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APPROVAL SHEET

THE VALUE OF PUBLIC HEALTH INFORMATICS FOR THERAPEUTIC ADHERENCE

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ABSTRACT COVER

THE VALUE OF PUBLIC HEALTH INFORMATICS FOR THEREAPUTIC ADHERENCE, A SYSTEMATIC LITERATURE REVIEW

Kevin E. Henderson

ABSTRACT

THE VALUE OF PUBLIC HEALTH INFORMATICS FOR THEREAPUTIC ADHERENCE, A SYSTEMATIC LITERATURE REVIEW

Kevin E. Henderson

The goal of this study is to determine the value that public health informatics contributes to improve the critical public health problem of therapeutic non-adherence. Therapeutic adherence is a significant public health problem. Estimates of the size of patient non-adherence amount to $100 to $300 billion dollar in health care waste and poor outcomes

This study examined key questions and relevant literature regarding public health informatics and adherence. From its impact on chronic diseases to the current tools that are being implemented, systematic analysis of relevant literature was conducted.

The study results reveal that public health informatics is currently playing an important yet limited role in facilitating adherence to therapy. A number of innovative uses have been implemented; however, the potential impact is significant across a number of chronic disease conditions. Analysis, review and discussion on the topic suggest that the problem of non-adherence must continue to be addressed through new informatics tools, therapeutic approaches, and frameworks to meet the challenges associated with non-adherence. Further research on the topic is needed.

THE VALUE OF PUBLIC HEALTH INFORMATICS FOR IMPROVING THERAPEUTIC ADHERENCE, A SYSTEMATIC LITERATURE REVIEW

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A report submitted to the
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Table of Contents

Introduction

Focusing on Patient Adherence

According to the Chief Medical Officer of CVS Caremark, Troy Brenan MD MPH, the overall cost of medication and therapy non-adherence for chronic conditions is valued at $1.3 trillion dollars (e.g., cancer at $319 bn., diabetes $132 bn., and hypertension at $312 bn., etc.). Based on this research, adherence clearly continues to be identified as a critical issue for managing chronic conditions and non-adherence is a significant driver to overall healthcare costs and poor outcomes.

The clinical and epidemiological impacts of non-adherence on public health outcomes are clear. For example, non-adherence is associated with approximately 30 – 50% of treatment failures and 125,000 deaths annually. According to recent studies, non-adherence to cardio-protective medications increases the risk of cardiovascular hospitalizations by 10-40% and mortality by 50-80%. Non-adherence also increases the relative risk of mortality (approximately 12-25%) for statin treatments (Brennan, 2014). Studies also show the damaging effects beyond mortality such as increased healthcare costs. For example diabetes subjects that are non-adherent to their therapy pay on average of $3,756 more per year from increased emergency room visits, longer in-patient hospital days, and more days away from work. Similar results are also true for subjects with asthma or high cholesterol (COPD), with losses of $1,258 per year. (Brennan, 2014).

Studies on prescription drugs, show that fewer than 40% of original maintenance prescriptions are filled and 31% are never filled. (Brennan, 2009). Studies by Roebuck et. al, show that with higher adherence levels annual medical costs could be reduced as well as hospital readmissions. In his study, Medication Adherence leads to lower health care use and cost despite increased drug spending, Roebuck shows how improvements in medication adherence lead to lower health care costs and increased use. This study

as well as Cutler and Everett's, Thinking Outside of the Pillbox – Medication Adherence as a Priority for Healthcare Reform, describes the problem of non-adherence and the need for broader informatics based solutions. These studies serve as the problem context from which the impact of public health informatics will be explored.

Problem statement

As previous research on adherence shows, the problem of therapeutic non-adherence is vast. According to Cutler and Everett, the impediments of non-adherence consists of three primary obstacles – financial barriers (i.e., level of copayment, etc.), data and data infrastructure limitations (e.g., lack of current solutions for holistic patient data sharing), and payment reform challenges (e.g., how healthcare organizations are rewarded for improving outcomes – fee for services, etc.). The focus of this research does not include analysis of the financial or payment reform challenges of the adherence issue. Rather, this research is focused on understanding the impact that informatics solutions can have on the data and data infrastructure component of the problem.

The value of researching public health informatics impact on the problem is to find new ways of solving the challenges that exist in patient engagement, data infrastructure and communication. The research hypothesis is that implementing public health informatics solutions will be able to significantly improve therapeutic adherence and will also drive value across the dimensions of the triple aim (i.e., – to improve the health of populations, to improve individual health, and to reduce the cost of healthcare). The literature review approach is to first examine studies on the current state of therapeutic non-adherence. This includes previous studies by Brenan, and Roebuck on the topic of adherence. Next, articles that focus on public health informatics applications for adherence and their impact will be analyzed. This includes articles by Yasnoff and Kufkala among others. Finally, to validate the hypothesis, information and architecture standards that facilitate informatics solutions for

adherence will be examined. This includes review of the work done by Snee, Eyler, and case studies from Iron Mountain.

Purpose

This thesis explores how PHI can drive improved patient adherence. By conducting a systematic meta-analysis of PHI literature, the thesis will systematically explore the following questions related to the overall value that PHI contributes. Key Questions:

- Is there a consensus regarding the use of public health informatics to drive therapeutic adherence?
- What is the impact of public health informatics on therapeutic adherence?
- What tools (e.g., social, mobile, web) are currently being used and how do they impact different populations?
- What role do information architecture standards and interoperability play in facilitating therapeutic adherence?
- What is the value of public health informatics to therapeutic adherence for improved outcomes?

Significance of Public Health Informatics

The history of the informatics discipline as well as the origin of the word informatics begins nearly one half century ago (Araujo et al., 2009). However, the theoretical foundations go back 300 years when Blaise Pascal constructed the first working calculator and Gottfried Leibniz demonstrated a digital mechanical calculator as the field of computer science emerged.

The earliest literature associated with the modern emergence of informatics as a discipline can be found in the 1950s publication of Informatik: Automatische Information-sverarbeitung or Informatics: Automatic Information Processing by the German computer scientist Karl Steinbuch. In 1962, Phillipe Dreyfus used the French word, "informatique" and its various English translations—"informatics." Around the

same time, "informatics" also was defined by Walter F. Bauer as a combination of the words information and automatic to describe the science of automating information interactions((Mikhailov, Chernyl, & Gilyarevskii, 1966). From hence, the discipline of informatics was born and its definition distinguished it from its earlier predecessor computer science. As such, informatics concepts were embraced by public health as an important way to systematize the evidence based orientation of public health practice (IOM Committee for the Study of the Future of Public Health, 1988).

Public health informatics (PHI), according to Yasnoff, et. al., is the systematic application of information and computer science and technology to public health practice, research, and learning.(Yasnoff, O'Carroll, Koo, Linkins, & Kilbourne, 2000). PHI extends the application of public health from, the science and art of preventing disease, prolonging life and promoting health, to incorporate the utilization of informatics applications. In 1988, the Committee for the Study of Public Health at the Institute of Medicine declared that the effective use of public health practice requires timely, accurate, and authoritative information from a variety of (data) sources (IOM study). Ever since this groundbreaking study was conducted, the field of public health informatics has been evolving and serving the needs of populations globally. Helping further diverse public health goals, from utilizing informatics solutions to prevent disease and supporting intervention delivery to facilitating compliance with immunization delivery and enabling surveillance. These are just a few among a number of other innovations that PHI has contributed in recent years. With it focus on prevention, PHI differentiates itself through a unique perspective. This perspective informs health care providers and the health care system regarding how to understand and effectively communicate actionable information from which public health problems including therapeutic adherence and disease prevention can be solved.

Regulatory Changes Affecting the Public Health Informatics Landscape

Recent regulatory changes have increased the importance of public health informatics. With the passing and current implementation of the Patient Protection and

Affordable Care Act in 2010, consumers and the general public have a more urgent need to analyze and interpret of healthcare information (Kaiser Family Foundation, 2014). PHI facilitates the interpretation of such information.

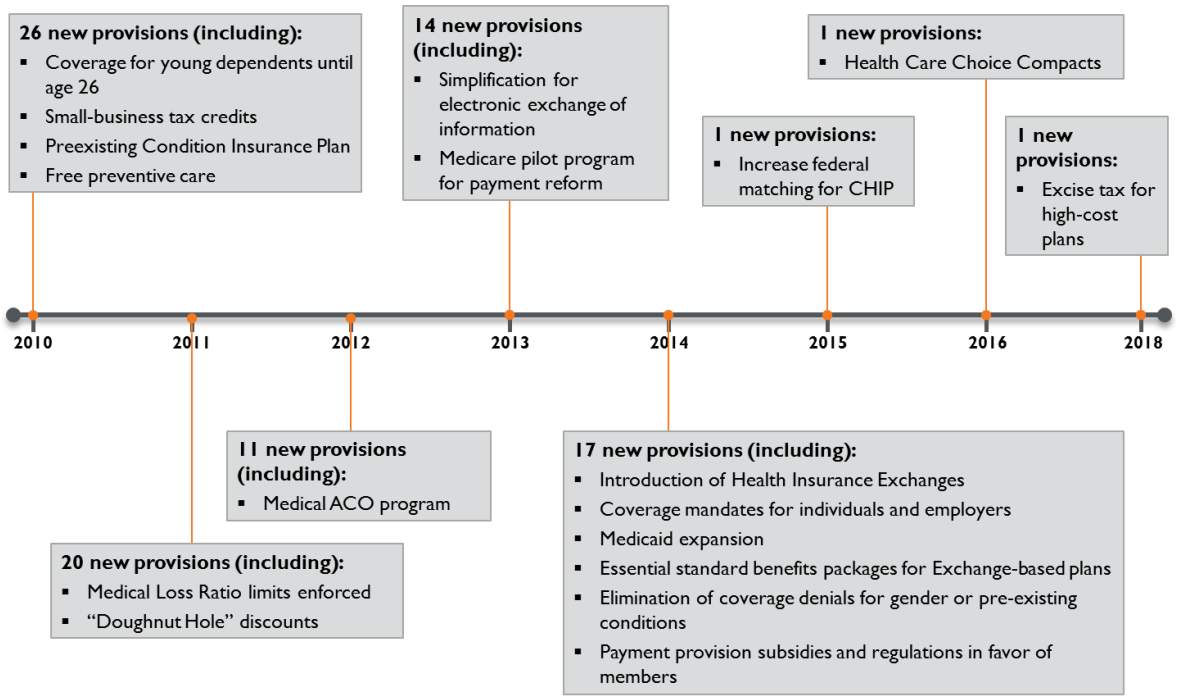

Figure 1 - Patient Protection and Affordable Care Timeline

In 2010, new provisions were implemented to expand health care coverage and provide preventative care increasing the need form timely public health information and informatics solutions. From 2011 – 2013, Accountable Care Organizations were established to facilitate better care coordination among providers, public health and health insurers. Health information exchanges were enhanced to simplify the exchange of electronic health information (e.g., personal health records, etc.) to enable better population health management. In the fall of 2013, federal and state health insurance exchanges were implemented, Medicaid was expanded for those states that opted in, and member payment subsidies were enacted to assist those who met eligibility requirements. All of these forces are influencing the need to design and build greater public health informatics solutions for the present and increasingly complex future.

As an example, health insurance companies and pharmacy benefit managers are sharpening their focus on clinical, care management initiatives, and public health activities. In its 2013 Annual Report, CVS Caremark's strategic vision extended the work that it had been doing to improve public health outcomes through its Pharmacy Advisor informatics solution. The tool allows CVS pharmacists to communicate with members who have chronic conditions in real time by enabling the pharmacist to identify specific groups of at-risk individuals and intervene through dialogue or reminders. This is a perfect example of public health informatics tools in action commercially. (Brennan, 2009).

Selection of JAMIA for Article Submission

To complete a manuscript format MPH thesis at Emory, submission of a summarized thesis article is required. The Journal of the American Medical Informatics Association (JAMIA) was selected given the style of thesis that is being prepared, a systematic literature review. Below are the guidelines from JAMIA that outline the requirements of the article submission, on which the article must follow.

JAMIA Review Requirements

- Review articles contain systematic reviews of the literature or concise tutorials on topics of broad interest to the readers.
- The structured abstract and text for a systematic review should follow the same format as the one required of Research & Applications articles described above.
- The structured abstract for a tutorial should contain the headings: Objectives, Target Audience, and Scope (covered topics).
- Word count: up to 4000 words.
- Structured abstract: up to 250 words.
- Tables: up to 4.
- Figures: up to 6.
- References: unlimited.

Literature Review

This literature review drew upon peer reviewed articles published from 1995 through 2014 in the areas of PHI, patient adherence and factors that related information's to patient adherence. The literature search produced a total of 84 articles. Articles included in this studies review had to meet the search criteria in PubMed consisting of the terms: adherence, public health informatics, or consumer health informatics. Once return the articles were mapped to the specific research questions. The final review resulted in 24 peer reviewed articles and 7 non-peer reviewed articles or case studies. After the final articles were categorized and analyzed, they were filtered for relevance in answering the different research questions. They were then assigned to each question and the different research questions were answered based on the current body of work in that area. Finally, a summarization and assessment was made based on the research findings to answer the research questions and determine the overall value that public health informatics has on therapeutic adherence.

The Problem of Non-Adherence

The overall cost of medication and therapy non-adherence for chronic conditions is valued at $1.3 trillion dollars (e.g., cancer at $319 bn., diabetes $132 bn., and hypertension at $312 bn., etc.), according to the Chief Medical Officer of CVS Caremark, Troy Brenan MD MPH. Based on this data, adherence clearly was and continues to be identified as a critical issue for managing chronic conditions as non-adherence and is a significant driver to overall healthcare costs and poor outcomes.

The clinical and epidemiological impacts of non-adherence on public health outcomes are clear. For example, non-adherence is associated with approximately 30 – 50% of treatment failures and 125,000 deaths annually. According to Roebuck and Brenena, non-adherence to cardio-protective medications increases the risk of cardiovascular hospitalizations by 10-40% and mortality by 50-80%. Non-adherence increases the relative risk of mortality (approximately 12-25%) for statin treatments

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Current Perspectives in Public Health Informatics

The current body of research around public health informatics builds upon the prior work done by Yasnoff et. al., Public Health Informatics : Improving and Transforming Public Health in the Information Age (Yasnoff et al., 2000). In the initial research, Yasnoff argues that, "Development of effective public health information systems requires understanding public health informatics (PHI), the systematic application of information and computer science and technology to public health practice, research, and learning. PHI is distinguished from other informatics specialties by its focus on prevention in populations, use of a wide range of interventions to achieve its goals, and the constraints of operating in a governmental context."

Examples that were provided in the early research focus on the need to move beyond systems automation to focus on reengineering systems that focus on preventing disease from likely populations through sophisticated analytics and surveillance technologies.

In a national agenda for public health informatics: summarized recommendations from the 2001 AMIA Spring Congress, Yasnoff also defined the principles for improving public health in the near and long term (Yasnoff, Overhage, Humphreys, & LaVenture, 2001). These defined public health as focusing on information science to promote healthier populations, applications that prevent disease focusing on environmental characteristics that cause disease, analyzing weak links in the causal chain that could lead to disease or disability, and focus on the government context in which public health is practiced.

At the AMIA Public Health Informatics conference in 2011, leaders in the field of public health informatics met to discuss progress and develop recommendations to guide the field. The participants identified 62 recommendations, which clustered into three key themes around the field's emerging needs. The key themes focused on enhancing communication and information sharing, improving consistency of public health informatics through terminology and rigorous evaluation methodologies, and promote effective coordination and leadership that will move the field forward. One of the key recommendations in the technical framework section was to promote widespread, effective, and responsible use of social networking and new media tools and informatics to achieve public health goals.

Is there a consensus regarding the use of public health informatics to drive therapeutic adherence to therapy?

Rita Kukafka DrPH, in her 2005 journal article Public Health Informatics: The Nature of the Field and Its Relevance to Health Promotion Practice asserts that public health informatics is driving improvements in health promotion and prevention through improved health education and informatics applications. "With the emphasis

on the health of populations and prevention, increasingly the motivation for new information systems is to improve consumer health. Health behavior and health education theories are gradually becoming an essential component to public health informatics. It is this application of informatics to consumer health that demonstrates new avenues for health promotion practice"(Kukafka, 2005). She goes further to suggest that the investments in the nation's public health infrastructure (i.e., more than $2 billion), initially focused on bioterrorism and surveillance, can also be leveraged to recognize individual health care scenarios and provide individually tailored health communication for purposes of health promotion and disease prevention (e.g., adherence or overdue mammograms, etc.). Adherence is a classic example of how health promotion and prevention can be improved through changing therapeutic behavior.

Public Health Informatics for Consumers and Clinicians

Cutler and Everett describe medication adherence as a critical priority for healthcare reform. In their paper, "Thinking Outside the Pillbox — Medication Adherence as a Priority for Health Care Reform", Cutler and Everett describe the importance of the data and infrastructure required to support improved therapeutic adherence. They discuss the need to incorporate multiple sources of data (e.g., medication histories, rates of filling, etc.), integrate them into the EMR, and develop tailored solutions per patient. They also argue that this data needs to be shared across providers and care settings, including the hospitals, pharmacies, home health agencies, public health, and others (Cutler & Everett, 2010).

Policy research by Elyler has also confirmed similar findings. After a systematic review of the evidence, he confirm that consumer oriented public health informatics applications engage the public, enhance clinical interventions, and improve both immediate and clinical outcomes (Eyler, 2011). Findings also concluded that there is

further support for informatics tailoring, and personalization. Most of the impact that was identified dealt with improvements in behavioral outcomes (e.g., adherence).

According to Dixon et. al. in their 2013 study "An informatics approach to medication adherence assessment and improvement using clinical, billing, and patient-entered data", they state that adherence is a complex challenge that requires patient and provider team input, necessitating an integrated approach using advanced EHR, clinical decision support, and patient-controlled technologies. Because most prior research focused on a single approach using EHR data, pharmacy data, or patient entered data, the research often relied on a physician asking specific questions or checking adherence at each patient visit (Dixon, Jabour, Phillips, & Marrero, 2013). Their research findings assert that by integrating survey assessment tools into the EHR and medical practice, adherence is improved due to increased maintenance and provider patient communication. This is especially important for chronic diseases such as diabetes. The authors also suggest, future research should focus on integrated strategies to provide patients and providers with the right combination of informatics tools to help them adequately address the challenge of disease prevention by improving adherence to complex medication therapies.

Another study conducted by Trief et. al, showed how informatics interventions increased adherence rates among poor elderly Hispanic American and African American diabetic patients. The study looked at the mediated effect of glycemic control (A1c) levels in subjects to determine effectiveness over the 5 year study period. When compared to the control groups, self-reported adherence rates improved significantly over the usual care ($p <= 0.001$). Minority subjects had consistently lower adherence rates when compared with white subjects. And overall findings showed that comorbidities were a predictor of poorer adherence (Trief et al., 2013). Key conclusions were that tailored informatics solutions to diabetes self-care were effective in improving adherence among the total population. However, African American and Hispanic

subjects would benefit from more tailored informatics approaches as their adherence was systematically lower than that of whites.

Clearly, there appears to be an agreement among leading researchers that consumer oriented public health informatics improves adherence to therapy. It also improves overall therapeutic behavior for chronic and acute conditions. This is important because PHI now provides public health researchers and administrators with the tools to specify populations to target for interventions. This is useful because public health administrators will be better able to implement interventions based on these new tools and approaches.

What is the impact of public health informatics on therapeutic adherence?

In May 2001, at the American Informatics Association Spring Congress, a panel was convened to explore issues and opportunities at the intersection of informatics and public health. Leaders from both fields were present. One of the key topics explored was how the change in medical care delivery continued to diminish the lines between clinical medicine and population health and opportunities emerging from the new care delivery models. A key question that was raised during the panel discussion was around this very topic. Patrick W. O'Carroll addressed the issue with the following response, "I will mention three possible areas where informatics might assist in maximizing the joint efforts of public health and clinical care: harnessing public health outreach efforts to promote better clinical care (e.g., via better compliance with preventive medical regimens); linking clinical data to public health morbidity surveillance efforts; and providing prevention information and screening guidance at the patient caregiver interface."(Kukafka et al., 2001). He goes on to explain that many patients fail to adhere to medical regimens intended to prevent disease and that public health efforts used to promote prevention may also be used to promote adherence to such medical regimens.

Hypertension is a disease that has a straightforward treatment plan for most conditions. However, the drugs that are frequently prescribed have unpleasant side effects and therefore poor compliance is to be expected in the long run. When clinicians recognize that patients are not adhering to their care regimens (e.g., drug plan or visits), there could be an opportunity for public health and medicine to partner by providing a community based outreach workers that leverages informatics. O'Carroll suggests that clinical – public health informatics could hold the key to this through collaboration and sharing of patient level information to be captured in an EMR or clinic based medical system but leveraged for public health or community based outreach (Kukafka et al., 2001). Another example that was highlighted was in the area of morbidity surveillance.

In this case, public health informatics would be used to help physicians monitor near-real-time clinical morbidity information (e.g., increase in sore throats, etc.), they could check prevalence information of streptococcal pharyngitis to increase orders for antibiotics. In this instance, the public health informatics solution would help physicians and patients by ensuring that the forecasted demand for antibiotics could be anticipated and met.

It is widely known that vaccination adherence is one of the most successful public health initiatives to date. Having a successful vaccination program is key to reducing vaccine preventable disease. In their research, "A brief Review of Vaccination Coverage in Immunization Registries", Goldstein et. al. analyze several studies that analyze the characteristics of successful vaccination registries. The research shows how the use of regional registries – utilizing a hybrid paper and informatics approach - increases vaccination coverage and greater adherence to vaccination schedules. In their study, the authors assert that to ultimately move to a holistic informatics based solution, registries must expand coverage to include broader areas. Decision support capabilities and therapeutic provider reminders that utilize these public health informatics solutions can improve adoption and adherence rates (Goldstein & Maiese, 2011).

Another area where informatics is beginning to play an even greater role and have a much greater impact is in the area of health promotion and disease prevention. There are a number of recent studies that draw the link between better health promotion lead to better adherence and disease prevention. These studies, while not specifically focused on therapeutic adherence, provide the tools needed for self-care that drive greater adherence. For example, at Harvard Pilgrim Children's Center in Boston, the hospital is utilizing personally controlled electronic health records to augment the Behavioral Risk Factor Surveillance System (BRFSS) and other traditional methods for monitoring preventive and self-care for diabetes. This was done by leveraging social media and enhanced patient provider communication to drive improved self-care and adherence. (Husting & Gadsden-Knowles, 2011). Another

example is at the Rocky Mountain Center for Translational Research in Public Health Informatics, where Utah's research activities include implementing a visual analytic and decision support system to enhance community health assessment and public health surveillance and utilizing social and behavioral sciences and other disciplines to exchange information relevant to public health practice (Husting & Gadsden-Knowles, 2011). These initiatives were a part of the CDC's effort to establish centers of excellence in Public Health Informatics and were part of the $4.37 million of allocated funding.

I*nformatics Impact on Specific Therapeutic Conditions*

According to Klein (2002), the future of public health informatics "will become integrated with medical care, electronic medical records, and patient education to impact the whole process and business of health care"(Klein-Fedyshin, 2002). In their comprehensive study of the impact of these informatics on health outcomes, Gibbons, et. al., reviewed the evidence on the impact of informatics applications on health outcomes. The evidence was from consolidated searches from across a number of key databases, including MEDLINE, EMBASE, The Cochrane Library, Scopus, and CINAHL. These studies also confirmed the impact that Ho describes in her article on informatics and care delivery models and Dey's article Consumer Health Informatics: an Overview on Patient Perspectives(Ho, 2010) (Dey, 2004). The primary areas of interest for therapeutic adherence were in physical activity, alcohol and smoking cessation, diabetes, and asthma.

Physical Activity

In the area of diet, exercise and physical activity, studies were evaluated to determine the extent to which informatics applications would impact health outcomes. Studies showed that there was a significant effect on measured outcomes (e.g., reduction in body weight, BMI, and percent weight loss) through adherence to targeted therapeutic routines via self-monitoring technology (Gibbons et al., 2009). Other studies showed similar improvements to tailored fat, fruit, vegetable, and calorie intake, and

overall behavioral modification. Informatics modalities showing positive adherence and behavioral change ranged from web based tailored nutrition education and social media groups, to tailored interventions and feedback tools.

Alcohol and Smoking Secession

In terms of alcohol and smoking secession, outcomes were also measured to evaluate informatics applications to assess self-management and program adherence impact. Informatics applications and interventions ranged from web-based tools and self-help guidance to computerized assessment and tailored feedback. Studies showed significant positive outcomes on program adherence via online alcohol use evaluation among problem drinkers. Other studies showed positive outcomes via tailored feedback applications resulting in the reduction in drinks per week. Similar studies showed significant positive adherence outcomes to smoking secession programs for informatics applications that included tailored web-based feedback and computer based technologies (Gibbons et al., 2009).

Diabetes

Diabetes was another area that showed significant positive impact as it relates to informatics application to therapeutic adherence. Studies utilizing a computer based feedback mechanism demonstrated an increase in adherence to program therapy and in self-efficacy. For example, utilizing computerized feedback mechanisms, a study by Richardson et. al. showed improvement in adherence to therapy measured by the mean hours wearing a pedometer and increase in the likelihood of wearing a pedometer. Other significant improvements include increases in patient satisfaction, number of steps taken and usefulness of the informatics application (Gibbons et al., 2009). The diabetes results also confirm previous studies around user centered design and informatics intervention (LeRouge & Wickramasinghe, 2013).

Asthma

For Asthma and Chronic Obstructive Pulmonary Disease (COPD), informatics applications have also shown to have a significant positive effect on therapeutic adherence. A study by Krishna et. al., evaluated the health outcomes of children who had asthma and how utilization of web-enabled interactive media improve knowledge, self-management, and overall monitoring adherence to the therapeutic program(Gibbons et al., 2009).

In addition to the above conditions, the Gibbons study also highlighted a few more areas where the informatics solutions had a significant effect on improved outcomes and increased patient adherence. For example, a study by Kukafka et. al. showed how web-based cardiovascular disease system could increase self-efficacy to label symptoms and improve responses to symptom sensations. There was also a study by Harris et. al, that demonstrated how computer generated, tailored health educational systems improved adherence to recommended physical activity. The study also showed improvement in vaccination rates among those who enrolled in the computer based intervention (Gibbons et al., 2009).

What tools (e.g., social, mobile, web) are currently being used and how does each impact different populations?

The Patient Engagement Framework

The National e-Health Collaborative has defined the patient engagement framework (Hoffberg, 2013) that describes five stages to improved patient engagement. This framework addresses key PHI goals through a structured approach to capture and share patient related information with and across health care institutions and public health. This framework provides the foundation for analyzing public health and consumer health informatics in support of patient engagement and therapeutic

adherence. The idea is that by increasing the level of patient engagement maturity, health care organizations will begin to drive better patient engagement, adherence, and better health outcomes. Consumers will be better equipped to manage their own health (Eyler, 2011). According to, Goldberg et. al., for innovative eHealth systems to have true value and impact, they must first and foremost be usable and accessible by clinicians, consumers, and other stakeholders (Goldberg et al., 2011). This is a key goal of the patient engagement framework.

The patient engagement framework is broken down into five key stages – the inform stage, the engage stage, the empower stage, the partnering stage, and the support stage. Each stage is aligned with increasing meaningful use standards from the HITECH Act of 2009. At each stage of the framework, there are a number of tools, information, analytics, data and integration to enable core capabilities. Each stage has the opportunity to leverage advanced technologies such as social mobile and web capabilities to drive greater patient engagement through PHI.

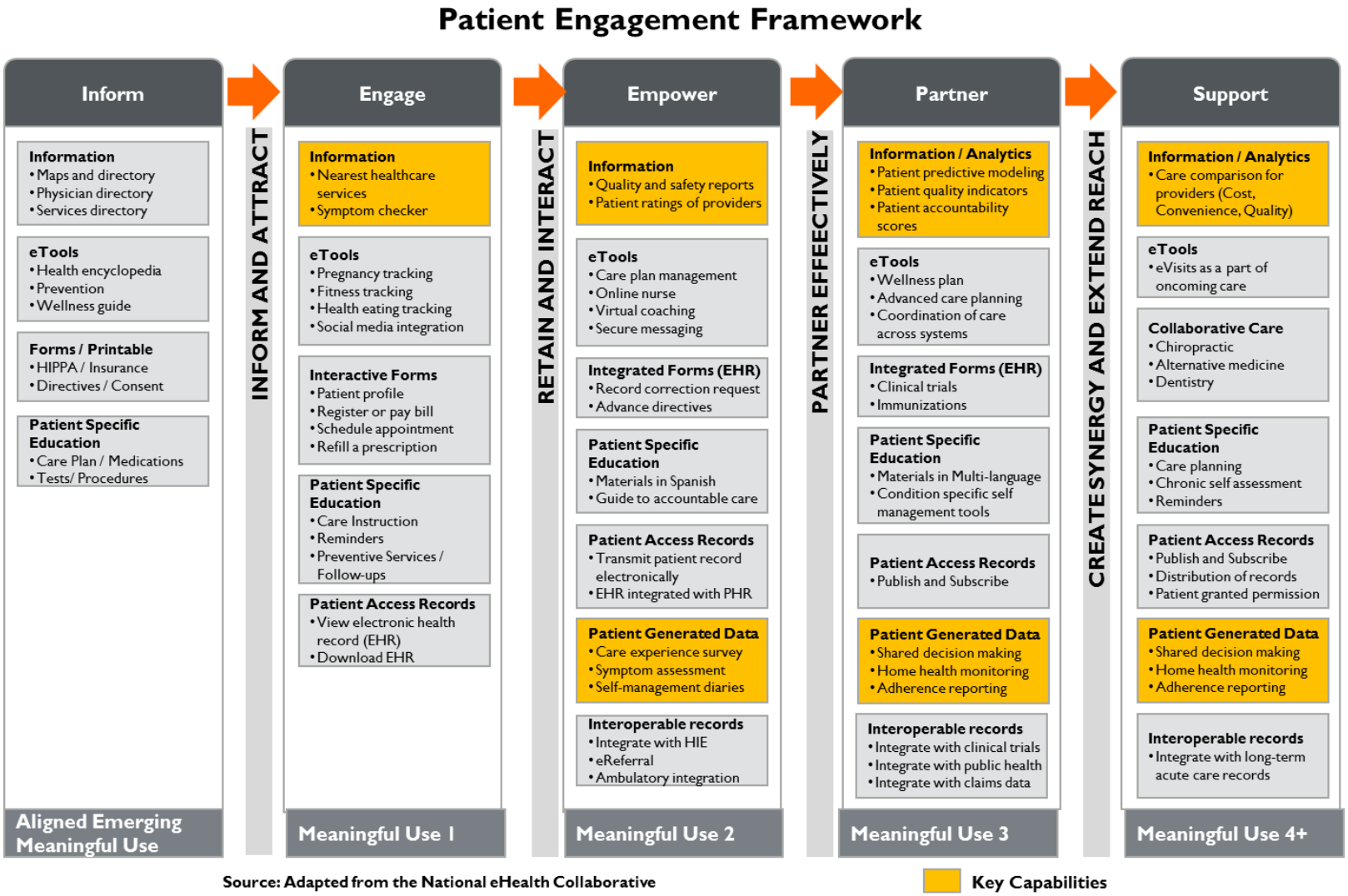


Figure 2 - Patient Engagement Framework Adapted from National eHealth Collaborative

1. Inform Me - Healthcare providers in this phase demonstrate basic levels of patient engagement by using simple tools that make healthcare more convenient and accessible (Hoffberg, 2013). This includes basic tools that allow the patient to search for physician information, see specific services rendered, and utilize self-service tools for wellness and prevention. These tools help facilitate adherence and the impact of non-adherence.
2. Engage Me - This phase is indicative of more mature therapeutic engagement strategies and shows increased use of eHealth tools and resources. In this stage patient can access their electronic health record, are encouraged to use fitness trackers and other eHealth tools, and are able to complete health related administrative tasks online (Hoffberg, 2013).
3. Empower Me - Providers in this phase demonstrate advanced patient engagement activities through substantive use of health informatics. Attributes of this phase include use of secure messaging between patients and providers, integration of basic patient-generated data into EHR systems, online quality, safety and therapeutic experience ratings, and participation in a health information exchange or similar effort to enhance care coordination between provider settings (Hoffberg, 2013). This phase helps to drive increasing adherence through more sophisticated engagement and self-service tools.
4. Partner With Me - This phase reflects providers who use health informatics to make the patient a true partner in his or her care. Providers support patients with condition-specific management tools and access to care summaries. They also integrate significant amounts of ongoing patient generated data, such as preferences, self-care, wellness and home health device data, into their EHR system. Patient records are connected to public health reporting systems and coordination of care happens seamlessly across primary, specialty and acute care providers (Hoffberg, 2013). In this phase, adherence to therapy is more focused and specific through specific condition management tools and care summaries.

5. Support My e-Community - This phase is the culmination of a provider's progress in fully leveraging and implementing eHealth tools to connect a patient with their full care team and support his or her care management both in and out of the healthcare setting. Tools and activities here include fully interoperable EHRs, record sharing among providers and non-provider members of the patient's care team, while granting patient access to privacy controls. Patients and caregivers are also provided with online community support from providers, opportunities for e-visits, and information like cost comparisons and outcomes reporting to help patients make more informed decisions about their care and treatment. Providers at this phase will likely be found participating in an accountable care or patient-centered medical home model (Hoffberg, 2013).

Social Media

Social media is one of the key channels though which patient engagement is conducted. It is also one of the key tools used for CHI and PHI is social media. Social media refers to 'software that enables individuals and communities to gather, communicate, share, and in some cases collaborate or play', typically in the context of applications accessible through internet browsers or mobile devices ('apps'). The term overlaps loosely with both 'web 2.0' and 'social network sites'(Muhlen & Ohno-Machado, 2012). Results from a study by Lau et. al., confirm the need to further explore social media's effectiveness for healthcare. "By analyzing how people search and navigate social media for health purposes… should provide valuable insights on present and emerging health behaviors on a population scale. We encourage the health informatics community to consider the socioeconomic class, age, culture, and literacy level of their populations, and select an appropriate medium and platform when designing social networked interventions for health (Lau et al., 2011)."

Social media has broadly affected PHI and CHI, perhaps most publicly by enabling increased communication with and among patients. Examples include emergency broadcasts during natural disasters, access to free (but often questionable) medical information online, and virtual patient communities. Impact has also been felt internally as a new generation of clinicians enters training with ingrained communication habits unimagined by their predecessors, and through social media websites specifically catering to clinician use, sometimes categorized under 'Medicine 2.0'(Muhlen & Ohno-Machado, 2012).

A study by Muhlen and Ohno-Machado, shows that while social media accounts are common among health science students they are not as common among practicing physicians. Further, attempts to incorporate social media approach in clinical training have been met with mixed results. The social networking platform Doximity is on the rise with physicians as a way to network and share complex cases. The platform is not currently setup to engage with patients. Current research to quantify social media impact is in its infancy. Researchers expect that the use of social media to improve therapeutic engagement and collaboration is on the rise. Examples of this collaboration are highlighted in case studies by S.A. Adams. In his example, he describes how the use of blogs can help drive therapeutic behavior change through documentation of health related experiences (Adams, 2010). Based on this research, we can expect platforms like Doximity to continue to increase in importance. Further research in this area is needed.

Mobile and Cellular Technology

Mobile technology is another critical channel through which therapeutic engagement is conducted. According to research by Google and Compete's Hospital Survey (2012), Mobile is the patient's constant companion. Their research points out

that roughly one-third of patients used tablets or mobile devices on a daily basis to research hospitals or book appointments. For example, sixty-one percent of patients used search at home on their mobile and cellular device, twenty-seven percent while at work, twenty-three percent while visiting friend or family and sixteen percent while in the doctor's office.

Further insight by the study shows how therapeutic behavior differs across search and sites. The research also highlighted the positive effect on mobile health usage for CHI and PHI.

Patient behavior differs across search and search sites

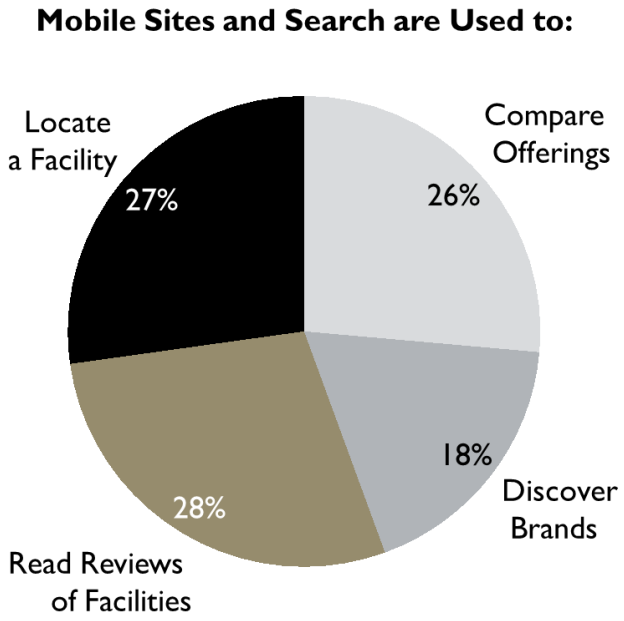


Figure 3 – Adapted from Google Patient Behavior Research

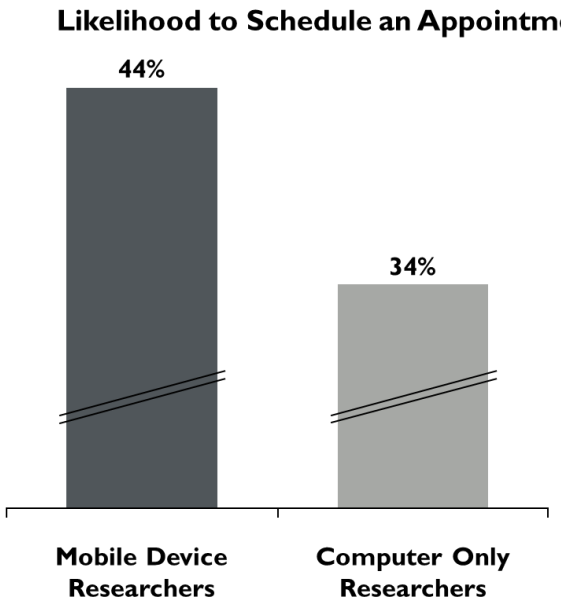


Figure 4 – Adapted from Google Mobile Research(Compete, 2012)

Web

The web is generally considered one of the most important channels through which patients are engaged. Within the context of the web, search is considered one of the most critical components. According to research from Google et. al., "Search is indispensable in therapeutic journey" (Compete, 2012). Based on the results of their study, 77% of patients use search engines when researching hospitals, 76% use hospital sites, and 52% use health information sites. Patients are also increasingly using search to investigate treatments, procedures, and conditions. This research also confirms earlier research done on this topic by Bouhaddou et. al. (Bouhaddou, Lambert, & Miller, 1998)

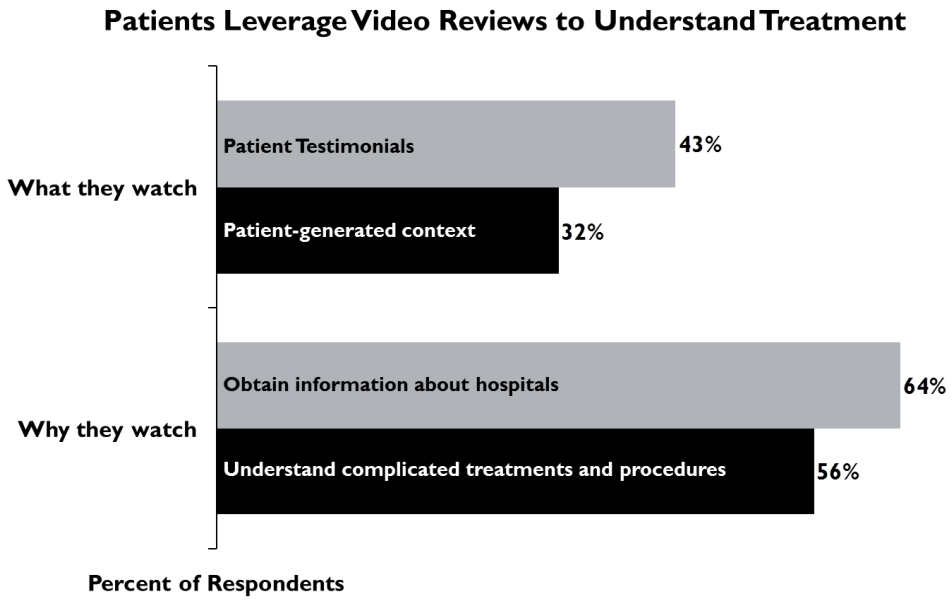


Figure 5 – Adapted from Google Search Types(Compete, 2012)

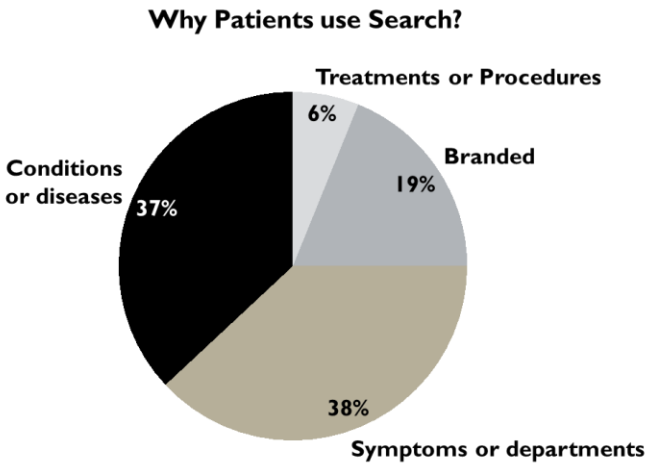


Figure 6 – Adapted from Google Patient Video Reviews(Compete, 2012)

The use of video also had an impact in terms of patients booking appointments. These example confirm prior research done in this area (Alamantariotou & Zisi, 2010).

What role do information architecture standards and interoperability play in facilitating patient adherence?

The landscape surrounding the public health domain is extremely fragmented and enormously complex. The goal of healthcare interoperability continues to be hindered due to a large number of conflicting health IT standards, versions, and implementations. According to Tim Benson in his book "Principles of Health Interoperability", 80% of survey respondents said that there is a lack of sufficiently developed standards for health IT .

"Our public health future depends on information technology", Nancy Snee and Kathleen McCormick stated in their 1999 article (Snee & McCormick, 2004). They further assert that capturing individual citizens who move within the health care domain from ambulatory and outpatient/ambulatory care, to inpatient environments, sometimes back to extended care, assisted care, home care, and nursing homes is a great challenge. To bridge the information between these environments that links all episodes of care and healthcare utilization, data must be linked through integration (Snee & McCormick, 2004).

According to Staes et. al, public health is a broad domain that requires coordinated uses of disparate and heterogeneous information systems…. The next-generation public health information systems must overcome barriers to integration and interoperability, leverage advances in information technology, address emerging requirements, and meet the needs of all stakeholders (Staes et al., 2009). This is a large part of the goal for public health informatics and consumer health informatics. How do we create a public health informatics infrastructure that supports information interoperability? How will these systems be defined utilizing consumer informatics to facilitate therapeutic adherence?

The need for data and system integration has primarily been driven from the highest level of the federal government. The primary driving force has been the development of the National Health Information Infrastructure (NHII), which has focused on eliminating the obstacles around collecting evidence in healthcare,

information about the quality of care, reliable information on health encounters, episodes of care, performance of care givers and the difficulties in measuring the cost of care. The focus is designed to help establish the infrastructure for clinical and population health (Snee & McCormick, 2004).

Under the direction of the NHII, the Center for Disease Control and Prevention developed additional standards for the Public Health Information Network (PHIN). This network creates standards for data integration at the hospital and clinic level. For example, National Electronic Disease Surveillance System (NEDSS) captures encounters and cases across laboratory response networks. SNOMED, ICD-9-10, CPT and HL7 contribute to the standardization of EMR data. These data standards help healthcare organizations share data through the effective use of data standards that facilitate interoperability and lead to improved health outcomes (Snee & McCormick, 2004).

The Technology Architecture of Public Health and Consumer Health Informatics

In order to support these sophisticated therapeutic engagement and adherence strategies, hospitals, ACOs, public health organizations and private companies need to establish the foundational technology architecture required to support public health and consumer informatics. For these systems to work, data must be combined across multiple systems and data types. The data must then be converted in order to be prepared for analysis. This requires a foundational data architecture utilizing data warehouses and data marts to execute sophisticated data conversion techniques to generate reports. These reports and analytics help drive member communication and decision support for these organizations. It also is the foundation for public health and consumer health informatics program support and evaluation that drive improvement between actions and across outcomes.

The diagram below is an example of a conceptual technology architecture that delivers the required functionality to support advanced capabilities needed for informatics solutions.

Conceptual Informatics Architecture

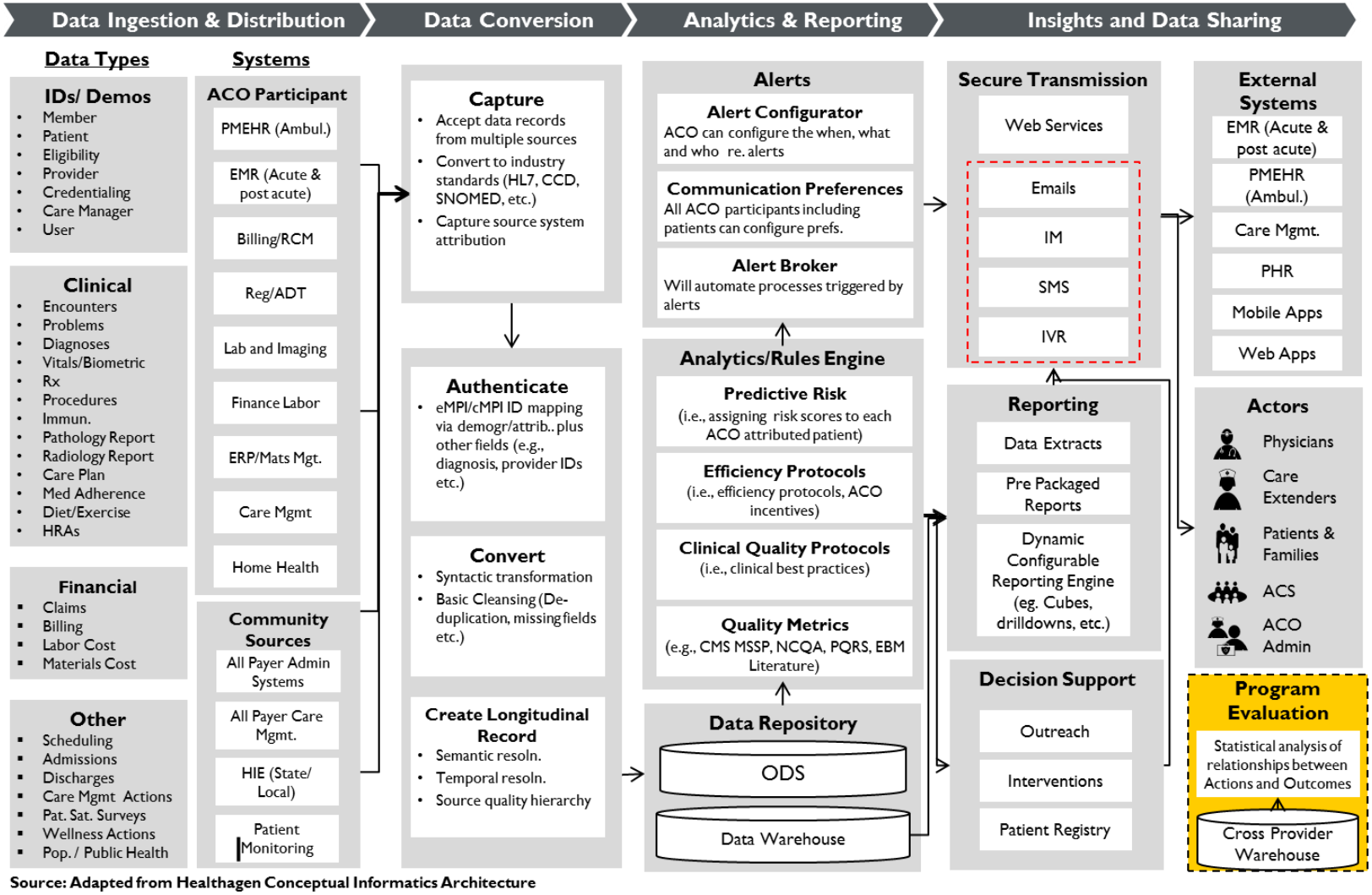


Figure 7 – Adapted from Architecture for Public and Consumer Health Informatics(Healthagen, 2013)

Domain	Description
Data Ingestion and Distribution	• Acquire source data fragments from multiple, heterogeneous systems (Healthagen, 2013)
Data Conversion	• Normalize source data fragments to common format • Attribute source data fragments to correct individual or entity • Incorporate source data into coherent record of events with appropriate clinical relationships and context (Healthagen, 2013)
Analytics and Reporting	• Store processed and raw source data fragments in centralized repository • Analyze clinical outcomes against quality metrics • Analyze performance against clinical best practices • Analyze financial performance against efficiency metrics • Assigning a risk score to attributed patients • Development of reports that ranges from data file extracts to pre-packaged reports to OLAP drill down capability • Data derived from source information and system analytics that will impact end user decision making and workflows (Healthagen, 2013)
Insights and Data Sharing	• Securely transmit alerts via web services to external constituent systems • Generate and initiate direct to constituent multi-channel communications (Healthagen, 2013)

Intermountain Healthcare Case Study

An excellent example of how information architecture standards play an important role in facilitating therapeutic adherence is the example at Intermountain

Healthcare (IMH). Intermountain has received a number of awards for their utilization of informatics solutions to maximize the quality of care while reducing costs (e.g., 2002 National Exemplary Practice Award, 2003 Most Wired Innovator Award, 2004 Baseline Magazine ROI Award) (Barlow, 2005). This has been done through sophisticated clinical quality indicators and advanced analytics. In order to do this, however, a sophisticated information and technology architecture is required. According to Steven Barlow, former director of Information Management at IMH and current co-founder of Health Catalyst, the vision for the analytics solution at Intermountain was to create a single source for complex data analysis and reporting. In other words, data integration, centralization, and interoperability were critical.

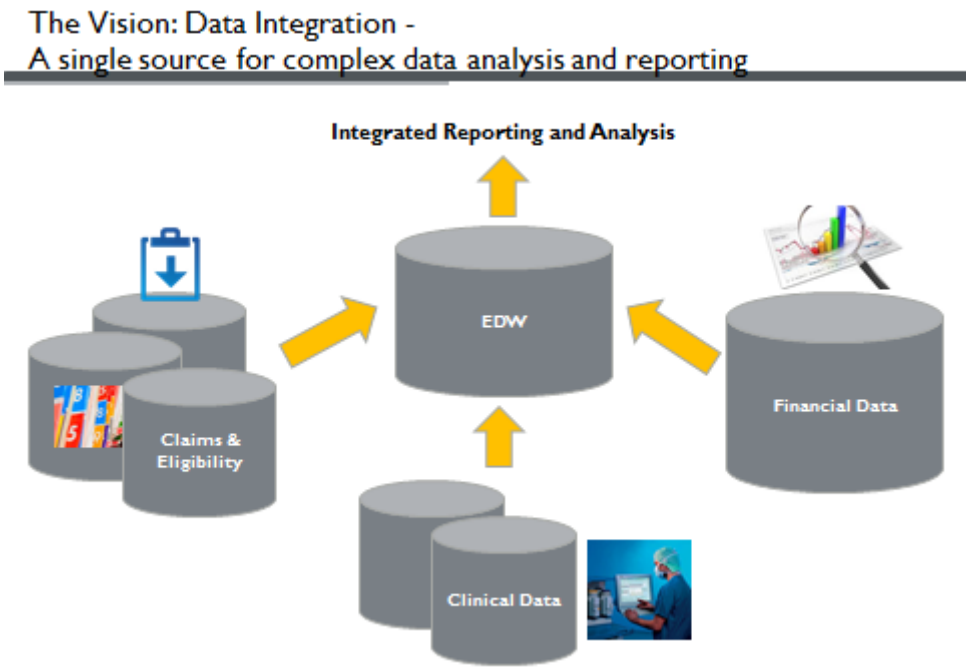


Figure 8 - Adopted from Intermountain Data Vision

In order to realize its vision, IMH had to establish information architecture flexible enough to accommodate data integration from multiple sources of data. This includes data sometimes having differing formats and underlying data structures. The solution for IMH was to integrate data from multiple sources and store this data in an

enterprise data warehouse that could then be accessed from multiple users through specific– Online Analytical Processing (OLAP) cubes. The data sources that were integrated include but are not limited to lab systems, claims, pharmacy, EMR, radiology finance systems, state and external federal – public health systems. The cubes could then be analyzed according to specific therapeutic conditions, therapies or other dimensions. This allows for specific interventions to be implemented and care management/adherence programs to be monitored or measured. The architecture was used to support the end to end continuum of care, from identification of the health need and diagnosis to the specific procedure, outcome and measurement of patient perception and care management program.

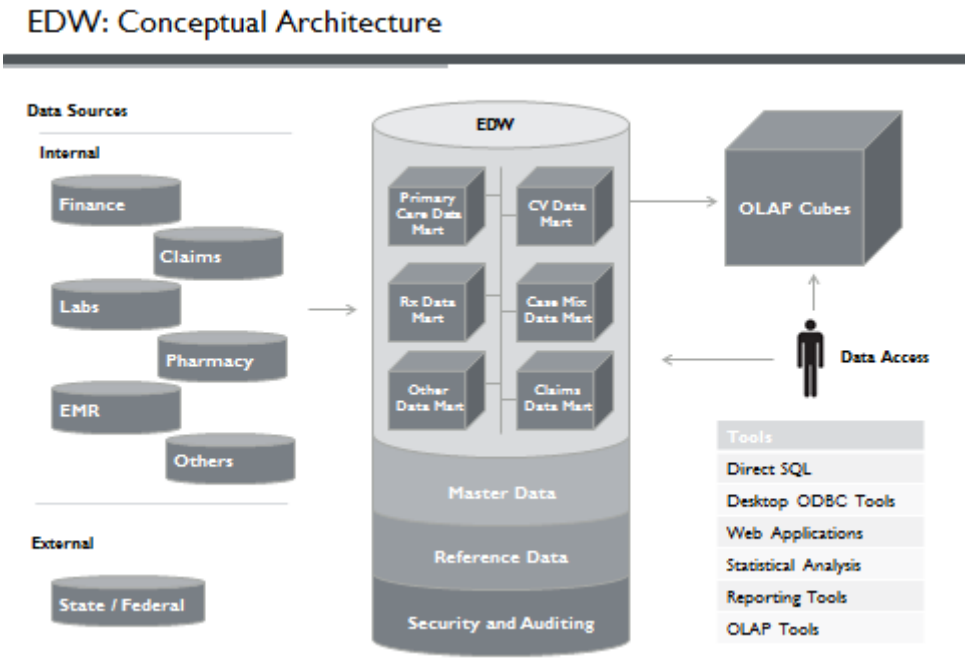


Figure 9 – Adapted from IMH Conceptual Architecture(Barlow, 2005)

In order to facilitate data standardization and interoperability, IMH utilized a fundamental data strategy known as the bus architecture. The data bus integrated various data sources through the utilization of common data attributes with standard

names and data types. Data elements included patient member ID, encounter ID, IHC facility ID, CPT code, DRG code, ICD 9 procedure code, ICD 9 diagnosis code, patient type, patient member demographics, and other elements key to supporting the sophisticated analysis. This master and reference data management approach eliminated some of the most common data management issues by standardizing data attributes and metadata through the bus architecture.

Another area, almost as important as the underlying architecture for IMH, was the data governance and stewardship process. According to Barlow, IMH utilized data stewards for setting data policy and security standards. These individuals were focused on data quality – ensuring that data is used for its intended purpose and only individuals who should have access to different data sets have that access. The data stewards also utilized meta-data reporting tools to facilitate standardization, promote reuse, reduce deduplication, and minimize logic errors.

Intermountain Healthcare – Increasing Adherence to Asthma Medication

After the informatics solution architecture was built, the next question is how can it be used to improve adherence to drug therapy? Leaders at IMH were able to utilize its sophisticated enterprise data warehouse and analytics solution to increase patient medication use and reduce asthma related ER visits based on an analysis of health plan claims and other summary data. After implementing an asthma related intervention program, physicians and hospital leaders worked together to analyze and measure the results of the program through the informatics solution.

As you can see in the graphic above, after the introduction of the asthma adherence intervention, there was a significant increase in adherence to asthma medications over time.

Over the same period of time, you can clearly see a reduction in ER visits as well. This is a clear example of how informatics solutions can be used to identify certain patients, by therapeutic conditions, develop interventions and them measure the effectiveness of those interventions through the use of public health and consumer health informatics solutions.

Methodology, Approach and Solution

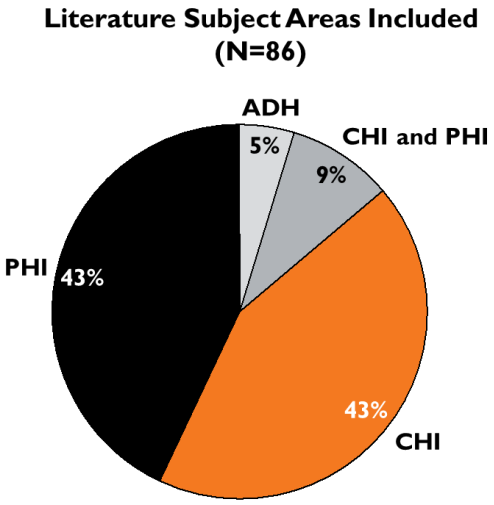
Body of Work, Search Strategy, and Inclusion Criteria

In order to understand the body of work that has been establish in the fields of public and consumer health informatics, a systematic literature review was conducted. Over 40 peer reviewed articles and journal entries were analyzed in PubMed from 26 different journals including the Journal of the American Medical Informatics Association, Yearbook of Medical Informatics, and numerous others.

The search used the following key words:

Term	Definition
Adherence (ADH)	The extent to which the patient continues the agreed-upon mode of treatment under limited supervision when faced with conflicting demands, as distinguished from compliance or maintenance (Mifflin, 2007)
Public Health Informatics (PHI)	The application of information and computer science to public health research practice and learning (Winslow, 1920)
Consumer Health Informatics (CHI)	A branch of informatics that "analyzes consumers' needs for information, studies and implements methods of making information accessible to consumers, and models and integrates consumers' preferences into medical information systems (Eysenbach, 2000)

The search results returned over 122 articles from 1995 to 2013, covering the topics of consumer health informatics, public health informatics, and adherence. The results returned 37 duplicates that were then removed leaving 84 papers.



One paper was excluded from the study since it did not fit the criteria. The results showed 43% of the articles were on PHI, 43% on CHI, 11% on both CHI and PHI, and 4% on Adherence.

At an aggregate level, there appears to be a 6% year over year increase in the number of published articles on this topic. The breakdown of articles by year and by type is shown below in the chart of articles over time by type and in table 1.

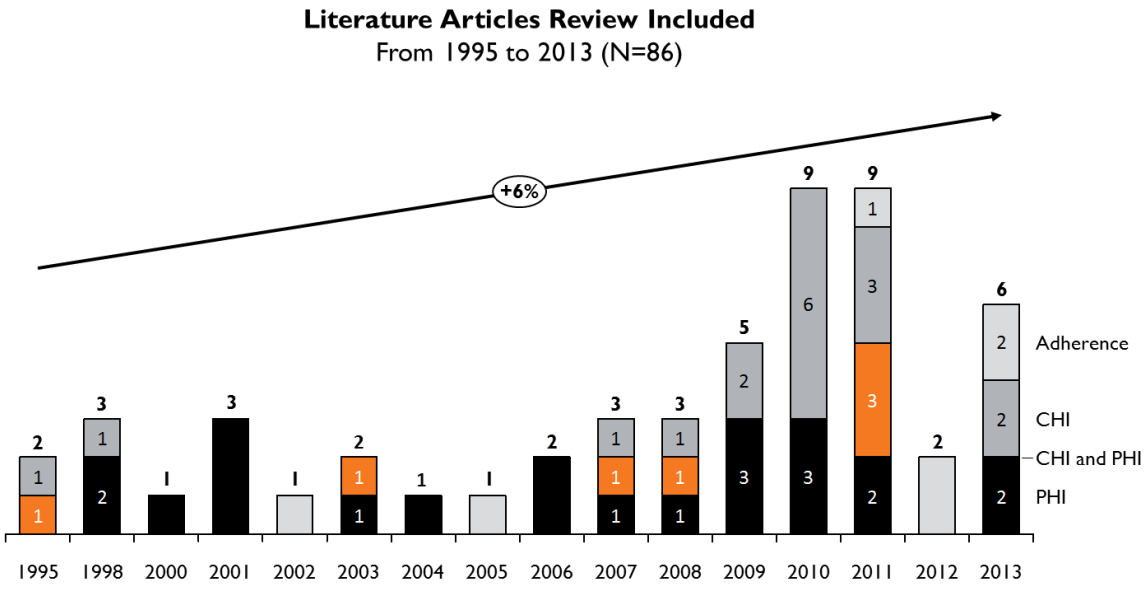


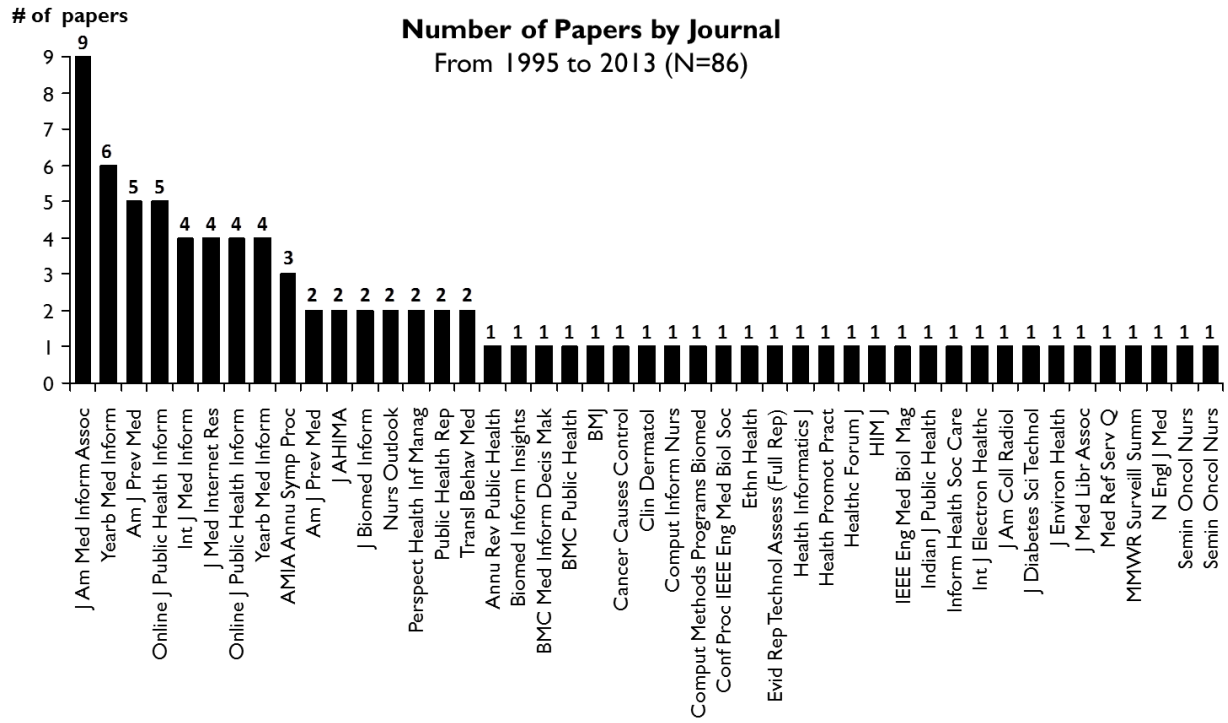
Figure 10 - Literature Article Review

Over the last 5 years, there has been an increase in the number of articles related to CHI, while articles on PHI have remained fairly flat.

Year	Adherence	CHI	CHI and PHI	PHI	Grand Total
1995		1	1		2
1998		1		2	3
2000		2		1	3
2001		4	1	5	10
2002			1	4	5
2003				1	1
2004		1		3	4
2005		2	1	1	4
2006				1	1
2007		5		4	9
2008		2		2	4
2009		5		3	8
2010		3	1	3	6
2011		6	3	2	12
2012	1	3	1	3	8
2013	2	2		2	6
Grand Total	**3**	**37**	**9**	**37**	**86**

Table 1 - Article by Type (1995-2013)

The most frequently published research was found in Journal of the American Medical Informatics Association followed by Yearbook of Medical Informatics.



Among the various authors, Yasnoff was the most frequently cited – appearing in over 7 of the published papers, followed by Eysenbach who appeared over 5 times.

The final review resulted in 24 peer reviewed articles and 7 non-peer reviewed articles or case studies. After the final articles were categorized and analyzed, they were filtered for relevance in answering the different research questions. They were then assigned to each question and the different research questions were answered based on the current body of work in that area. Finally, a summarization and assessment was made based on the research findings to answer the research questions and determine the overall value that consumer health and public health informatics had on therapeutic adherence.

Discussion

What is the value of public health informatics to therapeutic adherence for improved outcomes?

To evaluate the value of public health informatics for therapeutic adherence and improved outcomes, the triple aim framework was used. The framework is a relevant evaluation framework within the context of this thesis because it focuses on the different aspects of the thesis statement. First, to address the 1st leg of the triangle- better health for the population- a public health informatics assessment of therapeutic adherence, measures the extent to which value is created. To address the second leg of the triangle - better health for the individual – a consumer focused informatics assessment of therapeutic adherence, measures the extent to which value is created. To address the third, leg of the triangle – lower cost through improvement – measures the overall cost impact these improvements have on the broader health system.

CHI and PHI – Solving for the triple aim

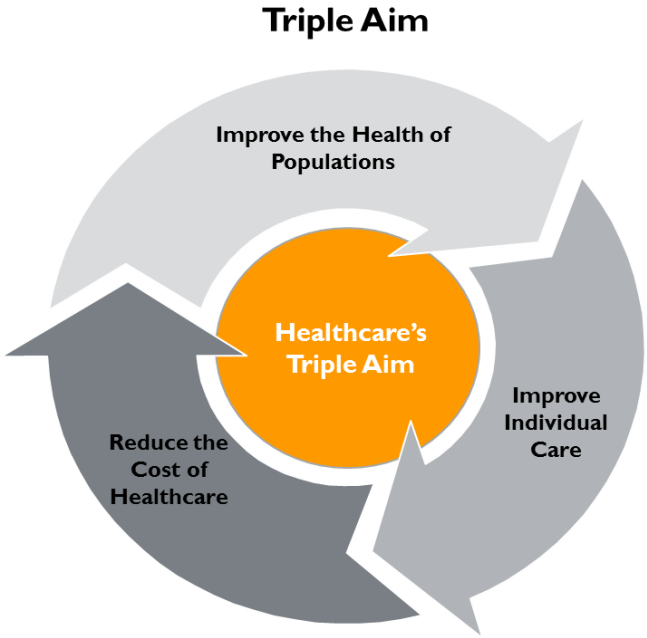


Figure 11 - Healthcare Triple Aim – Adopted from Institute for Healthcare Improvement (2014)

1. **Public health informatics will continue to drive better population health through a number of applications –** Improving therapeutic adherence is one important application. Leading researchers agree that public health informatics solutions will continue to enable greater outreach efforts to promote better clinical care (e.g., via better compliance with preventive medical regimens). It will also continue to enable integrated solutions by linking clinical data to public health morbidity surveillance information and screening guidance at the patient caregiver interface to help analyze and segment patient populations for interventions (Kukafka, O'Carroll et al. 2001).
    a. **Public Health informatics will continue to support immunization adherence and compliance** - Immunization registries are another area where public health informatics will continue to drive broader therapeutic adherence and compliance. Immunizations and vaccinations have been one of the most successful public health initiatives to date. Immunization registries are one of the most critical population based public health informatics solutions (Goldstein and Maiese 2011).
    b. **Public health and consumer health informatics collaboration will drive greater value through health promotion and adherence.** Consumer – public health informatics could hold the key to this through collaboration and sharing of therapeutic level information to be captured in an EMR or clinic based medical system but leveraged for public health or community based outreach. Because many patients fail to adhere to medical regimens intended to prevent disease, public health informatics solutions will need to continue to be used to promote prevention and innovated collaboration techniques used to promote adherence to medical regimens. For example, when clinicians realize that patients not adhering to their care regimens (e.g., drug plan or visits), public health and medicine will start to partner by

providing a community based outreach workers that leverages informatics.

2. **Consumer health informatics will continue to drive better individual care through therapeutic adherence solutions across a number of key therapeutic areas**. Consumer Health Informatics will become even more integrated with medical care, electronic medical records, therapeutic education, and public health to impact the health outcomes and impact the overall business of health care. These informatics solutions will drive improved adherence across traditional and new therapeutic / public health areas.
    a. **Diet / Exercise and Physical Activities** - CHI solutions showing positive adherence and behavioral change will move beyond web based tailored nutrition education and social media groups tailored interventions, feedback tools to real time fitness integration, monitoring and measurement.
    b. **Alcohol and Smoking Secession** - CHI applications will move beyond tailored web-based feedback and computer based technologies to more advanced informatics solutions integrating social and mobile channels.
    c. **Diabetes –** Solutions in this area will continue to improve adherence through advances in quantified self and wearable technologies that have real-time integration into monitoring solutions and other systems. Applications will move beyond number of steps taken to include a more comprehensive set of monitoring solutions.
    d. **Asthma and Chronic Pulmonary Disease –** CHI solutions in this area will continue to leverage web-enabled interactive media improve knowledge, self-management, and overall monitoring adherence to the therapeutic program but will also leverage advances in technologies to further the reach of potential patients.

e. **Cardiovascular disease** -Further research should be done to understand the effectiveness on CHI on cardiovascular disease. However, in the future web-based cardiovascular disease system will likely increase self-efficacy adherence through greater patient physician collaboration and engagement.

f. **Patient Engagement –** The continued shift to ACOs and PCMH will increase the level of therapeutic engagement in the future. Health care organizations will begin to drive better patient engagement and subsequently better adherence through the use of CHI tolls and public health, clinical and consumer health informatics. Consumers will be better equipped to manage their own health (Eyler 2011).

g. **Wearable health devices –** Future advances in wearable technologies and the shift to the quantified-self movement will have a significant impact on therapeutic adherence across a number of dimensions.

3. **CHI and PHI Informatics solutions that help to increase adherence to therapy will continue lower overall healthcare costs** - According to the Chief Medical Officer of CVS Caremark, Troy Brenan MD MPH, the overall cost of medication and therapy non-adherence for chronic conditions is valued at $1.3 trillion dollars (e.g., cancer at $319 bn., diabetes $132 bn., and hypertension at $312 bn., etc.) based on 2009 data. Based on this data, therapeutic adherence clearly was and continues to be identified as a critical issue for managing chronic conditions as non-adherence is a significant driver to overall healthcare costs and outcomes. Studies continue to show that, in 2009 fewer than 40% of original maintenance prescriptions were being filled and 31% were never filled (Brennan 2009). Results indicate that although improved medication adherence by people with four chronic vascular diseases increased pharmacy costs, it also produced substantial medical savings as a result of reductions in hospitalization and emergency department use. Therefore based on these studies, even though adherence

initially raises costs for patients in terms of higher pharmacy costs, the total costs savings to patients who have a chronic disease are significant. The cost benefit ranges from 2:1 for adults under sixty five with dyslipidemia to more than 13:1 for older patients with hypertension (Roebuck, Liberman, Gemmill-Toyama, & Brennan, 2011)).

4. **Impact of Non-Adherence is critical** - The effects of non-adherence on public health outcomes are clear. Almost half of all Americans, approximately 133 million people, live with at least one chronic disease (Roebuck et al., 2011)). . Patients who adhere to their medication regimens enjoy better health outcomes and make less use of urgent care and inpatient hospital services, compared to patients with similar medical conditions who are not adherent(Roebuck et al., 2011)). Yet despite the evidence of improved outcomes from adherence, the World Health Organization reports average medication compliance rates in developed countries of just 50 percent (Roebuck et al., 2011)). Non-adherence is associated with approximately 30 – 50% of treatment failures and 125,000 deaths annually.

Given these findings, both public and private health should continue to look for new and innovative ways to leverage public health and consumer health informatics to improve patient adherence to therapy especially for those who have chronic conditions. The time is now. The technology is available and the impact is substantial.

Study Limitations

This study had a various limitations. First, the literature search was limited to PubMed, the internet, professional client cases, and parsing through social media and web content sources. Also, the search utilized narrow definitions of adherence to medication therapy. I did not include broader topics of compliance that are synonymous with adherence. In terms of the body of work, a long time frame was considered. The timeframe from 1995 to 2013 allowed for early research considerations about the value of PHI and CHI for adherence.

Secondly, when evaluating the value of PHI and CHI on therapeutic adherence, a detailed cost effectiveness analysis across the various conditions and potential value compared to alternatives was not conducted. Such analysis could help to better prioritize in which specific chronic conditions PHI and CHI would provide the most value. This research did not attempt to quantify the overall impact of specific interventions and how those interventions would specifically reduce the cost of non-adherence. Further research in this area would be interesting to understand the dollar impact of different CHI and PHI adherence intervention solutions.

Finally, neither interviews nor primary data collection was included as a part of the study. Adding interviews and primary research would be interesting in this case to understand the qualitative effects of such PHI and CHI interventions. Future research could also utilize controlled experiments to understand the extent to which newer CHI applications such as the quantified-self movement and fitness devices help to drive therapeutic adherence. The research could also analyze how the tight coupling of PHI and CHI and quantified self could change the game as it relates to therapeutic adherence and improve overall health outcomes.

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