described one such quality improvement effort undertaken to identify gender disparities in the treatment of osteoporosis, “…so then I did actually go through – but I didn’t formulate it out – I did it as a conscious effort for me to improve what I did with them… but I didn’t actually plan it out as a structure and graph it and do that. I just went in and looked at the figures and…worked out in my own head a schematic of basically improving it in my day-to-day consultation skills. So, it was self-improvement, but not qualified or quantified.”

Moreover, there is a sense of being controlled by government entities. For example, Practice Incentive Payments (PIP) offered by the public insurer for meeting certain standards of care (e.g., 90% of women getting pap smears every 2 years) were considered manipulative because of payment caps and payment structures. As the informant explained, “It is called the freedom to manipulate the patients in your system to make it work for the government treasury.”

Care improvement relationships

Local NGO

Local – The informant connected with a local research group in their efforts to understand physician behavior.

5.4.2.2 ICSNG1

This informant was a medical oncologist at a private hospital in a large city. In this role, the informant was at the frontline of care provisioning with direct patient interactions and a member of a multidisciplinary care team.

Role in care improvement

Doer
Table 5-27 Overview of role and CI activities - ICSNG1

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Details</th>
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</thead>
<tbody>
<tr>
<td>Service Delivery</td>
<td>Provider (self); Provider-Patient</td>
<td>Participating in multidisciplinary care teams</td>
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</tbody>
</table>

This informant helped improve care by participating in a MDT. Each MDT was overseen by the appropriate division within the “structure of medicine,” and provided individual clinicians with a glimpse of the larger picture of cancer care. The presence of a local cancer service network provided opportunities for inter-hospital interactions. The informant described the state cancer control organizations had a “major impact” in colorectal cancer care by bringing together clinicians from surgical, medical, and radiation disciplines and a host of allied health professionals like nurses and epidemiologists.

This informant acknowledged being bombarded with by a series of “unrealistic” and “unattainable” care improvement appeals and directives from various government and professional bodies and “people who sit in desks and never see a patient.” On the other hand, the informant also received regular news of impending budget cuts and staffing shortages. In an environment like this the informant says, “quality improvement is an impossible, unattainable goal in the current circumstance” due to “poor infrastructure,” “no staff,” and “barely enough time.” All the guidelines and directives were useless without the proper infrastructure required to support physicians undertake these care improvement project. For example, during accreditations departments are given feedback about below average performance around certain metrics, with the expectation that it will be fixed, but without the promise of any additional resources and this is the “greatest threat” to care improvement because, “…I won’t be given one additional staff or opportunity to do that. It’s just fix it…the greatest threat is more fix-its without any change in capacity.”

Furthermore, care improvement activities were undertaken by providers by their own initiative and was done over and above their work responsibilities and thus care improvement was dependent on the goodwill of a few towards the practice of medicine. As an example, the informant noted that due to staffing shortages, the informant spent the vast majority of time seeing patients and completing required paperwork, that left very little time to undertake any care improvement projects. The frustration associated with the clearly conflicting position of care improvement while cutting resources were best summarized by informant in these lines, “…so instead (or real infrastructure support) meaningless directives will come, meaningless forms will be filled out…we will all appear to be chanting the right mantra but nothing really will be done.”

The informant pointed out that one of the major issues in care improvement was maintaining sustainability of efforts over time. Efforts that were started under using external funding and guidance often “don’t get taken up” by the pilot sites, mostly due to lack of resources, once the external funding ran out, thus disrupting continuity of the effort, nullifying any gains, and future improvement possibilities.
Care improvement relationships

State Govt; Local NGO

State: The state cancer control organization is a key partner in care improvement along with the state clinical care network.

Local: The local care service network is another major partner in improving care
5.5 Summary

This section will provide a summary of all the information presented in sections 5.1-5.4 which are summarized in three tables - Table 5-28, Table 5-29, and Table 5-30. Key findings from across levels and across sectors comparisons from each table are discussed in the text preceding each table. Graphical depictions of the data presented in these tables can be found in Appendix F Supporting graphs and tables for Chapter 5

5.5.1 Characteristics of care improvement efforts within a health system

Health system role – Regulatory activities were mostly confined to commonwealth and local levels, both in the non-government sectors. Commonwealth level regulated providers, healthcare organizations, and payers. The local levels regulated only the providers. Stewardship was shared across both the public (government) and private (non-government) sectors but occurs at the higher levels of the health care system. The government is more likely to be a steward of systemic issues aimed at reducing disparities, whereas, the non-government sector is more likely to be stewards for professions, people, and health conditions. Resource development occurs at all levels and sectors of the health system. This is probably because there are various types of players (patients, providers, healthcare organizations) and also resources can be therapeutic area specific (diseases or cross cutting). Moreover, there is a certain level of duplication of efforts in this area due to multiple players operating in silos within the same area. Service delivery occurs in mostly the lower levels (local and individual) of the health system and is largely occurs in the private sector. Even in public facilities, individual service providers are often contracted private practitioners. This is important because this explains why governments may have very little direct control or leverage over healthcare providers. Service financing/service payments can occur at commonwealth, state, or local levels and can be in private or public sectors. Service provisioning occurs at the higher (commonwealth and state levels) levels of the health system, usually occurred in the government sector.

CI target(s) – All three levels (commonwealth, state, local) governments were interested in improving care by focusing on improving healthcare organizations. Commonwealth and state governments were interested in improving care by focusing on physicians, patients, and the health system. Non-governmental organizations at all levels focused were interested in improving care by focusing on physicians. State level organizations from both sectors focused on physicians, patients, healthcare organizations, and the health system. Local organizations from both sectors were interested in improving the physician-patient interfaces.

CI classification – Governmental organizations at different levels of the system have different care improvement interests, despite some overlaps. Commonwealth and state government organizations tend to have more diverse interests in care improvement compared to local governments.
The care improvement interests vary considerably between the government and non-government sectors. This highlights the need to be mindful of the different interests of various stakeholders within a health system.

Funding and implementation sectors of CI -- Commonwealth, state, and local governments at all levels primarily fund care improvement initiatives, which are implemented in government and non-government sectors. Commonwealth and state level NGOs getting funding from both government and private funds; however, most their care initiatives are implemented in the NGO sector. These findings highlight the large role that is played by the NGO sector in improving care, both individually as a contractor to government organizations.

Motivator of CI – This is very diverse range of motivators for CI within and across sectors. Payers have fewer direct motivators for improving care compared to organizations that are directly involved in the provisioning or delivery of care. There also appears to be an inverse relationship between the sectors. If the government sector has few CI motives, then the corresponding NGO sector seems to be very diverse (as seen with the commonwealth here) and vice versa (as seen at the state levels). Individuals generally tend to be more clinically focused and wish to provide the best possible care as their primary motivator.

Table 5.28 Summary of CI activities

<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Activity Type</th>
<th>CI Classification</th>
<th>Funding Sector of CI</th>
<th>Implementation Sector of CI</th>
<th>Motivator for CI</th>
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</thead>
<tbody>
<tr>
<td><strong>Commonwealth - Government</strong></td>
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<tr>
<td>5.1.1.1 Service Payment</td>
<td>Providers; Healthcare organizations</td>
<td>Appropriate payments/incentives</td>
<td>Incentives - Financial</td>
<td>Govt</td>
<td>NGO</td>
<td>Demonstrate value for money</td>
</tr>
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<td></td>
<td>Service Provisioning</td>
<td>Health system</td>
<td>Ensure service availability</td>
<td>Patient-focused: Improved Access</td>
<td>Govt</td>
<td>Govt</td>
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<tr>
<td></td>
<td>Stewardship</td>
<td>Health system</td>
<td>Reducing disparities</td>
<td>Patient-focused: Improved Access</td>
<td>Govt</td>
<td>Govt</td>
</tr>
<tr>
<td>5.1.1.2 Resource development</td>
<td>Providers; Patients</td>
<td>Curriculum; Treatment Guidelines</td>
<td>Organizational – Professional behavior change</td>
<td>Govt</td>
<td>NGO</td>
<td>Promote best practices and</td>
</tr>
<tr>
<td>Health System Role</td>
<td>CI Target</td>
<td>CI Activity Type</td>
<td>CI Classification</td>
<td>Funding Sector of CI</td>
<td>Implementation Sector of CI</td>
<td>Motivator for CI</td>
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<tr>
<td>Stewardship</td>
<td>Health system</td>
<td>Improved access to care</td>
<td>Patient-focused: Improved Access</td>
<td>Govt</td>
<td>Govt</td>
<td>Healthy People</td>
</tr>
</tbody>
</table>

5.1.1.3 Resource development

- Providers; Patients; Healthcare Organizations; Regulators; Provider-Patient
- Curriculum; Treatment Guidelines; CI Toolkits; performance measures
- Organizational – Professional behavior change
- Organizational - Culture Change
- Data-driven interventions
- Govt
- NGO; Govt
- Promote best practices and evidence based medicine

5.1.1.4 Resource development

- Health system; Healthcare organizations
- Data operating principles and governance; accreditation models
- Organizational – Core Processes (Safety and Risk Mgmt.)
- Govt
- NGO; Govt
- Promote best practices and evidence based medicine

5.1.1.5 Resource development

- Patients; Policymakers; Researchers
- Statistical analysis and reporting
- Data driven interventions – Public reporting
- Govt
- Govt
- Healthy people

**Commonwealth - NGO**

5.1.2.1 Regulation

- Healthcare organizations
- Accreditation
- Regulatory - Institutional
- NGO
- NGO
- Uphold minimum standards of care

5.1.2.2 Stewardship

- Providers
- Policy advice, professional advocacy
- Organizations – Professional behavior change
- Govt
- NGO
- Uphold clinical and industry standards; Help
<table>
<thead>
<tr>
<th>Health System Role</th>
<th>CI Target</th>
<th>CI Activity Type</th>
<th>CI Classification</th>
<th>Funding Sector of CI</th>
<th>Implementation Sector of CI</th>
<th>Motivator for CI</th>
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</thead>
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<tr>
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<td>Stewardship</td>
<td>Providers</td>
<td>Policy advice</td>
<td>Organizations – Professional behavior change</td>
<td>Govt</td>
<td>NGO; Govt</td>
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<tr>
<td>Resource Development</td>
<td>Providers</td>
<td>Curriculum development; Training materials</td>
<td>Healthcare delivery – Primary care</td>
<td>Govt</td>
<td>NGO</td>
<td>Uphold clinical standards</td>
</tr>
<tr>
<td>Regulation</td>
<td>Providers</td>
<td>Credentialing</td>
<td>Regulation - Professional</td>
<td>NGO</td>
<td>NGO</td>
<td>Uphold clinical standards</td>
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<tr>
<td><strong>5.1.2.4</strong></td>
<td>Service Financing</td>
<td>Healthcare Organizations; Provider-Healthcare Org</td>
<td>Purchase of service contracts with CI clauses</td>
<td>Organizational interventions – Professional and institutional behavior change</td>
<td>NGO</td>
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<td>Resource Allocation</td>
<td>Healthcare Organizations</td>
<td>Funding to do CI projects</td>
<td>Organizational interventions - Professional and institutional behavior change</td>
<td>NGO</td>
<td>NGO</td>
<td>Minimize risks; build reputation for quality</td>
</tr>
<tr>
<td><strong>5.1.2.5</strong></td>
<td>Service financing</td>
<td>Healthcare organizations</td>
<td>Service contract negotiations</td>
<td>Organizational interventions – Professional and institutional behavior change</td>
<td>NGO</td>
<td>NGO</td>
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<td>Health System Role</td>
<td>CI Target</td>
<td>CI Activity Type</td>
<td>CI Classification</td>
<td>Funding Sector of CI</td>
<td>Implementation Sector of CI</td>
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<td><strong>Resource development</strong></td>
<td>Provider-Healthcare Org</td>
<td>Performance monitoring</td>
<td>Data driven – Performance reporting &amp; accountability</td>
<td>NGO</td>
<td>NGO</td>
<td>Minimize risks</td>
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<td>Provider</td>
<td>Peer credentialing</td>
<td>Regulation - Professional</td>
<td>NGO</td>
<td>NGO</td>
<td>Uphold minimum standards of care</td>
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<td>5.1.2.6</td>
<td>Resource development</td>
<td>Provider - Patient; Caregivers</td>
<td>Training materials</td>
<td>Patient focused – Health literacy and shared decision-making</td>
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<td>NGO</td>
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**State - Government**

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<tr>
<th>5.2.1.1</th>
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<th>Hospitals</th>
<th>Reducing quality disparities</th>
<th>Patient-focused: patient experience</th>
<th>Govt</th>
<th>Govt</th>
<th>Healthy people</th>
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<td>Service provisioning</td>
<td>Providers</td>
<td>Standardized medication charts</td>
<td>Data driven – Information and knowledge mgmt.</td>
<td>Govt</td>
<td>Govt</td>
<td>Minimize risks</td>
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<th>Improving infrastructure and access</th>
<th>Patient focused – Access; Organizational intervention – Core processes</th>
<th>Govt</th>
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<th>Leveling the playing field</th>
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<td>Funding staff for cancer care</td>
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<td>Govt</td>
<td>Uphold minimum standards of care</td>
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<td>Providers</td>
<td>Care management pathways</td>
<td>Organizations – Professional behavior change</td>
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<td>NGO</td>
<td>Uphold minimum standards of care</td>
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<td>Incidence reporting</td>
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<td>QI training for individuals and organizations</td>
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<td>NGO</td>
<td>Promote best practices and evidence based medicine</td>
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<td>5.2.1.4</td>
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<td>Govt</td>
<td>Govt; NGO</td>
<td>Promote best practices and evidence based medicine</td>
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<td>State - NGO</td>
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<td>Policy; Advocacy</td>
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<td>Healthy people</td>
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<td>Govt</td>
<td>NGO</td>
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<td>Health System Role</td>
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<td>5.2.2.3 Stewardship</td>
<td>Patients; Environment</td>
<td>Policy; Advocacy</td>
<td>Regulatory – Market, Patient Protection</td>
<td>NGO</td>
<td>Govt</td>
<td>Publicize disease or issues</td>
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<td>Patients development</td>
<td>Treatment protocols; consumer representation training</td>
<td>Patient focused – patient experience</td>
<td>Govt</td>
<td>NGO; Govt</td>
<td>Help patients obtain best care</td>
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<td>Program awareness and training</td>
<td>Organizational intervention – Professional behavior</td>
<td>Govt</td>
<td>NGO</td>
<td>Uphold clinical and industry standards; Help run successful clinical practices/businesses</td>
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**Local - Government**

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<thead>
<tr>
<th>5.3.1.1 Service Financing</th>
<th>Healthcare organizations</th>
<th>Improving safety, access,</th>
<th>Organizational – Core processes Patient centered interventions</th>
<th>Govt</th>
<th>Govt</th>
<th>Level the playing field; Minimize risk</th>
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<tbody>
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<td>Organizational – Institutional behavior</td>
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<td>Govt; NGO</td>
<td>Demonstrate value for money</td>
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<td>Patient-Provider</td>
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<td>Organizational intervention –</td>
<td>Govt</td>
<td>NGO</td>
<td>Help patients obtain best care;</td>
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<td>Health System Role</td>
<td>CI Target</td>
<td>CI Activity Type</td>
<td>CI Classification</td>
<td>Funding Sector of CI</td>
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<td>help provide best care</td>
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<td>NGO</td>
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<td>Patient – Provider</td>
<td>Case management; CQI</td>
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<td>Service delivery</td>
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<td>Multidisciplinary care teams</td>
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<td>Provider</td>
<td>Clinical cancer registry data collection</td>
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<td>Govt</td>
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<td>5.4.1.2</td>
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<td>CI Target</td>
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<td>5.4.1.3</td>
<td>Resource Generation</td>
<td>Provider</td>
<td>Treatment guidelines; Teaching; Training</td>
<td>Organizational – Professional behavior</td>
<td>Govt</td>
<td>Govt</td>
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<tr>
<td>Individual - NGO</td>
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<td>5.4.2.1</td>
<td>Service Delivery</td>
<td>Provider (self)</td>
<td>Clinical care self-audits</td>
<td>Data-driven – Performance reporting and accountability</td>
<td>NGO</td>
<td>NGO</td>
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5.5.2 Organizational roles in care improvement within the health system

The data trends (Table 5-29) indicate that government and non-government organizations have very distinct roles in improving care. The commonwealth NGO sector played the most number of roles in improving care, followed by the state and local NGOs. Moreover, there appeared to be specializations, as evidenced by a general decline in the number of roles played in care improvement, as we moved from the federal to the local levels. Very few organizations took on the role of a funder of care improvement, on the other hand there were more organizations playing the roles of an “implementer” (i.e., those involved in making a CI project happen, either within their own or at other organization). Governments organizations often played the role of “coordinators” of CI by bringing together various stakeholders and funding care improvement projects.

Table 5-29 Summary of organizational roles in CI

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5.5.3 Characteristics of care improvement related relationships with the Australian health system

Commonwealth government had strong CI relationships with the State govs and with CW NGO sector. Strong relationships are due to money/funding relationships with the states and contracted relationships with several NGOs (also seen in the CW-NGO 6 of 6 ties). Commonwealth NGOs had stronger connections with the Commonwealth govt than within their own sector. This makes sense because they derive all the funding from the govt and not each other. State govt had some ties with the Commonwealth govt, but was heavily tied to itself and the local governments for CI. This indicates a power player, due the state government’s direct role in healthcare provisioning, who do extensive CI related heavy lifting. Both Commonwealth and State NGOs reported relationships with the State govt, though the state agencies themselves did not report them, indicating perhaps the state government sector was more important to the NGO sector than the other way around.

Table 5-30 Summary of CI relationships

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6 Data and Care Improvement

This chapter will discuss, in depth, data related relationships, the role of data in care improvement, and facilitators and barriers related to data use or sharing for each individual entity. This chapter follows a format that is similar to the previous chapter 5 Actors, roles, and care improvement. Organizations were placed based on their positioning on one of the 4 major levels – Commonwealth, State, Local, and Individual – of the health system and by the sector – Government or Non-Government – within which it operated.

6.1 Commonwealth

6.1.1 Government

6.1.1.1 CWG1

Data sources and relationships

This organization had access to numerous sources of data that were maintained by the Commonwealth government. As the national payer for healthcare in Australia, the Commonwealth funded datasets tended to have access to billing/administrative data from individual practitioners and certain kinds of population health (e.g., histological, pathological) data and epidemiological data from disease specific registries. Their datasets were nationally representative but lacked the depth of data collected by the states. The Commonwealth did not have access to any patient level health outcomes data. This organization received data reports from other commonwealth government organizations and reported to the Australian minister for health. This agency also had a memorandum of understanding with the commonwealth organization that administered Medicare; this enabled the sharing of data between the two agencies to help them achieve their common goals. The organization also had data reporting relationships with the state health departments.

Role of data in care improvement

Operation; Monitoring; Problem Identification; Reporting - Oversight

Sub agency 1

They monitored billing and healthcare utilization data from Medicare’s database to understand problems and set payment policies accordingly. However, this agency did not have access to any clinical patient outcomes data which prevented them from setting payment incentives for achieving better health outcomes by understanding which areas might require more intensive interventions.

Sub agency 2
As a population health program, this entity made extensive use of data for operations, specifically for patient follow up in cases where treatment was needed. These follow ups continue until the patients get treated or express the desire to stop follow up.

This agency uses the data from its cancer registries to evaluate their screening programs and to provided reports to a government oversight committee on the state of affairs of the various screening programs under the aegis. For example, they looked at the number of people being screened, participation rates, and sought to understand if the trends could be explained by a closer look at the underlying population. Having access to registry data made this sub agency an important source of information for other agencies - "And we’ve got data available here that isn’t available more broadly on cancer, and so it becomes like a de facto kind of, how we’re going in cancer is how we’re going in screening."

Additional uses of data included the development of performance indicators for cervical and gynecological cancer, these performance indicators are published publicly so that people can access them (political accountability) and are also used for financial accountability due to the use of government money.

Data issues

**Barriers:** Lack of clinical outcomes data; problem of attributability; Fragmentation – screening/treatment or public health vs. personal health; Fragmentation – State vs. Commonwealth

Sub agency 1 would like to structure their incentive payment system away from the current system which pays people for “having things” rather than for “doing things or achieving things.” The idea is to pay people for doing something good instead of doing anything. To do this, this agency will have to be able to attribute the desirable health outcome back to one provider. From a implementation perspective, It is difficult to attribute the health status of a person to any one provider because one patient could be under the care of multiple doctors and practices. This is also difficult because this agency can track insurance claims at the individual data but the data has no clinical outcomes information.

Lack of clinical outcomes data makes it difficult for the agency to intervene based on the performance. For example, if the data showed that screening rates were 90% for one community and half that in another, the data could be used to “lift everyone else to 90%,” which is an improvement that aligns with the societal value of equity – “we like equity; we like to think that everyone’s getting the same treatment or the same access to treatment."

Sub agency 2 has fragmentation issues that led to gaps in the data collection. For example, a certain screening program tracks cancer positive participants until they follow up with a doctor but their data does not capture subsequent transition into treatment or not; decision-makers assume that screened patients transitioned into care.
Sub agency 2 also mentioned that their data publications only present the national level view of issues because they do not have the “authority to publish below that level.”

**Facilitators: National Imperatives; legislated data sharing agreements; using health technology to reduce physician administrative burden**

Governments, commonwealth and state, have worked together successfully to collect data and share data is in the face of problems that are considered important at not just the state level but also at the national level. These are conditions that led to the set of the cancer registries for breast, cervical, and bowel cancers. The data shared due these imperatives are used by states to identify problems and develop interventions to address those problems. For example, one year the rates of cancer detection were lower for one state compared to the others. The state authorities drilled down on that issue using their own data sources, identified the source of the problem and built training programs to address that issue. This has led to improved performance in cancer detection over time.

Health information systems that reduced physician administrative burden facilitate better care by allowing them to focus on patient care.

Another facilitator to data sharing were funding agreements that included provisions for data sharing across lines of authority (e.g., commonwealth and state). Legislated data sharing agreements force the transfer of data across these barriers, effectively allowing it to flow within a system. For example, in Australia the Public Health Outcomes Funding Agreement (PHOFA) laws have data sharing clauses that require state governments to submit performance indicators (e.g., characteristics of services with high vs. low performance) to the commonwealth government for program evaluation purposes. These shared data are often used for performance and financial accountability purposes by the both governments, with some of the data made publicly available by the agencies. Similarly, some legislations (e.g., the Bowel screening program) allowed one government to overcome the traditional permission seeking of the states to get direct access to the data because the registry was set up through Medicare instead of the states. Thus, in spite of traditional lines of control in a federated system, careful legislation can used to facilitate data flow across these boundaries.

6.1.1.2 CWG2

**Data sources and relationships**

Primary sources of data were Medicare (e.g., screening registry data), research literature and project specific data (e.g., from a focus group). Primary relationships included the commonwealth department of health, the Medicare registry, and the commonwealth health data collection agency which provided routine analysis and reports.
Role of data in care improvement

Monitoring; Intervention Support

The only clear use of data that could be isolated from the interviews was the use of routinely available data (e.g., population screening reports) to monitor program uptake and the use of project specific (e.g., focus groups, interest group meetings) and research data to support a policy recommendation for a problem posed by the Australian ministers.

While informants within Cancer Australia acknowledged the need for benchmarking and performance measurement to improve quality, they also acknowledged that these activities were important only to the extent they were relevant to their policymaking task at hand because they could not act directly on these kinds of data. As one informant explained their position, “I mean it [performance measurement] would be useful information for us, and whether it would then provide evidence where there were some gaps in government policy...the area where we work is in government policy and research...where I think these two things would fit. And so, where the commonwealth had some responsibility for those areas where there were performance measurements, then it would help us to revisit that government policy and provide better advice, and look at where there might be some opportunities for research.”

Data issues

Barriers: Lack of intermediate clinical outcomes data; inconsistent data collection; lack of linkages in existing data; incomplete data entry; privacy laws

This agency’s desire to work with payers on benchmarking was hindered by the lack of intermediate health outcomes data. The biggest barrier was getting access to epidemiological data points from census data. At the time of the interviews only diagnosis and death were available; there were no intermediate census points or any ways of knowing if the patient received any treatment for their cancer.

Moreover, the informant noted that the ability of existing clinical cancer registries to collate data was extremely limited and population based registries did not fill in that void due to lack of clinical treatment information; moreover, there were variations in the data points collected and the quality of data collected at the local level clinical cancer registries with no cross-jurisdictional benchmarking process in place that would enable decision-makers to look at people’s cancer-related journey consistently beyond when they were diagnosed and when they died.

This particular agency would like to see local benchmarking around average length of stay, complication rates, discharge rates, 30-day and 60-day mortality rates, subsequent treatment decisions, local and distal occurrence rates; however, they are concerned that practitioners were not going to collect the data unless consumers drove the process by demanding answers from providers around these benchmarks.
Some of this agency’s ability to understand the performance of screening programs was hindered by lack of linkages between currently available dataset. The data from screening services and the data from funding service deliveries were not linked, in spite of no known legal restrictions that prevented this from occurring. Together, these two datasets could provide powerful insights on if there was alignment between the data received as part of the screening registry and the data received for delivery of screening related services. Linking would allow for vetting of data and provided more accurate estimates of screening rates because providers were very complete on charging for the services and were less compliant when it came to uploading data to the screening register. There were instances of linked data being used in other population health programs (e.g., immunization); however, that program was not emulated in the setup of other population health programs. Linked data could also useful for researchers that wish to study a certain area. As the informant described, “There is a group at the University of XXX that are wanting to identify all women who have a distant metastasis. Now, you’re going to be — either you actively chase every woman, find out, you got a metastasis, yeah?... Or you link it all up and say, here are people, post-diagnosed with breast cancer that have been admitted to hospital with a principal diagnosis with a code of breast cancer, or are on tamoxifen suddenly, or are on a chemotherapy suddenly, you can, by linking, get close enough to get a good feeling for what’s going on. So the answer is link or live in darkness, really.”

Another barrier was the use of privacy laws to hide from accountability. This was one of the reasons why a lot of currently existing data remained unused within any healthcare system. As an informant pointed out, “They [consumers] don’t know [the provider’s performance], the hospital doesn’t know, and neither do we [government]. And that’s because all the data that is sitting there that could be used to show that, can’t be linked because of all the privacy voodoo and the lack of resources, and there are people that don’t want to find out... The data are out there. Under the banner of privacy, there are all these walls. Even though there’s a technology for linking, such that you generate the identified databases for population based, statistical collections.”

6.1.1.3 CWG3

Data sources and relationships

This agency relied extensively on cancer registry data to conduct its monitoring activities and on cancer care related clinical data to drive its care improvement related activities. This agency used data from Commonwealth, State and sometimes, local (hospital based) level cancer registries. This agency had access to Medicare based cancer screening registries and state clinical cancer registries through the commonwealth data agency. Their other major data related relationships were researchers, who sought guidance and provided information on the latest cancer research coming in the field.
Role of data in care improvement

Problem Identification; Evidence Generation; Monitoring; Program Evaluation; Reporting

This organization used data extensively in its care improvement activities ranging from identifying gaps, building evidence, developing quality measures, tool development and reporting on quality. For example, this organization’s care improvement projects used data to “look at areas where we knew from the data that were problems…” to develop interventions to address those gaps. Once, these interventions were developed and implemented, data were collected to evaluate the success of the program in bringing about the desired change. Similarly, periodic data reports were promised to local decision makers in exchange for their participation and support of the care improvement efforts.

In another example, this organization conducted an extensive set of reviews around various issues in women with breast cancer ranging from communication, body image, sexuality etc. They used these reviews to produce the first ever set of psychosocial care guidelines for women with breast cancer. They also used data to development comprehensive indicators of breast cancer care, especially around areas that were traditionally left unconsidered (e.g., multidisciplinary or holistic approach to care).

Between 2009 and 2011, this organization partnered with a professional standard setting agency to audit the clinical management data provided by providers participating in the National Breast Cancer Audit Public Health Monitoring program. At the time of writing this dissertation, these reports were found archived on a commonwealth website. The informants also reported using their performance measure reports as incentives to gain stakeholder engagement when dealing with Cl project with organizations at other levels.

Data issues

Barriers: Lack of data management

The informants indicated that there was a underuse of existing data due to problems with data management. The problems stemmed from the lack of resources assigned to managing the collected data. These data management tasks included cleaning data, quality checks, timely reporting and data sharing. These tasks can add considerable overhead and in the absence of additional resources to address these issues (e.g., hiring a data manager), collected data can remain unused.

Facilitators: Automated data collection and reporting tools

This organization developed tools that reduce the burden of data collection, management and reporting in those that participate in their care improvement initiatives. As the informant reported, “…don’t make it onerous…these things will need to be collected over and above everything that everybody’s already doing.” The goal was to provide provider groups tools that could help them understand how they were performing in a specific area (e.g. proportion of care performance indicators met).
Data sources and relationships

This organization has ongoing contracts with the commonwealth data agency for routine and project specific reporting. This organization did not appear to collect any major data on its own but recommended the standards, like data elements and data governance processes, needed for the setup of major national level quality and safety datasets. It was unclear to what extent their work relied on the availability of routine data.

Role of data in care improvement

Reporting

The single most important use of data was through this organization’s government-granted role of public reporting on the state of safety and quality of Australian healthcare; the informant acknowledged that it was “a powerful lever in itself, one that had to be used with absolute precision and integrity.” They reported through the Australian Ministers and were held accountable for the contents of this report. The role of data in helping the standards development work is unclear.

Data issues

Barrier: Inability to publish data; inaccurate data collection; variable funding for data collection

There were several barriers. The first was the political obstacle course to publishing any kind of healthcare related data. Stakeholders disagreed on a range of issues starting with what data should be published to what the government would finally allow to be published.

Next, there was a need for data accuracy, especially in the context of patient handover, so that the right information could travel with the patient to the right place at the right time. The informant expressed a need to explore where information technology could assist and not create more problems, as had been evidenced in several international settings, where data were considered sacrosanct and accurate because it was on the screen, even though that was not the case.

This informant also echoed other informants about the impact of variable levels of funding for various public registers stating, “…the registries have been operating by the blood, sweat, and tears largely. Some have had some funding…. while others have had very little.”

Facilitator: Clear measurement and feedback of data to the source, linkages to existing evidence, evidence distillation; strong data governance

In order to successfully change practice, there needed to be a clear measurement of what was being done and that had to be fed back appropriate to all stakeholders along with information on any other
evidence that might be available in a domain. Evidence distillation and dissemination was also important in increasing provider awareness of care practices and professional development.

While there was a need for measurement data, good data governance practices were key to reduce stakeholder discomfort and preventing potential abuses of the system. For example, providers might be fine entrusting their clinical practice data with their peers or their professional network where there real likelihood of bringing about change. However, there was also fear of being targeted by funders, payers, and bureaucrats based on the performance metrics. This could be mitigated by strong data governance policies to control unauthorized access and use of data.

6.1.1.5 CWG5

_Data sources and relationships_

This organization served as the repository of several health and healthcare based datasets that provided data on adoptions, aged care, alcohol and drug use, cancer, children’s’ health, indicators of chronic diseases, disabilities, health expenditures for general practice and hospital services, indigenous populations, maternal health, tobacco use, health risk factors, and health workforce composition. This organization received some data from the other national statistics agency that complemented its collection of health data. Some of these data were also received from state agencies and aggregated at the national level to describe trends and summaries.

Data collected by the commonwealth payer database were analyzed by this organization and they were responsible for reporting on the health of the nation. Several commonwealth government agencies, including the department of health, contracted with this organization to obtain data and analyses for both one off projects and for ongoing monitoring activities (e.g., cancer screening efforts). This organization also received data, in the form of a minimum mandated dataset, from each the statewide cancer registries of each state. These data were compiled into a nationwide database. This compiling effort created a lag between the time the data were published by individual states and on a national basis. This allowed AIHW to have their figures verified by each state before publishing the national figures. As a national repository of health data, this organization also provided researchers with access to datasets and advice on how to link the data to other data sources like the state cancer registries to study population health outcomes.

_Role of data in care improvement_

_Monitoring; Reporting_

In an organization like this, data collection, management (cleaning, validation), analysis, and reporting were fundamental day-to-day tasks. This organization was instrumental in putting together various
discrete pieces of data together to provide a bigger picture view of the health of the nation. For example, they monitored screening programs, stratified at the state level and by zip code. They looked at participation rates by zip code, location type (rural vs. urban) and by socio-economic status. They also built performance indicators (e.g., number of colonoscopies started, and abandoned) to assess the quality of the national screening programs; however, benchmarks were yet to be developed to help put the performance indicators in context. They produced periodic report on the performance of each of the screening programs back to the program specific advisory committee which then reported back to the national level committees and finally to the ministers of health.

However, this organization’s role in care improvement is fairly limited because they were essentially providers of data and information to decision makers and did not have any direct influence in the decision-making process. In some ways, their role stooped at providing requested statistical analyses, indicators, and reports; it was up to the various program specific committees to decide what the performance benchmarks for each of these indicators. These expert panels, in conjunction with government officials, then set policy initiatives to address gaps or enhance existing services.

Thus, this organization served as a “technical expert” in matters of data collection, statistical methods and analysis to various commonwealth bodies, but was not directly involved in care improvement policy making efforts. This organization, however, did provide data quality/validity related feedback to agencies like Medicare, which in turn lead to the initiation of specialized billing codes (e.g. colonoscopy for screening vs. other reasons) that helped Medicare capture specific pieces of information that were of interest to them in the future. This organization served a major role in improving the quality of data available through their data management and verification processes. Particularly relevant to the effort of improving data quality was the work done by the hospitals classifications and performance group that was responsible for developing performance indicators, comparing hospitals, and reporting them to government agencies. Some of these performance reports eventually got published publicly.

Data issues

Barriers: Lack of automated data collection and reporting; lack of enforcement; underuse of existing data; fear of publication; fragmentation

The informant shared that one of the reasons that screening programs have been struggling to get data back from physicians, despite being offered financial reimbursement, included the overwhelming time burden on the physicians. The forms that need to be filled out were “clumsily conceived” and required the clinicians to fill in the data and did not support the pre-population of common fields (e.g., patient name, address, identifiers etc.). Moreover, the reporting function was not mandatory which gave another reason for physicians to ignore them along with the paltry payments that went with it.

Additionally, the agency indicated that currently agency policies are such that facilitate underuse of existing data. For example, despite there being no legislative barriers that prevent linkages between
Medicare and cancer registry data, that linkage has not yet been allowed to be established by Medicare because people are “very nervous” about sharing their private information. Allowing this linkage would have allowed AIHW to drill down at screening data at a much more granular level than is currently undertaken.

There also appeared to be concerns about publishing performance data. The informant described talks of releasing information to consumers about hospitals around certain metrics (e.g., mortality rates for surgeries etc.). However, these efforts had been tempered by concerns from individual physicians that they would be identified and targeted, if these data made were made publicly available. Similarly, there are concerns from hospitals that these data would not reflect the case-mix (e.g., older patients could increase mortality rates) that each organization might be facing. Additionally, there were a “whole raft of ethical and privacy and clinical issues” around posting such information online including systematic discrimination against patients that could compromise the hospital’s performance along these publicly available metrics.

6.1.2 Non-Government

6.1.2.1 CWNG1

Data sources and relationships

Hospitals undergoing accreditation provided self-assessment data to this organization; this information coupled with the use of research data to identify benchmarks against which hospitals were evaluated formed the two major sources of data for this organization. This organization did not share its data with anyone because it is a private company with no reporting duties to any external bodies; however they do provide feedback to the healthcare organizations undergoing accreditation.

Role of data in care improvement

Problem Identification; Feedback; Evaluation

At its very core, the process of accreditation was about meeting or exceeding average thresholds and keeping variances within acceptable limits. The accreditation process was highly dependent on the use of routine and project specific data, both qualitative and quantitative.

One of the major uses of data was to “give coherence” by outlining a framework for prioritizing a healthcare organization’s care improvement needs and the steps that people needed to undertake to get to the “end of your journey.” This step was valuable for people at an operational level (e.g., hospital administrators) who got bombarded with information from lots of sources.

The conditions of accreditation require ongoing use of data to monitor key metrics and address any unacceptable levels of variances in performance. This organization used data to drive the various factors
that are included in the accreditation process. For example, it had a total of 44 criteria and of those, only 12 were mandatory. They also had a five-point performance scale (described earlier in Chapter 5) that was used to score performance along each criterion.

**Data issues**

**Barrier: Performance measurement is controversial; fragmentation – public vs. private**

Performance indicators were controversial on several levels for many reasons. The informant explained, “…a lot of people don’t like indicators - and they don’t like them for a number of reasons. One, there are a small minority of people who don’t want their performance measured anyhow – that’s a personal observation. But, there is disagreement about what indicators are important, and then there are all sorts of concerns about how the indicators are developed.” Apart from the controversy around their use, there is additional controversy around the process of data collection and management surrounding the process including how the information in the database is collected and who (doctors or administrators) had control over the processes.

Finally, the informant made a very important point of when performance indicators were sensible to use – “So, simply saying oh, let’s have some indicators can be a fraud process in itself, unless there’s consensus within a clinical community that these would be useful; and these are the indicators that we would like you to collect; and then we’ve got a system which allows that to happen.”

Another barrier to using data was the level of fragmentation between the public and private sectors that prevented the sharing of information between the public and private sectors. As the informant explained the history of information technology has been a “litany of disasters, one after the other, across all states.” Actors within the health system work independently that led to an inconsistent approach between the public and private sectors which made it a real problem to share information.

6.1.2.2 CWNG2

**Data sources and relationships**

The informant did not report on any specific sources of data.

**Role of data in care improvement**

**Problem Identification; Intervention Support**

This organization was in a unique position due to its deep knowledge of both the high level and the ground level issues in general practice; this enabled them to articulate challenges and opportunities in the Australian health system to the policy makers. For example, this organization understood the need to provide access to records and results in an electronic format because it ensured easy retrieval for general practitioners, who received some test results electronically. Similarly, they were a proponent of local care
improvement collaboratives because their experience with collaboratives indicated that practitioners often firmly believed that their clinical practices followed best practices until their own clinical practice data were used to prove otherwise. However, once the initial skepticism was overcome, this kind of feedback of data and comparison of performance with local and state level colleagues was one of the proven ways of changing provider behavior.

Data issues

Barrier: Doubting the data; underuse of existing data; lack of data linkages

One of the main barriers to use of data was the distrust expressed by participants about the quality of data. The informant noted that any new system of feedback that produced less favorable results would face some sort of pushback from the recipients of the feedback expressing doubts of the findings; however, trust could be built by allowing individual practitioners to work with their own data and use it to make comparisons with local colleagues. This practice could be helpful in achieving professional behavior change.

The informant also noted that health information systems are underutilized all the time with approximately 70% of general practitioners using them as a data repository only or as a medical ordering system. They did not use the data for decision making or to evaluate their own performance. This was partly driven by the fact that there are no data linkages between software provider, practitioner, patient and payers. This made the it difficult to put together the desired data together for the practitioner which hindered data use.

Facilitators: Monetary incentives for completing paperwork

Generally, it difficult was to get individual and local practitioners to share their data without monetary incentives. As the informant noted “…they [government] send out a pack, you know, lovely glossy pack with lots of bits of paper and lots of forms to fill in, and whatever. It won’t happen. Guaranteed, guaranteed nothing will happen.” In fact, even in environments with lots of data, data sharing is still very dependent on payment incentives – “…unless there’s a payment reason or a financial reason to do it [data collection/paperwork], you won’t get everyone.” Some doctors will do it as a part of their professional role, but many won’t unless there is a “reasonable payment” associated with this effort. The informant noted that current initiatives like Medicare’s Practice Incentive Payments were designed to gently ease practitioners into making more use of their data. Even with payment incentives in place, the business case for the practice needed to be worked out – i.e., there needed to be a balance between the paperwork and the outcomes benefit. If the paperwork requirement is huge, then providers started to question if the monetary benefit was worth their time and effort.
6.1.2.3 CWNG3

Data sources and relationships

The primary source of data appeared to be data from the research literature. It might also receive project specific data from commonwealth level government agencies to execute certain contracts based project responsibilities (e.g., quality frameworks). This organization received and compiled research data as part of the evidence base needed to support evidence based practice for its members; it received data from its member physicians and shares its research based guidelines with them.

Role of data in care improvement

Intervention Support; Evaluation

Data were primarily used for building develop clinical practice guidelines and for developing educational programs. This evidence based approach to clinical care standard setting allowed them to "hold that line on what does the evidence say and where does it go" even in the face of ethical or fiscal conflicts that can arose from not endorsing newer potentially money-making therapies in favor of established care routines. They also credentialed/licensed physicians that enable clinical practice privileges.

Data issues

Barrier: underuse of existing data; inconsistent data collection; privacy laws; performance measurement is controversial

Firstly, the informants noted that GPs were not harnessing the power of electronic health records by limiting use to serve as patient data repository or for prescription ordering functions alone; the decision support capabilities of these software were rarely used.

Secondly, private practice data were not collected in a systematic fashion which limited their utility in comparative care improvement exercises.

Finally, clinical data that were collected were inaccessible to anyone but GPs, partly because the system was set up around the value of patient privacy. That aside, there are two other factors, driving the lack of data sharing at the local (i.e., across physicians within a practice or across practices) level. First, practitioners are concerned about the legal ramifications of sharing clinical data; these concerns include using the data provided to “beat them about the hip (with a stick)” and to subsequently being “engineered out” (or targeted by bureaucrats) of the health system due to perceived performance issues. At a more personal level, physicians were concerned about sharing at the local level due to concerns of “being identified” by their peers because the GP profession is small, making it easy enough to identify the clinician in a local setting. Furthermore, there was the added concern of finding out that “you’re the worst
practice in your region” and it was demoralizing because “everybody likes to think they’re doing a good job.”

**Facilitators: Awareness of the value of data; national coding systems; linking clinical and economic data**

One of the ways to increase the ability to share data was by ensuring that the data are collected in a systematic and standardized fashion. To that end, it was important to build awareness in practices that standardized entry of data is valuable to do - i.e., there needed to be “a shift towards actually seeing the computer as a tool rather than as annoyance.” Further, for some practitioners, the ability to share the standardized data would allow them to learn more from their peers. Related to the previous point was the need for a national coding system that was a requirement for all clinical software vendors because, unless this was sorted out, it was impossible to achieve inter-operability within information systems and make any sense of the data.

The informant noted that yet another way to facilitate the use of data was by connecting the findings of a clinical audit software with economic data such that it was not only a care improvement tool but also a business improvement tool. This kind of an approach would provide clinical practices with a sense of the amount of fiscal gain that might be associated with providing the guideline prescribed amount of care. For example, a physician could be losing money for not following up as often as the guidelines recommended, thus missing an opportunity to provide both higher quality care as well as increased revenue.

6.1.2.4 CWNG4

**Data sources and relationships**

The major source of data for this organization was their private claims databases. This organization had regulatory and accountability data reporting requirements to the commonwealth government, specifically to the commonwealth department of health, due to the regulatory relationship. This organization received healthcare utilization data in the form of claims filed mostly by private hospitals. They also received accountability reports from hospital administrators certifying their adherence to the stipulations of the contracts.

**Role of data in care improvement**

**Operations; Reporting**

This organization did not use data to improve care directly. They used data for billing and administrative data to pay for healthcare services. Their quality related contracting stipulations appeared to be loosely based on what were generally considered industry best practices; there was no clear sense of whether data were used to drive the process. At the time of the interviews, the performance of provider
organizations was not measured, relying instead on certifications of compliance to contracting stipulations by the CEO of each organization, and healthcare organizations were not paid based on their performance on clinical outcomes.

Data issues

Barrier: Fragmentation – customized vs. standardized care processes

The “individualized” and “customized” nature of healthcare practice made it fundamentally unsuitable for “computerization.” If the underlying nature of the production of healthcare did not change, then introduction of health information systems is suboptimal because “…we tried to bolt IT into such diverse production processes.” This complex nature of the interactions, couple with professional autonomy that is inherent in the existing medical culture makes standardization of processes harder to achieve in healthcare compared to other professions like accounting or law.

Facilitators: Standardized processes for simpler/general care settings; consolidation of specialty healthcare providers

While complexity of care made standardization of processes difficult, it was possible to use health information systems more successfully in general practice settings than specialty practice. The informant used the example of U.K where general practices have very high IT adoption rates (same as Australia). The high rate makes sense because, “…even though general practice is very fragmented but its production process is quite simple compared to say, hospital interventions and so, there is a chance that they will make it…make it work I think for the first time.”

Within the specialty care and hospital setting, the informant expressed a desire to see the standardization of technology and the production of care processes through the consolidation of the healthcare provider industry. Consolidation of providers would allow the pooling of resources that can be used to tackle quality problems that are both complex and resource intense (e.g., HIT systems for collecting data) in nature compared to those that can be tackled by smaller private practices.

6.1.2.5 CWNG5

Data sources and relationships

This corporate office of a large healthcare chain was responsible for providing individual facilities with continuous monitoring and feedback on their performance relative to existing industry standards. They also served to connect each facility with the latest in best practices in each area of care and this included the idea of providing each facility with a suite of Key Performance Indices (KPI) required for improving clinical governance, financial performance, and quality of care. At the very least, each facility was required to report data required to analyze performance around metrics needed for hospital accreditation.
Additional performance measures were collected depending on what other high priority services were provided. The corporate office in turn shared some performance data with payers or insurers, but that was largely based on organizational discretionary. The amount of service data shared by the corporate office was largely dependent on their relationship with a payer or insurer. If the relationship was strong and the corporate office was confident that their data were not going to be used punitively, then additional requested service data were shared. In the absence of a trusting relationship, only the minimum data required to get reimbursed was shared and requests for additional data are generally ignored or only “spits and spats” of data are shared. A variant of such a data sharing based on trust relationship also existed between the local facilities and the corporate office. Local facilities may or may not provide beyond the minimum required data to the corporate office. Finally, the corporate office also shared some internal performance data with the commonwealth health and safety organization to support the development of new quality and safety measures; the extent of the sharing with was unclear.

**Role of data in care improvement**

**Monitoring; Problem Identification; Feedback; Evaluation; Reporting**

Data were used extensively to monitor healthcare utilization, clinical processes, and health outcomes for each facility. At the time of the interview, monitoring was limited to certain health specialties that had been identified as either: 1) high volume and/or, 2) high visibility and/or, 3) high risk. High volume procedures were important to the corporate office because they constituted the bulk of the services and associated revenues for each facility; an example of such a procedure would be routine orthopedic knee surgery. High visibility items were areas of care where the presence of even a few adverse events could result in a disproportionately large negative publicity in the media and amongst the public; such high visibility events include safety related events like inadequacy of safety protocols to prevent falls in the elderly (or frail) patients or the ability to control nosocomial infections. High risk items were classified as such due to two reasons: 1) the nature of the procedure was inherently risky (e.g., obstetrics); or 2) there was a high prevalence of medical malpractice litigations within that area.

The corporate office used its collection of healthcare utilization, billing, and health outcomes data to periodically monitor the performance of each facility. The performance was usually measured relative to established benchmarks (e.g. ACHS), where available, or against internally created benchmarks. They generated periodic benchmark reports using a performance index, called the FBI Index. Performance on each indicator is quantified and color coded to indicate the frequency of sentinel events (e.g., <=10 sentinel events per months is green). Once, the color changed from green to yellow, these metrics started “coming on the radar” and if a facility crossed over to red, they were identified to state managers and the CEOs. The state level manager then contacted the CEO and other clinical officers (e.g., Director of Clinical Services) to participate in the conversation on how to address the gap. Data formed a big part of the conversation because the state managers would often request additional data in the upcoming
months in order to confirm that impact of the intervention. Similarly, state mangers would often use data to identify success stories from other facilities and help local management identify interventions that could be used or adapted to address the identified gaps.

**Data issues**

**Barrier: Variable reporting requirements to external agencies; data use concerns**

There were two significant data related barriers reported. The first barrier arose due to large variances in the data collection and reporting requirements by various regulatory and payer/insurer agencies. The informant reported that streamlining data collection and reporting requirements by external regulatory organizations will not only help control the “astronomical costs” of running and administrating data collection and reporting systems that meet the needs of such diverse stakeholders but will also help promote “collegial relations” with various agencies through sharing of agreed upon data. At the time of the interviews, the peak government safety and quality organization was working with various stakeholders to streamline data reporting requirements for healthcare provider organizations within the Australian health system.

The other major barrier was a lack of clarity around how shared data might be used by the recipient organization; there were fears of punitive measures being used on lower performing hospitals based on data that might not be robust.

6.1.2.6 CWNG6

**Data sources and relationships**

This organization received data from the research it funds and also data from the commonwealth government for any project they might be contracted to execute.

**Role of data in care improvement**

**Problem Identification; Intervention Support**

This organization used data for problem identification purposes. For example, they invited 15,000 consumer and caregiver feedback on their experiences with both practitioners and around the disease. The feedback made them realize that people from multiple disease areas reported having issues around depression and anxiety. They also reported being treated well enough on their signs and symptoms of the illnesses but got nothing else. This feedback allowed them to choose which disease areas required the most awareness around the comorbidities of depression and anxiety. This organization then “infiltrated” that area by putting money on the table and buying the interest of researchers in assisting the organization in their efforts to spread awareness.
They also use data to build an evidence base that also served as a tool for persuasion. For example, this organization wanted to promote prevention and early intervention in depression and anxiety. So, they conducted a literature search of the literature, which was then shared with various stakeholders – clinicians, policymakers, consumers, and caregivers. The informant noted that, “So while it appears that we are a consumer and caregiver driven organization, we actually only put information up that has the research…qualitative or quantitative to back it up…”

**Data issues**

**Barrier: Data alone are inadequate; privacy**

This organization reported issues surrounding the inadequacy of data alone in bringing change. Even when data are available, the informants reported collecting data and interrogating it such that they have a good idea of the health of the nation, the pressure points, and the intersection points for people. However, despite collecting and knowing quite a lot about the health of the country, they found themselves unable to always address it with data alone. They provided the example of the federal government, which has Medicare data but funding decisions are often made based on *“the ground swell of requests for new items on Medicare that don’t come from data.”* Data are necessary to “back up the action” but not sufficient to drive the final decisions, which are made by the professional advocacy groups influencing politicians to say that a certain area is important because it’s affecting some significant number of people.

The second barrier was around the reluctance to data sharing within the Australian health system because of reason discussed by other informants – the unwillingness to share the data due to bad experiences that other countries have had with the health cards (e.g., UK) and due to the potential embarrassment factor.

**6.2 State**

**6.2.1 Government**

**6.2.1.1 SG1**

**Data sources and relationships**

This state health department was a repository of several databases of service level data from hospitals under its management and included incident and risk assessment systems that monitored the safety of its population and its services. This organization also conducted several population level health surveys to assess the health status of the population. There were data sharing relationships with several other key state government agencies. It received and shared data with the local (or area) health services under its jurisdiction. Similarly, it also had data sharing agreements built into the funding agreements with the commonwealth government.
Finally, this organization provided a way for patients, providers, researchers, and education agencies to access data using its web interface to produce tailored reports from its repository of population health survey and health service data.

**Role of data in care improvement**

**Monitoring; Problem Identification; Reporting - Public**

In spite of access to extensive data resources due to its position as a state agency, the role of data in the care improvement activities was rather restricted. While the agency used data for identifying potential solutions, and monitoring, and reporting pre- and post- intervention changes, it had limited ability to effectively evaluate its programs in the context of cost-effectiveness or understanding the factors that drove the success of the program. The latter was needed for successful implementation of the program in the future.

Using the example of the implementation of the medication management program, the intervention was selected based on a national directive and was accepted because the “literature tells us” that this intervention will improve certain aspects of behavior leading to better patient outcomes. During the implementation process, the state made efforts to use data to conduct formative evaluations by putting into place audit requirements; however, no efforts were made to understand if the program was bringing about the changes desired. Thus, despite having the ability to measure various processes, access to observational data, and incident information management systems there was still no way to “tell the difference between a heightened awareness in medication safety and a heightened reporting as a result of that…”

Using the example of an intervention to ensure rapid access to care for the frail elderly, the informant noted that there was they were unable to measure the usefulness of the program because they believed that a large volume people would have to be avoided before it showed any impact on the bottom line and the pilot program was small. Secondly, there was no linked data that would have enabled them to compare costs of providing this care in a community setting versus in an emergency care setting.

Finally, this organization published performance reports of state run facilities for the public. These reports consisted of performance around specific metrics of safety or public trust events, among other things.

**Data issues**

**Barrier: Lack of linked data**

The informant noted that one of the major barriers to data use was the unwillingness to set standards to enable performance measurement of any proposed interventions. In cases, where data such as statewide reports or peer hospital tables were available, state authorities might not provide any guidance on what
might be considered a “benchmark,” instead relying on hospitals to drive that process, expecting that “hospitals would take their own local data and do their own performance improvement from there.”

**Facilitators: Routine reporting and publication of performance data**

The informant noted that they often produced routine reports on the performance of the health services in annual reports. This report triggered action amongst managers and personnel of departments that were lagging behind. Publication of non-flattering performance data was a powerful incentive to take action and was more powerful than any mandate.

Another important facilitator of data use was clinician engagement. Any data that was presented had to be presented in a way that is real and relevant to the clinician because most interventions aim to change physician behavior. Working with local professional support bodies was a great way to learn how to present data in a way that was meaningful to the clinicians being targeted.

6.2.1.2 SG2

**Data sources and relationships**

This organization had several sources of data including state and commonwealth data sources. It administered the statewide cancer registry which provided epidemiological information about cancer in the state. The data contained in this registry was considered of be high quality or “pristine.” Along with vast data resources of the state health department, one of the most important data related relationships was with the commonwealth’s Medicare payer database which provided cleaned and compiled data to the state regarding programs that were of common interest to commonwealth and state government agencies.

**Role of data in care improvement**

**Monitoring; Reporting; Persuasion**

One of the primary uses of data was for monitoring of public health related programs. For example, data were used to monitor adverse events associated with screening programs.

Data were also used to drive engagement activities, to set the stage for informed dialogue instead of a “blue sky” discussion. There was a perceived need for better data collection and management to fully meet the organization’s needs. To that end, this organization had invested significantly in building and funding the data collection and management infrastructure, in partnership with the state health department. Their accreditation framework included a database of clinical indicators and software to help local health departments to help evaluate if the organization had “strategies” in place to collect, manage and analyze routine care processes data.
In yet another project looking at improving the functioning of multidisciplinary cancer care team, this organization tried to put “some rigor around data capture” and “standardization” including the building of a data dictionary to guide the development and use of associated outcomes related quality indicators. These steps at standardization were required because the data being collected was so unreliable that it could not be used for performance measurement activities over time.

In addition to capturing clinical processes like MDTs, the Cancer Institute had conducted a survey of about the experiences of 4,500 patients from both inpatient and outpatient care settings for use as baseline for measuring future improvements in cancer care delivery. They have developed a data base of clinical indicators to support local health departments and for subsequent inclusion in the accreditation process. This organization planned to use the data acquired from the accreditation process to look collected from accreditation to assess patterns of use and track how the practice has changed in response to the clinical indicators over time.

Finally, this organization published performance statistics on their website for access to all. Even though data were important for improving quality and transparency, sometimes, it came associated with its own perils. As an informant noted the publication of performance data can make the healthcare system appear bad. As the informant noted - “Well what we do at the moment is we tend to publish because I think the system needs it…But it is a challenge because the more you publish data where things are nearly there, but not there, or not there at all, then it creates the impression in the public I guess that the system’s bad, but if it’s never been measured before, it’s probably actually better than it was or it might even be actually better than it’s been measured before.”

**Data issues**

**Barrier:** Variance in data collection; incomplete data; unreliable data; irrelevant data; poor documentation; lack of access; labor intense data collection; forgetting key data stakeholder; fragmentation – commonwealth vs. state

The most common problem was related to the process of data collection and management. Like many other organizations, this organization suffered from the lack of availability of high quality, reliable, and meaningful routinely collected data that would enable them to formally monitor and compare performance and to conduct care improvement efforts at the organizational and program specific (not individual) levels.

The data quality was affected due to incomplete data collection. Sometimes data can be incomplete because it fails to capture data from all relevant parts of a process (e.g., stopping at a point before the outcome of screening becomes known) or can be incompletely filled out by a physician. The latter problem was aggravated by clumsily designed forms and lack of automated data entry. As an informant described, “I’ll give you an example. So, for every month they tell us how many adverse outcomes there have been – some months there aren’t any. So, when you get the histopathology report – and the histopathology report is actually four pages long, and they’re four separate pages and they have to be
completed by hand – it must be the only manual histopathology form in existence in the world. And not only that, but the pages are missing a unique identifier so if you drop them on the ground, you don’t know that this is Mrs. Jones 1, Mrs. Jones 2, Mrs. Jones 3 – they are generally not completed or they’re only half completed and there’s no way of ascertaining if the data is accurate, so there are huge data gaps – so you really wouldn’t want to do any modeling on the adverse reactions that come out of any of those reports. The colonoscopists often do not send you the outcome of the report, so we have dreadful figures about the amount of reports we get from how many colonoscopies were completed – we really don’t know.” Lack of automated data entry put an enormous burden of already busy clinicians and they remained reluctant to invest in data entry.

Some of these problems arise, when people key data related players are excluded from consideration when designing an intervention policy. For example, ignoring the role of Medicare, as an informant noted - “I think people forget about them [Medicare], I think people see them as being a part of the process – as being – a fairly perfunctory role in just processing data, and actually that’s not the case at all. They’re the custodians of the data, they receive the data, they do the data checks – it’s so important when we do anything with the program that we check it’s going to work with their systems and that we understand how their systems work. And on some occasions some ideas have been run with without ever checking whether that will actually work with the way the data is collected.”

In cases, where the reverse happens (e.g., commonwealth forgetting about the state government as a stakeholder), any data that are shared turn out to be meaningless to the recipient organization. This was a major problem, as noted by two informants – “But at the moment the reports – we get reports from the Commonwealth, but they’re large data dumps – they’re not data that we can analyze very easily because we don’t get post code, or we don’t get region of the state, or we don’t get where they had their colonoscopy or anything like that.” Another respondent echoed saying, “Well the other problem, too, is no matter how much we’ve asked – they [Medicare] will not quantify what it [adverse event] is – we don’t know whether the person sneezed or died. So…it means nothing.”

Sometimes, this also results in lack of data sharing between key stakeholders. The informant described one such lack of access on a screening project - “Well, there are two things: we don’t have access to the data to know who the invitees are, so we know that there are going to be, you know, seven-thousand people this month who will receive a kit, and we don’t know who they are. Medicare knows who they are – we don’t. We’re not able to have their[Medicare’s] data. Other screening systems are very successful because you know who they [screening invitees] are, and you can ring them up, and you can remind them, and you can tell them to do it, or you can write to them – we can’t do that.”

Finally, fragmentation of power between the state and commonwealth governments can offer barriers by diffusing the sense of ownership (and responsibilities) to a program and slowing down the pace at which changes can be made, once problems are detected. The consequence of such fragmentation has been described as – “Well, we’re not allowed to [fix any problems with screening forms]. It’s a national program
and it’s a national register. So we have program managers in every state, and every two months we have a teleconference – and the same issues are brought up again and again and again.” This helplessness to bring about change was echoed in yet another example – “Well no one can do anything, unless [commonwealth agency] calls all the shots, it owns everything. It owns the register, it owns the forms, it owns the process. We can’t do anything. I don’t think [this organization] has any more clout than anyone else because they don’t have to listen to anyone.”

Facilitator: Data linkages; high quality data

Establishing linkages within existing data has been proposed as a way to start using data already being collected. The informant noted one such effort to help with routine reporting of data - “That’s also why we’ve set-up the linkage unit because we actually have a lot of data in our database that is not being used right now…The data linkage unit is now ready to do all of those things, we really just set this thing up, it’s been about 18 months when we get all the records together.”

One of the bigger challenges faced by the organization has been around the validity of the data and the resultant reports that are being generated. The agency has purposefully invested lot of resources around data collection in hospitals. Such investments include hiring of several data managers to oversee data collection and quality and investments in automated data capturing and reporting. High quality data collection is needed because once clinicians and policy makers are convinced of the data quality, then they might be more amenable to using the data to make improvements in care delivery.

6.2.1.3 SG3

Data sources and relationships

This organization had access to the state government’s data resources. Common sources of data included state level sentinel event surveillance data and specialized healthcare utilization data from the state data repository. The state health department provided this organization with the healthcare data required to achieve its mission of safety and quality.

Role of data in care improvement

This organization used data extensively in its efforts to improve care. The reporting system of eight sentinel events resulted in a 30-fold increase in reporting of these safety events in one year. These sentinel events were analyzed using the root cause analysis to get to the heart of the patient safety issue. This organization positioned the reporting system as a “systems issue rather than a personal punishment issue” to allay concerns from the clinical community. Once, the data started pouring in, this was followed by efforts to put in incident monitoring systems, even though only 4-5% of all incidents were being reported, this data provided them with enough information to “get some trend lines” about the occurrence of “public trust events” (or adverse events) across the community. At the time of the interviews, there
were plans to put into place a feedback mechanism through the incident management system because audit and feedback has been useful in changing provider behaviors in other Australian experiences. This feedback loop would include clinicians and possibly governance units, and area health units. This information would also enable stakeholders to lobby politicians and try to change the system because the “governance is in the Minister’s office, which means that every decision is political…”

Driving home the point of this effort, the informant summed it up saying, “it’s our job to actually put the programs in place that address those trend lines.” For the most parts this organization has had to use implicit judgement for prioritizing care improvement activities (e.g., patient impact measures) because “many things you do in safety and quality don’t have the evidence base.” Finally, this organization reported great success in improving provider performance once they started publishing hospital level performance data because publishing data leads to peer pressure which can be a large driver of improvement.

**Data issues**

**Barriers: lack of routine data collection; lack of data publication; fragmentation – clinician vs. administrator; lack of enforcement**

One major barrier reported was the sheer lack of routine data collection. At the time of the interviews it was possible to get performance measures in about 7-8 high volume disease areas like heart failure, asthma, COPD, diabetes, etc. These data were not routinely collected and it is not possible to monitor the state’s progress at any given point in time. It also meant that data for performance indicators had to be collected manually by physicians, which reduced the chances that they would do it. This lack of routine data collection can be partially explained by the lack of information technology infrastructure. This lack of infrastructure is also related to the problem of data quality, which stems from the lack of seamless HIT systems that can facilitate data collection. As the informant noted, “So if we want to get good performance measure, we need to be able collect it so when it becomes part of the system, part of the electronic health record, that we can actually get that information out quite easily. And that’s why if we go build electronic health record, the evidence suggests if you build an electronic health record, it’s of no value to you in terms of safety because all it is replacing what’s written on page. What you have to build into it are the systems that give you information that will add to it. So you need to build quality systems into the record, so that you can then collect the information and spit out the performance indicators that you want. And if you can then do that, and you can do it without creating a large amount of unnecessary extra work, and you only have to collect that information once, you don’t have write it down once, then enter into datasheets and onto a computer, which is what people have to do now in Australia, then you will start to get good data collected and you might better show that you can drive change. And you have to be able to convince people that the data is best practice, so you need to do that.”
There was a similar break in the feedback loop between clinician and hospital management teams. The informants noted that individual physicians would often audits of their own performance that are not necessarily formal processes but informal audits in areas that are of interest to the individual practitioner. However, the findings from these informal ad-hoc audits are never fed back to the management (e.g., area health departments) because there is no process around that and it is not a requirement. This is problematic because the management team needs to understand those issues so that they can provide appropriate resources to improve care in those domains.

Another data issue noted was the lack of routine publication of available data. The informants noted that several state agencies have got “wonderful information on [cancer care] outcomes” and there is nothing published or shared with other state agencies that are interested in the area. This lack of publication makes it difficult for organizations to compare how well they and their system is performing compared to the rest of country and the rest of the world. The informants also noted that the patients are a key stakeholder in a public payer system and they deserve the right to know.

Finally, the informants noted that the use of performance indicators was undermined because there were no consequences of not meeting the benchmarks. This was because public hospitals are traditionally underfunded and are running on tight resources. So, in spite of not meeting some of the key performance indices, hospitals are not sacked or required to meet them by the government authorities.

**Facilitators: Data publication; data feedback; lower burden of data collection and reporting**

The informants noted that publishing data was one of the most potent ways to use data – “And the other thing is, it’s about publishing. Nice article recently showed… basically, what it showed was you know, you need to publish the data if you want to get best results from the data.” Adding more to the power of publication of data, the respondent cited a project where as soon as the project data were publicly available, people made efforts to improve their performance. The informant noted, “It’s about publication. It’s about public knowledge, but in this particular sense, it’s not the public that’s finding out, it’s your peers finding out, and the one thing you don’t like is being poorly performing against your peers. “

In cases where data were collected and performance data were available, there was a lack of a feedback loop. The informants noted that physicians were interested in understanding their own performance but current systems were not set up to provide have the performance data fed back into the system, in spite of the data being available. The informant mentioned that feedback of appropriate information was one of the most reliable ways to change provider behavior based on their past experiences with a project on auditing surgical mortality where after the first 12 months, 73% of physicians indicated changing their clinical practice because of the feedback they received from the audit.

The respondent highlighted the fact that even small increases in per patient data collection burden could weigh heavily upon private practitioners, who were already very busy. So, in order to promote collection of any additional data several things need to happen at once, one of them being provision of additional
resources - “Very, very complex question - multi, multi barrels that you have to fire off all at once, vast resources of human time to get people on board because it has to be done at the individual level…You need to provide some incentive to do that, and that’s either funding hospitals and health areas to provide the data support or funding the individuals to provide the data support. Somehow or other, you’ve got to make well intentioned, well trained, altruistic people, which is the majority of health professionals, you’ve got to provide them with the extra resources or the extra to do more than they’re doing now… [a researcher] said, I want you to collect this extra information. And it’s trite, but they said, 30 seconds per patient? He said, yeah about that. They said, 40 patients a day, that’s 20 minutes, that’s no lunch.”

6.2.1.4 SG4

Data sources and relationships

This organization received data from the state health department. At the time of the interview, this organization received service related data collected by the state government through the state department of health. These data sources include “broad numbers” aggregated at the State level; they are not provided with any further (local health department) breakdowns.

Role of data in care improvement

Problem Identification; Reporting

This organization was very cognizant of the need for data to drive improvement in clinical care and was supportive of building an IT structure that would promote robust data collection, management and reporting systems. They helped the clinical networks build and maintain databases and other information systems to facilitate this very goal. They also conducted studies to identify “bottle necks” in a care pathway and reported those findings to state health departments for redressal along with policy recommendations.

Data issues

Barriers: Lack of capacity to collect data; lack of resources for data collection; unreliable data

The informant described how there were “major impediments” to resourcing data collection efforts and that the system lacked the capacity to collect reliable data. Moreover, the clinicians were “very suspicious” about integrity of the data reported through the Commonwealth’s Medicare data collection system. The informant stated that this distrust in the data was promoted by the fact that a commonwealth report had accidentally reversed the numbers stating a 70% public and 30% private sector split in provisioning of colonoscopy services. This reversal of data was mentioned by at least two other informants from other state organizations. This lack of trust in the data made data less useful for decision making and care improvement purposes by clinical networks.
Facilitators: De-identified and aggregated data; reliable data

The informant indicated that people were not too concerned about de-identified data being aggregated at the local level. This kind of data could be very useful in understanding “major disparities” in the health system and promote the uptake of successful programs. The informant used the example of a program developed in respiratory care that was developed by a local physician for people in the community. This intervention resulted in a major drop in admissions for acute respiratory illness and was being considered for implementation in other local networks.

The informant emphasized that data collection was very resource intense because it involved a lot of legwork involving data quality and validity checks as well as making sure that a high rate of participation in the data reporting process. It was important to consider funding not just for the infrastructure but also for personnel to manage and follow up on the processes need to ensure the integrity of the data collected. It was important that stakeholders could trust the data before they can make decisions based on them.

6.2.2 Non-Government

6.2.2.1 SNG1

Data sources and relationships

This organization used a combination of several large existing population databases to study the way care (including cancer care) has been delivered. This included linked data sets with population health and health services utilization data collected by state health departments. These data allowed researchers to connect patients to doctors and their hospital records. Other sources of data included the collection of primary data for specific projects.

Role of data in care improvement

Problem Identification; Intervention Support

Research data were used to identify gaps and build evidence base around topics to enable evidence based policy making. Thus, this organization was only involved in a few steps of the cycle used to improve quality of care but data played a huge role in its limited efforts because they were entirely research and evidence driven.

Data issues

Barriers: Performance measurement is controversial; lack of enforcement; lack of publication; lack of funding
The informant noted that they did not do enough work around performance measurement because there was essentially no demand for them from their clients (the state health departments). This was because there was a feeling that this kind of comparative performance data, if made publicly available, will be used by the media to portray the health system in a negative way to “create an unfortunate climate.” This negative portrayal would “destroy” the morale of the staff and reduce the people’s willingness to use that service, and also reflect badly on the agencies responsible for its management. This lack of demand for comparative performance means that there are no funders of this kind of research and also there are very few opportunities to publish due to there being “a lot of sensitivities in the system about publishing,” which deters a lot of researchers from wanting to work in this area.

Other than the public backlash of performance measurement, the informant noted that the states did not have any real consequences for facilities that did not meet performance standards. Sometimes the pressure on the system to provide care, any care, is such that enforcing performance standards is not even an option in certain cases. The informant used the example of screening program accreditation and said that even when the state knew that some institutions weren’t meeting accreditation standards they weren’t able to “de-accredit” the services because the “political and community ramifications would have been too great.”

**Facilitators: Safe culture of reporting; research funding**

One of the big facilitators to improving reporting of performance data would require a cultural change. This culture would allow organizations to feel safe reporting their shortcomings. For that to happen, there was a need to change how media would handle such information. The media would need to understand that not being able to deal with this information sensitively would only prompt people to contain any such information.

Finally, funding was the other key piece. Funding in the form of fellowships, project funding that would allow the growth and development of a “generation of scientists who are really interested in working in this area.”

6.2.2.2 SNG2

**Data sources and relationships**

This organization received data from individual physicians through its cancer registry and from patients describing their cancer care experience. This organization shared the cancer care registry with the state cancer control agency and with a state cancer care improvement group.

**Role of data in care improvement**

**Monitoring; Reporting; Intervention Support**
This agency served as a repository of cancer related epidemiological data for reportable cancers within the state. They also reported on this epidemiological data. The role of data was mostly as a way to monitor health trends and not for any population level interventions. This organization also funded research and used data to generate disease specific knowledge base, which was useful for its advocacy efforts.

**Data issues**

**Barriers: Unreliable data; inadequate data**

The informant noted data quality as the main barrier. When trying to improve care any data that is shared should be reliable before it can be used to effect change. As the informant explained, “…and it has to be data that people can believe in. It’s no use sending out this information to people if they can pick holes in it and say, well on the other hand, it doesn’t mean what it says and generate all the excuses. So, that would certainly be my priority that we would have to have good clinical data at a population level.”

In addition to unrealizable data, the other problem was lack of collection of key data points. The state registries were focused on collecting incidence statistics and offered no survival information which was the kind of data that would be needed to plan healthcare provisioning.

**Facilitators: Effective feedback mechanisms**

One of the facilitators of data use for accountability was not through publication but through effective feedback. The informant used an example of bowel cancer related survival rates for various integrated cancer care networks where there significant variances in the survival rates across various networks. The informant relayed this information to all the program directors of the networks and assured them that no information would be published until everyone agreed. Administrators associated with the lower performing programs were nervous but the informant got around this problem by turning the reason for publication upside-down. The proposed publication of data was not meant to be for the mere purposes of accountability but would be couched as a way to demonstrate that the current data do not explain the differences in performances because no one knew the details of the care received by the patients. For the networks to be truly accountable more data were needed. This approach to publication met with approval and the data were eventually published.

6.2.2.3 SNG3

**Data sources and relationships**

The primary sources of data seem to be that from research publications. None of the relationships were data related. They use data to generate position statements around various aspects of policy around cancer care issues.
Role of data in care improvement

None

The informant indicated a lack of knowledge of any availability of comparative performance improvement data being available to consumers or to the general public. The informant noted that such data “ought to be available.” No other role of data in care improvement was noted.

Data issues

Barriers: Fear of disclosure; lack of long-term care outcomes data

The informant noted a very nuanced barrier to sharing health information data across providers. The concern put forth the notion that sharing a person’s entire history, including information that might not be directly relevant to the care at hand, may affect the social aspects of the care received negatively. The informant used the example of domestic violence to note—“I think people – there’s a lot of bidirectional fear about disclosure of personal information. Well one of my doctors put it this way: as a GP, I might know that there’s a history of domestic violence. You might not want your cancer surgeon to know that. It’s relevant to me, it’s not relevant to them. So if your full health record is available to another health practitioner, that could change the way they treat you. Not medically treat you, but their attitude...their social engagement with you, yes.” However, the informant also noted that “we [organization] don’t see it that way” citing that people already share a lot of personal information online (e.g., banking details) and if people can be happy with the protections offered in those domains then, “why are we suddenly concerned about health issues?”

The informant noted a lack of long-term outcomes data in informational resources that were aimed at patients. These outcomes of interest included “issues like quality of life following treatment, survivorship issues, outcomes stuff, isn’t in fact covered” by the patient’s relationship with their treating specialist, and comes much further down the track. Stuff that someone once called outside the 5-year square.

6.2.2.4 SNG4

Data sources and relationships

Local divisions of practice and research data appeared to the two main sources of data for this organization. In addition, they received project specific data from the its contracts with the state and commonwealth governments to support their work around specific areas (e.g., screening programs). This organization received aggregated program implementation data from each of the local divisions and also had a bi-directional sharing of data with the national peak body.

Role of data in care improvement

Problem Identification
At the time of the interview, this organization was mostly involved in developing training programs for clinicians and the role of data in their work was minimal. The organization did not appear to collect any routine data of its own. Instead, they received project specific data as part of their contracts. For example, they stepped in as consultants with local health departments and used their data to help them identify service issues (e.g., access to clinicians) pertaining to general practice. The primary use of data for this organization was to “spot trends” at the division level that could be used to inform their engagement with key stakeholders. For example, the organization would also point out areas (and divisions) that might be lagging in some areas of care and need improvement. Practices in these areas would then be approached by local divisions with offer of support to improve those areas.

The informant also described the organization’s plans to participate more fully in a care improvement collaborative that would train clinicians to clean and manage their own practice data using specially designed electronic tools to generate evidence based performance indicators. These indicators would enable clinicians to monitor their practice and subsequently take steps to improve their own practices and adhere to best practices around certain diagnostic areas like diabetes, kidney disease etc.

**Data issues**

**Barriers: Silos; performance measure is controversial**

The informant noted that data was widely used for service planning by local health departments; however, everyone involved in the care pathway plans in silos. As the informant explained, “I’ve worked at an area health service for 10 years and looked at the systems and how you plan. And what happens at the moment is everyone’s got lots of data in their plan, but they plan in silos. So, the area health service has all their data about cancer hot spots and that sort of thing, or whatever it may be. Therefore, we need to do the screening, but they don’t do it conjunction with general practice or divisions and your local council areas…”

The informant also noted that even when data are available, it is “critical” to look at how it can be used to support individual practices. Monitoring of individual clinical practice was a “very sensitive issue,” especially when it was used to compare clinician performance.

**Facilitators: Payment for data**

The informant noted that in order to get performance data from practitioners, it was important to incentivize them using additional payments to provide data on an annual basis for certain outcomes of interest (e.g., diabetes, cervical screening rates, smoking cessation rates etc.). However, the informant also warned that depending on the individual situation, even payment incentives might not suffice because this kind of commitment requires systemic change, which is often difficult because status quo (i.e., doing nothing) is always an option.
6.3 Local

6.3.1 Government

6.3.1.1 LG1

Data sources and relationships

LHDs collected their own data and supplemented it with reports from the facilities under them also receive reports generated from data from the state databases.

Role of data in care improvement

Monitoring; Problem Identification; Reporting

Data were used extensively in all aspect of care improvement. Local health departments collected data extensively and each had assigned units that are focused in improving the care delivered by the hospitals under its governance. Data were commonly used for monitoring, problem identification, and reporting purposes.

Data issues

Barriers: Lack of political will

The federated health system in Australia meant that there were multiple (at least two sets, commonwealth and state) of political figures involved in bringing about major change. The informant noted that there was a aversion to measuring or learning about bad performance. The political cycle was such that at any given point time there is “one minister…going to the polls in the next six to twelve months who does not want to sign up to that program.”

6.3.1.2 LG2

Data sources and relationships

The primary source of data here was project specific data; some of it was primary data collected as a part of a study. The organization had contributed two indicators of psychosocial care into the performance data that was to be collected by the state cancer control agency.

Role of data in care improvement

Intervention Support

The primary role of data was to demonstrate the effectiveness of various possibilities to improve care. For example, in a project looking at the implementation of routine data collection for psychosocial care,
the researchers noted that various structural and social barriers made it very difficult for clinicians to improve the delivery of psychosocial care.

**Data issues**

**Barriers: Lack of funding for CI research**

The informant pointed out that there is a lack of funding for research looking at care improvement activities because funders were not used to the non-randomized methodologies used in such studies. Specifically the informant noted that, "I think there is probably a lack of understanding about research in this area [care improvement] amongst the funders, they are used to funding randomized controlled trials, this sort of large scale systems sort of research that's familiar, it's very expensive…but I think it does make it difficult to get funding…it's not easy research to do, it's not easy research to get buy in from the institutions to participate, so you do need a very strong team that are well respected by the groups in order to participate" This lack of funding hampered the ability to advance care improvement research.

**6.3.2 Non-Government**

**6.3.2.1 LNG1**

**Data sources and relationships**

This organization (a private hospital) reported having an extensive in-house IT department to support the development and use of large and complex data collection and management systems. These systems were capable of, among other things, supporting this organization’s case management efforts. The choice of going with an in-house IT solution was prompted by their desire to customize or "develop pretty much what it is we actually need, rather than what can actually come out of box from big companies."

Routinely collected clinical data were used for both day-to-day clinical care delivery and for care improvement purposes. The hospital had ongoing data sharing relationships with three stakeholders – payers, providers, and patients. In addition, it also shared data external regulatory organizations to maintain accreditation status.

**Role of data in care improvement**

**Operations; Monitoring; Problem Identification; Intervention Support; Feedback; Reporting**

Data were used extensively to drive decision making within the hospital. For example, the hospital used data to manage the clinical care of patients and to bill private payers for the care. Data were also used extensively to provide “evidence” and “supporting figures” to “make changes.” They also used data to monitor variances in key metrics (e.g., length of stay) associated with clinical pathways; these metrics met and exceeded those required for routine accreditation purposes. When undesirable variances are noted, data were used to identify potential reasons that might explain the variance (e.g., presence of a new staff
Finally, the hospital used the data collected for case management to produce reports and to provide feedback to the members of the multidisciplinary care teams where problems are discussed and solutions sought. The hospital reported to regulatory bodies and routine generated data were used by departments throughout the hospital.

Data issues

Barriers: Lack of standardized screening instruments

The informants noted that the lack of standardized instruments in certain areas, especially psychosocial care in cancer patients. In the absence of standardized instruments, the care team had to rely on anecdotal evidence of need for extra care. The informants noted that having an objective measure would be useful because it would give them the “evidence” they would need to direct more resources and to change practice patterns in psychosocial care.

Facilitators: Performance data reporting with context

The informant noted that they would prefer seeing performance data put in the context of action taken to redress any problems. Using the example of distress screening, the informant said that just reporting high proportions of patients screened would be misleading as an indicator of high performance because it is not about the act itself but the actions taken subsequently to in patients who were screened in. It is only when the final outcomes of the screening were reported would the data make sense. “…I think it’s great to be able to say yes, we screen people for distress, but do we just leave them sitting at number 10 on the thermometer, or do we actually bring that down?”

6.4 Individual

6.4.1 Government

6.4.1.1 ICAG1

Data sources and relationships

This organization (hospital) was a major repository of clinical and financial data, which included a clinical cancer registry that tracked patient journeys as the received care for their tumors. The organization’s major data related relationships were with the local health departments and with the state cancer control organization. The data collected from the clinical cancer registry were shared with the LHDs and the state cancer control agency.

Role of data in care improvement

Operations; Monitoring; Feedback; Reporting
Data were used for monitoring the activities of the MDTs, like for keeping track of adverse events. The other source of data that are used to drive improvement came from the clinical cancer registries run by the hospital. The informant indicated awareness of the state government’s plans to accredit cancer services and recommended the effort, stating, “accreditation can be a pain, but if you get good indicators, the right indicators, then it gets- it’s not about the practitioner, it’s about the patient.” Despite concerns about data quality, the informant hinted at the larger role of data in the future, saying, “the train is at the station, it’s here, and I welcome it.” Moreover, the informant and the organization were actively trying to promote the use of data in improving care by reducing the variance in the quality of data collected in the clinical cancer registry.

Data issues

Barriers: Unreliable data

The informant noted concerns about the quality of the clinical cancer registry data and that it was the “best we have, so use it to drive improvement.” Using the cancer registry’s data was problematic for the hospital because it got challenged frequently by clinicians who were familiar with it’s the registry’s issues with data quality.

Facilitators: Funding

The informant noted that having external funding served to provide support for data management which could improve the reliability of the data collection and management process.

6.4.1.2 ICRG1

Data sources and relationships

Commonwealth and state screening data were the two sources of data discussed in the interviews.

Role of data in care improvement

Problem Identification; Evidence Base; Policy Making

The informant spoke primarily from the research perspective and noted several examples of data being used to identify gaps (e.g., staffing shortage, inadequate tracking of patients) in the screening system and potential fixes for it. This discussion included the need for closer scrutiny of the competence of non-physician providers of endoscopy services along with the need for higher standards of safety for screening programs because screening programs often deal with individuals that had been “picked off the streets through positive fecal occult blood tests” and not individuals who were approaching the health system on their own due to some suspected problem.
Data issues

Barriers: Privacy issues; fragmentation – commonwealth vs. state

The informant noted that one of the big barriers to data sharing was privacy issues. The commonwealth especially seemed reluctant to share information in an individual person identified positive tests to the states or the regions where those people are, in order for the pathway to be tracked adequately. The informant went on to note that, “I cannot see what their problem is because those individuals when they engage in the program, sign a consent form to allow their information to be used for, if you like, downstream clinical management. So there’s no reason on a privacy grounds as far as I can see why that information cannot be transmitted at a very early stage to the people on the ground.”

Another problem was delays in sharing of screening data between the commonwealth and the state governments. There was a 6-month delay in the data sharing which means “…So that person…can only start acting 6 months down the pathway. Most of us think that’s far too late to be engaging.” This delay also blunted the impetus to act on the problems identified by the data because the findings were no longer relevant.

Facilitators: Data linkages

The informant cited an example of a centralized database available elsewhere and mentioned the need for a health database that would enable “connectivity” between disparate databases across healthcare providers, in a de-identified fashion. This would enable administrators and researchers to “drill down onto the relevant fields, and produce an integrated report along some specification insofar as the information is collected in those databases.”

6.4.1.3 ICSG1

Data sources and relationships

The hospital was the single largest source of routine data for the clinical practitioners. Specialists shared routinely collected clinical data with patients and other clinicians on a as needed basis. This organization had data reporting relationships with the commonwealth research funding agency due to its participation in clinical trials. Similarly, this hospital shared routine utilization related data with the local health departments within which it operated for planning and management purposes. The hospital also shared accreditation related data with the state cancer control organization.

Role of data in care improvement

Monitoring; Problem Identification; Feedback; Reporting

The use of data for improving clinical performance was limited. It appeared to be restricted to the clinical reviews done as a part of the multidisciplinary care teams. During these clinical reviews, all adverse
events or other events of note that occurred within a two-week time period were compiled and discussed at the multidisciplinary care team meetings. This served as a learning experience for everyone. Similarly, data were used during departmental meetings to identify “…our pitfalls, [and] our shortcomings…” However, the use of data to improve clinical quality stopped with this acknowledgement and it appears that it is there is some confusion as to what the next steps might be in the process to improving care, as our informant remarks, “…apart from acknowledging it [pitfalls and shortcomings] it, I don’t see that we have much in place.”

Data issues

Barriers: complexity; fragmentation – clinician vs. administrator; feedback without resources; performance measurement is controversial

The informant expressed concerns about the feasibility of being able to capture all the relevant data needed to provide good feedback to clinicians because of two issues: 1) there are numerous points of entry and exit into the hospital system, and 2) these entries and exits exist by profession, clinical service type, department etc. The resulting complexity makes it difficult (but not impossible) to collect reliable data. The informant stated, “…So my question would be, how would you obtain the [health] information? Would it be a structure questionnaire or something that every patient would have access to, and at what point of entry in the system would they get this information? There would be some opportunity because our nurse practitioner where that could be done….the problem we have is we don’t have a door here, where everyone enters and gets in. We have a number of doors. So, one of my issues would be, how do we capture that through all the doors?”

The role of data was further limited by concerns of how the data would be used by administrators due long standing trust issues between clinicians and administrators [T35, Pg16]. These trust issues arose from a "lack of clinician input in service delivery” wherein clinicians felt ignored by the administration. The informant noted, “…this organization has a distinct lack of clinician-administrative trust…Sort a general failure to support of the years, a lack of clinician input in service delivery. We’re building a new hospital, but we have very little say in how it will be put together. We find rooms where we can practice because that’s all we can find. Then you try to do the best you can for someone, and then you realize you’re doing under very strained conditions, and I don’t think I’m saying anything different than how a lot of my colleagues feel at the moment in this organization, not just in cancer, but in other areas”

Within this perceived unsupportive context, there was a propensity to “get everyone caught up in the negativity” associated with any negative feedback data that were unaccompanied by any offers of support to improve the situation. Fears of negativity were the default expected response from administrators because as the informant explained, “…I am so used to the culture of it [positive response] not happening, that I don’t have a great deal of trust or confidence in it [performance data] being used in a positive way for us.” Lack of data and personal fears aside, the ability to use data to monitor individual
clinician’s performance was still a distant dream because there is no consensus around what might be good measures of individual performance and for group performance. The latter was especially important in cancer care teams are multidisciplinary teams and no one clinician could be held responsible for all the outcomes. At the time of interviews, the state cancer control organization had made some forays into the use of data to measure performance and for accreditation; however, numerous issues were awaiting resolution before any of those efforts to improve cancer care could gain acceptance.

6.4.2 Non-Government

6.4.2.1 ICNG1

Data sources and relationships

The practitioner had access to patient level clinical and administrative data. GP’s received clinical data from their patients; they also generated additional treatment related data. Some of these data were shared with payers (e.g., Medicare) to obtain reimbursement. The practitioner reported sharing data with the local cancer center on who were referred for further cancer screening.

Role of data in care improvement

Monitoring; Problem Identification

The primary role of data was in monitoring care processes through one-time “self-audits,” a process in which the clinician looked at his/her own data. The informant provided the example of using data to audit the coordination of PAP smears, PAP test results and follow ups like the percentage of patients that returned for a follow up at the request of the physician. Another example of such an audit was to look at whether they were engaging people who were at risk of osteoporosis through assessments, interventions, and education. However, the data are often looked at without any formal structure and the final outcome is not always quantified.

The role of data in improving care delivery is also diminished further because of the perceived redirecting of time in collecting and managing data that could be otherwise used for providing better patient care.

Data issues

Barriers: Lack of feedback; lack of resources to collect data; lack of automated systems; fragmentation – clinician vs. administrative

The informant reported sending information to local cancer centers on individuals who had been referred for further screening for bowel cancer but never hearing back from them about it again. They tallied their private (not through the government screening programs) fecal-occult screening kits to get a monthly list of those who got the kits done and the outcomes, but no such data came back from the national screening program. The confusion about the process was clear when the informant stated, “…3 months
later have got information from the cancer center to fill out a form. I don’t know why because I just fill out, ‘did I refer for colonoscopy or not’, so I know someone’s [government entity] looking at us, but we don’t get that feedback. We just know it happens in the background, which is where I need to learn how to become the academic to say, well I want that feedback…this hasn’t happened in the national data screening."

Another major deterrent to data use was the lack of infrastructure to collect data. The informant laid out the problems of staffing in the quote - “Partly the reason is we’re not paid well enough to fit it all in…cannot afford a nurse, can barely afford a practice manager, but did because of our middle years and we’re sick of doing it. In Australia, for every hour you work clinically it’s probably 15 to 20 minutes that you need to do paperwork that is unpaid. So, we actually, it’s…to earn the money we do, you’ve got to put in 12 to 15 hour days. And that’s without doing performance indicators…So to fit in the key indicators…you’d fit it in would have to be to have the practice manager do it, which would be fine if there were some – I mean it’d be fine if we could afford it.”

Along with additional staffing, the informant noted that health information systems that were automated, easy to operate, and aimed at reducing the human burden of data entry for small practices would facilitate the use of data in general. Within the current situation, choosing to do paperwork would mean that, “…more time in Australian general practice is taken away from patient care and put into doing graphs and fulfilling the forms, because you don’t have a system like that [automated IT systems like the UK].” Furthermore, these data collection efforts are perceived of as “purely for paperwork and bureaucracy…and its [an] absolute waste of time.”

Finally, another reason for lack of data sharing is due to the lack of alignment between the clinicians and the administrators (payers, commonwealth government). The general practitioner reported sharing practice information every year with a local research group that looks what is going on with general practices. The practitioner stated that this relationship was valuable because these researchers “have the best understanding of what goes on in general practice and they “want to look at what we do, not for us to save costs on something, not for us to fit in with a set of norms that aren’t relevant to patient care.” The cost saving reference was to a report from the National Prescribing Service that reported how government money the physician had spent on specific kinds of drugs like NSAIDs, antibiotics, anti-hypertensives etc. These kinds of performance measurements were not of interest to this physician because it told them nothing about the appropriateness of the clinical care provided.

6.4.2.2 ICSNG1

Data sources and relationships

The hospital with which this practitioner is affiliated is a major source of data.
Role of data in care improvement

Identifying Problems; Operations

The most common role of reliable data would be for optimizing and rationalizing work load and for identifying problems, policy setting, and resource allocation. However, these were all hypothetical in nature because the informant indicated that the accuracy of the data was so disputed within the hospital that it was not a useful tool in making care improvement decisions.

Data issues

Barriers: Lack of trust in data; inaccurate data; performance measurement is controversial; feedback without resources

The single most important barrier to data use was the strong lack of trust over the accuracy of the data collected, either at the hospital or by other government agencies. At various points throughout the interview, the informant noted this problem saying, "I wouldn't believe any of it [data] because in my hospital repeatedly, I've found too many examples of data that is at variance with reality." The data that varied were reality were not just clinical data, but also fiscal data (like budgets) and this set off a big issue around trust. The informant was emphatic at noting, "…until the Commonwealth proves to me that this is reliable and trustworthy data and accurately reflects what happens, I would not accept a single change in policy, or funding, or staffing on the basis of any data collected in hospitals today."

Yet another barrier in data use was the general disagreement over performance measures. The informant indicated that agreeing upon the measurement criteria and what should be measure was the biggest problem. The informant used the example of how an organization realized that their performance measure used to assess MDTs was inappropriate three years into the program. "So the MDT is the best example, where the [local institution] has only just realized after 3 years that the way they assessed the MDTs, in other words, what percentage of the total number of new patients were presented, might not be a reasonable and an across the board correct way to assess activity of MDT, because they just realized that just saying that all 50 new patients seen that month were presented is not a realistic way of assessing whether it was an effective MDT, because it might be that everyone got 2 minutes of discussion and that was inappropriate because 10 of those 50 really need a half an hour of discussion and didn’t get it because we were too busy making sure that all 50 got it. So, I see that as the biggest issue, the debate about what the measures should be and what they mean. And only when that debate was successfully resolved would I then have no fears [in using performance data]."

Finally, there is the concern that performance measurement will be feedback without supporting resources to improve the outcomes. The informant noted, “It’s just that what I predict will happen is…[We will be] sent something back [performance data] saying, this is below an acceptable average fixer, but I
won’t be given one additional staff member or opportunity to do that. It’s just, fix it. And that’s the greatest threat. The greatest threat is more fix-its without any change in capacity.’

Facilitators: Accurate data; resources to improve data collection and management

According to the informant, collection of accurate data would be the first step to improving the use of data saying, “Well there’s no doubt that the first would be accurate data collection, and I’m not at all convinced that that’s happening, but I give credit to the [state cancer control agency] that that is their clear and stated goal, and they’re putting funding behind it to try and achieve that. I don’t have any sense that the rest of the Department of Health has anything like that degree of commitment to that issue.”
6.5 Summary

This section will provide a summary of all the information presented in sections 6.1-6.4 which are summarized in four tables - Table 6-1, Table 6-2, Table 6-3, and Table 6-4. Key findings from across levels and across sectors comparisons from each table are discussed in the text preceding each table. Graphical depictions of the data presented in these tables can be found in Chapter 9 Appendices 9.6 Graphical representations of summary data (Chapter 6)

Tables 6-1, 6-2, 6-3, and 6-4 will provide summaries of key data related information discussed throughout the chapter.

6.5.1 Characteristics of data sources and flows within a health system

There were several kinds of data sources, almost all commonwealth and state level government reported using their own data. As funders of care, the commonwealth agencies had access to Medicare claims and billing data and also access to cancer registries. State governments had access to healthcare utilization and more importantly, health outcomes data and other detailed data at the state data. The commonwealth data were nationally representative, but the state produced a lot more health data and had access to details at the local level. The commonwealth could not get access to health outcomes data which the states could access. There was some sharing of data between the two governments, stipulated as part of the funding agreements. However, only bare minimum agreed upon data was shared. Local governments had data that was similar to that of the state government, but a more granular level. The state governments had access to the bigger picture at the state level and shared pertinent information required to guide the care improvement and overall performance of individual local health districts. The commonwealth level NGOs either had their own internal data or reported getting access to data from government organizations as a part of their project contracts.

Data flows were almost always associated with a corresponding flow of money between the two entities.

Table 6-1 Overview of data sources, data-related relationships, and data use

<table>
<thead>
<tr>
<th>Selected data sources</th>
<th>Data-Money relationships</th>
<th>Data flow across levels</th>
<th>Data flow across sector</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Commonwealth - Government</strong></td>
<td></td>
<td></td>
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<tr>
<td>6.1.1.1 Medicare claims (patient level);</td>
<td>I give you money, you give me data (with physicians);</td>
<td>State Govt</td>
<td>CW NGO</td>
</tr>
<tr>
<td>population cancer screening registries;</td>
<td>I give you money, I give you</td>
<td></td>
<td>State NGO</td>
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<tr>
<td>service performance data</td>
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<tr>
<td>Selected data sources</td>
<td>Data-Money relationships</td>
<td>Data flow across levels</td>
<td>Data flow across sector</td>
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<td>------------------------------------------------------------------------------------</td>
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<tr>
<td>6.1.1.2 Population screening data; research data</td>
<td>I give you money, you give me data (physicians)</td>
<td>Local Govt</td>
<td>CW NGO State NGO</td>
</tr>
<tr>
<td>6.1.1.3 National, state, and local level cancer registry data; research data</td>
<td>I give you money, you give me data (CW agencies)</td>
<td>State Govt Local Govt</td>
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</tr>
<tr>
<td>6.1.1.4 Commonwealth databases</td>
<td>I give you money, you give me data (CW agencies)</td>
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<tr>
<td>6.1.1.5 Medicare; internal data repositories; shared data from states</td>
<td>I provide data-driven service, you give me money</td>
<td>State Govt</td>
<td>CW NGO Local NGO</td>
</tr>
</tbody>
</table>

**Commonwealth – Non-government**

<table>
<thead>
<tr>
<th>6.1.2.1 Hospital process and outcomes data</th>
<th>I provide data-driven feedback, you give me money</th>
<th>Local</th>
<th>Other - Local Govt</th>
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</thead>
<tbody>
<tr>
<td>6.1.2.2</td>
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<tr>
<td>6.1.2.3 Research data; GP training data; project specific data</td>
<td>I provide data-driven service, you give me data and money</td>
<td>Individual</td>
<td>CW Govt</td>
</tr>
<tr>
<td>6.1.2.4 Internal billing and claims database</td>
<td>I give you money, you give me data (healthcare organizations)</td>
<td>CW Govt Local NGO</td>
<td>CW Govt</td>
</tr>
<tr>
<td></td>
<td>I give you data and money, you give me feedback</td>
<td></td>
<td>CW Govt</td>
</tr>
<tr>
<td>6.1.2.5 Internal clinical outcomes, utilization, and billing databases</td>
<td>I give you data, you give me money (payers); I give you money and data, you give me feedback</td>
<td>CW Govt State NGO</td>
<td>CW Govt</td>
</tr>
<tr>
<td>Selected data sources</td>
<td>Data-Money relationships</td>
<td>Data flow across levels</td>
<td>Data flow across sector</td>
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<tr>
<td>6.1.2.6 Research data; project specific data</td>
<td>I provide data-driven service, you give me data and money</td>
<td>State Govt</td>
<td>CW Govt State Govt</td>
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<tr>
<td><strong>State - Government</strong></td>
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<tr>
<td>6.2.1.1 State govt databases on utilization, outcomes, and safety</td>
<td>I give you data, you give me money (CW Govt); I give you data and money, you give me data driven service (State Govt); I give you money, you give me data (LJHD); I give you data, you give me nothing (general population)</td>
<td>Local Govt Individuals</td>
<td>Local NGO</td>
</tr>
<tr>
<td>6.2.1.2 State govt databases on utilization, outcomes, and safety; Population screening registries</td>
<td>I give you data, you give me money (Local Govt); I give you data, you give me money (State Govt)</td>
<td>CW Govt Local Govt</td>
<td>Local NGO</td>
</tr>
<tr>
<td>6.2.1.3 State govt databases on utilization, outcomes, and safety</td>
<td>I provide data-driven service, you give me data and money (State Govt)</td>
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</tr>
<tr>
<td>6.2.1.4 State govt databases on utilization, outcomes, and safety; research data</td>
<td>I provide data-driven service, you give me data and money (State Govt); I give you data, you give nothing (Local Govt/NGO)</td>
<td>Local Govt</td>
<td>Local NGO</td>
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<tr>
<td><strong>State – Non-government</strong></td>
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<tr>
<td>6.2.2.1 State govt databases on utilization, outcomes, and safety; research data</td>
<td>I provide data-driven service, you give me data and money (State Govt; Local NGO)</td>
<td>Local NGO</td>
<td>State Govt</td>
</tr>
<tr>
<td>6.2.2.2 State cancer registry; research data</td>
<td>I give you data, you give me money (State Govt); I provide data, you give nothing (individual)</td>
<td>Individual</td>
<td>State Govt</td>
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<tr>
<td>6.2.2.3 --</td>
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<tr>
<td>Selected data sources</td>
<td>Data-Money relationships</td>
<td>Data flow across levels</td>
<td>Data flow across sector</td>
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<tr>
<td>6.2.2.4</td>
<td>Project specific data from CW and State govt</td>
<td>provide data-driven service, you give me data and money (State Govt.; CW Govt)</td>
<td>Local NGO</td>
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<td><strong>Local - Government</strong></td>
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<tr>
<td>6.3.1.1</td>
<td>State and Local databases on utilization, outcomes, and safety</td>
<td>I give you data, you give me money (State Govt)</td>
<td>State Govt</td>
</tr>
<tr>
<td>6.3.1.2</td>
<td>Research data</td>
<td>I provide data-driven service, you give me data and money (CW Govt)</td>
<td>CW Govt</td>
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<tr>
<td><strong>Local – Non-government</strong></td>
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<tr>
<td>6.3.2.1</td>
<td>Internal clinical outcomes, utilization, and billing databases</td>
<td>I give you data, you give me money (Payers)</td>
<td>CW NGO</td>
</tr>
<tr>
<td><strong>Individual</strong></td>
<td></td>
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<tr>
<td>6.4.1.1</td>
<td>Internal clinical outcomes, utilization databases; hospital based cancer registry</td>
<td>I give you data, you give me money (Payers)</td>
<td>State Govt Local Govt</td>
</tr>
<tr>
<td>6.4.1.2</td>
<td>Internal clinical outcomes, utilization databases; hospital based cancer registry</td>
<td>I give you data, you give me money (Payers)</td>
<td>State Govt Local Govt</td>
</tr>
<tr>
<td>6.4.1.3</td>
<td>Internal clinical outcomes, utilization, and billing databases</td>
<td>I give you data, you give me money (Payers)</td>
<td>State Govt Local Govt</td>
</tr>
<tr>
<td>6.4.2.1</td>
<td>Internal clinical outcomes, utilization, and billing databases</td>
<td>I give you data, you give me money (Payers)</td>
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<tr>
<td>6.4.2.2</td>
<td>Internal clinical outcomes, utilization, and billing databases</td>
<td>I give you data, you give me money (Payers)</td>
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</table>
6.5.2 Characteristics of data use for CI within a health system

Most commonwealth government agencies reported several types of uses of data improve care. Most common use was for problem identification (17 instances), reporting (14), monitoring (13), intervention support (11), feedback (6), and evaluation (6). Most organizations reported moderate to high levels of data use in certain aspects of the CI processes. Most organizations did not report using data to undertake all the steps (monitoring, identification, intervention support, feedback, and evaluation) in the CI process. Most organization used data for 2 of the 5 processes.

Table 6-2 Overview of the role(s) of data in CI

<table>
<thead>
<tr>
<th>Operations</th>
<th>Reporting</th>
<th>Monitoring</th>
<th>Identification</th>
<th>Intervention Support</th>
<th>Feedback</th>
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<td>Oversight body program performance</td>
<td>Care utilization; population health</td>
<td>Problems with program uptake</td>
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<td>Evaluate program uptake</td>
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<td>Program uptake</td>
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<td>Recommend evidence-based policy options</td>
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<td>--</td>
<td>Identify quality of care gaps</td>
<td>Psychosocial indicators for cancer care</td>
<td>Clinical audit of surgeons</td>
<td>Evaluate intervention success in behavior change</td>
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<td>6.1.1.4</td>
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<td>Screening program participation</td>
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*Commonwealth - NGO*

<p>| 6.1.2.1    | -- | -- | -- | Care improvement needs | -- | Prioritizing needs; outlining steps to goals | Accreditation | High |
| 6.1.2.2    | -- | -- | -- | Challenges and opportunities to physicians and practices | Policies to reach physicians and practices | -- | -- | Low |
| 6.1.2.3    | -- | -- | -- | -- | Clinical practice guidelines; education programs | -- | Credentialing | High |
| 6.1.2.4    | Payment of services | Oversight - community risk ratings | -- | -- | -- | -- | -- | Moderate |
| 6.1.2.5    | --- | Subordinate bodies – state managers | Utilization, clinical processes, health outcomes | High risk; high visibility safety events | -- | To state managers to address performance issues | Identify success stories of interventions | High |</p>
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<th>Operations</th>
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<td>--</td>
<td>Identify gaps in public awareness</td>
<td>Evidence base to support mental health policies</td>
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**State - Government**

| 6.2.1.1    | Public    | Interventions | Identifying care areas that need interventions | Evidence base to support intervention choice | --        | Formative evaluation | Moderate (could be high if more data were available) |
| 6.2.1.2    | Public    | Adverse events from public health programs | -- | -- | -- | -- | High |
| 6.2.1.3    | Public – Sentinel Events | Incident Management | Patient safety root cause analysis | -- | -- | -- | Moderate (could be high if more data were available) |
| 6.2.1.4    | Oversight | --          | Bottle necks in care pathways | -- | -- | -- | Moderate |

**State - NGO**

<p>| 6.2.2.1    | --        | --         | --             | Evidence gaps - policy making | Build evidence base for policy making | --        | --        | High |</p>
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<th>Operations</th>
<th>Reporting</th>
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<th>Org Reliance on data</th>
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<tr>
<td>6.2.2.2</td>
<td>--</td>
<td>Public – registry statistics</td>
<td>Trends in epidemiological data</td>
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<td>Evidence based resources for consumers</td>
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<td>6.2.2.3</td>
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<td>Service issues pertaining to general practice</td>
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<td>6.2.2.4</td>
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**Local - Government**

| 6.3.1.1    | --        | Oversight body; Subordinate body | Utilization, clinical processes, health outcomes | Bottle necks in care pathways | -- | -- | -- | High |
|------------|-----------|----------------------------------|-----------------------------------------------|-------------------------------|----------|------------|--------------------|
| 6.3.1.2    | --        | --                                | --                                           | Intervention efficacy, barriers, facilitators | -- | -- | -- | Moderate |

**Local - NGO**

<p>| 6.3.2.1    | Manage clinical care; bill payers | Oversight body; Subordinate body; Clinical teams | Utilization, clinical processes, | Bottle necks in care pathways | Provide evidence and supporting | Feedback on undesirable variances to MDTs | -- | High |</p>
<table>
<thead>
<tr>
<th>Operations</th>
<th>Reporting</th>
<th>Monitoring</th>
<th>Identification</th>
<th>Intervention Support</th>
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<th>Org Reliance on data</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td>health outcomes</td>
<td>figures to make changes</td>
<td></td>
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</tr>
</tbody>
</table>

**Individuals - Government**

6.4.1.1

- Manage clinical care; bill payers
- Oversight body – LHD; Clinical teams
- Adverse events

| Bottle necks in the screening pathways | Evidence base to improve bottle necks | Feedback on undesirable variances to MDTs | -- | -- | Moderate |

6.4.1.2

| -- | -- | -- | -- | -- | -- | -- | Moderate |

6.4.1.3

| -- | Clinical teams | Adverse events | Identify shortcomings and pitfalls | -- | -- | -- | Moderate |

**Individuals - NGO**

6.4.2.1

- Manage clinical care; bill payers
- Self-audit of clinical practice data
- Identify shortcomings in care delivery

| -- | -- | -- | -- | -- | -- | Low |

6.4.2.2

- Optimizing and rationalizing work load; resource allocation
- Identify shortcomings in care delivery

| -- | -- | -- | -- | -- | -- | Low |
6.5.3 Barriers and facilitators to using data for CI within a health system

The main barriers to the use of data in CI were related to data collection and management. Many informants reported a lack of trust in data due to inaccurate, inconsistent, and incomplete data. There appeared to be high variances in data collection practices. Data management concerns were primarily related to 3 areas: 1) lack of funding to undertake management processes (e.g., clean up, validation, follow up), inability to link to existing data resources, and 3) inability to share data due to fragmentations within the health system.

The main facilitator to data use would be improvement in quality of data such as to promote trust and confidence in decision making and availability of funding to support the setup, collection, management, analysis, and reporting of data.

Table 6-3 Overview of barriers to data collection and use

<table>
<thead>
<tr>
<th>Set Up</th>
<th>Collection</th>
<th>Management</th>
<th>Analysis</th>
<th>Reporting</th>
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<tbody>
<tr>
<td><strong>Commonwealth - Government</strong></td>
<td></td>
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<tr>
<td>6.1.1.1</td>
<td>Not set up to collect clinical outcomes data</td>
<td>Fragmentation – CW vs. State</td>
<td>--</td>
<td>Problem of attribution of outcomes</td>
</tr>
<tr>
<td>6.1.1.2</td>
<td>Not set up to collect intermediate epi data</td>
<td>Inconsistent data; Incomplete data</td>
<td>No data linkages</td>
<td>--</td>
</tr>
<tr>
<td>6.1.1.3</td>
<td>--</td>
<td>--</td>
<td>Inadequate data mgmt. support</td>
<td>--</td>
</tr>
<tr>
<td>6.1.1.4</td>
<td>Variable funding</td>
<td>Inaccurate data; Variable funding</td>
<td>Variable funding</td>
<td>Variable funding</td>
</tr>
<tr>
<td>6.1.1.5</td>
<td>--</td>
<td>Lack of automated collection; No enforcement of data submission requirements</td>
<td>Underuse of existing data (sharing)</td>
<td>--</td>
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<tr>
<td><strong>Commonwealth - NGO</strong></td>
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<td>Set Up</td>
<td>Collection</td>
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<td>6.1.2.1</td>
<td>--</td>
<td>Fragmentation – Govt. vs. NGO</td>
<td>Fragmentation – Govt. vs. NGO (sharing)</td>
<td>Performance measurement disagreement</td>
</tr>
<tr>
<td>6.1.2.2</td>
<td>--</td>
<td>Inaccurate data</td>
<td>No data linkages</td>
<td>Underuse of existing data for performance measurement</td>
</tr>
<tr>
<td>6.1.2.3</td>
<td>--</td>
<td>Inconsistent data</td>
<td>Privacy laws restrict sharing of patient data</td>
<td>Underuse of existing data for performance measurement</td>
</tr>
<tr>
<td>6.1.2.4</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>Fragmentation – individualized vs. standardized</td>
</tr>
<tr>
<td>6.1.2.5</td>
<td>Variable regulatory reporting requirements</td>
<td>--</td>
<td>Performance measurement disagreement (sharing)</td>
<td>--</td>
</tr>
<tr>
<td>6.1.2.6</td>
<td>--</td>
<td>--</td>
<td>Privacy concerns about data use, if shared</td>
<td>--</td>
</tr>
</tbody>
</table>

**State - Government**

<p>| 6.2.1.1 | -- | -- | No data linkages | -- | -- |
| 6.2.1.2 | Fragmentation – CW vs. State (forgetting key stakeholders) | Inconsistent data; Incomplete data; Inaccurate data; Irrelevant data; Fragmentation – CW vs. State (collection); | Poor documentation; Fragmentation – CW vs. State (access to data) | -- | -- |</p>
<table>
<thead>
<tr>
<th>Set Up</th>
<th>Collection</th>
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<th>Analysis</th>
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<tbody>
<tr>
<td>6.2.1.3</td>
<td>Lack of automated collection; lack of routine data</td>
<td>Fragmentation – Administrator vs. Clinician (no feedback)</td>
<td>--</td>
<td>No publication</td>
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<tr>
<td>6.2.1.4</td>
<td>Lack of capacity for routine data collection; inaccurate data</td>
<td>--</td>
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</tbody>
</table>

**State - NGO**

| 6.2.2.1 | Lack of funding | -- | -- | Underuse of existing data for performance measurement | No publications |
| 6.2.2.2 | -- | Unreliable data; inadequate data | -- | -- | -- |
| 6.2.2.3 | Lack of long-term outcomes data | -- | -- | -- | Fear of disclosure |
| 6.2.2.4 | -- | -- | Departmental silos | -- | Performance measurement disagreement |

**Local - Government**

| 6.3.1.1 | -- | -- | -- | Lack of political will (to measure) | Lack of political will (to know) |
| 6.3.1.2 | Lack of funding | -- | -- | -- | -- |

**Local - NGO**
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<td>6.3.2.1</td>
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<td>Lack of standardized instruments</td>
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**Individual - Government**

| 6.4.1.1 | -- | Unreliable data | -- | Unreliable data | -- |
| 6.4.1.2 | -- | -- | Privacy concerns; Fragmentation – CW vs. State (sharing) | -- | -- |
| 6.4.1.3 | Complexity of health system | -- | -- | Performance measurement disagreement | Fragmentation – clinician vs. administrator; No accompanying resources |

**Individual - NGO**

<p>| 6.4.2.1 | Lack of resources; lack of automated collection | Fragmentation – clinician vs. administrator | No communication between data collector and provider |
| 6.4.2.2 | Inaccurate data | Performance measurement disagreement | No accompanying resources |</p>
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<td>Legislated data sharing agreements</td>
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<td>Automated health technology use</td>
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<td>Standardized coding systems (reduce variance)</td>
<td>Linkages to existing data (economic/clinical)</td>
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<td>Reliable data</td>
<td>Deidentified data</td>
<td>Aggregated data</td>
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**State - NGO**

| 6.2.2.1 | Research funding | -- | -- | -- | Safe culture of reporting |
| 6.2.2.2 | -- | -- | -- | -- | Effective mechanism for feedback |
| 6.2.2.3 | -- | -- | -- | -- | -- |
| 6.2.2.4 | -- | Financial incentives for data submission | -- | -- | -- |

**Local - Government**

| 6.3.1.1 | -- | -- | -- | -- | -- |
| 6.3.1.2 | -- | -- | -- | -- | -- |

**Local - NGO**

| 6.3.2.1 | -- | -- | -- | -- | Performance data reporting w/context |

**Individual - Government**

| 6.4.1.1 | -- | Funding to collect data | -- | -- | -- |
| 6.4.1.2 | -- | -- | Linkages to other data | -- | -- |
| 6.4.1.3 | -- | -- | -- | -- | -- |

**Individual - NGO**

| 6.4.2.1 | -- | -- | -- | -- | -- |
| 6.4.2.2 | -- | Accurate data; More resources | More resources | -- | -- |
7 Synthesis of Findings

This chapter will present a summary of key findings based on the individual level findings discussed in Chapters 5 and 6.

7.1 There were five key intervention points to for CI

This study indicated that there were three fundamental entities around whom (or whose interactions) care improvement activities revolved – the patient, the provider, and healthcare institutions (hospitals or clinics). Care improvement approaches targeted individual patients, providers, or institutions, and the patient-provider interactions and the provider-organization interactions.

Figure 7-1 Types of CI efforts within a health system

7.1.1 Patient-focused approaches

This approach aimed at improving care by focusing on empowering the recipients of the care. Care improvement strategies in this space included – 1) spreading awareness, 2) providing patient and caregiver resources to seek appropriate and timely care, and 3) giving them a voice in public policy and advocacy. Examples include awareness generation campaigns highlighting the importance of mental health checks among patients with cancer. Patient resources would include a checklist of questions that a patient could take to his/her consultation with a physician. An example of consumer advocacy involved training patients to be better represent real-life concerns of patients and to “put a human face” to a clinical condition during policy making discussion. Vast majority of these activities occurred in the non-government sector with larger organizations at the national and state levels being dominant in bringing about change. These organizations might be disease specific (e.g., heart, diabetes) or be formed around issues that are cross cutting (e.g., depression) across several disease areas.
7.1.2 Provider-focused approaches

The second approach aimed to improve the quality of the clinicians. The most common approaches was through – 1) education, 2) credentialing, 3) training, and 4) clinical guidance.

*Education* related activities tried to improve the basic medical training of clinicians and tailored the curriculum to reflect the changing practice of medicine. However, changing curriculum was a resource intense endeavor and could not be undertaken as frequently as would be necessary to stay truly responsive. Education and curriculum changes occurred in the non-government sector, overseen by organizations responsible for professional standards and ethics with funding by government agencies.

*Credentialing* was generally also done by professional standards setting and ethics bodies (NGOs) that generally operated at the national levels; these organizations worked with the state health departments to support state-specific credentialing requirements. Once physicians are credentialed, efforts to improve them continued through continuous medical education (CME) and other specialized trainings offered by various professional support agencies, which are again mostly NGOs.

The final approach was to provide *clinical guidance* such that physicians could uphold expected standards of clinical practice. These guidance documents took the form of treatment guidelines, checklists, and clinical pathways. Clinicians could follow this guidance to adhere to best practices in their areas of practice, thereby reducing variance in care delivery.

7.1.3 Institution-focused approaches

The third approach aimed to improve the quality of healthcare institutions (hospitals, clinics) through 3 primary approaches – 1) accreditation, 2) payer contracting, and 3) risk mitigation.

*Accreditation* was an attempt to maintain minimum standards for institutions. Accreditation, usually overseen by NGOs, was generally a flexible, multi-year process that may or may not be voluntary. In cases, where accreditation was voluntary, financial incentives could be lined up by payers, such that accreditation remained voluntary in name only.

*Payer contracting* tended to be broad-based directives requiring the contracted healthcare organizations to adhere to accepted standards of care and maintain industry standards, in order to obtain best possible reimbursement. Payer contracts aimed to improve the organizational (and not always the clinical) aspects of care delivery by leveraging the underlying business efficiencies of healthcare delivery. Pay-for-performance was a special case of payer contracting that was more detailed than most common kinds of payer contracts. The efficacy of these contracts in improving care was highly dependent on the level of enforcement and scrutiny that accompanied the contracts. Care improvement through payer contracting was done by government and non-government organizations.
Risk mitigation, in contrast to accreditation or payer contracting, was an internally-driven initiative at improving care. Risk mitigation involved routine internal monitoring of key efficacy and safety outcomes of high risk, high volume, or high visibility procedures to maintain institutional image. High risk procedures were procedures that are inherently risky in nature (e.g., obstetrics). High volume procedures were important because the healthcare institutions performed a lot of these (e.g., hip and knee replacements). High visibility procedures were those where even a small number of adverse events could cause disproportionately high levels of bad press or public outrage (e.g., deaths due to rare infections, staff negligence, or other breaches of protocol). Healthcare organizations desired to reduce its exposure to risk by improving care such that it retained both public trust and reduce the incidence of malpractice suits. In such cases, ongoing CI efforts could have an impact on the company bottom-line. Risk mitigation units could be local (parts of a healthcare organizations) or exist at state or national levels (for hospital chains with centralized corporate offices) and could be governmental or non-governmental.

7.1.4 Provider-Patient interface focused approaches

Yet another approach to improve care was by improving the processes at the patient-provider interface. This kind of care improvement is very communications focused. For example, when patients received care from a multi-disciplinary care team, it could be overwhelming for a patient to navigate the processes. In such cases, physicians may be specially trained to be cognizant of such situations or for dealing with delicate situations (e.g., delivering bad news, handling conditions like depression that have social stigmas attached to them). The other, often complementary, option was to provide access to allied healthcare professionals like case managers or patient navigators to help patients in their treatment journey.

Additionally, healthcare organizations could improve provider-patient interfaces using technologies like telehealth or e-health portals that could provide improved (faster) modes of communication between the patient and providers or their staff. These efforts generally occurred in the non-government sector.

7.1.5 Provider-Institution interface focused approaches

Attempts to influence the provider-healthcare organization relationships, primarily included peer credentialing, provider incentives, and provider feedback mechanisms.

Peer credentialing was a control mechanism where an applicant physician was vetted by a team of clinicians practicing at the organization prior to being granted practice privileges at the healthcare organization; this allowed the hospitals to maintain a certain minimum quality standards.

Incentive payments were another approach. Healthcare organizations could offer some or all of any incentive payments they received from payers for meeting certain target outcomes. For example, Medicare offered practice incentive payments for achieving high rates of immunization rates and these could be shared by the practice with individual clinicians to encourage good care giving practices.
Feedback was the process of closing the loop on provider-institution communications. Healthcare organizations had a system of feedback that allowed communication between hospital administrators and clinicians. If there was a problem, then administrators could communicate with the physicians (generally through clinician leaders) to improve performance on those issues. Hospitals and clinicians had an organic relationship that allowed for several ways to influence each other to provide better care all around.

7.1.6 Health ecosystem focused approaches

Finally, all three central entities – the patients, the providers, and healthcare institutions -- influenced the ecosystem within which they operated through membership in advocacy organizations. Patient advocacy bodies spread awareness around a wide range of activities that could improve the experience of patients as they navigate through the healthcare system. One example of such impact was through the initiation of a legislative bill that would allow terminally ill patients earlier access to their retirement funds without penalty. An example of provider advocacy would be through changing (e.g., adding new procedure codes, increasing the rate of existing codes) payment and reimbursement structures for various procedures or to get payments for certain kinds of emerging clinical workforce – e.g., nurse practitioners or physician extenders that were increasingly being used to fill in for traditional physician roles. Example of institutional advocacy (or industry advocacy) bodies included efforts to streamline reporting requirements for various regulatory bodies. The government was a key partner in these ecosystem modification efforts because they had the legislative power to bring about sweeping changes through resource allocation and policymaking to improve equity, access, governance, accountability, and innovation.

The various CI efforts described in Figure 7-1 provided a piece-by-piece description of how various attempts were made to improve various aspects of the patient-provider-healthcare institution triad. In order to provide a better context to CI within a health system, a framework was designed in Figure 7-2.

This framework includes not only the triad described above, but all also depicts several additional stakeholders (depicted in red) who influence various aspects of the triad. In turn, these stakeholders carried back concerns from members back to their organizations, setting the stage for advocacy efforts to provide a better health ecosystem for stakeholders. Thus, these intermediary organizations provided a two-way interaction between a health system and its key CI actors. These figures in red are sometimes government organizations, but mostly consisted of members of the NGO sector.
Figure 7-2 Framework for understanding CI within a health system

Note: Oval is the health system within all actors are embedded. Figures in red are organizations involved in CI at various intervention points (patients, providers, institutions and relationships between these entities).
7.2 NGOs play a critical set of roles for CI within health systems

While the government sector was invaluable in CI efforts that required authorities that were uniquely available to government agencies, like legislative or policy change, the data indicate that governments were very dependent on NGOs to help achieve CI. NGOs were valuable for several reasons, six of which are noted below:

7.2.1 NGOs can directly influence key stakeholders

NGOs came in many shapes and forms, which allowed them to connect with individual professionals and patients across a broad range of issues (e.g., support, advocacy). Governments on the other hand, even in its most powerful role as a payer were not necessarily successful in connecting with individuals at this level. Informants consistently pointed out that providers tended to be independent spirited and resisted attempts to be directly controlled by the government. In such situations NGOs stepped in to serve as the intermediary in a variety of CI endeavors such as awareness generation, training, and support. Similarly, governments did not have direct connections with patients and all CI efforts were undertaken through NGOs with direct connections with the patients. Government agencies generally tended to contract with NGO around resource intense care improvement activities (e.g., curriculum revisions), whereas less resource intense activities (e.g., patient awareness brochures) could be done using private funding from NGOs alone.

7.2.2 NGOs can do CI in highly specialized areas

Most informants from government organizations indicated engaging in CI activities that were broad based and general in nature and not specific to any one therapeutic area due to the limited resources. CI activities that were focused on specific therapeutic areas and/or groups of people/professionals were conducted through the NGO sector, which were in a better position to respond to unmet needs of a diverse group of stakeholders (disease specific, people specific, purpose specific) in due to inherent diversity in the nature and purpose of the NGO sector.

7.2.3 NGOs serve as generators and disseminators of CI related knowledge

A bulk of the research knowledge (and data) was generated in the non-government sector. NGOs generated and disseminated knowledge needed to bolster CI efforts. Knowledge was generated through contracts (e.g., research grants); conversely, some NGOs also commissioned knowledge generation activities as funders. Examples of CI knowledge generated and disseminated included treatment guidelines, treatment pathways, clinical performance measures by disease and/or professional focused NGOs. Systematic evidence generation, comparative effectiveness and program evaluation was done by contract research NGOs. Epidemiological and interventional research data (e.g., trying out new CI changes) are often generated by academic NGOs. Similarly, certain disease specific NGOs generated
data through participation in research (e.g., allowing scientists access to disease-specific patient registries).

7.2.4 NGOs can mitigate concerns of governmental conflicts of interest

In certain cases, like enforcement of standards for individuals (e.g., credentialing) or organizations (e.g., accreditation) were done through the NGOs sector. This allowed the government organizations to keep an arm’s distance from enforcement roles where there might be conflicts of interest (e.g., where the government owned and or operated healthcare organizations). Similarly, standard setting (e.g., performance measures) that often form the underlying standards for regulators were also generated by the NGO sector for similar reasons.

7.2.5 NGOs can act as independent monitors of governmental CI policies

Influential or well-respected NGOs were valued for their ability to critique government policy-making or take a position that may be unpopular. These NGO could potentially point out issues that government employees might not be able to put forth due to professional or political concerns. Thus, NGOs serve as very important counterbalance to work done by the government organizations.

7.2.6 NGOs subsidize CI through private fundraising

Many NGOs undertook varying levels of private fundraising to achieve their goals, some of which were essentially public goods (e.g., public immunization, population screening programs). Traditionally the role of providing for the public good was a responsibility of the public sector and consequently NGOs that participated in these activities effectively served to reduce the burden on and to subsidize the public sector.
7.3 CI is a payer driven effort

The interviews revealed that payers were the better equipped to drive CI within a system. Both administrators and clinicians indicated that monetary incentives were key to driving CI activities, making the role of a payer crucial in driving CI.

7.3.1 CI is often undertaken in response to money or in anticipation of money

Data indicated a wide-range of motivations to pursue CI – organizations that existed on multiple levels of a health system (governments, payers, advocacy/support organizations, healthcare organizations,) as opposed to organizations that tended to exist in primarily one level (e.g., individual providers, standard setting, mostly national, researchers, mostly local), appeared more likely to engage in CI for non-clinical reasons. Three key motivators for CI emerged; understanding the differing underlying motivators for care improvement could promote a better understanding of more effective stakeholder engagement strategies and the ability to understand the role of payers in this process.

7.1.3.1 CI for intrinsic reasons

Improving care was in itself a laudable goal. All entities reported clinical motivations to improve care including the desire to provide the best possible care, to uphold professional and industry standards, to promote evidence-based medicine, and in general, to help build and maintain a healthy population. These were standard motivations for CI. However, data indicated that organizations and individuals that engaged in CI for intrinsic reasons alone were outliers within the health system.

7.1.3.2 CI for bottom-line purposes (in anticipation of money)

The non-clinical reasons for improving care highlighted the fact that healthcare was as much a business as it is about doing good. CI or even the “reputation” of engaging in CI served as a powerful business value proposition, which, when marketed well, served to attract more patients and better clinical talent. Thus, CI could be good for business and the bottom line. For example, in certain circumstances, clinicians could make more revenue, if they provided the guideline recommended care (e.g., certain number tests or followed up as recommended) than what they would if they disregarded the guidelines. Similarly, CI could reduce safety risks (e.g., of falls or infections) and bolster the profitability due to fewer malpractice suits.

In Australia, private payers (minority payer) noted leveraging the fear of public health systems failing to come through in times of a health need. This fear was to some extent promoted by extensive media coverage of public healthcare system debacles like long emergency departments wait times, staffing shortages, and safety incidents. This dynamic has triggered an interesting relationship between the public-private insurance systems in that the private system tracked the “failures” of the public system to sell their product; every time the public sector failed to deliver quality care, the private sector benefited.
from that negative publicity. The flipside of benefitting from the failures of the public sector meant that the private sector insurers had to work hard to make sure that they “do not devalue that [benefit] equation” by having their subscribers face similar suboptimal care situations.

7.1.3.3 CI for accountability purposes (in response to money)

Governments improved care to improve their financial accountability by investing in services that were efficient and high performing. For example, commonwealth governments used data to figure out which facilities were high performing and which facilities were struggling. Subsequently they allocated resources to bolster weaker facilities and reward high performing facilities. They also improved care to reflect the broader societal values like equity by investing in reduction of disparities in care (e.g., by improving access) and outcomes.

7.3.2 Clinicians participate in but do not drive CI

The money driven nature of CI meant that most individual clinicians were not in a position to drive CI. The clinicians reported being too busy providing care to engage in any continuous CI projects. Individual clinicians also reported working in resource stressed environments that did not provide the support needed to undertake and sustain CI efforts. Moreover, many healthcare organizations did not have any formal internal frameworks to guide any efforts, leading to a high dependence on external agencies or processes (e.g., participation in clinical trials) to instill some sense of standardization of daily care processes.

7.4 CI is a top-down effort

7.4.1 Specialization of CI roles

The data indicated that organizations at higher levels of the health system played greater number of roles in improving care and this pattern stayed consistent across both government and non-government sectors (Table 7-1 Distribution of CI roles, by level and sector). Some roles — like regulation — were consistently undertaken by the NGO sector whereas innovation was a government role. Commonwealth and states organizations reported an average of 6 or so roles, where as local organizations only reported 3 of these roles.

Table 7-1 Distribution of CI roles, by level and sector

<table>
<thead>
<tr>
<th>Level</th>
<th>Number of CI roles</th>
<th>Exclusive CI roles</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Government</td>
<td>Non-Government</td>
</tr>
<tr>
<td><strong>Commonwealth</strong></td>
<td>6/9</td>
<td>7/9</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>State</strong></td>
<td>6/9</td>
<td>5/9</td>
</tr>
</tbody>
</table>
### 7.4.2 Specialization of CI targets

The data also indicated that organizations at higher levels of the health system not only played greater number of roles in improving care but also had a more diverse range of interventions that were aimed at a wider range of targets including physicians, patients, healthcare organizations, and health system, whereas local level organizations largely focused on targeting only two or so targets per sector.

#### Table 7-2 Distribution of CI targets, by level and sector

<table>
<thead>
<tr>
<th>Level</th>
<th>Government</th>
<th>Non-Government</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MD</td>
<td>PT</td>
</tr>
<tr>
<td>Commonwealth</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>State</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Local</td>
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</tr>
</tbody>
</table>

Note: MD=Physician; PT=Patient; HO=Healthcare organization; M/P=Physician-Patient interface; M/H=Physician-Healthcare organization interface; HSY=Health System; OT=Other

These data imply that specialization in CI activities occurred closer to service delivery (i.e., closer to the fore front of care). Organizations at higher levels of the health system are more likely to have multi-pronged approach to improving care compared to local or individuals, thereby indicating that organizations at the top were the true visionaries of CI. Consequently, it might also be expected that organizations at commonwealth and state levels would have more diverse CI-related data needs (e.g., financial, utilization, clinical) compared to local organizations.

### 7.5 Successful CI efforts may result in negative system feedback

Successful CI efforts in conducted in one part of the health system might have negative repercussions up and down the treatment pathway. In extreme cases, negative consequences include loss of physician autonomy and cost-shifting.
7.5.1 Successful CI can stress out weaker links in a health system

In certain places of the health system, the struggle to offer basic services is so real that improving care is the last priority. This can be particularly true in rural areas with low density of care providers (general and specialty) or organizations where the demand for services far exceeds the staffing or funding available to provide those services. In such cases, any monetary aid offered (including money from competitive care improvement grants) is going to be redirected to provisioning of basic services instead of being invested in projects that are aimed at improving care delivery.

Due to the connected nature of the healthcare system, in resource, strained situations like these, successful care improvement efforts in one area might result in a system feedback that stresses the overall healthcare system in other ways. For example, a commonwealth population health screening program could direct large number of people from screening onto the state-run treatment facilities that may or may not enough infrastructure or availability of trained staff (e.g., shortage of trained staff to perform colonoscopies) to handle this increased flow of patients. Thus, providing better care or even more efficient systems may stress out other parts of what is an inter-connected health system.

Yet another example of CI related stressing within a health system arise from data-driven pursuits of CI that required detection of problems prior to fixing. In certain cases, detection of problems alone had a deleterious effect on staff morale. As one informant explained that the more people dug into data looking for problems with care delivery, the more likely they were to detect problems with care. Thus, CI attempts could suddenly make a health systems appear worse on paper compared to real life, triggering a negative feedback cycle. Similarly, CI attempts at providing, usually critical, feedback to individuals or teams without the provisioning of additional resources to help address the problem led to worse staff performance and care delivery.

7.5.2 Generates perverse incentives to shift costs from weaker to stronger parts

In a joint public-private payer system, there was a lot of incentive for cash strapped public sector to reduce its obligations to the public. There are two ways to achieve this: 1) by providing less than acceptable levels of care in certain areas, and/or 2) through reorganizations of care delivery such that all (or part) of the care is now delivered in a different setting.

The idea behind the first strategy is that as public confidence in the publicly funded health system plummeted, more people would invest in private health insurance and get their care in private hospitals, thereby relieving some of the stress on the public sector. For example, state government facilities that were stressed out due to the high influx of colonoscopy patients from the commonwealth colorectal cancer screening program responded to this stress by increasing colonoscopy wait times, thereby prompting some patients to seek out colonoscopies at private facilities covered by their private insurance which resulted in some cost shifting from the public to the private sector. When the costs were shifted to
the private sector, it was often able to bear the cost, but lacked both the infrastructure and the human
capital that was needed to deliver in the face of increasing workload. Similar cost shifting can occur
across any natural fragmentations. An example of the second strategy included a reversal in cost shifting
by states on to the commonwealth by reducing the length of state hospital stays, which could be achieved
by sending patients home earlier but sicker and on expensive drugs covered by the commonwealth’s
pharmacy benefits. Thus, cost shifting provided continued coverage of services at the expense of
uncertain quality of infrastructure or treatment.

7.6 There were 7 uses of data to achieve 4 fundamental end goals

Using inductive analysis, this analysis found six different categories of data use for doing care
improvement work – 1) operations, 2) performance reporting, 3) monitoring, 4) identification, 5)
intervention support, 6) providing feedback/program evaluation. Each of these categories were defined
and discussed in detail below.

The six identified categories of data use in a system were interconnected. A closer examination of these
categories indicated a hierarchical connection between some of these categories. This analysis indicated
that the six categories of data use could be reduced to achieve four primary end goals – operations,
knowledge generation, reporting, and care improvement (Figure 7-3). These primary categories were
freestanding and one or more categories could be mixed and matched to create any desired action. For
example, an organization that had no need to improve could simply use data for operational purposes.

At the very least most organizations use data for operational purposes. If the organization had a duty to
report, internally or externally, it could be indicated with the addition of that function. On the other hand, if
the company had a problem and needed improvement, then a system to monitor existing data or set up a
new system to initiate collection of relevant data could be established as well.

CI started with monitoring. Once a monitoring system had been put in place the next question was to
figure out if there is a problem. If monitoring identified a problem then new (often project specific data) or
existing data could be used to identify the problems, its causes, and in general get better insights into the
issue. The next step would be to decide if there is an already available solution (using existing
knowledge) or if there is a need to create a new solution. If the solution existed then it would get
implemented and data would be collected for feedback and/or program evaluation, creating a continuous
CI cycle. If the solution did not exist, then data would be used to identify alternate solutions. While many
organizations made judicious use of data throughout the process, intervention support was often intuition
driven, mostly due to time and financial constraints (e.g., no time/resources to invest in a review of the
evidence base around the proposed interventions) that prevented the use of data. When the
intervention(s) were chosen and implemented, data were collected for feedback and/or for program
evaluation and monitoring of this change. These care improvement efforts may or may not come with
reporting requirements; hence it was appropriate that data use for reporting is an independent category to be chosen depending on need.

**Figure 7-3 Relationship between various categories of data use in a health system**

7.6.1 Data Use – Operations

This category included the use of data to serve and improve the day-to-day operations of an organization. Examples in this category included the use of data to for reimbursement, uphold regulatory standards, offer incentives, and to aid decision-making about service provisioning and resource allocation.

Operations data were used to improve care and was most commonly used by administrators. The use of data for operational purposes were most commonly reported by organizations that were payers (public or private) or those that routinely interface with payers (e.g., healthcare organizations).

7.6.1.1 Incentive setting/demand generation

This was a common use of operations data by payers. Payers tracked healthcare utilization (inpatient, outpatient, pharmaceutical) and used these to incentivize the uptake of certain kinds of services (e.g., certain levels of immunizations). Some sophisticated payers could even cobble together a sense of the health status of individuals from the claims data and some chose to intervene, indirectly through the
physician, to promote certain healthy behaviors (e.g., check for polypharmacy, get screened for a condition). However, most payers expressed a strong reluctance to intervene into clinical matters due to negative experiences (usually pushback from clinicians). While clinicians appreciated any intervention that reduced their administrative burden (e.g., reminders for pap screens), they did not appreciate any direct interference with clinical care delivery from payers.

7.6.1.2 Obtain and maintain regulatory approvals

Local organizations like private practices/hospitals used routine data for billing and to generate all the organizational performance metrics required to receive and/or maintain their accreditation status from regulatory agencies.

7.6.2 Data Use - Care Improvement

7.6.2.1 Monitoring

This category of data use was one of the most prevalent within the health system and could be found at all four levels studied here. This finding makes sense because theoretically-grounded CI efforts were cyclical by nature and needed a system to monitor deviations from the desired quality levels. For example, public health agencies monitored the general health status of the people and also used active surveillance to protect against biological threats. Insurers and payers used data to monitor service payments, healthcare utilization, and patient satisfaction. Healthcare facilities (both public and private) monitored performance on quality and safety metrics. Commonwealth and state government agencies monitored the trends and the availability of clinical and non-clinical workforce to staff their healthcare facilities. Individual practitioners used data to monitor and manage the clinical care received by their patients with chronic health conditions. However, despite common use of data for monitoring, many CI efforts stopped here due to lack of traction for further effort in the real world.

7.6.2.2 Problem identification

This was the use of data to understand and identify any unusual or negative deviations from trends, which were usually indicative of problems. Further, data could be used to hypothesize causes and identify drivers of success and failure, get a sense of the bigger picture and to identify gaps in service or coverage. For example, commonwealth NGO advocacy organizations used health data to identify “pressure points and intersection points for people.” On the other hand, commonwealth level government agencies use data to identify service gaps - areas that needed more intensive interventions and identified factors associated with high or low performing services. Local health districts in conjunction with state and local professional advocacy organizations used a combination of service usage data and social data to identify problem “hot spots” and its potential causes like low socioeconomic status, high single parents, high migration of families or even provider/practice level characteristics (e.g., no bulk billing by physicians). It appeared that combining social and health services data provided a more powerful way to
gain insights into a problem and solve it compared to what could have been achieved through the use of any one of those data sets alone.

7.6.2.3 Intervention selection

This included activities that were designed to help in the identification, choice and implementation of safety or quality improving interventions. Examples of data use in this category included the use of data to engage stakeholders, to establish quality measures, to support choice of an intervention strategy, to support learning and the development of a new intervention. Commonwealth and state government agencies provided data to national standard setting bodies to develop cancer care indicators; a state NGO policy think tank was also involved in this effort. Some of the measurement work was also accompanied by strategies to feed these indicators into either an existing accreditation system or into a new accreditation system to ensure incorporation into quality standards and enforcement. The use of data to support the development of quality and safety interventions was more prevalent within the NGO sector of the health system. Examples of such data-driven efforts included interventions in the form of hospital toolkits, checklists, and routine clinical audits.

7.6.2.4 Feedback/Program Evaluation

The final category of data use is for feedback or program evaluation. Feedback is different from reporting in that it presents information with the deliberate aim of bringing about change in the recipient(s). Most of the recipients of feedback within a health system are at the local/individual levels like clinicians/clinical teams or provider organizations like hospitals and practices. For example, state health departments used data to compare how the state-run healthcare facilities are doing compared to their peers at the local and state levels. Local professional support divisions use data to compare how their physician members are doing compared to their peers at the local, state, and national levels; they also use local practice generated data to provide feedback on how a practice could aim to optimize its revenues through proper follow up of patients because lost follow ups add up to lost revenues. Local hospitals provide feedback to clinicians at section meeting about quality and performance issues.

7.6.3 Data Use – Reporting

The third major category of data use within a health system was for the purposes of reporting. This made sense because periodic performance reporting was a common requirement within the highly regulated and increasingly accountable field of healthcare. This use of data were further classified into four sub-categories based on the intended consumer of the reports. These recipient categories are: 1) oversight bodies (internal/external), 2) subordinate bodies, 3) clinical teams, and 4) the public.
7.6.3.1 Oversight entities

These could be external or internal. Commonwealth level government agencies were required to report on the performance of their screening programs to an external oversight agency, which in turn reported to a commission charged with oversight of productivity (or performance) of all government run programs. State level government agencies had similar requirements to report on a series of national indicators to the national Parliament. These were examples of reporting to an external oversight committee. At a lower level, provider organizations like hospitals, both public and private, reported on a host of indicators to external regulatory agencies. Similarly, performance was often reported to internal oversight committees which were generally in the form of an administrative body. Hospitals that operated as part of a larger chains routinely report on quality and safety metrics to its regional and national level administrators. These reports are used to compare performance and helped bring on the radar any potential quality and/or safety issues.

7.6.3.2 Subordinate entities

This category includes any flow of reporting data from an agency higher up in the health system to an agency embedded at lower level. For example, the private hospitals share risk mitigation reports with the appropriate state liaisons who then relay the findings to local hospitals for remediation. Commonwealth government reports on the performance of its population screening programs to the state health agencies. In the public-sector state health departments provide performance reports to local health departments on their key initiatives around safety and quality.

7.6.3.3 Clinical teams

Another specific type of performance reporting that occurred within the organizational setting was reporting on the performance of a clinical care team. Multidisciplinary teams (MDTs) were often responsible for providing comprehensive cancer care. Hospitals with advanced data collection and management systems could report on the team’s performance on indicators like survival statistics. These reports were then used in conjunction with baseline data from state clinical cancer registries to evaluate the MDT’s performance.

7.6.3.4 Public

CI related performance reporting was pretty exclusively carried out by government agencies at both the Commonwealth and State levels. In Australia, the government was the largest provider and payer of health services in the country, and as a result they were also responsible for upholding the public trust through transparency and accountability. Even though the focus of the reports might be different, both levels of government provided some degree of safety and quality reporting to the public. For example, as a payer, the commonwealth was more concerned about fiscal accountability. The States on the other hand were more concerned with performance accountability because they administered most of the
public healthcare facilities. The power of public reporting was summed by very nicely in this quote, “It’s about publication. It’s about public knowledge, but in this particular sense, it’s not the public that’s finding out, it’s your peers finding out, and the one thing you don’t like is being poorly performing against your peers.” Private healthcare sector, both in the form of private practice and private hospitals were not subjected to the same levels of accountability to the public.

7.7 Data sharing occurred in response to funding in 5 distinct patterns

**Figure 7-4 Overall patterns of data and money flow within a health system**

At the very top of this health system sat the peak governmental agency (in this case, the Australian Parliament, Figure 7-4); beneath this sit the federal government healthcare and affiliated bodies (indicated in purple). This level included agencies that operated at the highest (or national levels). One layer down in the hierarchy were the state level health departments. It was important to note that even though state governments were considered at a different level than the federal bodies; this should not be construed to imply a subordinate status of the agencies themselves. In Australia, as in the United States, state and federal governments were, in theory, equal with demarcation of powers and authority.
Underneath the state governments were local or area level (indicated in blue) government and non-government organizations. Finally, there were individuals, clearly distinguished as providers (physicians) and patients. Finally, there were certain organizations that existed at several levels (e.g., national level organization with state and local level chapters) of the healthcare system; these organizations were indicated in white.

7.7.1 Pattern 1 - Accountability

This relationship was characterized by the one-way flow of data from one organization to another, in response to funding. These relationships were seen across all levels, but are more prominently seen within the government sector. Generally, these relationships occurred when there is one entity is a payer in-charge of distributing resources and the recipient of these resources.

**Figure 7-5 Accountability related data-money flows in the health system**

Note: Purple boxes are commonwealth organizations, yellow boxes represent state organizations, blue boxes represent local organizations, green boxes represent individuals. Clear boxes represent organizations that could exist on multiple levels within a system. Organizations are aggregated across type, sector, or levels (i.e., exact configuration for individual player might differ).

The reporting of data is to the payer entity and generally constituted the fulfillment of an accountability relationship. For example, state governments provided program performance data to commonwealth
government in exchange for funding; similarly, local health departments provided data to state health departments in exchange for funding. Individual physicians provided claims data to commonwealth government in exchange for payment and incentives. Generally, the senders of data did not know what was done with the data – i.e., the data essentially vanished once it was sent. These kinds of relationships were common in the highest tiers of the government sector, especially in areas of public health, where the nature of the programs was so large that it was not possible to provide individual feedback. The downside to this one-way relationship was the possibility of disengagement by the providers of data, which may or may not be mitigated by additional incentive payments.

7.7.2 Pattern 2 - Direct care improvement

This relationship was characterized by a two-way flow of data and a one-way flow of funding between two organizations (Figure 7-5).

Figure 7-6 Direct CI related data-money flows in the health system

Note: Purple boxes are commonwealth organizations, yellow boxes represent state organizations, blue boxes represent local organizations, green boxes represent individuals. Clear boxes represent organizations that could exist on multiple levels within a system. Organizations are aggregated across type, sector, or levels (i.e., exact configuration for individual player might differ).
For example, state health departments provided feedback to local health departments. The flows were like the accountability pattern, but the two-way data feedback loop made a huge difference in the impact of this relationship. The data that were being fed back to the sender by the payer, were usually designed to evaluate the sender’s performance in a domain of care (e.g., rate of immunization) and this data could be used for future CI efforts by the sender of data. These kinds of relationships occurred both in the private and the public sector, especially at the state and local levels, which were closer to clinical care provisioning.

7.7.3 Pattern 3 - Indirect care improvement through contracts

These data-money flows (Figure 7-6 and Figure 7-7) were characterized by one way across sector flow of data and money; this pattern can be seen at levels of the health system. There were two variants within these cases. While the pattern of money and data flows remained the same in both cases, the purpose was of the relationship was different.

7.7.3.1 Implementation and support

Figure 7-7 Implementation and support related data-money flows within health systems

Note: Purple boxes are commonwealth organizations, yellow boxes represent state organizations, blue boxes represent local organizations, green boxes represent individuals. Clear boxes represent organizations that could exist on multiple levels within a system. Organizations are aggregated across type, sector, or levels (i.e., exact configuration for individual player might differ).
In the first case, money and data flowed from government institutions to non-government support organizations. This kind of pattern indicated the presence of CI contracts that were implementation oriented. For example, government agencies rolling out new population screening programs would enlist the help of physician support bodies to spread awareness about the program and to train physicians around the clinical and administrative changes resulting from the program. Another example would be the use of these contracts to help physicians with setting up HIT systems or to teach physicians and practice staff how to clean and manipulate practice data to obtain key performance metrics.

7.7.3.2 Knowledge generation and dissemination

Figure 7-8 Research and dissemination related data-money flows in the health system

In the second pattern money and data flowed from government institutions to non-government research and voluntary health organizations. This kind of pattern indicated the presence of CI contracts that were designed to generate and disseminate knowledge. Non-government organizations relied heavily on government funds but also raised their own funds to generate all the knowledge that is available within a
health system. For example, governments funded academic researchers to develop and test interventions to increase the detection rates for psychosocial distress in cancer patients during routine check ups.

7.7.4 Pattern 4 - Regulatory approval

This relationship (Figure 7-9) was characterized by a two-way flow of data and a one-way flow of money from data sender to data recipient. These kinds of relationships generally occurred between providers or healthcare organization and regulatory bodies. For example, hospitals submitted performance data and paid a fee to undergo accreditation by a regulatory body. Similarly, physicians paid a fee and took tests to be credentialed by professional standard setting organizations. This relationship was different compared to direct care improvement relationships in the direction of the flow of money. In the direct care improvement relationships, the payer gave feedback; in the regulatory approval relationship, the payer received feedback.

Figure 7-9 Regulatory approval related data-money flows within the health system

Note: Purple boxes are commonwealth organizations, yellow boxes represent state organizations, blue boxes represent local organizations, green boxes represent individuals. Clear boxes represent organizations that could exist on multiple levels within a system. Organizations were aggregated across type, sector, or levels (i.e., exact configuration for individual player might differ).
7.7.5 Pattern 5 - Transparency

This relationship was characterized by a one-way flow of data in the absence of any overt flow of money (Figure 7-10). This did not mean that money did not flow between the two entities. For example, government agencies provided hospital performance reports and national health status (morbidity, mortality for key conditions) data in the public domain. These were undertaken for to remain transparent and to empower the public (the tax payer) to make better care choices.

Figure 7-10 Transparency related data-money flows within the health system

Note: Purple boxes are commonwealth organizations, yellow boxes represent state organizations, blue boxes represent local organizations, green boxes represent individuals. Clear boxes represent organizations that could exist on multiple levels within a system. Organizations were aggregated across type, sector, or levels (i.e., exact configuration for individual player might differ).
7.8 Existing data resources were underutilized

Data collection and management systems were very resource intense investments, so, in the absence of external subsidies (e.g., government schemes) most organizations did not want to invest in it unless they had some way of using or leveraging the data to obtain maximum return on their investment. Organizations that collected data for one purpose did not maximize it reusing it for other appropriate uses were said to “underutilized” their data. The underutilization of existing data resources was a common theme across levels and sectors.

Several informants noted that most physicians used their HIT as a direct replacement for paper records or for writing prescriptions. More sophisticated features like decision support went largely underutilized. Similarly, data collected by HIT were also underutilized for a few different reasons, described below.

7.8.1 Data quality is suboptimal

Data were described as inconsistent, incomplete, and inaccurate. Inconsistency had to do with variances in the data collection process which hampered both the data quality of at the lowest unit level but also the ability to compare across units. For example, informants reported that local cancer registries shared few or no common data points, making any local comparisons of health outcomes nearly impossible. This occurred partly due to variable levels of resourcing available to various local registries. Some registries did not have the resources required to clean and manage their data.

Incompleteness of data referred to completion of only a subset of the required data points. For example, commonwealth government officials responsible for population health programs noted that physicians participating in the screening program did not completely fill out all requested data, resulting in high levels of missing data.

Inaccuracy related issues were around errors in the value of the data. Several informants reported an error in a commonwealth report which erroneously switched the fractions of colorectal cancer care conducted within the public and private health sectors. This would have led to subsequent care provisioning (how much staffing? Budgeting?) problems by data users at the state government level, had it not been detected.

Together, these issues reduced the level of confidence individuals and decision makers could put in the data. While some informants expressed the desire to do the best, given the quality of data at hand, others expressed reluctance to base any policy decisions using the flawed data. For example, physicians, healthcare administrators, and professional advocacy bodies expressed persistent concerns about the use of performance measures derived from faulty data.
7.8.2 Data collected is irrelevant to some stakeholders

This occurred when the data being collected were such that they did not serve the needs of all the key stakeholders. Sometimes this could occur when a key stakeholder was not consulted or did not participate in the database development process. In cases where there was stakeholder participation this could occur due to couple of reasons: 1) the relevant data variables are missing in the data set, or 2) the level of granularity or response options are inadequate. The former case occurred when databases failed to evolve in response to changing needs. For example, epidemiological databases collected incidence and mortality data while overlooking other relevant variables like cancer staging at diagnosis or treatment seeking behavior, thereby limiting usage beyond basic epidemiology like helping states with service planning or even understanding disease progression.

The latter case involved inappropriate levels of data aggregation (e.g., state level data when local level data were needed to intervene) that is inappropriate for meaningful use by another stakeholder or lack of meaningful codes that will enable differentiation and subsequent intervention. This problem occurred when several organizations collaborate on a complex CI project and the dataset designers overlooked input from key stakeholders or failed to account for organizational data sharing agreements with other entities. Sometimes, there were several bureaucratic barriers (e.g., controls over form development and deployment lie with someone else) that made it difficult to achieve alignment and resolve any issues in a timely manner. Problems like this could result in “data dumps” and underuse of data, even when data were shared, and inefficient use of existing resources.

7.8.3 The administrative burden of linking and using data is too great

Several informants indicated their willingness to use data to improve care but noted very high levels of burden associated with data use and reporting. This was especially a problem for informants that were at the frontline of care giving, who are either too busy to engage in additional administrative duties or did not have the resources required to set up automated systems to facilitate data collection, management, and reporting.

Another type of burden arose in situations where informants had access to multiple complementary databases (e.g., inpatient visits, inpatient billing data) but the datasets could not be linked due to technological or political/legal restrictions. In such cases, there was a sense of frustration associated with the knowledge that data were available but with significant barriers to their use.

7.8.4 Privacy laws and reluctance to permit secondary use of data

While privacy laws were designed to protect illegal dissemination of patient information, these were often interpreted too stringently by entities that were not in favor of data sharing. Organizations, such as those designed to promote population health, often had broad data sharing powers granted by legislations, however, officials might choose a stricter interpretation to not share or not link the data to other datasets,
thereby reducing preventing a fuller picture from developing. Finally, certain older population based datasets were originally developed for very limited purposes (e.g., understanding disease epidemiology) and organizations might be hesitant to use that data for other purposes (e.g., to inform the development of population based interventions). Funding, adequate staffing, and automated systems were the most mentioned facilitators in the use of data in improving health care.

7.9 Data sharing was hindered by 3 overarching types of fragmentations

It was common for fragmentations to exist within any health system. Fragmentation resulting from naturally occurring differences in lines of authority across various domains hinder the easy flow of data within health systems. This means that special attention needs to be paid to the kinds of fragmentation that are expected to be encountered and necessary measures should be built in to overcome the barriers that these present to data flow. Fragmentation can disrupt the flow of data either due to inherent misalignments in the information collection and management processes or due to conflicts over control of information channels (i.e., ownership of data). Several kinds of fragmentation were noted:

7.9.1 Fragmentations resulting from sovereignty or ownership issues

This category of fragmentation could be thought of as a power struggle resulting in a tug-of-war between two or more somewhat similarly motivated (e.g., both interested in public health issues) entities.

7.9.1.1 Commonwealth vs. state governments

This was a common problem within federated systems due to the fundamentally sovereign nature of both governments. Further, data-related legislations, where applicable, governed the ability of these governments to share and or publish any collected data. Carefully crafted pieces of legislations, often tied to funding agreements, had been successfully used to facilitate data flow across this fragmentation. In the absence of funding ties, it is difficult to obtain cooperation or consensus, unless the problem was perceived as a pressing issue for both governments. In a system where healthcare responsibilities were divided between the two levels of government – priorities could be very different and obtaining alignment of CI interest could be a challenge.

7.9.1.2 Public vs. private sectors

There was a clear barrier in the flow of information across the public and private sectors. Both sectors had implemented health information systems at different rates and with different purposes in mind. The rate of HIT implementation differed because of two major factors: 1) magnitude of the investment, and 2) number of stakeholders. In the former, the government sector was at an advantage due to the large pool of resources. The size of the investments put several types of players (e.g., individual practitioners, smaller group practices) operating in the private sector at a disadvantage. In the latter, the private sector had an advantage because, typically, public sector agencies had a longer list of stakeholders and had to
jump through more hoops before they could undertake any resource intense project. Private sector stakeholders on the other hand, generally needed approval from fewer key stakeholders before they could undertake a project like this. As both sectors embarked on embracing HIT at their own paces, they designed systems that did not relate to each other. Generally, there was no need to relate, unless someone takes a bigger picture view. As a result, data were not collected in a consistent fashion and consequently could not be harmonized to form a complete picture of the care received by any patient. It was also noted that current legislations prohibited the mixing of data from public and private hospitals and this has interesting implications because most public coverage decisions are based on data from the public sector, however that data only reflected a part of the story for health conditions such as cancer, where the private sector is large player. Thus, public decision making was made based on incomplete data.

7.9.2 Fragmentations resulting from breadth or specificity issues

This kind of fragmentation hampered data flow due to the fundamentally different data needs for each stakeholder, making it extremely difficult to reconcile in one dataset. This kind of fragmentation was likely to produce irrelevant data from the perspective of one or more of the stakeholders.

7.9.2.1 General care vs. specialty care

Informants indicated that patient transitions between from cancer-specific care to primary care could be “brutal” – specialty cancer physicians did not show interest in managing the patient’s other comorbidities (generally done by GPs) and general practitioners shied away from the week-by-week management of the cancer care regimen undergone by patients (construed as the responsibility of specialists). Thus, there was a clear division of the turf on which each practitioner operated when in fact, the patient stood to benefit the most from a less clearly delineated approach to care where both physicians focused on providing the best care for all the entire patient instead of focusing on just the diseases within their turf. This break in continuity was especially relevant for cancer care where the screening and detection occurred through general practice but the treatment was overseen by a specialist; all this happened even as the GP remained responsible for managing the care of other existing or new health conditions. There was often little or no communication between the specialist care and GP. Many patients fell through these cracks in the system resulting in poorer health outcomes and inefficient use of available resources. In this case study, data did not flow easily between these two settings. Government agencies that administered the screening programs noted that it is hard for them to get data from screening program participants once they transition into treatment pathways that was administered outside of the GP’s office. This care transitions into “specialist land” which is no longer centralized (for the commonwealth) and getting access to specialist data was a difficult process.
7.9.2.2 Inpatient vs. outpatient settings

There was often no connection between inpatient and outpatient health information systems which prevented the seamless transfer of health information. Similarly, lack of connection of the public hospital systems with cancer registries made it impossible to automate the routine collection of these data. The government databases had extensive coverage of hospital data but much of the data outpatient cancer care data remains a “big blackhole.” Clinical service redesign programs only looked at the part of the story because it “often stops at the hospital door because the patient’s is gone.” However, they were back in the system and there was no sustainable way to look at the patient journey from primary care (outpatient) to acute inpatient care. It was important to get the whole picture because it is only by redesigning (or improving) the outpatient setting, where most of the care was happening, could the patients be treated to prevent avoidable hospitalizations.

7.9.2.3 Clinician vs. administrator roles

Several clinician informants and some informants from professional support organizations echoed a deep distrust and fragmentation in the relationship between clinicians and administrators (both local and higher up). This relationship was fragmented because clinicians considered administrators to be out of touch with the clinical realities, instead perceived them as bureaucrats or “people who sit in desks and never see a patient” who made too many unrealistic and aspirational demands from clinicians in terms improving care through the institutionalization of several programs that had essentially increased the administrative burden of physicians where they “sit around ticking little boxes that will make bureaucrats happy.”

The other issue was that efforts to improve care from the administrator’s perspective were not accompanied by a commensurate increase in resources, especially staffing. There was also a perceived element of misalignment in the goals of these two sets of actors - the administrators were perceived to be more focused on saving money than improving care. Clinicians expressed serious concerns about letting administrators control any performance measurement processes. They also expressed distrust on the consequences of handing individual level clinical performance data to administrators or bureaucrats who were viewed as being there to serve the purposes of the government or corporations, instead of physicians.

7.9.3 Fragmentations resulting from philosophical issues

This kind of fragmentation directly hampered data collection and indirectly hampered data flow by challenging the very need for data due to belief sets.
7.8.3.1 Standardized vs. individualized model of care

This was a fragmentation of perspectives about the nature of healthcare. Standardized care lend itself to routine collection and use of data to inform decision-making processes, in ways individualized care did not. Individualized care, by definition, treated healthcare on a case-by-case basis and made it harder to evaluate performance of individual providers. Thus, individual willingness, to invest in routine data collection, management, or reporting systems, or to believe in the validity of performance metrics could be driven by one’s perspective of the fundamental nature of healthcare processes. This fragmentation was one of the issues at the heart of disagreements around performance measurement. Performance measurement required agreement around the “healthcare can be standardized” school of thought, whereas physicians that believed in the “healthcare is individualized” school of thought did not think performance measurement could be a good reflection of their true merits as a physician.
8 Discussion

This research was one of the first attempts, to the best of our knowledge, at examining the role of data in CI within a developed health system. By not focusing on the role of data from a narrow post-HIT-implementation perspective, this study also provides an “outside, looking in” view which is different from what is obtained by the traditional evaluations conducted post failure of HIT projects.

1.5.1 Payers are the leaders in CI

Regarding CI, the first important thing to note is the payer-driven nature of CI. By virtue of being a payer-driven enterprise, CI is also a top down process, which can be understood once we understand the high demand for accountability faced by payers. Payers wish to demonstrate their accountability, financial and performance, by investing in high performing projects. As attractive as it sounds, CI is not suited to be a physician-driven process because physicians are too many in number with very few chain-of-command controls to coordinate efforts at an individual level. Moreover, most health systems are resource strained and physicians lacked the extra time to conduct CI work on top of their clinical and administrative duties. There is just not enough financial bandwidth for individual clinicians to invest in CI. Additionally, if you wish to understand the driver of CI within a health system, all that is needed to identify the biggest payer within the health system. The organization and sector that covers the largest proportion of expenses would be the leader. All other payers will likely follow the lead, in a publicly funded system, that payer is the government and that is when the government gets to lead CI. Currently most existing data resources are used for operations and reporting purposes. More data need to be used for the purposes of CI related knowledge generation and care improvement. As indicated by our findings, a lot of CI efforts are collaborative in nature and are undertaken by the NGO sector. In order to scale up knowledge generation and CI use of data, funders need to work with the NGO sector to provide required funding assistance.

1.5.2 The value of data is not politics free

While data are considered neutral in nature, data use is inherently political. When governments (as major payers) lead CI efforts, it is important to remember that it is nearly impossible to untangle CI from politics. All decisions are political at multiple levels – organizational, state and national. For example, at the organizational level, nearly all informants that worked closely with providers or were providers themselves indicated that most providers believed that they provided good care, even the absence of any objective evidence. What they meant is that doctors had a firm belief that they are doing the best they can under their particular operating circumstances and they hoped that would suffice. Use of data to measure performance amplifies that fear of being proven inadequate and feeds into of the desire to not look bad in front of peers. This fear of data can result in refusal to use data or to cooperate with other departments with the organization.
The impact of national and state politics is dependent on how the political system is set up (election cycles, health related positions held by political appointees). In such context, data are both power and also a problem. Data could provide the support to get people to rally around an idea, data could also be shunned as a way to avoid accountability that comes with knowledge of suboptimal performance. Thus, political will is key consideration when thinking about data, especially large-scale HIT projects, because such sweeping changes are often undertaken by government agencies. There is need to figure out beforehand how data will be fit within the political ethos of the health system because unless HIT implementation considers political environments, it will likely fail in fostering data utilization.

1.5.3 Data exhibit money-like characteristics

Data and HIT systems are expensive to collect, manage, and analyze, making it a valuable resource just like money. Once data have been collected, there is a sunk cost associated with it, which means that data, like money, offer the greatest benefits when shared or reused repeatedly. While some entities do not wish to share their data, there are other organizations which might wish to reap the greatest return on their investments by facilitating data sharing. Taking the money analogy and exploring how money gets used and reused by banks through the lending process, we can learn two lessons: 1) data sharing should have a transactional fee associated with it, and 2) data sharing should be accompanied by rules governing the sharing and use process.

There are few different things that policymakers can learn from this analogy. First, our findings go against one of the fundamental assumptions underlying some of the large-scale HIT projects that assumed that once organizations had HIT systems, they would want to share data. Poor rates of data sharing demonstrate that this assumption is likely incorrect. Most entities won’t share their data unless there is an attractive reason for them to do so. The fundamentally expensive nature of data collection, management, and analysis means uptake will not be easy for independent practitioners. This is why governments in many countries (Australia and UK) had to step in to incentivize uptake. The need for a “transactional fee” to cover the cost of data sharing has been demonstrated repeatedly in the data where money flows were essential for generating corresponding data flows within a health system. Similarly, data sharing should also be accompanied be rules, like loans have repayment dates or interest rates governing each agreement. Having a set of formalized rules along with incentives and penalties can help establish confidence in the data sharing process and deter misuse.

1.5.4 Effective data-driven CI requires improvement-oriented environments

There are deep concerns about the fairness of using data to drive CI. These concerns span across topics on collection, management, measurement, methods, controls, and reporting. All these concerns were fundamentally tied to the possibility of casting certain players less favorably.
In healthcare, if data use were to be promoted, there is a need to provide an improvement-orient environment that is cognizant of the organizational challenges (e.g., post-data use care might seem worse compared to pre-data use periods) associated with data use as an organization adopts and then matures into the data-driven CI process. In a collaborative situation, this improvement-oriented environment has to exist across all participating organizations; failure to have an improvement-oriented environment among collaborator organizations could lead to a punitive set up, there by promoting resistance to the use of data among organizations. This is especially needed when new HIT systems are implemented, but should be available always within the system, albeit in different forms as organizations matures in its use of data for CI. Entities using data to improve care should be allowed to fail or underperform without fear of economic or public repercussion. This includes the responsibility of the media to not sensationalize any reports that might come from these data being made public. Media should make all efforts to report events in a sensible manner. Similarly, in a new data use environment, payers should consider gentler ways to promote better performance and build user confidence in the value of sharing performance data.

1.5.5 Fragmentations affecting data flows can be overcome

There are plenty of articles that acknowledge of the existence of fragmentation within health systems. However, most research only note it in the passing, almost like an abstract concept. There is practically no research that made any clear attempts to describe the nature or the types of fragmentations within a health system. This research sheds some light on both the nature and also the consequences of this fragmentation from a data/HIT use standpoint. While the types of fragmentations are not exhaustive, the overarching themes will likely hold across any other identified factors.

Sovereignty based fragmentations can be overcome through the judicious of monetary incentives to encourage data sharing and formalized relationships (e.g., memorandum of understanding or stronger legal recourse). Specificity and breadth based fragmentation can, perhaps, be overcome through provisions to link discrete datasets on a as needed basis to balance between irrelevance and creating large unwieldy datasets trying to incorporate multiple perspectives. Philosophical fragmentation may be overcome through awareness building and education in the topic of interest.
9 References

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**Health Management Information Systems**


### Appendices

#### A Assessments for condition selection

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
<th>Prostate</th>
<th>Melanoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-standardized incidence rank</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Total potential years life lost rank</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Cost to System</td>
<td>Female</td>
<td>N/A</td>
<td>N/A</td>
<td>Male</td>
<td>N/A</td>
</tr>
<tr>
<td>Gender Predominance</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Indigenous Risk vs. General Population</td>
<td>Probably reduced</td>
<td>Probably reduced</td>
<td>Uncertain</td>
<td>Probably reduced</td>
<td>Probably reduced</td>
</tr>
<tr>
<td>Variation in Current Quality (within or among cancers)</td>
<td>Likely – national screening program</td>
<td>Likely – national screening program</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Available† Performance Metrics (QIs)</td>
<td>Yes*</td>
<td>Yes**</td>
<td>Limited – guidelines only</td>
<td>Limited – guidelines only</td>
<td>No – NHMRC guideline ‘under review’</td>
</tr>
</tbody>
</table>

†ASSIST and selected ACOVE III indicators address supportive aspects of all cancer conditions

*QA Tools, ACOVE III, NHMRC Guidelines

** QA Tools, ACOVE III, NHMRC Guidelines

Because of practical considerations, we were limited to one condition – chose one where previous quality improvement work might affect ability to discern differences across the system – decided to focus on colorectal because of the two (breast and colorectal) where screening programs were in place, it is not gender-specific.
B Interview protocol

Number: ______________________________________

Site of Interview  □ In person  □ Telephone  □ Other__________________

I’m a general practitioner and palliative care doctor from the United States. I work mostly at the United States [name of institution]. I am here in Australia for 8 months studying healthcare policy and quality of care issues. I’m trying to understand current activities in your organization that might be helping or harming efforts to improve care for people with colorectal cancer. I’m focusing on two issues – one, how to use information to improve the follow-up of initially positive bowel screens, and how to use information to improve screening for psychosocial distress during the course of cancer. I’m particularly interested in performance measurement and important influences that help and hinder you and your organization’s efforts to improve care.

Checks / Reminders

- Aiming for 45 minutes
- Taping for transcription
- Confidentiality – no sensitive issues anticipated – will not publish any statements with information that allow for individual identification, and will remove any other information that would lead to the identity of your organization (i.e., names and location)
- Can stop at any time
- You will have the opportunity to review anything taken from this interview and approve it before it is used in a public setting (e.g., in a presentation or publication)

Order

- Start with some questions about your background and roles
- Broad questions about how you view quality improvement within your organization and related quality improvement activities
- A brief survey at the end – just to save time and focus on some things that you can answer quickly

A. Background

<table>
<thead>
<tr>
<th>Question</th>
<th>Probes</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your name?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is your job title?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you describe your roles and responsibilities here?</td>
<td>Describe how your responsibilities are relevant to quality</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Probes</td>
<td>Notes</td>
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<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Describe the relationship of this organization to other organizations</td>
<td>How is the role / responsibility / task of X different from Y?</td>
<td>Distinguish roles, especially Commonwealth from state and other levels within state</td>
</tr>
<tr>
<td>and its key stakeholders.</td>
<td></td>
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<td></td>
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<tr>
<td>Describe efforts your practice / organization has undertaken to</td>
<td>If not effort in cancer, then another exemplary effort…</td>
<td>Clinical area =</td>
</tr>
<tr>
<td>improve the quality of cancer care.</td>
<td>How was information about performance used in that effort?</td>
<td></td>
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<tr>
<td></td>
<td>How did your relationship with [level above, level below] affect [help, hinder] your quality improvement effort?</td>
<td></td>
</tr>
<tr>
<td>Describe your practice / organization’s efforts to improve the quality of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Care for colorectal cancer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Follow-up of a patient’s positive guiac /sigmoidoscopy?</td>
<td></td>
<td></td>
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<tr>
<td>c. Detecting depression or distress when patients have cancer?</td>
<td></td>
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<tr>
<td>In your effort to improve care [cancer / colorectal cancer care] how</td>
<td>Prompt if interviewee doesn’t know of anything.</td>
<td></td>
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<tr>
<td>do you use guidelines or frameworks?</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Where does cancer ‘fit’ within framework? What aspects of</td>
<td></td>
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<td></td>
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</tbody>
</table>

B. Overall strategy

(discuss general QI and acceptability – then focus on CRC and specifics)
<table>
<thead>
<tr>
<th>Question</th>
<th>Probes</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>cancer would ‘fit’? (how does prevention and palliation ‘fit’)?</td>
<td>Explain how you clinically prioritize areas for improvement.</td>
<td></td>
</tr>
<tr>
<td>a. In order to improve [screening f/u rates, psychosocial screening], what key changes in [practice, policy] are required?</td>
<td>Within your organization? Outside your organization? How might performance measurement affect those efforts?</td>
<td></td>
</tr>
<tr>
<td>b. What do you currently have planned?</td>
<td></td>
<td></td>
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</tbody>
</table>

Now I'm interested in considering how having more information about the actual performance of healthcare providers might affect your efforts [organization's efforts] to improve care. Show sample result.

How might your organization use information about [X]?

<table>
<thead>
<tr>
<th></th>
<th>Describe any advantages there might be to having such information?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Describe concerns you might have about the use of such information? (or that have arisen in the use of performance information)</td>
</tr>
</tbody>
</table>

Beyond your organization, to whom are you [your organization] responsible with regard to delivering care? Who [or what organizations] is responsible to you for their role in delivering care?

<table>
<thead>
<tr>
<th></th>
<th>Are those relationships different for you vs. your organization?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Define role vs. other levels of care system – describe influences below</td>
</tr>
</tbody>
</table>

Often, a practice / organization cannot act on its own to improve care. Think about other organizations that might influence the follow up of colorectal screens, psychosocial care for cancer patients.
<table>
<thead>
<tr>
<th>Question</th>
<th>Probes</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do other organizations [level above, below] influence [help, hinder] your organization’s effort to improve colorectal cancer care?</td>
<td>Proportion of patients with + FOBT who were followed up with colonoscopy?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Proportion of patients with cancer screened at any time for psychosocial distress?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Specific influences identified in intro question</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the most important policy opportunities for improving [these aspects of quality, routine use of data to guide improvement]?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>How do you think the role of the Commonwealth vs. the state (Cancer Australia vs. DoHA vs. other Commonwealth agencies) should differ?</td>
<td></td>
</tr>
</tbody>
</table>
C Participation request email

I was referred by [insert name]. I am a physician employed by the United States [name of organization]. I am currently residing in Australia as a [name of fellowship] fellow, based at [organization] in [city]. I am conducting research on factors that might promote or hinder quality improvement for cancer in Australia. I am interested in learning more about your organization’s role in delivering or improving cancer care and your ideas about how colorectal cancer care could be improved. I would like to try to arrange an interview to talk to you about these issues.

The interview will require about an hour of your time, and I will meet you in person, or we can talk by phone, as you prefer. I would like to record the interview for my records although this is not mandatory: before we start I will ask if you would prefer that I not use the recorder. I will make sure that if I make use of any of your comments from the interview, they will be completely anonymous (removing any references to names, places, or your specific organization that would reveal your identity). I will also make sure that you are allowed to review any quoted comments before I include them in a public presentation or report.

I will be following up in the next several days. Thanks for your consideration.
D Sample performance measurement data

A printed copy of a performance tracking report was presented to the informants to help guide discussions around use of data to drive CI within the organization.

**CLINICAL TRACKING REPORT**

1. **MONTHLY PERFORMANCE BY SITE AND REMINDER**

<table>
<thead>
<tr>
<th>Month or Week</th>
<th>Jan-08</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
<td>SITE 1</td>
</tr>
<tr>
<td>Colorectal Ca Screening + Followup Rate</td>
<td>44%</td>
</tr>
<tr>
<td>Depression Screening in Cancer Rate</td>
<td>78%</td>
</tr>
</tbody>
</table>

![Graph 1: Colorectal Ca Screening + Followup Rate](image)

![Graph 2: Depression Screening in Cancer Rate](image)
E Description of the primary project

This is a description of the projects for which the data used here in were originally collected.

“Assessing the possibilities for performance improvement in Australia” draws on multilevel frameworks for quality improvement to target Australian cancer organizations at federal, state, hospital or health system, and clinician / clinical microsystem levels. The project is querying individuals representing the dimensions of public and private, outpatient and hospital, physician and nursing, in general practice, oncology, and surgical settings (excluding rural and indigenous sectors) in mostly New South Wales, but also to a limited extent Victoria. I am conducting semi-structured interviews with leadership, and when appropriate, lower levels of each key organization using a snowball sampling strategy. Questions for the interviews ask participants to: characterize key organizational stakeholder relationships, describe an exemplary effort to improve quality (in general or for cancer / colorectal cancer in particular), explain what concerns might arise in the use of performance information (for internal use and accountability), and to characterize policy priorities for promoting a performance-driven, continuous quality improvement-oriented system for colorectal cancer. The project will also conduct a structured review of archival materials contributed by each organization and available on the public Internet. All interviews and archival materials will be transcribed and coded for themes by 2 experienced qualitative researchers, and anonymized quotations approved by participants will be used for subsequent reports. Products will include a map of organizational relationships, characterization of the degree and nature of colorectal quality improvement activities at each level of the care system, barriers and facilitators to routine performance measurement and improvement, and a consideration of policy priorities.
F Supporting graphs and tables for Chapter 5

Distribution of organizational roles in improving care within a health system

Distribution of health system organizational roles
Distribution of various classes of CI activities

Distribution of targets of CI activities within a health system
Distribution of funding sources for CI initiatives within a health system

Distribution of CI initiative implementation within a health system
Distribution of CI motivators within a health system

- Uphold minimum standards of care
- Uphold minimal clinical standards; develop reputation for quality care; minimize risk
- Uphold clinical standards; minimize risks
- Uphold clinical standards
- Uphold clinical and industry standards; Help successful clinical practices/businesses
- Uphold clinical and industry standards; Help professionals get the best reimbursement
- Publicize disease or issues
- Provide best possible care to patients
- Promote best practices and evidence based medicine
- Minimize risks; build reputation for quality
- Minimize risks
- Minimize risk
- Maximize profits
- Leveling the playing field
- Level the playing field; Minimize risk

Distribution of CI relationships within a health system

<table>
<thead>
<tr>
<th></th>
<th>CW-Govt</th>
<th>CW-NGO</th>
<th>State-Govt</th>
<th>State-NGO</th>
<th>Local-Govt</th>
<th>Local-NGO</th>
<th>Individual</th>
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<tr>
<td>Individual</td>
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<td>1 of 5</td>
<td>3 of 5</td>
<td>1 of 5</td>
<td>1 of 5</td>
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</tbody>
</table>

Note: Numbers report the number of organizations at each level that reported CI related ties to other organizations, classified by level and sector. For example, 4 out of 5 commonwealth government organizations reported CI relationship with other commonwealth government entities.
G Supporting graphs and tables for Chapter 6

Level of reliance on data for CI activities

Note: Local NGO data is not useful due to only 1 case in the sample.
H Framework for classifying CI interventions

Leatherman and Sugarland [39] created a taxonomy of types of healthcare improvement activities and classified them as follows:

<table>
<thead>
<tr>
<th>CI intervention classification</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-focused</td>
<td>These interventions recognize the role and contribution of patients as active participants in securing appropriate health care at both an individual and collective level and are increasingly regarded as the proper and respectful mode of providing health services, patient-focused interventions can also contribute to better outcomes in certain clinical conditions, and constructively influence health system reforms.</td>
<td>Increasing health literacy, shared decision-making, self-care, safety, access, and patient experience</td>
</tr>
<tr>
<td>Regulatory</td>
<td>These interventions address three key functions: to improve health care, to guarantee minimum acceptable standards and to reassure the public about quality of care. More specifically regulations can be directed at institutions, professionals or markets.</td>
<td>Institutional regulation: Accreditation, Inspection, Target-setting, Standard setting; Professional regulation: licensure, certifications, and credentialing Market regulations: managing competition, patient protection, and capacity</td>
</tr>
<tr>
<td>Incentives</td>
<td>These interventions focus on various motivators to improve quality and include both rewards and sanctions. Financial and non-financial incentives can be differentiated in terms of their focus on professions, patients or institutions.</td>
<td>Monetary rewards for individuals: clinicians, organizations, or patients. Non-financial incentives include intangible benefits like earned autonomy, enhanced reputation, development opportunity</td>
</tr>
<tr>
<td>Data or IT driven</td>
<td>These interventions seek to harness information to improve quality of care. The interventions are broadly classified into two categories: 1) Health Information Technology (HIT) which includes knowledge management initiatives across</td>
<td>Examples of data or HIT driven reporting include public reporting, performance monitoring and feedback. Similarly, data or HIT driven</td>
</tr>
<tr>
<td>CI Intervention classification</td>
<td>Description</td>
<td>Examples</td>
</tr>
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<tr>
<td>delivery of health-care services, policymaking, administration and the training/education of health sector workforce, and 2) Performance/quality reporting systems that provide feedback to providers of care at systemic, institutional or individual levels; and information to users and payers of services for accountability and choice.</td>
<td>information/knowledge management includes electronic patient records, and decision support for clinician/patients.</td>
<td></td>
</tr>
<tr>
<td>Organizational change</td>
<td>These interventions focus on improving managerial, professional and institutional behaviors. They include initiatives that are concerned with personnel and institutional capacity; changing organizational culture and professional behavior; the use of Continuous Quality Improvement (CQI) techniques and learning collaboratives for improved performance; and the provision of reliable quality assurance and controls (e.g. infection control, risk management).</td>
<td>Changing skill mix, staffing levels, facility layout and design; use of opinion leaders, clinical audits, and continuous quality improvement techniques</td>
</tr>
<tr>
<td>Healthcare delivery models</td>
<td>‘Health-care delivery models’ are innovative interventions in the resourcing, organization and delivery of health-care services, often focused by specific clinical condition/disease or population groups in the research literature.</td>
<td>Performance measurement and reporting, prevention, health promotion, primary care, acute care, chronic care, long term care, palliative care.</td>
</tr>
</tbody>
</table>

Note: Adapted from Leatherman, 2007 [39]