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www-dot-screening: An Internet-based Application to Improve Community
Screening Interventions for Coronary Heart Disease

by

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A thesis submitted in partial satisfaction of the requirements for the degree of

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in the

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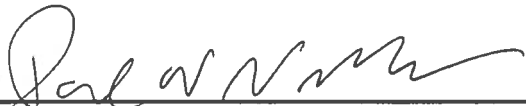



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Spring 2002

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Interventions for Coronary Heart Disease

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by

Jonathan Paul Singer

Dedication

This thesis is dedicated to my mother and father, Margie and Peter Singer. It is through their unending love, support, and illustration by example that this thesis, as well as what I hope to accomplish in my life, has become clear to me. Thank you guys!

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www-dot-screening: An Internet-based Application to Improve
Community Screening Interventions for Coronary Heart Disease
A Literature Review

Introduction

Cardiovascular disease (CVD), including coronary heart disease and stroke, continues to be the leading cause of morbidity and mortality in industrialized nations [1], [2]. Several risk factors associated with CVD have been identified, many of which are modifiable. Major improvements in the prevention of CVD have been made through the reduction of risk factor levels through lifestyle changes and medication [3]. Indeed, Grundy, et al, suggests that 75% of coronary heart disease could be prevented by the adoption of healthy lifestyles [3].

Effective prevention of CVD requires successful collaboration between public health efforts and medical services. Educational screening programs in communities serve two purposes: to motivate and educate all participants in the importance of reducing their risk factor levels for CVD and to identify high-risk patients who require immediate medical attention.

Although effective, several barriers in community screenings for CVD continue to frustrate all involved. Quantitative risk assessment is not currently used in the majority of CVD screenings, effective data gathering and knowledge sharing among interventions continues to be suboptimal, and formalized automated mechanisms for facilitating referrals for follow-up are not currently available. Furthermore, adherence rates to referral recommendations consistently fall between 50-70%- a rate in critical need of improvement. The relatively recent rift between public health and medicine described by Roz Lasker [4], has contributed to poor coordination and collaboration between public health services and medical care. The Internet and its associated technologies offer a

revolutionary potential to address these shortcomings and facilitate collaborative efforts between public health and medicine.

The purpose of this literature review is to trace the evolution of collaborative community interventions targeting CVD and to identify the significant barriers for maximum effectiveness. This review also seeks to demonstrate that a carefully designed Internet application has the potential to improve many of the identified barriers to collaborative community interventions by utilizing automated protocols, data analyses, and database building capabilities that are otherwise unfeasible for smaller projects. In order to support this argument, this review will assess several of the numerous Internet applications that are being developed to address health care needs.

Thus, this literature review first discusses the “Exemplar” or classic community interventions in CVD followed by a discussion of present day interventions and their design considerations. And last, current and future Internet applications designed to address health care needs will be reviewed to demonstrate the potential of this technology to address the identified weaknesses in community screen and treat interventions in CVD.

The “Exemplar” Programs

Background

In the early 1970’s, as today, cardiovascular disease (CVD) including coronary heart disease and stroke was the leading cause of death and disability in industrialized countries [1]. Over the three decades preceding the initiation of the Stanford Three Community Study, several large prospective epidemiological studies concretely elucidated several risk factors highly associated with the development of coronary heart disease. The Framingham Study, arguably the most well known cohort study of heart

disease, was initiated in 1949. Samples of residents of Framingham, Massachusetts have now been studied for 3 generations, producing powerful quantitative data linking risk factors to the development of atherosclerotic heart disease.

Many of the risk factors discovered are modifiable, while others are not. Interestingly and key to future interventions was the discovery that CVD is largely preventable and reversible through modification of risk factors [1]. Major risk factors susceptible to modification include high total cholesterol, low HDL-cholesterol, high blood pressure, cigarette smoking, sedentary lifestyle, obesity (related to both activity level and nutrition), and diabetes mellitus [3]. Risk factors not susceptible to modification include a family history of heart disease, age, and gender [3]. Framingham, along with other studies, demonstrated that individual susceptibility is enhanced by culture, economic factors and environment [1].

Once risk factors had been established, it was a logical step for researchers to move from observational studies like Framingham to experimental studies in attempts to prevent cardiovascular disease through risk factor reduction. One of the first major interventional studies to attempt community-wide risk factor reduction was the Stanford Three Community Study [5]. It, along with a sister program in North Karelia, Finland, was initiated in 1972. The program's end goal was to change both individual and community behavioral patterns in order to reduce CVD risk factor levels, thereby reducing CVD mortality and morbidity.

The Stanford Three Community Study (STCS) was the earliest community-based study in the United States [5]. The STCS targeted CVD risk factors on a community-wide scale through broad multidisciplinary health promotion education programs

delivered through media and interpersonal channels. The study involved two Experimental Cities, which received the mass media education campaign and one control city, which did not receive the education campaign and served as the reference city [5]. The study resulted in significant improvements in smoking, cholesterol, and blood pressure levels in the 2 experimental cities versus the reference city [6]. The North Karelia Project, also reported positive risk factor reduction results [5]. In addition to reduced risk factor, the success of North Karelia and STCS resulted in the generation of larger programs that sought to extend the scope and objectives of the earlier STCS.

The three major “Exemplar” projects birthed from the experience in the STCS and the North Karelia Project were the Stanford Five City Project (SFCP), the Minnesota Heart Health Program (MHHP) and the Pawtucket Heart Health Program (PHHP) (Pawtucket, RI). The SFCP was initiated in 1978 with MHHP and PHHP following in 1980. They all received funding through the National Heart Lung and Blood Institute. All of these studies were firmly grounded in academic theories of behavior modification, utilized mass-media as well as community programs as their primary means of intervention, and all had very similar goals. As a result of these similarities, I will not discuss all the projects in detail. Instead I will focus on the SFCP as an example, supplementing the review with examples from the MHHP and PHHP as needed.

A major assumption of the SFCP, MHHP, and the PHHP was that small risk reductions across the total community would lead to higher reductions in event rates than large reductions in those at highest risk [2]. This assumption of a powerful public health effect achieved through small changes across a population led the designers of the Exemplar Programs to target entire cities for intervention, rather than segmenting the city

into smaller units for specifically tailored interventions- a trend that has become popular today.

The Exemplar Programs were different from the STCS in several capacities. They dealt with much larger communities that were more socially complex, the education campaign was more extensive, the intervention period was longer, the age range of monitoring was broadened, and event rates (eg. angina, stroke, myocardial infarction, death) were measured. The SFCP was a 6-year intervention, from 1980-1986, that targeted all residents in the two experimental communities of Monterey and Salinas, CA. Three other cities- Modesto, San Louis Obispo, and Santa Maria, CA- served as reference cities and did not receive the intervention.

The two major hypotheses of the SFCP were that 1) community-wide education could result in lasting reductions in risk factor levels in the general population aged 12 to 74, and 2) the decline in risk factor levels would lead to a decline in CVD morbidity and mortality in those aged 30-74 at significantly greater levels in the experimental cities versus the reference cities [5].

The project had 3 main goals. First, to produce a 20% reduction in overall CVD risk in the experimental population versus the reference communities by persuading people to reduce their blood pressure, cholesterol, and weight, to quit smoking, and to increase their levels of exercise [5-7]. Within this goal was the plan to test models of behavior change [7]. Second, to create a self-sustaining health-promotion infrastructure at both the individual and community level [6] [7]. The individual-level infrastructure would rely on media messages to teach individuals to recognize and address their risk factors. The community-level infrastructure would consist of organizations that would

maintain educational interventions after the cessation of the SFCP. This concept is also known as Capacity Building. The third goal was to analyze secular trends in CVD risk factors and CVD morbidity and mortality across both the experimental and reference cities [6].

All three Exemplar Programs were quasi-experimental in design [1], [5], [6], [8]. Constraints on city selection, particularly concerning media markets precluded randomization of the final cities approved for assignment to either experimental or reference categories. The SFCP city criteria included a northern California geographic location, a population >30,000, a 5-city total population >300,000, similar ethnicity and SES demographics in all 5 cities, relative independence from the other cities, no shared print or electronic media between treatment and control cities and between control cities, shared media between the experimental cities (to reduce costs), and a relative independence of the two experimental cities, excluding the shared media [1], [5], [6]. The reference cities were not deprived of any natural development outside of the education that comprised the intervention in the treatment cities [9]. After baseline population surveys, the 2 experimental cities began the 6- year education program targeting all residents between the ages of 12 and 74. Investigators also conducted CVD morbidity and mortality surveillance in all 5 cities for 9 years, beginning at the initiation of the education campaigns.

The survey methods included both cross-sectional as well as cohort groups [1], [5], [6], [10]. After baseline cross-sectional surveys of all the cities, the effect of education on risk factor reduction was assessed by comparing biennially conducted cross-sectional surveys conducted in the two treatment cities with similar cross-sectional

surveys in 2 of the 3 reference cities [6], [9]. Only morbidity and mortality rates were recorded in the final reference city [6]. Cross-sectional surveys were used because the samples were not subject to the effects of aging, repeated-measure bias, or dropout bias [6]. The researchers also resurveyed a randomly selected group from the pre-intervention cross-sectional survey group three times to allow for an evaluation of the process of behavior change in a cohort group. The community was the unit of analysis and the individual was the unit of observation. The “combined event rate”, including nonfatal and fatal myocardial infarction, stroke, and fatal CHD, was chosen as the main outcome variable for analysis a priori [1].

As investigators were analyzing the data, they realized that the risk reduction in the treatment cities was occurring slower than predicted and that 1986 represented a premature endpoint to event rate monitoring. Surveillance was extended to 1992 with 1979-1985 being termed the Early Period and 1986-1992 being termed the Late Period. Investigators re-hypothesized that trends in the late period versus the early period would be more favorable in the treatment cities versus the reference cities [10].

The actual intervention was a multidisciplinary educational campaign theoretically grounded in community organizational change, with multiple components designed to reinforce and amplify the effects of other components. The theoretical foundation for the educational components of the intervention campaigns included the Social Learning Theory, the Communication Persuasion Theory, the Innovation-Diffusion Theory, as well as several lessons from Social Marketing. These theories guided the design and implementation of the intervention in order to effect community-wide behavior change to reduce risk factor levels for CVD.

Theoretical Models of Behavior Change

Albert Bandura's Social Learning Theory guided the development of the educational materials [5], [10]. The Social Learning Theory posits that new behavior development results from exposure to significant role models [11]. New behaviors are sustained over time through reinforcement at both the individual and societal levels.

The Communication Persuasion Theory is based on the hierarchical process of learning and behavior change [12]. The first step establishes a credible message source. Recipients of the message then pass through 4 main phases. First, recipients enter an awareness (of the issue) and knowledge acquisition phase. Second, they move into the motivation and skills development phase. Third, action is taken and behavior is modified. And, fourth, behavior change enters the maintenance phase. Recipients may cycle between phases, but when they regress, they do so with greater knowledge, self-awareness, and perception of risk. Along the way, recipients must be able to develop a positive view of self-efficacy and must learn self-management if the maintenance stage is to be successful.

The Innovation-Diffusion Theory posits "healthier behaviors are innovations that diffuse through the social networks of a community" [12]. Key opinion leaders in the community were recruited to introduce and endorse the innovation. Mass media and face-to-face contact comprised the diffusion process of this theoretical model. The theory also segments the target audience into four main groups. The groups, in order of adoption of the new behavior, are referred to as the Innovators, the Early Adopters, the Early Majority, and the Late Majority.

Social marketing's 4 Key "P's" also provided a framework for the design and implementation of the educational components of the intervention [12]. The four "P's": Product, Promotion, Place, and Price were used to develop education messages, define the target audience for each message, select the most effective media vehicles for delivering each particular message, and in determining how to monitor the message dissemination for effective evaluation.

The Social Marketing principles also demonstrated the need for audience segmentation. For each educational component, it is important to segment the target audience into homogeneous units. In order to do so community analysis must provide a thorough investigation into the relevant knowledge base, attitudes, social norms, and behaviors of each target audience. [13]. Typically, investigators and advertisers segment their audience according to demographic variables. Indeed, past studies have shown SES, gender, age, and education levels to be predictors of health behaviors. But, as demonstrated by Slater and Flora, behavior is not always related to demographics. Another method of audience segmentation is according to *lifestyle analysis*, also known as psychographics [13].

Psychographics is a multivariate clustering technique used to identify subpopulations within an demographically homogeneous group that share patterns of social norms, beliefs, and behaviors. Although this technique is most often used by market researchers, psychographics can be applied to the design of health interventions [13].

In one such example of applying psychographics to public health, researchers identified health and nonhealth-oriented clusters [13]. In the Health-oriented clusters,

groups were given identifying titles such as Healthful Adults, Healthful Young Adults, Healthful Talkers and Young Athletes. The unhealthy clusters were termed Unhealthy Adults, Unhealthy Young Adults, and Worried Older Adults. Each category was clustered according to lifestyle choices. Target interventions for each cluster are designed to utilize or minimize certain features of each cluster's behavior patterns.

The Worried Older Adults, for example, think and worry about their cardiovascular health but are uneducated in risk reduction strategies. Additionally, they lack confidence in their ability initiate behavior change [13]. The high rates of ethnic minorities in this cluster may be explained by cultural or language patterns acting as obstacles to knowledge acquisition attempts at behavior modification. An appropriate intervention would thus be designed to increase awareness of risk factors and provide skills training on how to reduce them. The intervention would seek to develop behavior change skills and increase the cluster member's self-efficacy regarding the adoption of risk reduction behaviors.

The nonhealth clusters are not the only clusters that pose dilemmas for those in public health. Indeed, the largest cluster overall, the Healthful Adults, poses a unique problem to intervention efforts. Although this cluster has high participation rates in screenings and other interventional activities, many in this cluster already possess the healthy lifestyles advocated by the interventions. As a result, their behavior change will be minimal, reducing the impact of an intervention on the health profile of a community [13].

Thus, audience segmentation is conducted to identify target audiences, guide the design of the educational messages, identify the appropriate media delivery vehicles, pre-test material, and evaluate program effectiveness.

Study Design

Media comprised a major proportion of the education. TV and radio were used to heighten and change attitudes, knowledge and motivation of community members [5]. Public service announcements (PSAs), news stories, and hour-long programs containing risk factor reducing information and instruction were some of the messages found on television. Radio was used for announcements and brief (5 min) informational programs. Spanish language messages were a major component of the radio intervention since it had been discovered in the pre-intervention community analysis that radio was a major information source for Spanish speaking Mexican-Americans [5].

Print materials including pamphlets, newspaper articles, kits, and books were developed to facilitate skills training [5], [8], [10], [14], [15]. Print materials were distributed via direct mailings and through organization sites, workplaces, medical sites, and churches. Weekly newspaper columns appeared in both English and Spanish [5], [8], [10], [14], [15]. For example, for weight reduction alone, 20 newspaper columns per year dealing with nutrition and weight were run in a weekly paper, all households were sent weekly tip sheets describing heart health nutrition, and a 4-page weight loss kit was developed [8]. Print material was in addition to the classes, workshops, seminars, TV and radio also dealing with weight issues.

In addition to the media component, programs were held in a variety of formats ranging from one-on-one counseling to classes to seminars and workshops [5], [8], [15].

The programs were founded in Social Learning Theory, Communication Persuasion Theory and various community organization models [1]. The target audience was evaluated and segmented to lead the design and monitoring of the various intervention programs. For example, in considering newspaper columns, investigators first needed to research whether or not the target audience read newspapers, whether they spoke the language being used in the article, whether the material was appropriate for their culture, reading level, etc. After designing a program, it was pre-tested with community members and then introduced. Programs were held in health departments, schools, community colleges, voluntary organizations, hospitals, workplaces, and nonprofit health service agencies [5]. Investigators calculated that each adult in the treatment city would have been exposed to 527 educational episodes totaling approximately 26 hours evenly distributed over 5 years [15].

Thus, the intervention design established messages with goals ranging from awareness stimulation to behavior modification and delivered the messages through the most appropriate media vehicles. Television, with its quick pace and high visibility allowed for effective awareness raising, whereas print material and classes were reserved for in-depth behavior modification.

Results

After 6 years of educational interventions, statistically significant improvements in CVD knowledge [6], [10], systolic and diastolic blood pressures [6], [15] smoking rates [6], [10], [15], resting pulse rate [15] and cholesterol measures [6], [10], [15] were demonstrated in the cohort samples versus the reference cities. In the cross-sectional samples, significant improvements in CVD knowledge [6], [10], systolic and diastolic

blood pressure [10], [15], resting pulse rate [6], [15], and BMI [6] between the treatment and control cities were documented. BMI increased in both treatment and control cities but significantly less in the treatment cities [8].

In mid-intervention analysis, investigators found that the treatment cities had a 15% decrease in total mortality score and a 16% decrease in CHD risk scores but these were not significantly different from improvements in the same scores in the reference cities [6], [15]. The treatment city cohort sample showed a 13% decrease in smoking rates but a large decrease in smoking in the reference cities, paralleling secular trends nationally, also occurred and so this decrease was not significantly different [15]. Both men and women in the treatment and reference cities showed improvements in composite health status measures during the intervention.

Discussion

Populations based, multi-pronged intervention strategies are vulnerable to a number of threats to evaluating the effectiveness of the study design and, although the cohort group demonstrated greater risk factor reductions than the independent samples, several features of the communities complicate the clarification of the conclusions. First, the cross-sectional samples had recent immigrants that had not been exposed to the full education campaign. Indeed, only 67% of the final cross-sectional sample in the SFCP had lived in the treatment cities for the full 6 years of the program [15]. Also, the repeated measures of individuals in the cohort group and repeated elucidation of personal risk status may have resulted in greater responsiveness to the education campaign and motivation to change lifestyle behaviors. Additionally, the cohort may have represented a different subgroup of the community than the cross-sectional sample. Due to dropouts,

the cohort represented older, better-educated, geographically more stable residents who were fully exposed to the intervention when compared to the cross-sectional study participants [15].

The results of the SFCP, as well as the other Exemplar Programs, were complicated by strong nationally documented secular trends towards lower risk factor levels. In a comparison between the Early and Late periods of evaluation, both treatment cities and reference cities demonstrated improved CVD knowledge, yet the improvement was significantly greater in the *reference* cities [6]. This may have been due to the secular trend of lowering risk factors that resulted in the reference cities “catching up” to the risk factor improvements documented in the treatment cities during the intervention.

Thus, the SFCP and its sister Exemplar Projects demonstrated reduced risk factors that were, in many cases, modestly higher than the risk factor levels in the reference cities. Surprisingly, though, the combined-event rates (fatal and nonfatal myocardial infarction and stroke plus fatal coronary heart disease) demonstrated no significant differences among the cities [10]. In the Late Period, combined event rates had uniformly downward slope trends in all cities.

Additionally, investigators found a clear negative association between education and composite CHD risk [14], [16]. Investigators also found a positive association between years of education and rate of educational resources use, with the group with the highest education level having 3-5 times the likelihood of reporting use as the group with the lowest education level [14]. Importantly, utilization rates for educational materials

were similar for Hispanic and Anglo populations in the treatment cities. In 9 of 10 intervention categories, there was, at most, a 4% difference in use by ethnicity [14].

Several hypotheses attempt to explain the Exemplar Programs' apparent failure to link significantly reduced risk factor levels to morbidity/mortality rates above those of the reference cities (only the MHHP demonstrated significantly decreased combined event rates). First, the interventions may not have been extensive enough. Or the methodology of the interventions themselves may have been ineffective. Additional considerations include the potential that the risk factors are not causal of CVD, that the risk factor changes should begin earlier in life, the risk factor changes were not big enough, and that the risk factor changes did not last long enough to result in changes in morbidity/mortality incidence.

Fortmann and Varady [10] acknowledge that, even if the changes in risk factors had occurred in the 6-year intervention, the changes would have occurred toward the end of the time of intervention. There would have been a presumable delay between risk factor reduction and morbidity-mortality change that may not have been detectable at the time of follow up. Also, investigators may have overestimated the ability of education campaigns to accelerate lifestyle and risk factor changes into 6 years [10], [15]. More sustained efforts may have been necessary. Additionally, highly effective clinical therapies were introduced in the mid-1980s that were rapidly adopted nationwide that may have obscured the effect of risk factor change on event-rates [15].

In addition to the aforementioned hypotheses, strong secular trends towards lower heart disease risk factors that were occurring nationally during the time of the interventions may have compromised the ability to demonstrate interventional effects.

Investigators acknowledged their underestimation of the strength of these trends in both risk factor reduction and CVD incidence in the control cities and the country as a whole [10]. The SFCP documented increased CVD knowledge and downward trends in blood pressure, total cholesterol and smoking rates in the reference cities [6]. In fact, in the MHHP the secular trends toward lower risk factor levels in the reference cities were often greater than the intervention effects hypothesized by the investigators at the outset of the intervention [1]. For example, investigators hypothesized a 3% decline in smoking versus an observed 11.3% in the reference city. They also hypothesized a 7-mg/dl decrease in total cholesterol yet observed an 11-mg/dl decrease. And they hypothesized a 2mm Hg decrease in blood pressure but documented a 6.3mm Hg drop in reference cities [1]. The SFCP also documented strong secular trends around decreased cholesterol and smoking rates in reference cities [6] and noted increased BMI in women and men in the treatment cities and in women in the reference cities.

Secular trends may have occurred due to the popular press's health promotion unrelated to the intervention, the increased activity of organizations such as the American Heart Association and the American Cancer Society in the reference cities, and the effects of broad federal programs such as the National High Blood Pressure Education Program and the National Cholesterol Education Program [6]. Investigators documented secular trends of increasing exposure to media messages to reduce risk factors, increased health promotion and decreased risk factors in both treatment *and* reference cities in all of the Exemplar Programs [1], [6], [10], [15]. Thus, the actual quantitative differences in message exposure between treatment and reference cities may have been limited, blunting the intervention effect and resulting in risk factor reductions in the treatment

cities that were not significantly greater than those reductions recorded in the reference cities.

When forming conclusions, it would be an oversimplification to use the results of Exemplar Programs inability to effect morbidity and mortality reductions to conclude community-wide interventions are ineffective as a concept. Indeed, there were many net benefits of the interventions, despite the modest effects on event-rate incidence. Many individual components of the Exemplar Programs have been demonstrated to be effective in other studies. Risk factor screening and education, smoking cessation classes and contests, and dietary changes on weight reduction and CVD risk reduction have all been validated outside of the Exemplar Programs. Also, the interventions accelerated positive risk factor changes above the rates of the secular trends. The interventions developed effective models and strategies for CVD education on a community-wide level that are still in use by many agencies today. And, most importantly, they provided direction for future collaborative efforts and community interventions.

A critical lesson learned from the failure of the Exemplar Programs to reduce morbidity and mortality over the duration of the intervention was the understanding that a 5-6 year concentrated intervention may not be long enough to produce noted morbidity and mortality reductions for final project analysis. Rather, more targeted outcomes that are more closely tied to intervention strategy and more consonant with behavioral change theory, such as improved risk factor levels, rates of visits to physicians for health maintenance, and healthy lifestyle habit adoption may be more relevant endpoints to measure [17].

An important lesson is that it is easier to change the risk profiles of those specifically participating in programs than it is to engage a large enough percentage of the community to change an entire community's risk profile. The modest net differences in risk factors between treatment and reference cities suggest a need for new designs and interventional models. Based on theories of behavioral change and audience segmentation, it is possible that by targeting an entire city for intervention, the "community" was defined too broadly. Cities are not homogeneous unit and designing messages acceptable to a broad spectrum of recipients may have resulted in messages so generic as to fail to motivate any one group enough to effect statistically significant behavior change. Current interventions seek to target higher-risk, more narrowly defined populations to maximize their program effectiveness. Higher-risk populations include those in low socioeconomic conditions and minority populations [6].

Thus, both the outcomes and lack of outcomes demonstrated in the Exemplar Programs paved the way for present-day interventions to identify target communities for intervention along higher-risk categories and carry out the design, implementation, and evaluation of their interventions in a more realistic fashion.

Present Day Interventions and Design Considerations

Present day interventions have evolved significantly since the Exemplar Projects. Communities are defined much more narrowly to allow for more culturally and demographically tailored messages and programs. The current trend of community

interventions is based on segmenting the target audience into smaller and more homogeneous units along high-risk categories.

The Exemplar Programs were all extremely large endeavors with enormous evaluation components and budgets. More recent community intervention programs are much smaller in virtually all areas: budget, staff, goals, ability to monitor and evaluate programs, and timeline. Also, they tend to have more focused objectives with clear delineation and operationalization of variables. As a result, when designing a community intervention, although it is important to be aware of the many lessons the Exemplar Programs afford, it is equally important to be aware of the differences between interventions of large and small scope. These differences will affect each stage of the design and implementation of a project. This section discusses each step of project execution from initial design through interpretation of results and important considerations found in each phase.

Study Design

In both Exemplar and Typical interventions, Community Analysis comprises the first of three main phases. This phase is critical to a project's success since the information gathered guides the design and implementation of the project components. Also, it is the time when networking is conducted to identify and recruit community leaders who will be involved in the next two phases of the project. Leaders are often found from several community sectors- not just health [18].

The Intervention phase represents phase two and this can assume many forms. In the Exemplar Projects, this phase lasted an average of 5 years. For Typical projects, this phase may range from 1 day (eg Health Fairs, church screenings, etc...) to a few months

(eg. smoking cessation or weight loss programs) [7], [19], [18]. Typical intervention designs will be discussed below.

The last phase is the Institutionalization phase and is theoretically a phase lasting as long as the program exists. The final goal of many projects is to organize and activate existing community resources to continue the intervention effort after the original project has been completed. Most components of a well defined CVD prevention infrastructure are already present in many communities but a formal method of connecting these components has not yet been devised [18].

When designing an intervention that will utilize a screening component the project director chooses between two types of screenings- case-finding or educational. The Exemplar Programs all used educational screenings extensively [9]. Educational-screenings programs use the opportunity of the screening to educate every participant on risk factor reduction and general CVD knowledge. Participants found to be at high risk are referred for follow-up care. Puska, et al [9], demonstrated that the results of the Educational Screening used in the MHHP resulted in risk factor reductions in all the participants, not just those found to be at high risk. Indeed, 1 year post-screening, participants in a CVD screening showed significantly lower blood pressure, total cholesterol, heart rates and improved eating patterns versus non-participants regardless of risk status.

Screenings also afford a unique opportunity to identify and incorporate high-risk patients who have been previously excluded from the health care system.. Indeed, in the MHHP, over 50% of the participants identified as at-risk and referred for medical follow-up for high cholesterol actually did so [9]. These rates are encouraging; yet they also

point to a large room for improvement considering 100% of those referred for follow-up care should have done so. It is important to target the time between screening and follow-up care when attempting to increase the rates of follow-up.

Puska, et al [9], Mittelmark, et al [18], and Hennekens [20] identify several drawbacks to screening programs that may make them prohibitive for typical community interventions. First and foremost, they are relatively expensive and intensive [9]. They require high levels of professional staffing and an infrastructure for providing follow-up care to those identified as high risk [9]. Additionally, long-term sponsors are difficult to recruit, making institutionalization doubtful for many programs [18]. Lastly, as stated earlier, screenings tend to attract two populations- the worried well and informed sick [20]. It is difficult and expensive to recruit those who would benefit most from a screening program- the Unhealthy Young Adults and Unhealthy Adults.

While determining which category of screening to use project directors identifies the particular community they are interested in targeting. Size is an important consideration. Larger sizes offer increased potential to extrapolate the results of the study to outside populations. Increased numbers of participants also offer greater statistical power and an ability to analyze more data endpoints in the final project analysis. Large studies, though, that attract national press may contribute to secular trends that end up blunting the intervention's effects. Smaller size can be desirable in that it is easier to accomplish the intervention efforts and offers the ability to better segment the target population into a homogeneous unit. Present day interventions typically target smaller community sizes [17].

After the target community is identified, a reference community should also be identified. By definition, the reference area must be as similar to the target community as possible. For example the investigators in the North Karelia project selected Kuopio as their reference area for its similarity to North Karelia in CVD mortality/morbidity rates, geographic, occupational, economic, and social features [9]. In reference area selection, the initial community analysis also identifies and evaluates possible secular trends outside of the intervention. Additionally, trend analysis should be conducted throughout the duration of the study since lifestyles are constantly changing and secular trends may occur after the initiation of the intervention [9]. If a project does not include a reference population, it may choose to compare its results with national trends. Although appealing, this creates a large possibility for bias since the community targeted for intervention may be unique from the overall population in many ways. Thus, reference communities should match target community demographic profiles as closely as possible.

Puska, et al, [9] maintain the size of the target community dictates what endpoints the study can evaluate. If a study is small, the final events such as myocardial infarction and stroke will not occur in numbers great enough to permit statistically significant analysis. Instead, Puska, et al, contend that smaller studies should focus their attention on participation rates and risk factor changes as their endpoints for data collection instead of changes in morbidity or mortality, unless the disease is of extremely high prevalence and the intervention is proven to reduce mortality within the study time span.

Just as size dictates the endpoints that can be evaluated, so too does the duration of the project. The optimum evaluation period varies for different endpoints. For example, health behavior changes occur relatively soon followed by risk factor level

changes months later. Changes in incidence of cardiac events follow the risk factor level changes by 2-3 years [10]. Finally, changes in mortality become detectable [9]. As a result, a short intervention cannot demonstrate changes in mortality and morbidity. Indeed, the North Karelia Project was able to show demonstrate reduced risk factor levels but their follow-up period was not long enough to detect a net change in mortality [9]. Thus, study endpoints should be carefully chosen according to size of the population and the duration of the intervention and follow-up monitoring.

Mittelmark, et al, [18] contend that service-oriented community CVD prevention programs should avoid assessing changes in risk factor levels. Risk factor modification assessment is complex and expensive, samples must be large, surveys frequent, and the study period long. The statistical analysis required to document change is also quite advanced and may be beyond the resources of a project to conduct. Mortality and morbidity as endpoints are also unrealistic for the same reasons. Further complicating morbidity and mortality rate documentation is that using a disease registry to document cardiac events is dependent on individuals seeking health services and on health professionals coding the events correctly. Also, health professionals must maintain the same diagnostic criteria throughout the study duration [9]. Furthermore, the intervention may increase awareness of signs of cardiac events resulting in an increase in the number of people seeking medical care as the intervention progresses. This may falsely increase cardiac events incidence in outcome evaluations. Mittelmark and colleagues [18] point out that for some projects, even behavioral endpoints may be unrealistic. The issue for some intervention efforts is not the ability to *affect* behavior, but rather the ability to *measure* the change in behavior.

Flora, et al, [7] maintain smaller interventions should also avoid Summative Evaluations. These evaluations seek to evaluate the program effectiveness, the causal influence an intervention has on intervention recipients, and cost effectiveness. Evaluating each of these areas is complex and expensive and, if not conducted thoroughly, is of little benefit.

Service-oriented community CVD prevention programs on tight budgets, can use participation rates as a primary outcome measure [18]. In the design of the program, directors should select program components with proven effectiveness and aim for high community participation. Evaluation consists of reporting on the success of component execution and participation rates.

In addition to participation rates, community analysis and formative evaluations are two critical categories of information for all community interventions [18]. Community analyses, discussed earlier, are not currently being shared in a formal, easy manner, leaving a void in data sharing that can increase smaller project's efficiencies and capabilities. Included in such analyses is the identification of the target community demographics, community leaders, contacts, and active organizations that may be partnered with to increase a project's acceptance and success.

Formative Evaluations are conducted prior to program initiation. They provide data for designing education programs and materials by defining the needs and preferences of the target audience. Formative evaluations identify message delivery medium exposure patterns and audience receptivity to potential message components [21]. For example, if a project intends to write a newspaper column on recognizing the signs of myocardial infarction, the author needs to know if the target audience reads

newspapers, reads the language the article will be written in, if the article is written at the appropriate reading level, and if it is culturally appropriate [22]. In pretesting, target audience samples are exposed to preliminary versions of the interventions and their reactions are used to modify the project before finalizing the design [7].

In the Formative Evaluation, it is important to assess the education level of the target audience and tailor the project accordingly. Most studies use 5 categories: <12 (less than high school), 12 (completion of high school), 13-15 (some college or technical school), 16 (college graduate), >16 (postgraduate) [19], [22], [23]. In a SFCP substudy, Winkleby, et al, demonstrated that appropriately designed multimedia health education campaigns can reach populations with lower levels of educational achievement [23]. The authors also assert that with 23 million Americans considered to be functionally illiterate and an additional 34 million considered to be semiliterate, health information should focus not only on print materials, but also include electronic media, peer communication and incorporate community and family supports [23].

Before a project is initiated, several other evaluations should also be completed. Feasibility studies assess whether the intended activities can be established and whether or not existing community health services can be organized to accommodate the program goals [9]. Cost analyses assess both the direct project costs as well as the financial implications to the community. Consequence analyses evaluate the positive and negative consequences of undertaking an interventional effort in the identified community. For example, if an organization decides to conduct a health screening at one church, it runs the risk of alienating the other churches that were not selected for the project, potentially damaging future partnerships. Project directors must also be cognizant of other

organizations active in the community attempting to achieve the same or similar goals. Decisions to include or exclude collaboration with these groups are also key issues to address in the design of the project. [17], [9].

Once a program has begun, and if resources permit, community interventions may elect to conduct Process Evaluations. Important issues to document and evaluate are the message delivery vehicles, the responsiveness of the target audience, and the quality of the program implementation. Message delivery vehicles used in the Exemplar Programs and used by present day interventions include TV, radio, newspapers, mass-distributed print materials, screenings, health fairs, face-to-face interactions and environment modifications such as smoking policies, grocery store shelf labeling, and menu labeling [7]. Thus, the various evaluations are used to come up with an intervention design that utilizes successful intervention components from past projects and possibly innovative components tailored to the cultural features of the target community.

Study Design: Location Selection

Included in the project design is the selection of a program location. The location may be in the workplace, schools, churches, parks or other outdoor areas, community buildings, or may be self-help programs without a physical location. Various interventions have demonstrated each location to be an effective launching point for screenings or educational interventions [7], [9], [18], [19], [21], [23].

First, workplaces represent excellent settings for interventions because employee interest and participation in programs are often high [18]. Also, costs are manageable, especially when volunteers are used. The initial program can then dovetail into other health promotions using the same delivery mechanisms. An example of a workplace

intervention is the Minnesota Heart Health Program (MHHP) weight loss program. The program demonstrated high recruitment, low dropout, and a reasonable short-term average weight loss of 7 lb/person [18]. The weight loss was not maintained though. In another study, a workplace setting smoking cessation campaign in the MHHP demonstrated a 28% reduction in smoking prevalence [18]. Similarly to the weight loss program, the reduction was not maintained. Thus, workplaces offer excellent locations for stimulating awareness and initial participation but are less effective in creating sustained behavior change.

Second, places of worship offer their own unique blend of advantages and disadvantages. Large populations are accessible since over 50% of the US population reports membership in an estimated 286,811 religious congregations [24]. Interventions in places of worship also feature modest staff requirements due to an active volunteer network. For example, the Pawtucket Heart Health Program (PHHP) had 1 staff person serving all 16 church sites conducting diet-modification programs in the project [18]. The church interventions in the PHHP demonstrated significant improvements in diet related behaviors in participant versus non-participants [18]. Predictors of participation in interventions based in places of worship include level of activity in the religious organization, geographic proximity, and health characteristics [24]. Participation rates have also been linked to increased levels of CVD risk factor knowledge suggesting active promotional campaigns should precede educational and screening programs in places of worship [24].

Third, school-based interventions are important and unique because they target young members of the community. Youth have had less time to develop poor health

behaviors and also can secondarily engage their parents in health promotion activities. For example, the PHHP Heart Health Cook-off involved teachers and students. The teachers purchased food and, with student participation, modified recipes to be lower in fat and salt. Not only were the student's total cholesterol levels lowered by an average of 10%, but the program was so popular it has reportedly become self-sustaining [18]. A separate school-based smoking intervention in the MHHP demonstrated sustained positive effects on smoking control through grades 7-12 [18].

Fourth, self-help programs are beneficial and highly effective for several reasons. First, they participants are typically highly motivated to help themselves resulting in high program success. The programs are inexpensive and so may be good options for programs with modest resources. Also, programs feature high transferability between community interventions, low costs, and materials that are already available from several sources [18]. Self-help programs include smoking cessation kits, diet modification kits, and general risk-factor reduction pamphlets [7], [9], [18], [19], [21], [23]. Self-help programs can also be combined with one of the aforementioned intervention sites.

In addition to self-help programs, contests represent another supplement to intervention efforts that are of low-cost and produce successful results. Indeed, the SFCP conducted a smoking cessation contest that resulted in a 3-month cessation rate of 19% and a 12-month cessation rate of 15%. This was significantly higher than the overall community cessation rate of 6% [21]. A one-month promotion and recruitment period using radio and television PSAs, letters to parents via schools, and posters in businesses, libraries, and physician offices preceded the contest. The contest itself allowed for a one-month quitting period followed by a 2-week maintenance period that ended with a

drawing for prizes. The top prize, donated by a local travel agency, was a trip for 2 to Hawaii. The participants used relatively few community resources and materials as quitting aids [21]. Additionally, by using donated media promotion and prizes, costs were low.

Modern innovations include culturally specific parties with food and music that include an educational component, guided walks in parks where homogeneous groups are given time to discuss important issues around diseases and share ideas, contests, gift certificate incentives, etc. [17].

Study Design: Evaluation

Many present day interventions incorporate several of the aforementioned intervention components. Although debatable and a controversial approach, Mittelmark, et al, [18] argue that in evaluating a program, it is impossible to specify the effects of each component apart from the others and programs should not attempt to do so. Using multiple components to effect behavior change and increase participation in programs is based on the still unproven assumption of synergy among the components. Mittelmark, et al, contends that a component analysis with just few components is difficult and expensive; an analysis of programs with many components is unfeasible [18].

Data that should be collected during the project includes participation rates by SES characteristics and self-reported participant characteristics [18]. Self-reported characteristics include behaviors and attitudes toward health, risk factors, health status, satisfaction levels with the program, and past program participation. Mittelmark, et al, [18] advocate recording quantitative risk factor measurements to be available for collation with results from other programs . This, of course, requires a standard, easily

queried and updated system of risk factor recording and analysis- a feature not yet in place in most service oriented community interventions.

Thus, smaller programs with a service rather than research mission should focus on selecting previously validated project components and modifying these component frameworks to fit the specific needs and cultural features of their target community. A core goal of smaller projects is the community organization process. Evaluations should focus on community analyses, formative and process evaluations rather than conducting outcome evaluations that will most likely fail to demonstrate statistical significance.

Study Design: Adherence to Referral Recommendations

An additional area with room for improvement is adherence to referral advice. As stated earlier, integral requirements for successful interventions include accurate and reliable screening tests coupled with an education campaign and an active referral and follow-up component. Although numerous strategies have been developed to improve the rates of adherence to referral advice, formalizing and increasing adherence to referral recommendations continues to be an area of need.

In one study, MHHP investigators studied a subpopulation of those aged 20-69 to assess general adherence to referral advice. The population was comprised of those screened during one calendar year and who had 2 consecutive cholesterol measures of greater than or equal to 265mg/dl. They were referred for follow-up care and then contacted 6 months after the second screening to allow for the visit to take place and for the initiation of a treatment plan. Of those referred for follow-up, 57% actually attended an appointment [25].

Lefebvre, et al, [26] attempted to increase appointment booking follow through rates in referred participants in the PHHP by sending a letter to the homes of the participants. A control group of participants did not receive the letter. The PHHP initial screening identified those at risk for CVD in the SCORE (cholesterol Screening, Counseling and Referral Events) program. Those found to be high risk for elevated cholesterol were invited for a second screening. If the second screening confirmed the results of the initial screening, the participant received a letter from the Chief of Cardiology of a local hospital urging participants to book an appointment with a physician. The study showed that there was no significant difference in follow-up rates between those who did and did not receive the letter. But, of those who did see a physician, those receiving the follow-up letter were significantly more likely (44% vs. 27%) to state that high cholesterol was the primary reason for the visit. Those reporting the high cholesterol as the primary reason for the visit were more likely to report that their physician ordered further blood tests for cholesterol, that they received cholesterol related material from their physician, that their physician discussed ways in which they could lower their blood cholesterol levels, and that they were more likely scheduled for follow-up visits. Additionally, blood cholesterol reducing medications were more likely to be prescribed.

Of the patient population receiving the letter, 60% had scheduled a visit within three months of the second screening, 12% had an appointment scheduled for a time later than three months, and 13% saw “no need or desire” to visit a physician [26]. Very few cited cost as a barrier to following through with referral advice.

Thus, although the letter seemed to have no significant impact on the number who reported seeing a physician, it did affect the primary reason stated for making the visit. Also, the letter had an “agenda-setting” function on the patient-physician relationship. But, the letter did not increase the probability of a participant scheduling an appointment to meet with a physician.

These results suggest two areas for improvement in enhancing adherence to referral advice. First, overall rates of follow-up can be improved upon. Second, even after 2 positive screenings for elevated cholesterol and, for some, a follow up letter discussing the results, only one quarter to approximately half of patients reported high cholesterol as the primary reason for visiting their physician. Additional mechanisms should be in place to ensure that every physician meeting with a screening program participant identified as at risk for CVD understands their patient’s risk profile to be of primary importance in the appointment. The likelihood that the medical appointment is directed to the evaluation and treatment of high cholesterol or other high risk factors does not need to be contingent upon the patient presenting their risk profile as their primary reason for the visit.

In another study, PPHP investigators attempted to increase adherence to referral from the SCORE program by extending their intervention efforts beyond the participant to include physicians. This study created 3 treatment groups and one reference group. The Participant Intervention (PT) group received a personalized letter within one month of their screening which included their blood cholesterol levels, a reminder to meet with a physician, a list of specific lifestyle goals set at the SCORE program, and a SCORE magnet to hang the results/reminder letter on the refrigerator. In the Physician

Intervention (PH) group, physicians received a letter stating their patient had been referred to them on the basis of elevated blood cholesterol and CVD risk scores and listed the lifestyle goals of the patient set at the SCORE program. The letter also included a reminder postcard preaddressed to the patient. The third treatment group received both interventions (PTPH) and the reference group (UC for Usual Care) received no further intervention after the referral advice given at the SCORE program.

The results showed that neither the PT nor the PH group demonstrated increased adherence to referral advice, dietary recommendations, or lifestyle recommendations [27]. The PTPH group had a 5-times greater likelihood of recalling the physician referral than the UC group. The PT group was twice as likely but this was not significant, and six times as likely to recall dietary recommendations versus the UC group. Overall, 67% of participants made dietary changes, although assignment to the PT or PH groups had no effect. The PH and PT interventions had no impact on recall or adherence to lifestyle recommendations. Overall adherence rates for completed follow-up at the time of interview was 58% with an additional 12% having had booked an appointment for follow-up that was scheduled to occur after the interview was conducted.

Gans, et al, [27] report that one explanation for the intervention's lack of effect is that with compliance rates at 70% overall, the SCORE program itself had already approached the maximum referral compliance rate. To improve the rates beyond the overall rates, investigators recommend increased focus on the referral process. At the screening, the authors suggest more time should be spent discussing the referral and the discussion should be more interactive. Prior studies have demonstrated the validity of having participants sign follow-up contracts or verbally repeat the advice at the end of

the counseling session [27]. Multiple mailings, incentives, and telephone reminders are also suggested methods of increasing adherence. Nevertheless, new innovative methods of increasing adherence to referral advice are still needed.

Furthermore, adherence rates for those lacking regular physicians remain an area of frustration. In the same study, Gans, et al, distributed referral lists of physicians to participants without regular physicians who were then instructed to contact one of the names on the list. This process features several weaknesses that contribute to its low success. First, lack of a physician occurs for several reasons including lack of insurance, recent immigration status, mistrust in the health care system or general lack of information. What is common to the population lacking a regular physician versus the population with a regular physician is less familiarity and self-efficacy in how to negotiate the health care system. Distributing a physician list is a passive process and may meet with lower adherence than an active process, especially in a population without regular access to health care. Using a physician referral list that incorporates an active, focused intervention would referral adherence.

Thus, although significant improvements have occurred in collaborative screen and treat community interventions, significant needs still exist. Internet technologies offer a revolutionary possibility to address those needs in innovative ways. Quantitative risk factor analysis, automated referral protocols based on risk factor analysis, and easily queried databases containing community analyses can all be addressed by an appropriately designed Internet application. Only recently, though, has technology improved and been reduced in cost to the point where smaller interventions can incorporate Internet capabilities into their projects.

The Internet and Health

Background

Over the last 30 years, the healthcare industry and public alike has come to rely heavily on Information Technologies (IT). In fact, in 1996 IT constituted 56% of the industry's total net capital stock, the 4th highest percentage out of 53 industries examined by the US Department of Commerce [28]. An estimated 30 million users in the United States searched the World Wide Web (the Web) for health information in 1999. MEDLINE was searched an average of 300,000 times per day [28] and the Web boasts an estimated 10,000, or greater, health related websites [28]. The Internet is expected to only grow in presence, with an estimated 90% of households predicted to have Internet access by 2005 to 2010 [28].

With such a reliance on IT and an established demand in health care for Internet applications, the National Research Council charged the Computer Science and Telecommunications Board with identifying the range of health applications that could gain widespread use over the Internet in the foreseeable future and also study the technical requirements to support such applications. Their report, over 300 pages, describes potential applications, technical requirements and challenges, and barriers to implementation for Internet applications focusing on consumer health, clinical care, financial and administrative transactions, public health, professional education, and biomedical research. The report also addressed public policy issues related to each of the above categories

Due to the hundreds of Internet and Information Technology based applications currently available and in development and the constraints of space and focus of this literature review, all areas will not be reviewed. I focus my review on the applications in consumer health, clinical care, public health, and collaborations between public health and medicine. Many of the applications that will be described in this section do not directly relate to improving collaborative screen-and-treat community interventions. Rather, each application described addresses one or more components of a successful collaborative community intervention. These applications offer a glimpse of novel methods of addressing long-standing barriers to successful health care delivery and receipt. Additionally, this review attempts to demonstrate that despite a wide variety of IT based health applications in development, no application addresses, in total, the earlier identified barriers to successful coordination of care services facing collaborative community interventions. After describing various applications and illustrating the technological potential each offers, I will discuss how an appropriately designed Internet application could foster a method of collaboration between culturally based community interventions and medical treatment. Before discussing actual applications, though, four general network requirements of any Internet application must be addressed: bandwidth, latency, availability, and security. In its most general sense, a network refers to the infrastructure- hardware and computer protocols- allowing multiple computers to exchange data compatibly, flexibly, and securely.

Networking Considerations

Bandwidth refers to the data-carrying capacity of a network. Bandwidth is reported in the number of bits (the smallest unit of information; or kilobits or megabits)

per second capable of being transmitted across a unique link, or path, in a network or over the entire network. It is a property of the transmission material used for the network (e.g. fiber optics, coaxial cable, telephone wire, radio waves, infrared waves), network topology, and routing devices that guide the traffic through the network. An application's bandwidth requirement is determined by the amount of data to be transmitted and the time in which the transmission must be completed.

Latency quantifies the time required for an individual packet of data to be transmitted between communicating entities on a network. The Internet does not transmit a file as a whole package. Rather, the file is broken up into smaller units, referred to as packets, which are sent along various routes to the end user. The end user computer reassembles the disparate packets into the original file. Application latency requirements can vary enormously. For example, real-time interactive applications such as video conferencing require low latency whereas asynchronous applications not requiring real-time interactions, such as email, do not have large latency demands. A related concept to latency is *jitter*, which describes the variation in latency over time. Another related term, *response time*, describes the time required for the entire file to be transmitted and acknowledged.

Availability describes the likelihood a network will be available for service and functioning properly. The availability of a network may be compromised by a host of factors ranging from failed individual components or network links, software failures, computer protocol failures, hostile attacks, natural or man-made disasters, etc. Obviously, network availability for applications controlling medical instruments or involved in maintaining health is of the utmost importance.

Security refers to the capability of a network to ensure 3 things: availability (discussed above), confidentiality, and integrity. Confidentiality is the ability to prevent content from being disclosed to unauthorized parties. Integrity describes network capacity to prevent malicious or accidental alteration of data. Computerized dosimetry equipment that measures and dispenses drugs to patients illustrates the critical importance of integrity. Malicious or accidental alterations of drug doses could have disastrous results.

Security for health applications is more complicated and sensitive than current consumer websites' security capabilities. For example, most current vendors do not require authentication beyond a valid credit card and billing information. Credit card companies and online vendors expect some losses from fraud and consumers are protected from fraud by loss caps or insurance. Health care, where health and even life itself depends on minimal error, cannot tolerate such losses and other mistakes. Indeed, when polled, 92% of Americans reported concern about the potential misuse of their personal information on the Internet [29]. Organizations and application developers are faced with the challenge of having to protect various platforms that use diverse, often incompatible, interfaces, languages, and structures with varying levels of security requirements. Security design is further complicated by the constantly shifting relationships among health organizations, which places a great demand for plasticity on top of an already lofty demand for security.

Finally, Ubiquity describes the degree of access to a network. Currently, residential access is an important constraint on ubiquity. For many future applications to be described, sufficient upstream (ability of the end user to upload data to the Internet)

and downstream (ability to download data from the Internet to the end user) capacities need to be expanded. Current broadband technologies such as cable modems and digital subscriber lines (DSL) allocate more bandwidth to downstream capabilities than to upstream capabilities. This is because currently, the Internet is primarily used as a mechanism for distributing content from a centralized source to end-users. Widespread requirements for collaboration or interaction between multiple parties have not yet been realized.

An important concept linking many of the aforementioned requirements is Quality of Service (QOS). QOS refers to the ability of a network to provide a range of assured levels of performance [28]. Currently, resources (e.g. bandwidth) of a network are shared among active users. Each user has access to only a fraction of the network's bandwidth, with that fraction depending on the activity level and absolute number of other active users. Thus, bandwidth and latency vary throughout the day, and optimal conditions cannot be guaranteed at any given time.

Applications can be designed to take advantage of different networking alternatives. Networks can be public, such as telephones, where anyone willing to pay for access may receive access or they can be private. Private networks are designed to connect a finite number of sites using dedicated transmission links. A limited number of predefined users or geographic locations may access a private network. Users outside the network cannot access any of the network resources. Thus, usage of an outside network does not affect QOS in a private network. Also, a private network has fewer security risks since users are predefined and identified. Private networks are best suited for environments in which users and connectivity requirements are known beforehand and

are expected to remain stable over time. Of course, there are many examples of network configurations that blur the strict definitions of private and public networks but they will not be discussed here.

The Internet does not have the capability to support many of the applications currently in development due to shortcomings in the aforementioned categories for evaluating applications. As a result, in order to address future networking needs several federal agencies collaboratively initiated the Next Generation Internet Initiative (NGI) in 1997 [28]. The agencies involved in the NGI include the Defense Advanced Research Projects Agency (DARPA), the National Science Foundation (NSF), the Department of Energy (DOE), National Aeronautics and Space Administration (NASA), the National Institute of Standards and Technology (NIST), and the National Institute of Health (NIH). The NGI was charged with 3 missions. First, to carry out research and development of advanced networking technologies to improve Internet performance and functionality. Second, to develop and deploy 2 high-speed testbed networks. One network links 130 universities and federal agencies at speeds 100 times faster than the speeds available in 1997 [28]. The second network links 10 sites at speeds 1000 times faster than those available in 1997 [28]. These networks will support the development and testing of innovative applications, new technologies, and computer protocols. The third mission is the development and demonstration of applications that demand advanced networking not possible on the Internet of today. Example applications include a virtual human cadaver featuring a haptic (touch) interface for educational purposes, telemedicine, a national breast imaging archive and networking infrastructure to support telemammography, and online personal health records [28].

In addition to the government run NGI, the private sector is also working on a similar mission dubbed Internet 2 (I2) Project. The I2 Project links 100 member universities and partners to an advanced academic network where biomedical applications play a large role. The first demonstration of the network in October 1999 was an online broadcast of a gall bladder operation [28]. The operation occurred at Ohio State University and via a real-time Internet link, a physician located in Washington D.C. assisted in the surgery. Both the I2 Project and NGI will serve as launching pads for eventually advancing the public Internet.

Barriers to Widespread Adoption of Internet Applications

Several organizational and behavioral barriers exist that impede the development, acceptance, and implementation of novel applications. First, and already discussed, are security concerns on the part of both providers and patients. Second, the health sector is diverse and decentralized. Typically, local solutions are developed to address local problems making even incremental state or national level changes difficult, let alone shifts at the paradigm shift level. Third, a major obstacle is the paucity of reliable cost and benefit information on Internet applications in actual operational settings. With the Internet still relatively young and most of these applications untested, accurately evaluating and comparing various applications is difficult, if not impossible. This lack of data produces an understandable reluctance on the part of all involved in the health care industry to actively pursue various applications. Fourth, physicians are reluctant to adopt new technologies that may result in increased work without proven benefits to their patients or to their practices [30].

Fifth, adopting these Internet applications will create unforeseeable changes in the relationships between patients, physicians, hospitals, laboratory technicians, and nurses. Also, how medical care is accessed and distributed, especially with management of chronic illness, is rapidly changing. The effects of shifting relationships and methods of interaction will require resource and communication stream restructuring within the organizations and will require new skill sets for all those involved. The uncertainty presented by this potential contributes to an overall reluctance to be an early adopter of an application.

Sixth, and stemming from the fifth barrier, are the new organizational policies and procedures that need to be established to address the new mechanisms for health care delivery and reception. For example, policies need to be established to regulate email as a mode of interaction between patients and physicians. And policies regulating the liability of an organization that hosts an online discussion group might also need to be developed. Should an organization be responsible for the quality of information found in their online discussion group?

Seventh, in addition to organizational policies, public policies need to be drafted to guide new application development and utilization. This is extremely complicated because the Internet applications combine network infrastructure, hardware and software issues with end users operating in multiple health organizations with disparate policies, all guided by national policies not written to address Internet technologies. For example, telemedicine technologies are currently hampered by state-based licensing policies, which prevent the practice of medicine across state lines, and professional education applications require intellectual property protection. Currently, Health Insurance

Portability & Accountability Act (HIPAA) establishes regulations and standards for electronic claims payments, eligibility, and places security requirements on business processes and data transmission that will guide future policy decisions [29], [31].

Additionally, from the perspective of information distribution, unequal access to the Internet infrastructure, aka the Digital Divide, remains a growing problem. Future applications run the risk of exacerbating already disturbing inequities in access to health care. And, perhaps most importantly, is the lack of demonstrated value in many applications currently available.

Nevertheless, despite these and other substantial barriers, Internet applications are in various stages of development and will revolutionize the way health and illness is identified and treated around the world. Indeed, health processes in every arena from consumer care to clinical care to public health to education will be reshaped by the Internet and related technologies. As health care continues to shift to preventive medicine, consumers will be increasingly called upon to assemble more sophisticated health related information themselves. Consumers and health professionals alike will utilize the Internet to usher in this shift.

Consumer Applications

The most visible examples of Internet applications devoted to health are those targeting consumers. Current applications, building on the long recognized value and history of actively consumer involvement in their own health care and maintenance, provide information and tools that allow consumers to improve their own health. These sites demonstrate one way to address community education and behavior change on an

individually tailored basis, since users navigate and use the Internet according to their own preferences and interests.

Consumer oriented health websites include features such as static content, interactive risk assessment quizzes, chat sessions, resource compilations, and the ability to purchase health related products, find providers, and pose questions to health experts and professionals. Sites like drkoop.com, healthon/WebMD.com, and Betterhealth.com, provide these services free of charge and, as a result, are extremely easy to access for consumers with Internet access.

The rich resources these sites represent and the ease of access calls attention to the importance of site credentialing to establish information credibility. A search of Ewing's Sarcoma turned up 400 sites, 6% of which featured erroneous information and an even greater percentage contained misleading statements [32]. With illness or disease research comprising roughly 60% of the public's online health activity [33], it will become increasingly important to have a method of oversight to control misleading and erroneous health information. Several initiatives are already evaluating the quality of information on the Internet in different methods and these evaluations will become more widely available and established in the coming years [28].

Applications dedicated to patient monitoring and home care aim to exploit more robust networking capabilities. Control of medical equipment poses an arena ripe for connectivity with the Internet. In January 2000, Medtronic Inc announced plans to work with IBM and Microsoft Corp to develop technologies enabling heart patients with pacemakers, implanted defibrillators, and other monitoring devices to transmit cardiac data over the Internet to their cardiologists [28]. An additional step would complete the

communication loop by permitting reprogramming of those devices over the Internet, eliminating office visits. Currently, stethoscopes, glucometers and EKG monitors can all be equipped to support Internet connections and distributed for in-home use at low additional cost. In addition to heart patients, patients with implanted drug pumps could also receive dosage changes over the Internet after transmitting key data information to their physicians. This represents a huge benefit in time and cost, especially for rural residents living significant distances from their physician's office. These devices do not require much bandwidth on the end user side because individual data files are small but they do require significant resources on the provider end. First, the provider organization will require high bandwidth to handle the large aggregate load of monitoring potentially hundreds of patients. Second, new health professionals will be responsible for monitoring the incoming data for anomalies and danger signs. Third, data compression and analysis techniques and applications will need to be developed and new institutional policies on reimbursement will need to be established and, fourth, the requirements for availability and security cannot be overstated.

These applications offer the potential for better daily management of patient's health needs in an interactive way. By transmitting health information over the Internet to their physicians, patients are more informed involved in their own health care and management on a daily basis. This may have the added benefit of serving as a motivating force to effect positive behavior change. Additionally, these applications offer increased access to more vulnerable populations, such as those in rural locations who would not otherwise be able to consult with health experts on a regular basis.

Clinical Care Applications

Applications dedicated to enhancing clinical care require more extensive networking capabilities before assuming widespread use. A few examples of current areas of research and development include decision support systems, remote image and video consultation, telemedicine, and virtual reality training tools.

Two examples of decision support systems are DXplain and WebWeaver [34]. DXplain, developed by Massachusetts General Hospital, uses clinical findings to generate a ranked list of diagnoses coupled with clinical reasons on how the diagnoses were reached. The system also provides additional information and bibliographic references on each disease. WebWeaver, developed at Stanford University School of Medicine, combines DXplain, MEDLINE search capabilities, and web exploration into a single application. After DXplain presents its ranked list of diagnoses, users can run a MEDLINE search on any item in the diagnoses or users can find websites with material related to the diagnoses.

Remote image and video consultation offers professionals the ability to collaborate with other experts around the world. It also allows consumers to access health professionals regardless of geographic proximity. Already, a NGI funded project has activated one telemedicine application. The Armed Forces Institute of Pathology (AFIP) with 125 pathologists is available via the Internet to physicians worldwide. Pathologists can send high-resolution images as email attachments or directly upload images via the AFIP File Transfer Protocol (FTP). AFIP pathologists report back to the sender with a final diagnosis within 24 hours [34]. Network requirements for image and video consultation depend on several variables. First, the requirements depend on the

resolution required of the signal or image to support diagnosis. For example the AFIP project has high-resolution requirements but low bandwidth requirements because email or FTP interactions are asynchronous. Alternatively, cineo-angiogram imaging, for example, has high requirements in both resolution and bandwidth. Second, requirements are based on the timelines in which data must be received and interpreted- e.g. real-time versus asynchronous communications. Third, the ability to compress data while maintaining quality affects requirements. Fourth, requirements are increased if the entire data set must be transmitted as opposed to simply transmitting abnormal findings.

A logical extension of image and video consultation is telemedicine. Several NGI funded projects are currently focusing on utilizing Internet connectivity to connect physician movements with robots to control medical instruments from a distance, facilitating development of robotic surgery [34]. Or, applications will allow physicians to assist in surgeries via real time connections or to determine if a patient in a rural area is sick enough to warrant making a visit to the hospital by using a video-link along with Internet connected instruments in the home such as microphones, stethoscopes, thermometers, sphygmomanometers, EKGs, rudimentary microscopes, and glucometers [28].

Thus, the potential for collaboration between health professionals is greatly enhanced, allowing experts in each field to contribute to a patient's care to maximize health care effectiveness. These applications demonstrate the ability to connect disparate geographic locations through focused, formal communication streams to address specific predetermined needs.

Public Health Applications

Public health also stands to benefit greatly from Internet applications in development. Surveillance will benefit from applications designed to assist in the collection of data regarding an individual's health, risk factors, and medical treatments. Applications can also collect information on potential sources of disease and injury in the environment. Outbreaks may be identified earlier by tracking school attendance records or the sale of prescription and non-prescription drugs before community-wide symptoms reach levels at which people begin visiting doctors. For example, the authors of Networking Health [28] present the following scenario: an increase in the sale of anti-diarrheal remedies monitored by an Internet application might indicate a wide-ranging low-level epidemic of food poisoning or a contaminated water supply. Once identified, the application could automatically notify local public health officials to begin seeking the source of the illness. Pharmaceutical suppliers could be notified to deliver larger supplies of particular antibiotics or rehydration fluid. Also, automatic notices could be sent to hospital personnel identifying the signs and symptoms of the illness to increase medical preparedness and increase the likelihood of early detection [28].

An already functional example of a public health Internet application is the Washington State Department of Health Electronic Laboratory Reporting System allowing laboratories to report directly to the State Department of Health for certain conditions like tuberculosis. Prior to the system, reporting was conducted via mail or fax at which point a public health official would follow up with the afflicted patient's physician or patient themselves to begin investigating the causes and paths of contagion. This system was fraught with delays and errors due to the multiple communication

mediums involved and the various protocols for communicating with different organizations. The Electronic system slightly reduced the time delay from case identification to county notification to less than one day. The time delay from case identification to state notification improved from a mean of 40 days to just 1 day [28].

Thus, Internet applications have already demonstrated successful automatization and formalization of communication streams between previously unconnected organizations. Reports transmitted are modified to fit the presentation styles desired on the receiver end of the transaction, increasing the probability of the data being noted and addressed. By automating the process, consistency increases, formality emerges, latency falls, and the burden of reporting cases is not affected by individual circumstances that may result in timely or tardy information transmission.

Consumer and clinical care requirements for Public Health applications exceed current capacity of bandwidth, latency, and ubiquity [28]. Security is absolutely critical for accuracy reasons as well as the need to address the public's faith in public health that their data will only be used for the benefit of the community. Identifiers must be adequately stripped from the data to prevent reconstruction of personal identities.

Public Health also requires improved access and Internet education for Public Health workers. An assessment of connectivity in the Midwest showed that 50% of local health departments did not provide Internet access to some or all of their staff [35]. Also, although 85% reported having a computer that would allow access, access was defined as a computer with a modem equal to or greater than 14.4 Kbps and a random access memory of 8 or greater. The connection speeds of a computer with these features are so slow as to be of questionable utility to its users. Less than 20% of those interviewed

searched MEDLINE, while 2/3 desired training in MEDLINE and 3/4 desired more training in the Internet in general.

Collaborative Efforts

Internet applications are not restricted to singularly addressing consumer, clinical or public health needs. Several reports have called for increased collaboration between public health efforts and medicine [4], [28], [36], [37]. Indeed, the World Health Organization identified program goals of “combining health promotion and disease prevention efforts and developing inter-sectoral collaboration and community involvement” thereby “enhancing the role of health professionals” and “making better use of existing resources” [37].

Internet technologies can increase the facility with which such collaborations can take place by automating and restructuring communication and data-sharing streams. Additionally, Internet technologies can automatically adjust data presentation to accommodate public health or medical methods of interpreting data. Satellite locations can be connected in ways that allow data collection, analysis, and follow-up to be shared for maximum utilization of the unique skills and resources each participating organization brings to a collaboration.

An already demonstrated example of collaboration was the successful insertion of a computer based risk assessment module in an urban Emergency Department [38]. Rhodes, et al, suspected that long waiting times for non-emergent patients represented a wasted “teachable moment” and developed a computer-based interactive risk assessment quiz. After questions addressing disease categories were answered, users were prompted to see if they wanted additional information on healthy lifestyle habits or cessation

programs. After completing the survey, users received individualized computer generated health recommendations and any additional information requested during the quiz. Also, users received a 1-page summary to give to the physician that contained demographic information, major identified health risks, and referral recommendations. The results demonstrated that 95% of those completing the survey elected to receive additional information about specific health topics [38]. Additionally, 62% of those completing the quiz versus 27% of the control group remembered having received health advice from their physician. Thus, researchers demonstrated feasibility and user acceptance of the technology. Users were interested in using the waiting time as an opportunity to receive health information. Also, they were more likely to remember being given health advice. By taking the quiz, Rhodes, et al, [38] posit patients may have been attuned to their health during the visit with the physician and, as a result, more likely to remember advice given in the meeting.

Another example was the Touch Sensitive Computer System (TSCS) placed in physician waiting rooms to increase physician adherence to screening recommendations [39]. The system asked users a series of questions about their personal medical history, family medical history, and lifestyle. After completion, the system would print out reports on preventive care recommendations, reminder letters to patients, and summary reports on the physician practice's overall preventive care activities. Researchers, interested in evaluating secondary prevention outcomes for breast, colon and rectum, cervical, and oral cavity cancers, demonstrated significant improvements in rates of mammography screenings and clinical breast exams [39]. The other screening test rates improved but not significantly.

An impressive demonstration of the potential for Internet applications to facilitate collaborative efforts was a tuberculosis program that was part of the Applied Informatics project run by the US Department of Commerce Telecommunications and Information Infrastructure Assistance Program. Designed to promote collaboration between public health and medicine, the project demonstrated the ability of the national information infrastructure to coordinate health care. The goals of the project were to link Electronic Medical Records (EMR) of different organizations to allow data sharing, to improve adherence to accepted clinical protocols, to improve and streamline case reporting to the health department, to increase communication with mobile health care providers, to increase patient and provider access to educational materials, and to increase patient privacy [36]. A major assumption of the project was the ability to communicate electronically during every step of the project.

Tuberculosis was selected as the target disease because of its prolonged treatment and the involvement of multiple organizations, providers, and locations in TB treatment. The components of the project included automated detection and reporting, a TB isolation application, TB information resources, and wireless computer support for mobile health workers.

The automated detection and reporting utilized an automated decision support system that reviewed EMRs. If the system discovered a clinically suspicious situation in the chart, it automatically generated a message to the appropriate provider or department. A barrier to implementation was the application's ability to interpret written phrases, so a natural language processor application was instituted to convert phrases into unambiguous code. Analysis demonstrated a 92% agreement with the natural language

processor's interpretation and the actual written notes in radiograph interpretation [36]. The system reported cases 2 weeks earlier than the prior manual system [36]. Additional barriers were lack of clinically relevant data in electronic form and difficulty in automating complex clinical judgments. Nevertheless, the system demonstrated successful, rapid case identification and notification.

TB Isolation protocols used TB detection technology to implement hospital isolation policy. When the application detected a suspicious case based on patient EMRs, an email was sent to the hospital epidemiologist indicating whether the patient was inpatient and currently isolated. A retrospective evaluation of previously missed cases showed using the application would have resulted in the isolation or re-isolation of ½ of the previously missed cases [36].

A web-based information kiosk placed in a TB clinic targeted patients. The kiosk contained web-based versions of several TB pamphlets in both Spanish and English. The clinic director reported that the patients who used the kiosk were better informed and asked more meaningful questions of their physicians [36]. The Spanish language option was utilized 40% of the time. A major barrier was patient self- initiation of a session. The clinic director reported that clinic personnel needed to encourage patients to use the kiosk [36].

Finally, mobile health workers were outfitted with wireless stylus-based computers featuring specific applications designed for their needs. Prior to the program, workers expressed the need for improved communication with other providers, reduced paper work, access to word processing, printing, and information resources [36]. The wireless computers allowed workers to wirelessly receive their daily work lists, retrieve

clinical information on their patients, enter data about their visit, and review care plans, nursing policies, and TB protocols. Also, workers could access the names of relevant providers including physicians, social workers, home health aides, and emergency contacts. The main benefit cited by the workers was increased access to information at the patient's home. Also, the electronic forms eliminated the need to carry numerous bulky manuals and charts. Barriers identified before initiation included computer size, weight, battery life, and quality of display. Long-term barriers include availability, bandwidth, and system functionality.

Overall, the best predictor of whether a task was completed or technology was adopted was the degree to which it was perceived to be critical to the survival of the involved organizations [36]. If a feature was not considered critical, more important pressing issues inevitably superceded the utilization of the feature. Even monetary incentives did not result in long-term utilization of features considered non-critical.

This project demonstrated successful coordination of health care among disparate provider organizations and methodologies utilizing Internet technologies currently available. Automated decision support systems extend across organizations and already produce benefits. The Web successfully disseminates information to consumers. And, mobile computing is already feasible and is expected to grow significantly in health care.

Thus, as has been shown, a myriad of Internet applications have and are being developed that address virtually all areas of health and health care. Many of the identified barriers facing community interventions can be addressed by an appropriately designed Internet application. As noted, the Internet applications described above were

not designed to address the barriers facing community interventions, but many of the technologies behind the applications just described can be reworked to do so.

Conclusion

In conclusion, as this paper attempted to demonstrate, community-interventions have evolved significantly in the last 30 years and with the incorporation of Internet Applications, continued evolution is expected. Although producing disappointing end-results, the Exemplar Programs in CVD risk factor reduction established many techniques still used in community interventions today and uncovered erroneous assumptions that had existed in community outreach programs regarding the heterogeneity of communities and the complexity of behavior change. Present-day interventions have moved toward a more narrow definition of community, allowing their interventions to be designed to more effectively address the cultural values and norms of the target population. Furthermore, many smaller present-day interventions do not attempt to demonstrate unrealistic changes in mortality and morbidity rate within the time frames of most funded research and service projects but, rather, evaluate their programs based on successful transmission of information and participation rates. Present-day interventions with smaller budgets and more informed designs use previously validated intervention approaches and modify them to be culturally appropriate for their target audience.

Also reviewed was the Internet's tremendous potential for revolutionizing public health and medicine. Although many applications are not currently feasible considering the limited networking capabilities of the current Internet, several applications have already demonstrated significant abilities to improve health care and address identified

barriers to collaborative screening interventions at the consumer, clinical, public health, and collaborative levels.

In reviewing past and current community interventions, several needs were identified that can potentially be addressed by a single, multifaceted Internet application. Internet applications offer the revolutionary potential to electronically connect geographically and methodologically disparate organizations in order to facilitate the collaboration between and reintegration of public health efforts and medicine. In seeking to design an application for community interventions, several needs cited in this literature review should be addressed.

The application should be developed to support community interventions with smaller budgets maximize their resources and share their unique understanding of their target communities with other community intervention efforts. Indeed, community analyses conducted by smaller interventions are not currently being shared in a formal, easily accessible manner. By creating a private network accessible by project directors, information collected in community analyses, formative evaluations, and lessons learned can be formatted and queried more consistently and formally to increase future project's effectiveness.

Also, as Mittelmark, et al [18], suggest, applications can facilitate collation of multiple programs' quantitative risk factor measurements potentially allowing for pooling of similar data for statistical analysis. An Internet application can be designed to automatically analyze risk factors for a particular screening and automate follow-up procedures based on the analysis outcome. Also, the application should update an

ongoing database containing the risk factor measurements of participating interventions to identify and analyze geographic trends.

Furthermore, the application would address the communication breakdown that occurs between screening and follow-up care to improve appointment booking and show rates. The application should automatically notify caseworkers of participants in screenings that have been identified as at risk, allowing the caseworkers to proactively contact the participants to facilitate the process of booking an appointment with a physician.

Thus, the application should integrate automated risk factor analysis with formalized Internet based mechanisms to follow-up with those who have been identified as “at-risk”. It should also create an easily updated and queried database of community intervention’s community analyses, formative evaluations and project reports. By creating such a system that specifically targets identified barriers to success in collaborative community screening interventions, the potential exists to formalize referral procedures across interventions, increase adherence to referral advice, and allow heretofore discrete interventions to communicate and share their research and experiences more effectively with one another.

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www-dot-screening: An Internet-based Application to Improve
Community Screening Interventions for Coronary Heart Disease

Introduction

Cardiovascular disease (CVD), including coronary heart disease (CHD) and stroke, continues to be the leading cause of morbidity and mortality in industrialized nations [1, 2]. Many of the risk factors associated for CHD have been identified and are modifiable. As a result, up to 75% of coronary heart disease may be prevented by the adoption of healthy lifestyles [3]. Based on these data, major health promotion efforts focused on CHD prevention have been instituted to reduce of risk factor levels through lifestyle changes and medication [3].

CHD prevention screening programs attempt to reduce mortality and morbidity by modification of risk factors through behavior change. Although these efforts have positively affected the health of thousands of Americans, four common barriers continue to frustrate those involved in CHD community screenings. First, *quantitative* risk assessment is not currently used in the majority of screenings. Second, implementing follow-up is often labor intensive and inconsistently pursued. Third, effective data gathering and knowledge sharing among disparate interventions within the same organization continues to be sub-optimal. And fourth, adherence rates to referral recommendations consistently fall between 50-70%.

Internet based technologies have the potential to comprehensively address these shortcomings and aid community screening programs to more effectively and efficiently maximize their resources, identify and follow-up with “at-risk” community members, and collect potentially comparable data. Notably, information and Internet technologies have already been successfully integrated into consumer health, medicine, and public health arenas, as well as collaborative efforts between them [4-11].

This paper describes a pilot project in which a novel Internet-based solution was designed for use *in the field* to address barriers facing CHD community screenings. Current community health screenings were analyzed and areas with room for improvement were identified. An Internet-based solution was designed to address 6 problem areas, which became the goals of the project

Table 1. Identified Goals of Pilot Project

1. Introduce real-time quantitative CHD risk assessment into the field
2. Formalize/automate targeting those “at risk” for CHD for followup
3. Formalize/automate followup case assignment
4. Conduct World Wide Web supported follow-up procedures
5. Automate data collection in all phases of screening and followup
6. Establish backbone to link disparate screenings in online “data sharing community”

The first goal was to conduct real-time quantitative risk factor analysis. The second goal was to formalize and automate the identification of those “at risk” for CHD for follow-up. The third goal was to formalize and automate assigning those “at risk” to caseworkers for follow-up. The fourth goal was to use the World Wide Web to facilitate caseworker contact of “at-risk” participants. The fifth goal was to standardize and automate as much data collection at all stages of the project as possible. Finally, the sixth goal was to build the backbone for sharing of data and “lessons” learned between disparate projects in a way to maximize the productivity of small budget interventions.

This paper describes the conceptual model behind the design, the technology that was developed, and a field test of the project.

Background

Effective prevention of CHD requires successful collaboration between public health efforts and medical services. Educational community screenings serve two purposes: to motivate and educate all participants in the importance of reducing their risk factor levels for CHD, and to identify high-risk participants requiring medical attention.

With the identification of modifiable risk factors for CHD by the 1949 Framingham study, researchers logically moved from observational studies to experimental studies attempting CHD prevention through risk factor modification. The early ambitious “Exemplar” Programs such as the Stanford Five Cities Project (SFCP) sought to effect change on hundreds of thousands of people in single interventions [12-17].

Due to several factors, the Exemplar Programs failed to demonstrate statistically significant reductions in risk factor levels for CHD. But, they did provide numerous lessons that have helped to shape today’s CHD community screening programs.

First, many individual components of risk factor screening and education such as smoking cessation classes and contests have been demonstrated to be effective in other studies.

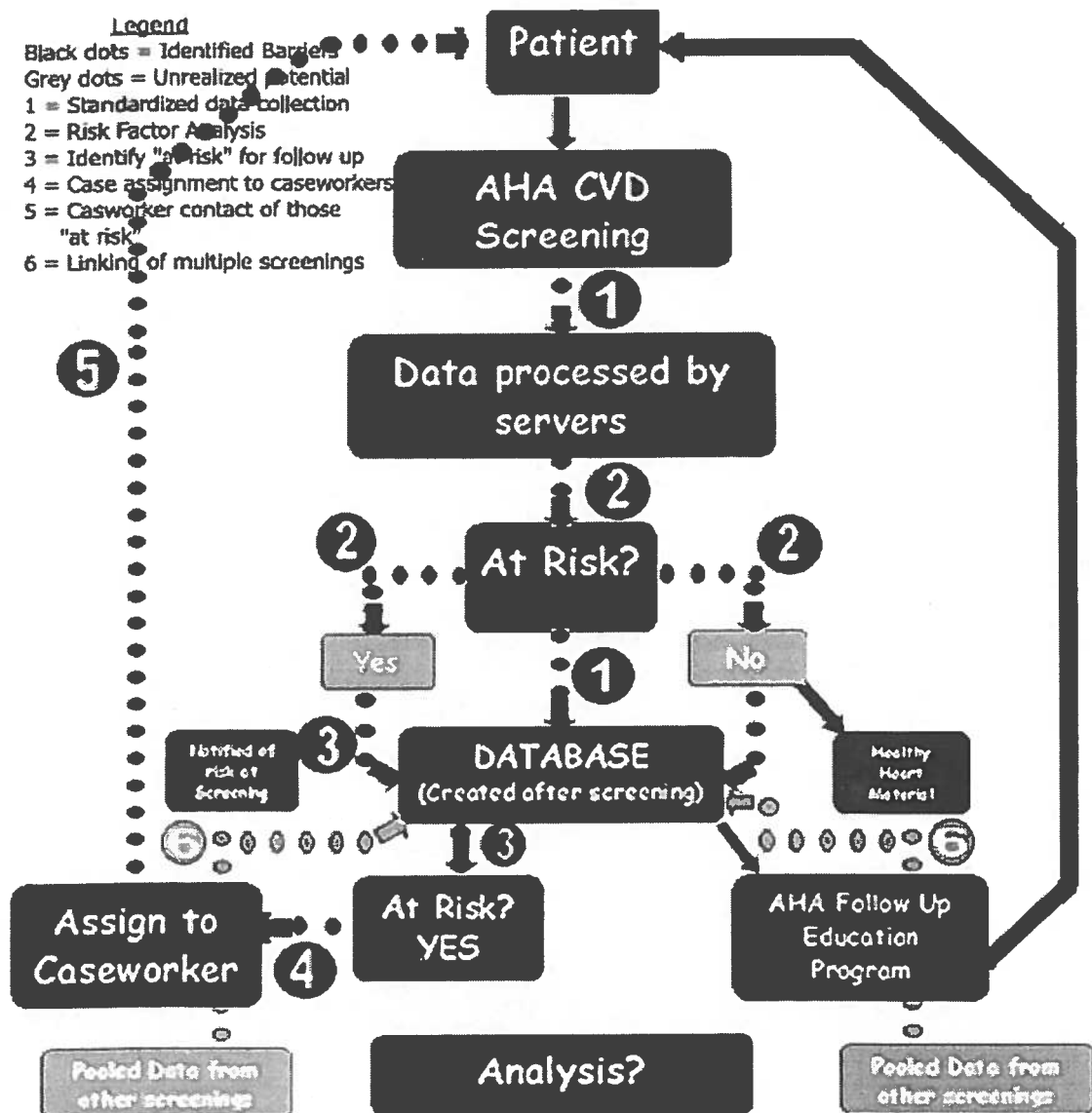
Second, intracommunity variation often confounded findings. Today, target communities are defined more narrowly to allow for more culturally and demographically tailored messages and programs [12]. Third, present-day interventions tend to have more realistic objectives with respect to timelines and budgets [18]. Risk factor modification assessment is complex and expensive, samples must be large, surveys frequent, and the study period long. Current small budget interventions use participation and follow-up

rates and healthy lifestyle habit adoption as primary outcome measures. Additionally, community organization is also a core goal.

And fourth, community analyses and formative evaluations are fundamental [19].

Included in such analyses are target community demographic assessment and the identification of community leaders, contacts, and organizations that may be partnered

Figure 1. Current Screening Protocol with Identified Barriers



with in order to increase a project's acceptance and success. Also included in these evaluations are "lessons" learned by organizing and executing an intervention targeting unique populations with respect to cultural customs, what types of intervention techniques worked well or did not work well, and other process evaluations.

Despite the positive evolution in community screening interventions, several problems continue to be under-addressed (Figure 1); barriers that information technologies are capable of addressing. First, at several steps in the screening and follow-up process, data is collected and processed by hand, resulting in significant workloads, potential for error, and time commitments for those involved. Second, risk assessment needs improving. In American Heart Association (AHA) community screenings, risk assessment is often qualitative. Importantly, the AHA *has* quantitative risk assessment formulas for CHD but has not yet fully integrated their use into small screenings.

Third, targeting those at risk for follow-up is inconsistent across disparate projects and even between a single director's individual projects. Fourth, a project director often assembles a list of those at risk and manually assigns them caseworkers. Fifth, follow-up frequently consists of phoning the participant and encouraging a physician consultation using a static script. Often, barriers to care are not assessed and information to overcome them is not available. And, the caseworker must manually record the call information and send this back to the project director. Each step is work and time intensive and has the potential for errors.

And sixth, community analyses and formative evaluations are not currently shared in a formal, easy manner. If shared, these data could increase a project's efficiency and

capabilities. By benefiting from the contacts established and cultural, financial, political, and logistical lessons learned by other project directors, project directors would not have to “reinvent the wheel”.

Importantly, small screening projects often have limited budgets, timelines, and sites of activity. Screenings are often held in nontraditional health service locations such as workplaces, churches, parks, and community buildings [15, 17, 20-22]. Thus, any technology used must be cost-effective, easy to learn and incorporate into existing plans, and offer flexible functionality for use in various locations.

Conceptual Model

The goal of this project was to design and implement an information technology solution in a community screening and follow-up environment that would address the aforementioned barriers by featuring the following capabilities.

Table 2. Current vs. Pilot Project Risk Assessment	
<p><i>Current Risk Assessment</i></p> <ul style="list-style-type: none"> • <u>Qualitative</u> <ul style="list-style-type: none"> • High risk in 3 of 5 major risk categories • HTN: > 140/90 • Diabetes (Y/N) • Smoking (Y/N) • Total Cholesterol: >240mg/dl • HDL Cholesterol: <40mg/dl • <u>Problems</u> <ul style="list-style-type: none"> • Binary risk assessment for each variable (eg. yes or no) • Not weighted according to age or gender • Assessed by hand → potential for error • Assessed by hand → potential that not all participants receive risk assessment 	<p><i>Automated Quantitative Risk Assessment</i></p> <ul style="list-style-type: none"> • <u>Quantitative</u> <ul style="list-style-type: none"> • Use formulas developed from Framingham Study * • 5 major risk factors weighted and incrementally graded * See Appendix B • <u>Benefits</u> <ul style="list-style-type: none"> • Not “all or none” → ↑ accuracy • Weighted according to age and gender → ↑ accuracy • Conducted automatically upon screening information entry → ↓ risk of error or variability in risk assessment • Conducted automatically → guarantees every participant receives risk assessment

entry of risk assessment data combined with contact information and other screening information builds a real-time database, obviating the need for data entry after the event.

Second, the technology formalizes follow-up procedures by automatically assigning at-risk cases directly to caseworkers. This has the potential secondary benefit of reducing the a project director's workload and reducing turnaround time from screening to follow-up.

Third, every stage of caseworker follow-up is enhanced and integrated. First, information needed for completing a follow-up contact is web-based, allowing the caseworker to work without separate logbooks, contact sheets, and scripts. Second, scripts are easily negotiable and interactive. The script changes based on previous responses and provides pop-up windows with pertinent information to questions posed by interviewees. This reduces the need for caseworkers to scramble to find responses for information requests in binders, thus allowing for smoother interactions. Third, the technology features an interactive capability unfeasible without a computer to demonstrate the potential of integrating web-based systems into follow-up procedures. Fourth, interviewee responses, requests for information, and end results are automatically captured and integrated with the interviewee's original screening information in real-time. This allows for faster, seamless data collection and integration, which could reduce workloads and errors in data compilation. Fifth, the database built from screening and follow-up information can be analyzed and queried via the World Wide Web (Web).

Sixth, by allowing internet-based "in the field" data gathering that updates a central database, the potential is created for cross-site data integration. For regional or national organizations that conduct community interventions, such a feature would allow

for real-time monitoring of local level interventions. Additionally, this central database could allow for macro-analyses. Often, small interventions do not screen enough participants to produce adequate numbers for statistical analysis. By integrating comparable information across sites, small interventions could contribute to a central data pool that would have adequate numbers for study. For example, a researcher could query for women between ages 55-65 with systolic blood pressures >140mm Hg. Data from all interventions that featured participants fitting these criteria would be included in the search return.

The Model: Concept to Practice

Screening

Laptop computers were selected as the hardware instrument for field use. The project was designed to perform quantitative risk assessment using AHA CHD risk assessment formulas and automatically store the data on the laptop harddrive in the event an Internet connection were unavailable. The display mirrored AHA screening intake forms.

Upon completion of the screening form, the application analyzes the data and conducts risk assessment. If at risk, the participant is notified and advised to consult a physician and the application automatically tags the case for follow-up.

Risk is determined according to “Prediction of Coronary Heart Disease Using Risk Factor Categories” updated using the National Cholesterol Education Program V recommendations [23]. The benefits of this design are ease of use, its “open source” (e.g. public access to the application), and the ability to update the *Risk Calculator* with

screening, the application is accessible via the World Wide Web using a standard web browser.

Second, by utilizing published quantitative assessments, screenings can offer instantaneous, accurate, and more consistent risk assessment without requiring volunteers to use age and sex charts to scale data. This eases volunteer workload and reduces the risk of error. And, third, automating risk assessment assures everyone screened actually receives a risk assessment.

Fourth, by using the programming language Java, flexibility is enhanced by allowing the screening program to be used on most platforms such as Win 98, 2000, Macintosh, Linux, and Solaris. Fifth, data is saved to the laptop hard disc as it is entered, ensuring no data is lost in the event of a computer crash. Sixth, the data can be downloaded into common spreadsheet applications like Microsoft Excel with no modification. Seventh, the application is small: 3 megabytes (1 floppy = 1.4 megabytes), and has minimal system requirements so even older laptops are fully capable of running this program.

Eighth, by automatically tagging cases for follow-up, the application addresses a potential communication breakdown between screening and follow-up. When an Internet connection is established, the application automatically assigns those identified as "at risk" in the screening to caseworkers. This reduces the project director's workload and downtime between the conclusion of the screening and follow-up initiation. Caseworkers receive an email notifying them to begin the follow-up phase of the project.

Caseworker Interface

Caseworkers access their list of participants to contact for follow-up using a standard browser. Each participant name is a dynamic url linked to the contact information and script appropriate for that person. Scripts were written for interviewees either with or without their own primary care physician (assessed at the screening). The appropriate scripts were assigned automatically, eliminating the need to juggle multiple script options.

As the caseworker works through the script, the application automatically captures responses so that upon call completion, the participant file is already updated, precluding the need for the caseworker to assemble a report for the project director. The script is also interactive, producing dynamic changes based on participant replies to previous questions. For example, if a participant replies that they have not yet scheduled an appointment to consult a physician, the next question presented to the caseworker by the program assesses reasons why an appointment was not made. Additionally, if certain barriers are identified, pop-up windows with information addressing these barriers appear. This interactivity allows contact to be formal yet fluid enough to change and address the needs of the interviewee. Furthermore, pop-up windows offer the caseworker the ability to rapidly address questions without having to search through binders of information.

As stated, another goal of the project was to demonstrate an interactive capability impossible without a computer. A feature was selected to target participants without a primary care physician who desire a physician in close proximity to their home. Based on the interviewee's address, the application generates contact information for 3

physicians in the same or immediately adjacent zip code. This illustrates the potential for more personalized follow-up.

Security consists of login names and passwords that allow caseworkers access to their interviewee list. User authentication (more robust security) was not integrated due to budget limitations and because this was not a published website. Additionally, the web address is not an address that can be guessed. The site is not run on a secure server due to budget constraints but is designed to run on one without need for modification.

There are several main benefits of this design for caseworker interviews with participants. First, the caseworkers only require an Internet connection; all contact information, scripts, and data collection is conducted via a web browser interface, obviating the need for the caseworker to have binders of information when conducting calls. Also, the dynamic generation of scripts allow the follow-up call to be fluid and change according to the needs of both the participant and the needs of the study. Furthermore, pop-up windows and physician referral information generated according to geographic proximity demonstrate how the Internet can provide more accurate, relevant information while reducing the workload exerted by the caseworker. And, lastly, follow-up data is automatically integrated into the participant's screening information, thus reducing the workload of further data entry, reducing the potential for error, and reducing the timeline from call completion to the availability of final data from potentially weeks to instantaneous.

Server/Database

After the screening, the data from each computer was compiled on a single floppy and transferred to the database via email. The database was run on a server programmed

to house the screening data, assign participants identified as at-risk to caseworkers and to notify caseworkers to initiate the follow-up phase of the project.

The database can be queried through the World Wide Web. Due to the pilot nature of the project, the ability to maintain and monitor multiple intervention databases was not introduced.

Results

Technology Assessment

The project was field tested on a single day at a Vietnamese Community CHD screening in San Jose, CA. Nine laptops provided by the AHA (PII 266) were used as stand alone units without onsite Internet connections. Volunteer physicians and medical students conducted screenings and data entry. Of the 168 people screened, 78 were found to be at risk for CHD. Table 3 shows the characteristics of those screened.

The technological results were largely successful. Risk assessment was accurate and consistent. The technology was stable and no computer crashed or encountered bugs. The data collection and compilation was fluid and as planned.

Caseworker notifications and their ability to interact with the webpage component of the project to conduct follow-up encountered no technological problems. The interactive scripts were fluid, without incident, and universally well received. Six real-time caseworker progress checks demonstrated all information to be current to the day and without bugs. In interviews following the end of the project caseworkers felt that the technology successfully addressed the goals set forth earlier. They reported that contacts were easily accessible through the Web and their workload was streamlined by the automated data collection. The pop-up windows feature was viewed positively.

The final data presentation in Microsoft Excel spreadsheet form was clean, without problems, and well received by the AHA project director.

Follow-Up Results

For the purposes of the study, the 78 at risk participants were randomly assigned to control and experimental groups for follow-up. The 39 participants in the control group received a phone call follow-up using a standard AHA script. Each participant was asked if they had already scheduled an appointment to meet with a physician to discuss their results. If they had not, they were encouraged to do so. The 39 participants assigned to the experimental group

Table 3. Participant Information	
Total Screened	n = 168
Gender	47% Women (n = 79), 53% Men (n = 89)
At risk	n = 78 (46%)
Average Age	56 yrs w/ SD of 12.9 yrs
% HTN	47.6% (n = 80) <ul style="list-style-type: none"> • 65 on BP medication (38.6 %) • 10 had systolic > 140 mm Hg • 5 had diastolic > 90 mm Hg (w/ systolic <140 mm Hg)
Average Total Cholesterol	210mg/dl w/ SD of 48.5 <ul style="list-style-type: none"> • 59% (n = 99) cholesterol ≥ 200
Average HDL	47mg/dl w/ SD of 16 <ul style="list-style-type: none"> • 17% (n = 29) HDL ≤ 35

were taken through the aforementioned web based follow-up protocol. A second call, 2 weeks after the completion of the first call, was conducted to assess appointment-booking rates for both experimental and control groups.

Three caseworkers were each assigned to contact an equal number of control and experimental participants. Completion of the first phase of calls required 27 days to complete and the second required 19. Of the 39 contacts attempted in each group, 9 (23%) of the experimental group and 12 (31%) of the control group were not completed

due to inability to establish contact (7 failed attempts). Of those who were contacted, 13 (33%) of the experimental group and 12 (30%) of the control group reported they would schedule or had scheduled an follow-up appointment with a physician. Ten (26%) of the experimental group and 8 (21%) of the control group were seeing either primary care physicians or cardiologists on a monthly basis and had already discussed their results from the screening. In the experimental group, 3 (8%) and 5 (12%) of those in the control group were unreceptive to caseworker contacts. 76 (97%) of those contacted preferred to speak in Vietnamese.

Table 4. Follow-up

	Experimental (n=39)	Control (n=39)
Failed Contact	n=9 (23%)	n=12 (31%)
Will consult or had consulted physician	n=13 (33%)	n=12 (31%)
Already in regular care	n=10 (26%)	n=8 (21%)
Unreceptive to contact	n=3 (8%)	n=5 (12%)
Native Vietnamese speaker	n= 76 (97%)	

Complications

We encountered several problems when testing this project. First, the physical layout of the screening event made the completion and collection of screening forms difficult. Through counting the number of cholestec cassettes used, we estimate 17% of those screened were not entered in the computers. Additionally, language barriers made data entry unacceptably long. The computer intake form was in English while the paper screening sheets were in Vietnamese. The predominantly English-speaking volunteers required additional time to enter data accurately. Thus, the total time to enter a case was approximately 5 minutes- a time that should be cut to 2 minutes to be practical.

Furthermore, finding enough volunteers to run the 9 computer terminals was difficult and, at times, impossible.

The complications encountered by the caseworkers were two-fold. First, the scripts, written in English and translated to Vietnamese, did not account for culturally specific language, forcing the caseworkers to change certain vocabulary. Second, the caseworkers felt the pop-up windows were extremely valuable but did not provide enough information.

Discussion

Technology

5 of the 6 technological goals set forth by this pilot project were successfully met and demonstrated to be feasible. Computer based quantitative risk factor analysis was performed in the field for the first time. Those identified as “at risk” were automatically flagged for follow-up. Case assignment to caseworkers was automated, reducing the workload of the project director and reducing potential delays from screening to first contact. Caseworker-participant interaction was facilitated via the web and data collection at all stages of the project was streamlined and automated. The database also allowed for integration with Microsoft Excel, allowing for spreadsheets to be generated. Furthermore, the data set can be queried through the Internet. At the time of this writing, the technology is being used again for a large CHD screening held at a Tet Festival in San Jose, CA.

The sixth goal, by the creation of creating a central database housing information from disparate interventions allowing for the sharing of data and “lessons” learned, was not attempted due to the pilot nature of the project. Such a feature can be integrated into

the existing design of the project and would greatly enhance the value-added of using this technology in further screening interventions. This goal represents an extremely valuable potential for this technology.

To accomplish this goal, a central database would be established and a webpage for project directors to add community evaluations, formative evaluations, and final project reports would be established. Included in such reports could be important demographic characteristics such as what percentage of the target population attends church, what percentage frequents community centers, what percentage has ongoing access to medical care, the level of health literacy, etc... Also included in the forms would be areas to evaluate intervention methods used (e.g. contests, drawings, location of intervention, or novel methods tested). These evaluations would be linked to the actual screening data and could be queried by project directors around the country.

The benefits of such a feature would be three-fold. First, data could be pooled in various ways to allow for macro-analyses of high-risk populations that each intervention alone would not be capable of performing. Second, regional and national directors of organizations could more easily monitor the activities of their local affiliates by creating a single dynamic source of information. Third, the ability of local project directors to communicate with each other in a more formal and accessible manner might facilitate and accelerate the sharing of ideas, experiences, and knowledge gained from each community screening.

Areas for improvement

Improvements can be made to speed up data entry at the screening, provide caseworkers with more information and improve the navigation of the caseworker's web pages.

Follow-Up

A primary goal of the project was to facilitate entrance of high-risk underserved at-risk individuals into the health care system. According to research on our target population, it was anticipated many would not have existing access to care [24]. However, based on our study, a high number of those found to be at-risk already had ongoing care with a physician. This raises several unexpected issues and areas for further study.

Was the population screened representative of the overall San Jose Vietnamese community? By holding the screening at a Convention Center, the risk of self-selection screening bias was high. Furthermore, why were so many of those with ongoing care, several of whom were being seen monthly, still found to be at high risk for CHD? Further studies are needed to better understand the community screened. Health literacy, cultural competency, and adherence to medical advice are relevant background areas of research to draw upon when looking to answer these questions.

From the standpoint of the Internet project, one feature to be added would allow for the generation of a formal screening report that could be mailed to the participant and his/her physician. A study focusing on CHD screening and follow-up interventions demonstrated that although mailing a letter to the home of the participant seemed to have no significant impact on the number who reported seeing a physician, it did affect the primary reason stated for making the visit. Also, the letter had an "agenda-setting"

function on the patient-physician interaction. CHD risk factors and treatment were addressed more directly in the encounter [25].

In conclusion, this pilot project successfully demonstrated that an appropriately designed Internet-based solution can be integrated into a small budget community screening for CHD. It improved risk assessment and automated several steps of the screening process, effectively reducing workloads and potential for error. Finally, a central database integrating disparate sites allowing for formalized, easy to access data and knowledge sharing among project directors is a promising next step for this technology.

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Appendix A: Technology Appendix

Screening

- The overall screening application was written as a personal JSP Web Application with Java Beans. A JSP Web Application is a small *Java* applet that can be embedded in an *HTML* page. Applets differ from full-fledged Java applications in that they are not allowed to access certain resources on the local computer, such as files and serial devices (modems, printers, etc.), and are prohibited from communicating with most other computers across a network. The common rule is that an applet can only make an Internet connection to the computer from which the applet was sent. Java Beans
- The *Risk Calculator* is a Java Class application designed to function as a stand-alone capacity or as a part of a larger application, as we used it for. Java is a network-friendly programming language invented by Sun Microsystems. A very common use of Java is to create programs that can be safely downloaded to your computer through the Internet and immediately run without fear of viruses or other harm to your computer or files. Using small Java programs (called "*Applets*"), Web pages can include functions such as animations and calculators.
- HTML was used for display. HTML, or hypertext markup language, is the standard, basic language for creating web pages.
- The data from each person screened is saved in "standard flat file coma delimited form" allowing the information to be opened by spreadsheet software such as Microsoft Excel.

Caseworker Interface

- Simple HTML allowed all major web browsers to access the web based scripts and JSP was used to capture participant replies automatically.

Security

- Caseworker logins consisted of simple string compared login names and passwords.
- The server was not secured due to the small nature of the project and budget constraints

Server/Database

- The server/database was a combination of a Microsoft Access database with a JSP with JavaBeans data retrieval application that used standard SQL queries. The data retrieval application automatically extracted the necessary demographic information for caseworkers and displayed it on their web browser. The database/server was housed on a PC clone PII 266MHz, 64MB RAM computer with a dedicated subscriber line (DSL) Internet connection that hosted the web frontend for caseworker access. Again, the design was geared toward ease of use and, as noted, flexibility across multiple platforms such as Oracle databases for Windows or Linux MySQL.

- Structure Query Language (SQL) is specialized language for sending queries to databases. Most industrial-strength and many smaller database applications can be addressed using SQL. Each specific application will have its own slightly different version of SQL implementing features unique to that application, but all SQL-capable databases support a common subset of SQL.

Appendix B: Caseworker Script for those with a Physician

A. Hello, this is [Name] from the American Heart Association. May I speak with [PARTICIPANT]?

Xin cha`o, to`i te`n la` [name] va` to`i la`m vie`.c cho ho`.i American Heart Association. Xin phe`p cho to`i no`I chuye`.n vo`"i [o`ng hay ba` NameHere depending on male or female]

1. PARTICIPANT IS NOT AVAILABLE [GO TO B]
2. PARTICIPANT IS AVAILABLE [GO TO C]

B. Can you tell me when would be a good time to call back to speak to [PARTICIPANT]?

[RECORD THIS INFORMATION ON SCHEDULING SHEET]

Xin o`ng/ba` cho bie`^t lu`c na`o tie`.n nha`^t -de`^? to`i co` the`^? go.i la.i -de`^? no`i chuye`.n vo`"i []?

C. Hello [PARTICIPANT]. Would you prefer I speak in English or Vietnamese? *Xin cha`o [...]. O`ng/ba` thi`ch no`i tie`^ng My~ hay tie`^ng Vie`.t?*

[NOTE PREFERRED LANGUAGE IN LOGBOOK]

This is [NAME] from the American Heart Association and I am calling to thank you for participating in the Heart Health Screening a few weeks ago. I'd like to now provide you with some additional information and ask you a few questions. This will take around 5 minutes.

To`i la` [Name] tu`" ho`.i American Heart Association go.i -de`.n. To`i ra`^t ca`m o`n o`ng/ba` -da~ tham du`" buo`^?i kha`m tim va`i tua`^n tru`"o`"c. To`i muo`^n cho o`ng/ba` bie`^t the`^m mo`^t va`i chi tie`^t kha`c va` cu`ng muo`^n ho`?i the`^m mo`^t va`i -die`^u. To`i chi? ca`^n khoa`ng 5 phu`t tho`"i gian tho`i.

At the screening, you were informed that your test results indicate you should meet with a doctor to discuss them. This does not necessarily mean you have heart disease, but we are concerned about your health and recommend you receive further follow up care from a doctor. At the Heart Screening you were encouraged to call one of the doctors on the Vietnamese Physicians Association list of doctors. I wanted to follow up on the advice given at the Screening to help make sure you receive the care you should receive. I would also like to assure you that everything you say in this phone call and your test results will all be kept completely confidential.

Ta.i buo`^?i kha`m tim vu`"a ro`^i, theo ke`^t qua? thu`"? nghie`.m o`ng/ba` -da~ -du`"o`".c chi? da`^?n ra`<`ng ne`^n -de`^n ga`<.p ba`c si~ cua? o`ng/ba` -de`^? thao? lua`.n the`^m

ve^` ti`nh tra.ng su`c khoe? cua? o^ng/ba`. -Die^`u khuye^`n na`y kho^ng co' nghia~ la` o^ng/ba` bi. be^`nh tim. Nhu`ng vi` su`c khoe?cua? o^ng/ba`, chu'ng to^i -da~ khuye^`n khi'ch o^ng/ba` ne^`n -di ga^`p ba'c si~ -de^`? -du"o".c cha^`m so'c the^`m. Ta.i buo^`i kha'm tim, chu'ng to^i co' -du"a mo^`t danh sa'ch ca'c ba'c si~ Vie^`.t Nam cho o^ng/ba` go.i tham khao?. Chu'ng to^i muo^`n cha<'c ra<`ng o^ng/ba` -da~ -du"o".c chua^`n be^`nh mo^`t ca'ch -da^`y -du?. Chu'ng to^i xin cam -doan ra<`ng nhu"~ng gi` o^ng/ba` no'i vo""i to^i va` ca'c ke^`t qua? thu"? nghie^`.m -de^`u -du"o".c giu"? ki'nh.

Just to confirm, is [PHYSICIAN'S NAME] your regular doctor?

Xin cho bie^`t ba'c si~ [Name] co' ddu'ng la` ba'c si~ cu?a o^ng/ba` kho^ng?

1. PARTICIPANT ANSWERS NO [GO TO D]
2. PARTICIPANT ANSWERS YES [GO TO E]

D. What is your doctor's name?

Xin ho?i ba'c si~ cu?a o^ng/ba` te^`n la` gi`?

1. RECORD IN LOGBOOK

F. Since the Heart Health Screening, have you called your doctor to set up an appointment?

Sau buo^`i kha'm tim, o^ng/ba` co' la^`y he.n vo+`i ba'c si~ chu+a?

1. PARTICIPANT ANSWERS YES [GO TO G]
2. PARTICIPANT ANSWERS NO [GO TO I]

G. Excellent, are there any reasons why you might have trouble getting to the medical appointment you set up?

Ra^`t to^`t. O^ng/ba` nghi~ xem coi co' ddie^`u na`o co' the^`? la`m tro+? nga.i buo^`i he.n cu?a o^ng/ba` vo+`i ba'c si~ kho^ng?

[CODE RESPONSES ACCORDING TO 6 POSSIBLE RESPONSES]

1. Transportation?
Kho^ng phu"o"ng tie^`.n -di la.i?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

2. Money to pay for the appointment?
Kho^ng co' tie^`.n tra? le^`. phi' cho ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

3. Is the appointment too far away for you?

Cho^? he.n qua' xa nha` ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

4. Are you too busy to make the appointment?

Ba^.n qua' kho^ng co thi` gio"" -de^? go.i la^y he.n ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

5. Not interested in following up on results.

Kho^ng quan ta^m -de^? go.i ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

6. Other.

Va^'n -de^` na`o kha'c ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

[PUSH ENTER ON THE WEBPAGE AT THIS POINT. RESPONSES TO THE BARRIERS IDENTIFIED BY THE PATIENT WILL SHOW UP]

[GO TO H]

H. So, you have scheduled an appointment to meet with [DOCTOR'S NAME OR NAME OF MEDICAL CLINIC] on [DATE AND TIME]. Is this correct?

Va^.y la` o^ng/ba` -da~ he.n vo"i' bac' si~ va`o nga`y Co' -du'ng va^.y kho^ng a. ?

On the day of the medical appointment, please bring the results from the American Heart Association Heart Health testing you received. If you have misplaced them, please let me know and we will send you another copy.

Khi -di ga<.p ba'c si~, o^ng/ba` nho"" mang theo to"" gia^y ke^t qua? thu""? nghie^.m ma` o^ng/ba` -da~ co'. Ne^u o^ng/ba` -da~ tha^t la.c no', xin cho to^.i bie^t -de^? chu'ng to^i go""?i la.i cai' kha'c.

[NOTE IF PATIENT NEEDS ANOTHER COPY OF THEIR SCREENING INFORMATION AND EMAIL JON SINGER]

You will be called a day or two before your appointment just to remind you. Thank you very much for your participation in the American Heart Association Heart Health Screening.

Va`i nga`y tru"o" c nga`y he.n, chu'ng to^i se~ go.i nha<'c o^ng/ba`. Xin ca'm o"n o^ng/ba` ra^t nhie^u vi` -da~ tham gia cuo^c thu"? nghie^m su" c' khoe? cu?a ho^i American Heart Association.

I. Have you scheduled an appointment with another doctor?

Va^y o^ng/ba` co' he.n vo+'i ba'c si~ na`o kha'c chu+a?

[IF YES, RECORD NAME AND DATE OF APPOINTMENT AND GO TO H.]

[F NO, PROCEED TO J]

J. What has prevented you from contacting your physician?

Xin cho bie^t vi` ly' do gi` ma` o^ng/ba` kho^ng the^? he.n ba'c si~ gia ddi`nh cu?a mi`nh.

[CODE THEIR RESPONSES ACCORDING TO 8 POSSIBLE CHOICES]

1. Transportation issues

Kho^ng phu"o"ng tie^n -di la.i?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

2. Money to pay for the appointment

Kho^ng co' tie^ n tra? le^ phi' cho ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

3. The appointment will be too far away

Cho^? he.n qua' xa nha` ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

4. Too busy to make an appointment

Ba^ n qua' kho^ng co thi` gio" -de^? go.i la^y he.n ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

5. Will schedule but haven't gotten around to calling

Ti`nh go.i la^y he.n nhu"ng chu" a co' ra?nh -de^ go.i ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

6. Not interested in meeting with a doctor to discuss results

Kho[^]ng quan ta[^]m -de[^]? go.i ba[^]c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

7. Other

Va[^]'n -de[^]' na[^]'o kha[^]'c ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

[PUSH ENTER ON THE WEBPAGE AT THIS POINT. RESPONSES TO THE BARRIERS IDENTIFIED BY THE PATIENT WILL SHOW UP]

[GO TO J]

J. So, now that we have discussed some options that can help you schedule an appointment we at the American Heart Association would like to encourage you to call your doctor and set up an appointment to discuss your results from the screening. We will call you in two to three weeks to follow up to see if you have been able to schedule a medical appointment. Thank you so much for your participation in the American Heart Association Heart Health Screening.

Chu'ng to[^]i dda~ ba[^]n vo+'i o[^]ng/ba[^] va'i y' kie[^]'n dde[^]? giu'p o[^]ng/ba[^] la'm he.n vo+'i ba[^]c si~. Chu'ng to[^]i tu+'ho[^].i American Heart Association khuye[^]n o[^]ng/ba[^] ne[^]n he.n vo[^]'i ba[^]c si~ -de[^]? tham kha?o the[^]m ve[^] ke[^]'t qua? thu"? nghie[^].m cua? o[^]ng/ba[^]. Chu'ng to[^].i se~ go.i la.i cho o[^]ng/ba[^] trong vo[^]ng hai hay ba tua[^]'n -de[^]? hoi? tha<m ve[^] cuo[^].c he.n cua? o[^]ng/ba[^] vo[^]'i ba[^]c si~. To[^]i xin ca'm o[^]n o[^]ng/ba[^] -da~ tham du". buo[^]?i kha'm nghie[^].m. cua? ho[^].i American Heart Association.

Appendix C: Caseworker Script for those without a Physician

A. Hello, this is [Name] from the American Heart Association. May I speak with [PARTICIPANT]?

Xin cha`o, to`i te`n la` [name] va` to`i la`m vie`.c cho ho`.i American Heart Association. Xin phe`p cho to`i no`I chuye`.n vo`"i [o`ng hay ba` NameHere depending on male or female]

PARTICIPANT IS NOT AVAILABLE [GO TO B]

PARTICIPANT IS AVAILABLE [GO TO C]

B. Can you tell me when would be a good time to call back to speak to [PARTICIPANT]?

Xin o`ng/ba` cho bie`^t lu`c na`o tie`.n nha`^t -de`? to`i co` the`? go.i la.i -de`? no`i chuye`.n vo`"i []?

[RECORD THIS INFORMATION ON SCHEDULING SHEET]

C. Hello [PARTICIPANT]. Would you prefer I speak in English or Vietnamese?

Xin cha`o [...]. O`ng/ba` thi`ch no`i tie`ng My~ hay tie`ng Vie`.t?

[NOTE PREFERRED LANGUAGE IN LOGBOOK]

This is [NAME] from the American Heart Association and I am calling to thank you for participating in the Heart Health Screening a few weeks ago. I'd like to now provide you with some additional information and ask you a few questions. This will take around 5 minutes.

To`i la` [Name] tu`" ho`.i American Heart Association go.i -de`n. To`i ra`^t ca`m o`n o`ng/ba` -da~ tham du`" buo`^?i kha`m tim va`i tua`^n tru`"o`"c. To`i muo`^n cho o`ng/ba` bie`^t the`m mo`^t va`i chi tie`^t kha`c va` cu`ng muo`^n ho`?i the`m mo`^t va`i -die`^u. To`i chi? ca`^n khoa`ng 5 phu`t tho`"i gian tho`^i.

At the screening, you were informed that your test results indicate you should meet with a doctor to discuss them. This does not necessarily mean you have heart disease, but we are concerned about your health and recommend you receive further follow up care from a doctor. At the Heart Screening you were encouraged to call one of the doctors on the Vietnamese Physicians Association list of doctors. I wanted to follow up on the advice given at the Screening to help make sure you receive the care you should receive. I would also like to assure you that everything you say in this phone call and your test results will all be kept completely confidential.

Ta.i buo`^?i kha`m tim vu`"a ro`^i, theo ke`^t qua? thu`"? nghie`.m o`ng/ba` -da~ -du`"o`.c chi? da`^?n ra`<ng ne`^n -de`^n ga`<p ba`c si~ cua? o`ng/ba` -de`^? thao? lua`^n the`m ve`^ ti`nh tra.ng su`c khoe? cua? o`ng/ba`. -Die`^u khuye`n na`y kho`ng co`

nghia~ la' o'ng/ba' bi. be^nh tim. Nhu"ng vi' su"uc khoe?cua? o'ng/ba', chu'ng to^i -
da~ khuye^n khi'ch o'ng/ba' ne^n -di ga^p ba'c si~ -de^? -du"o".c cha^m so'c the^m.
Ta.i buo^?i kha'm tim, chu'ng to^i co' -du"a mo^t danh sa'ch ca'c ba'c si~ Vie^t Nam
cho o'ng/ba' go.i tham khao?. Chu'ng to^i muo^n cha<c ra<ng o'ng/ba' -da~ -
du"o".c chua^?n be^nh mo^t ca'ch -da^y -du?. Chu'ng to^i xin cam -doan ra<ng
nhu"~ng gi' o'ng/ba' no'i vo"i to^i va' ca'c ke^t qua? thu"? nghie^m -de^u -du"o".c
giu"? ki'nh.

Since the Heart Health Screening, have you called a doctor from the list to set up a
medical appointment?

*Tu" ` buo^?i kha'm tim -de^'n nay, o'ng/ba' co' go.i la^y he.n ga<.p ba'c
si?chu"a?*

PARTICIPANT ANSWERS NO [GO TO D]
PARTICIPANT ANSWERS YES [GO TO F]

D. What has prevented you from contacting your physician?

Xin cho bie^t vi' sao o'ng/ba' kho^ng the^? -di ga<.p ba'c si~ -du"o".c va^y?

[CODE THEIR RESPONSES ACCORDING TO 8 POSSIBLE CHOICES]

1. Transportation issues

Kho^ng phu"o"ng tie^'n -di la.i?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE
TO MARK]

2. Money to pay for the appointment

Kho^ng co' tie^'n tra? le^ phi' cho ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE
TO MARK]

3. Unsure on how to use the physician list or how to book an appointment

*Kho^ng bie^t ca'ch xu"? du.ng to" danh sa'ch ba'c si~ hoa<.c kho^ng bie^t
ca'ch go.i la^y he.n vo"i ba'c si~ ?*

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE
TO MARK]

4. The appointment will be too far away

Cho^? he.n qua' xa nha` ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

5. Too busy to make an appointment

Ba^.n qua' kho^ng co thi` gio"" -de^? go.i la^y he.n ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

6. Will schedule but haven't gotten around to calling

Ti'nh go.i la^y he.n nhu"ng chu"a co' ra?nh -de^ . go.i ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

7. Not interested in meeting with a doctor to discuss results

Kho^ng quan ta^m -de^? go.i ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

8. Other

Co`n va^`n -de^` na`o kha'c ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

[PUSH ENTER ON THE WEBPAGE AT THIS POINT. RESPONSES TO THE BARRIERS IDENTIFIED BY THE PATIENT WILL SHOW UP]

[AFTER DISCUSSING THE BARRIERS TO CARE GO TO E]

E. So, now we have discussed some options that can help you schedule an appointment. I have given you the names of 5 doctors, any one of which you can call and set up an appointment with. We at the American Heart Association would like to encourage you to call one of the doctors and set up an appointment to discuss your results from the

screening. We will call you in two to three weeks to follow up to see if you have been able to schedule a medical appointment. Thank you so much for your participation in the American Heart Association Heart Health Screening.

Ba^y gio" to^i muo^'n ba`n vo+`i o^ng/ba` va`i ddie^`u dde^? giu'p o^ng/ba` go.i la^y he.n ga<.p ba'c si~. To^i -du"a cho o^ng/ba` te^'n cua" 5 ba'c si~. O^ng/ba` co' the^? go.i ba^t cu" ba'c si~ na`o -de^? la^y he.n cu~ng -du"o".c. Ho^i American Heart Association khuye^'n o^ng/ba` ne^'n he.n vo"i ba'c si~ -de^? tham kha?o the^m ve^` cai' ke^t qua?thu"? nghie^m cua? o^ng/ba`. Chu'ng to^i se~ go.i la.i cho o^ng/ba` trong vo`ng hai hay ba tua^'n -de^? hoi? tha<m ve^` cuo^c he.n cua? o^ng/ba` vo"i' ba'c si~. To^i xin ca'm o"n o^ng/ba` -da~ tham du". buo^?i kha'm nghie^m. cua? ho^i American Heart Association.

F. That is great. What is the doctor's name?

To^t qua'. Ba'c si~ -do' te^'n gi` va^y?

[FIND PHYSICIAN'S NAME FROM LIST AND RECORD ON SCHEDULING SHEET]

When is the appointment scheduled for?

Nga`y na`o o^ng/ba` -di ga<.p ba'c si~ va^y?

[RECORD DATE IN APPROPRIATE FIELD]

Are there any reasons why you might have trouble getting to the medical appointment you set up?

Co' ly' do gi` ma` o^ng/ba` kho^ng the^? -de^'n ga<.p bac' si~ trong nga`y he.n kho^ng?

[CODE RESPONSES ACCORDING TO 6 POSSIBLE RESPONSES]

What has prevented you from contacting your physician?

Xin cho bie^t vi` ly' do gi` o^ng/ba` kho^ng the^? lie^'n la.c vo+`i ba'c si~?

[CODE THEIR RESPONSES ACCORDING TO 8 POSSIBLE CHOICES]

1. Transportation issues

Kho^ng phu"o"ng tie^'n -di la.i?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

2. Money to pay for the appointment

Kho^ng co' tie^`n tra? le^ . phi' cho ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

3. The appointment will be too far away

Cho^? he.n qua' xa nha` ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

4. Too busy to make an appointment

Ba^ .n qua' kho^ng co thi` gio" -de^? go.i la^y he.n ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

5. Not interested in meeting with a doctor to discuss results

Kho^ng quan ta^m -de^? go.i ba'c si~ ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

6. Other

Va^`n -de^` na`o kha'c ?

[THERE WILL BE AN APPROPRIATE BOX ON YOUR WEBPAGE TO MARK]

[PUSH ENTER ON THE WEBPAGE AT THIS POINT. RESPONSES TO THE BARRIERS IDENTIFIED BY THE PATIENT WILL SHOW UP]

[GO TO G]

G. So, you have scheduled an appointment to meet with [DOCTOR'S NAME OR NAME OF MEDICAL CLINIC] on [DATE AND TIME]. Is this correct?

Va.^y la` o^ng/ba` -da~ he.n vo"i' bac' si~ va`o nga`y Co' -du'ng va^ .y kho^ng a. ?

On the day of the medical appointment, please bring the results from the Health screening you received. If you have misplaced them, please let me know and we will send you another copy

*Khi -di ga<.p ba'c si~, o^ng/ba`nho"" mang theo to"" gia^y ke^t qua? thu"?
nghie^.m ma`o^ng/ba`-da~ co'. Ne^u o^ng/ba`-da~ tha^t la.c no', xin cho to^.i bie^t -
de^? chu'ng to^i go"?i la.i cai' kha'c.*

[NOTE IF PATIENT NEEDS ANOTHER COPY OF THEIR SCREENING INFORMATION AND EMAIL JON SINGER]

You will be called a day or two before your appointment just to remind you. Thank you so much for your participation in the American Heart Association Heart Health Screening.

*Va`i nga`y tru""c nga`y he.n, chu'ng to^.i se~ go.i nha<'c o^ng/ba`. Xin ca'm
o"n o^ng/ba`ra^t nhie^`u vi`-da~ tham gia cuo^.c thu"?nghie^.m su"c' khoe? cu?a ho^.i
American Heart Association.*

Log Sheet

Number of attempted contacts _____

Date of Completed Phone Call ___/___/___

Control Group Experimental Group

Patient ID _____ M ___ F ___

Physician Name _____

Language of Choice:

Vietnamese ___ English ___

Receptivity to phone call:

1 2 3 4 5

- 1 = completely unreceptive/hung up
- 2 = unreceptive
- 3 = ambivalent
- 4 = receptive
- 5 = very receptive

Eagerness for follow-up:

1 2 3 4 5

- 1 = not interested in follow-up
- 2 = wary and may not follow-up
- 3 = ambivalent/ hard to know
- 4 = eager
- 5 = very eager

Do they need another copy of their screening information?

Yes

If yes, please send Jon Singer an email immediately to notify him that patient needs copy of their screening information.