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A Novel Approach to Adolescent Obesity in Rural Appalachia of West Virginia: Educating Adolescents as Family Health Coaches and Research Investigators

Robert A. Branch et al.,*
University of Pittsburgh, Pittsburgh PA
USA

1. Introduction

“Transformation happens less by arguing cogently for something new than by generating active ongoing practices that shift culture’s experience of the basis of reality.” – R.S. Zander (a psychologist) B. Zander (a conductor, in the Art of Possibility). (Zander & Zander, 2002)

The pandemic of obesity, with its attendant downstream complications of Type II, Diabetes (DM) and Cardiovascular disease (CD) is emerging as an international challenge to public health. (Adams et al., 2007; Grubb, 2002) Despite increased understanding of the complexity of the biology of energy balance, and evidence of how to maintain sustained weight reduction in the context of a randomized clinical trial, (Knowler et al., 2002) the actual epidemic is still inexorably increasing. (USBRFSS, 2002)

Each advance in our understanding of the biology of energy balance provides further evidence for the complexity of multiple interactive processes, and the amazing ability of the human body to auto regulate to counter external interventions and maintain what the body perceives as the ideal basis for competing in its environment. Thus, our perception of the dangers of obesity, based on future predictions of adverse events run counter to biological self-perception of the immediate present.

We have, however, found that perfection is not required to ameliorate an adverse future, as relatively modest reductions in weight, when sustained, provide disproportionate reduction in the risk of DM and CD. (Knowler et al., 2002) This perspective provides the basis for the belief that we can reverse the epidemic.

The authors’ opinion, mirrored by others, is that the primary root cause for the current dilemma of, ‘knowing what to do, but not doing it’ is a clash of biological and cultural

*Ann Chester², Cathy Morton-McSwain², Soleh Udin Al Ayubi¹, Kavitha Bhat Schelbert¹, Philip Brimson⁴, Shama Buch¹, Yvonne Cannon³, Steve Groark¹, Sara Hanks², Tomoko Nukui¹, Petr Pancoska¹, Bambang Parmanto¹, Stephanie Paulsen¹ and Elaine Wahl³

¹University of Pittsburgh, Pittsburgh PA USA

²West Virginia University, Morgantown WV USA

³University of Pittsburgh Medical Center, Pittsburgh PA USA

⁴University of Surrey, Guildford Surrey UK

perception. (Patton, 1990) Our tenant is that evolutionary adaptation faced with cycles of feast and famine has led to multiple, often subtle biological mechanisms for energy conservation, that are strengthened by social cultural behaviors of nurturing, sharing and preparing for future fasts. With the 21st century advances of food distribution and refinement, the continuous availability of high energy foods and more sedentary lifestyles now render us maladapted to this new environment.

We propose that this clash of perception is best addressed by enhancing learning skills in the community to consider each approach, and develop a new way forward. (Ausubel, 1962) Applying these learning skills to focus on a dialogue, between biological and cultural urges and knowledge of future risk, is required to create sustained changes in behavior that we know can work. From this prospective, success or failure of any obesity intervention in the long haul will be require to 'shift in cultures experience as the basis of reality' (referred to by the Zanders' quotation above) (Zander & Zander, 2002) as the essential ingredient for transformational change.

We describe an innovative strategy to create such a transformational change by directly addressing this primary root cause. We provide an educational forum through family-oriented learning rather than health care teaching. This strategy is being tested in a rural Appalachian community in the US that is stable, but geographically and economically isolated. It is at the epicenter of the US epidemic, with some of the highest obesity rates yet recorded. (Pancoska et al., 2009) Within this community, the primary target chosen for intervention is the adolescent with a secondary beneficiary being the adolescents' family. The benefits for this concept extend beyond the question of obesity alone, and offer a transformational model for community self-help and self improvement.

Our belief is that even though the infrastructure support for our new paradigm is substantial, it addresses the depth of sophistication needed to create sustained change. Elements of the program are generalizable and could be augmented by changes in local and national policies to improve for the interface between education and health care that could benefit affected communities.

In this chapter, we described the evolution and goals of the CAIRN program for rural Appalachia, (*Figure 1*) and point out the role of some of the multiple key players involved. For any program of this level of sophistication, the individual development will be different, and the key players to influence development will vary in the resources and ideas they contribute; however, it will be the key players who will influence the details of what is developed. We suggest that the common critical elements are community willingness to actively participate, the extensive need for voluntary input from as varied a resource base as possible, the need for help from academia and building a multisource funding base for organization and infrastructure.

2. The Setting: A community network of science clubs for adolescents in rural Appalachia

Rural Appalachia, although one of the most scenically beautiful regions of the US with its extended mountain range, is also one of the poorest in the country. The only state entirely in Appalachia, West Virginia (WV), the Mountain State, was initially settled by a wave of Scottish-Irish early immigrants looking for homestead farming. Its later wave of African-American and Caucasian migration came with the railroads to work coal mines. Those who remained despite the later depression are the communities for this sparsely populated

countryside. Even though poverty stricken and unsystematically educated, they are fiercely independent, proud and self-reliant, with a strong culture that centers on cohesive families. (Knowler et al., 2002)

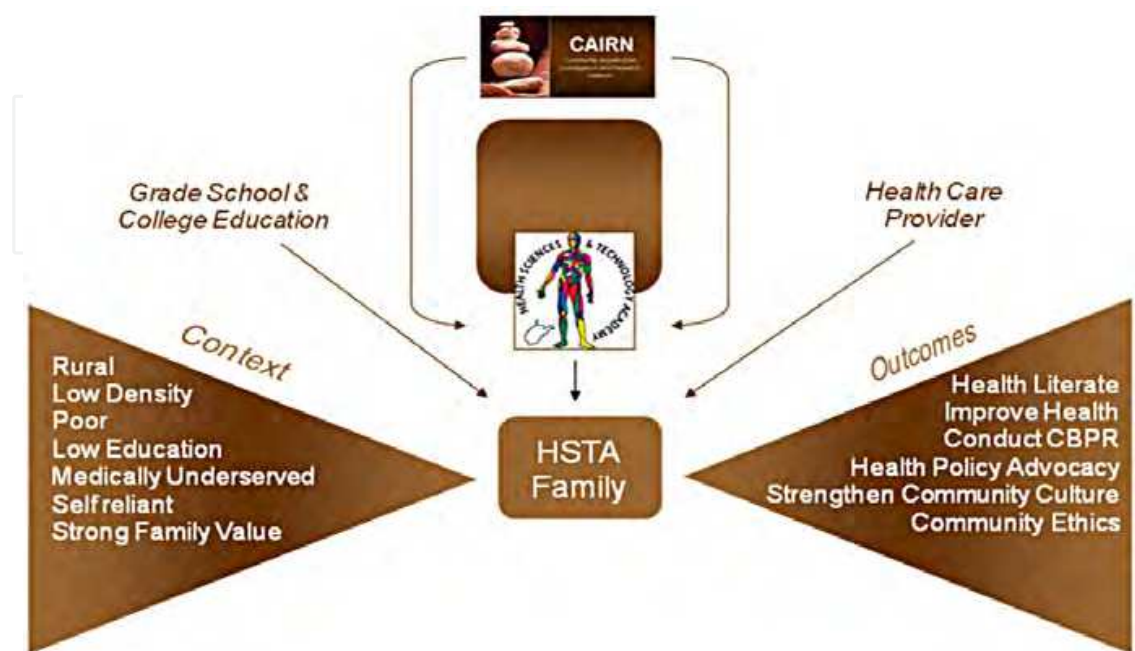


Fig. 1. The vision for the CAIRN collaboration between Pitt and HSTA is to learn how best to enhance cultural values, health related knowledge and life style behavior in rural Appalachian families to improve community health.

Two decades ago, there was a realization that the cycle of poverty could only be broken by a radical change from within the community itself. The initial response from community and academic leaders was to form a cohesive organization, Health, Science and Technology Academy (HSTA), led by the botanist Ann Chester PhD, to focus on education of high school students to limit high school dropout rates and encourage adolescents from families without a history of college education to be successful college graduates in disciplines of value to the community.

Dr. A. Chester, PhD: When I was in the 7th grade, in a new school, my achievement scores were accidentally misread, and I was placed in a tract for non-college bound students. From birth, my family told me I was smart and could do anything I wanted to do. Everybody, even my great grandmother, went to college in my family and I was expected to too. Up until that point, I was at the top of my classes. I was always "the good kid" and landing in a class of 'no expectations' was eye opening. To be told by teachers that I was not college material and that I was limited to being a seamstress or a secretary was news to me. My response was to quit trying. I began to get bad grades. I even cut up in class, and got sent to the corner. This went on for 6-weeks before my mother could unravel the situation and get me in the right tract. By that point, the damage to my self-esteem was huge and the 6 weeks of lost work in my new, fast paced classes seemed insurmountable. It took me years to get over what happened in just 6 short weeks. I did recover and went on to college and graduate school and on to obtain a Ph.D. Somewhere along the line, I realized that the potential of many of those other students in that non-college bound tract was no less than mine. The difference: they never got that chance I had. I kept imagining what the effect of a life-time of low expectations can do.

I began to work on this passion in 1985 when I joined the West Virginia University Health Careers Opportunity Program to help under-represented college students be successful in medical school, dental school and pharmacy school. In early 1990's the American Association of Medical Colleges posed a goal to every medical school to collectively get 3000 under-represented students into Medical School by 2000. WVU School of Medicine Dean, Dr. Robert D'Alessandri, asked me what WVU should do for the effort. By this point, after 7 years of trying to recruit under-represented students into a free program offered at WVU, and having trouble finding students that fit the description in the freshman applicants, the obvious solution was to reach into the high schools to capture and nurture them before they were weeded out of college tracts. Dr. D'Alessandri and I, along with others, conceived of HSTA, and got funding from Howard Hughes Medical Institute to start it with 44 kids and 9 teachers in 1994. The HSTA community-campus partnership infrastructure with its community-majority was developed and expanded with funding from the W. K. Kellogg foundation in 1996. It has since expanded to 800 students and 80 teachers with funding from many sources including the WV State Legislature and the Claude Worthington Benedum Foundation and National Institute of Health. HSTA still thrives today - 17 years later with community in the leadership role.

The infrastructure of HSTA is truly just beginning to be tapped as a change agent for bettering the education status, the economic status and health of West Virginians. As intended, HSTA has become a successful pipeline program for recruiting under-represented students to college and STEM careers. (Branch & Chester, 2009) What we never expected was how powerful the community leadership in this community-campus partnership is in changing lives. HSTA also persuaded the WV legislature to provide tuition and fee waivers to any successful HSTA graduate to any WV state college or university all the way through health professions school. HSTA persuaded the WV legislature to fund HSTA with a line item in the state budget. They have supported the students so that 97% of them go to college and 92% stay in WV to work and 73% are in STEM and health fields when they graduate from college to earn on average \$26,000 more than their highest earning parent. With community backing, the students are giving back to their communities immediately in the 9th-12th grades through improving health literacy in their families and applying science into everyday lives.

HSTA is a community based participatory learning model that is outside, but complementary to the State school system. Now present in 26 counties in WV, approximately eight hundred (800) 9th-12th grade underrepresented students per year are participating, in an after-school science club network of 79 science clubs. (Bardwell et al., 2009) It focuses on preparing students for the health sciences, and bringing healthcare information and healthcare professionals to the medically underserved communities of West Virginia. Student selection is based on local community nomination. Prioritization is given to poor families, minorities and families with no prior college experience. HSTA then provides the infrastructure and support for community-based science projects and community service in the students' individual communities. HSTA uses an interesting combination of mix and match of its students to encourage interactions. The summer science enrichment week long workshops are separated by grade while community based immersion science projects during the year include all club members across the four grades. Students are mentored by scientists, teachers, and community leaders during the school year. Here, the "learning experience" is translated to "a doing experience" with sharing of their new found knowledge back to their families and communities. With goals to improve science and health education, but self-empowers communities through leadership development of their youth, and ultimately will increase the number of health care

providers, scientists, and science educators in West Virginia's currently under-served communities.

The success of this program rests in the community's feelings of ownership and control, and long-term partnerships among higher education, public education at the state and local level, and rural communities. HSTA is governed by a state-wide Joint Governing Board with volunteer representation from 14 Local Governing Boards leading each region. HSTA's governing boards represent all partners: the parents, the students, the schools, communities, and higher education. The majority of the board members represent the local communities with the minority being representatives from institutions of higher education and health professions. This strategy reinforces the role of parents and community in the science education of the youth.

The initial education focus was any topic in the fields of mathematics, science, biology, ecology and technology. It has been amazingly successful. Over 1267 HSTA students enrolled at eighth grade have successfully graduated from high school. Ninety-six percent enter college in comparison to the 56% of the general WV population who attend college. Of these, 89% finish college, relative to 72% in the general WV population and 83% of HSTA African American students are attaining bachelor degrees or higher, compared to only 23% of African Americans of the general WV population. HSTA students earn post graduate degrees 23% of the time and they choose Science, Technology, Engineering and Mathematics majors (STEM) 51% of the time, 4 times more often than the general population of 16% of WV college graduates. Of the greatest importance to the community, 92% stay in WV and have more attractive career opportunities than their parents.

These advances in education of adolescents have not been mirrored by advances in health care in this community. In part as a consequence of the confluence of its geography and economy, rural Appalachia is one of the most medically underserved regions within the US, with all the rural counties in WV being classified as medically underserved. In 2008, the organization "West Virginians for Affordable Health Care" (WVAHC) issued a policy statement entitled "'Early deaths: West Virginians have some of the shortest life expectancies in the United States.'" (Ezzati et al., 2008) Drawing on a wide variety of resources, this document drew attention by three counties in WV (all with HSTA clubs) that have a life expectancy within the lowest 1% of all counties in the US. For the first time in US history, life expectancy in seven counties actually decreased in the decade of the 1990s. The reason for these changes were largely attributed to poor diet, inadequate exercise and resulting obesity. A plea for policy changes went to what were considered primary stakeholders. These included: local and regional Health Departments, the Bureau of Public Health, the Superintendent of Public Schools, the Secretary of Transportation, the County Commissioners, the West Virginia Department of Agriculture, the Governor's Office of Economic Opportunity, the State Board of Education, the Department of Health and Human Resources, the West Virginia Health Information Network and the State Legislature. The silence in response to this plea has been deafening! There is, therefore, an unmet community need to address this problem.

3. Education and Community Based Participatory Research (CBPR): Health as a focus for HSTA science projects

In 2007, as part of its mission, HSTA saw a need for more direct interaction with clinical scientists working side by side with HSTA students to dissolve barriers for pursuing science

and health care careers. The community itself identified obesity as a major health care concern. Encouraged by the prior success of HSTA initiatives (learning), leading to positive community projects (doing), HSTA's community-based joint governing board asked for the same principles to be applied to CBPR in obesity. They encouraged the HSTA students to go beyond baseline data gathering into a new phase of putting into practice the principles of clinical translational science and evidence based medicine, with the community itself playing the leadership role. They encouraged the CAIRN partnership with Clinical Translational Scientists from University of Pittsburgh.

The cross-state collaboration between West Virginia and Western Pennsylvania in the acronym CAIRN also alludes to the Celtic symbol of a beacon to direct a stranger within their country. In this instance, and by analogy, CAIRN is ideally positioned to provide a beacon or direction for self-help in health care behavior in rural Appalachia and to conduct investigational research into whether the strategies used are working. If they are, they have potential to expand and be relevant to Appalachian communities other than in West Virginia, and to be relevant for other diseases relevant to the community.

Initially, Robert A. Branch MD, Clinical Translational Research Scientist and Director of the Center for Clinical Pharmacology at the University of Pittsburgh (Pitt) was invited by HSTA to teach concepts about clinical trials to HSTA club members.

Dr. R. A. Branch, MD: My interest in this interaction was piqued by my own experience in entering an academic career. In this instance, I was a product of a highly regimented, dictatorial, conservative, English, private boarding school developed for military families which I found highly oppressive. I was told early on that the only 'escape' from this environment was to qualify for University in four years, instead of five, and told by my teachers that I would not qualify at all. Motivated by rebellion for learning by rote I developed my own approach to learning without guidance. By happenstance, I used concept mapping for problem solving. This allowed me not only to enter Medical School at 17 years, but obtain a distinction at the head of my medical class in obtaining a MD before the age of 21. The approach of concept mapping is readily adapted to problem based learning which I formally applied to the teaching of advanced therapeutics to medical students at the University of Pittsburgh. (Tofovic et al., 1998) This grounding in educational practice made immediately attractive the challenge of interesting bright adolescents, with essentially no health care background, to become health advocates and educators to their own families. The questions of: Is it feasible? How can it be done? What is its potential? These all became potential hurdles to overcome. The experience of conducting Community Research has proved to be substantially different from Clinical Translational research from three perspectives; firstly to gain trust, there has to be a long term commitment; secondly, the rewards are for an increase in community self-esteem, not the investigators ego and thirdly, the component of providing community feed back to participants at all steps in the process requires a major reorientation and effort. With these cautions, the rewards from the investigator come more from the community than peer group recognition from other scientists.

The first few minutes of the first day of the first summer week long workshop in 2007, organized by Cathy Morton-McSwain and run by Bob Branch, were pivotal to the subsequent program. A group of 22 HSTA students from 18 HSTA clubs had been assembled to teach principles of clinical trials, with a focus on obesity complications. In these first few minutes, the responses to three questions set the stage.

1. How many of you are or have family members who are obese?

Half of the students were obese, and all had at least one member of the family who was obese.

2. How many of you have a family member with diabetes?
18 of 22 hands went up. When teachers from those clubs were asked in a later meeting and a quarter were already diabetic themselves.
3. Rather than be taught a topic are you prepared to learn how to conduct CBPR and do something about your problem?

All 22 were enthusiastic.

These three questions provided a basis for the week long, total immersion into the problem of ethics, research and obesity. (Bardwell et al., 2009) Problem based small group learning experiences covered:

- Principles of ethics (Belmont Report, Helsinki Declaration), regulation of confidentiality used in research (HIPAA regulations)
- Principles of CBPR
- Domain specific information obtained from internet searches included
 - Energy Balance
 - Obesity
 - Diabetes Mellitus, Type II
 - Diabetes Prevention
 - Diabetes Management

It was also the basis of their formulation of a pilot prevalence study designed to establish the relevance of this problem in their own community. The students named their study “Diabetes Education to Protect and Defend our Families (DPD)” and participated in designing the written consent form.

4. Adolescents as investigators of obesity and diabetes

Having formulated ideas of what HSTA students could attempt to do as community projects in the following year, the challenge was to put together the logistics to allow the study to take place. With minimal editing and formatting, the protocol and consent from the DPD Study was formulated into a formal proposal to the WVU Institutional Review Board. This included written informed consent for adults, assent for minors and a HIPAA consent (this was for educational purposes, as the data to be collected was self reported and not the property of a covered entity).

Cathy Morton-McSwain: As one of two Education Coordinators responsible for the HSTA student and teacher programs and projects, and a teacher with 25 years experience in the classroom, I quickly realized this project was a learning curve of epic proportions. It was really important that I am a West Virginia girl. I could be trusted to ensure this project was for the good of all and would not in any way lead to making those involved look foolish or be ridiculed. I was born and raised here and I knew that any challenge put to our clubs would be tackled with a fierce determination to succeed. It is just the nature of, and explanation for, why we in WV so often overcome, what to others are insurmountable odds, made even worse by a daunting terrain and infrastructure that is not in any way conducive to success. I knew that to succeed we needed to challenge each hurdle, one by one and have the sass to just show the world we could make this a howling success. I also drew on the knowledge that humor and fun make every task or lesson more memorable. I developed guides and lessons including scripts to follow which allowed for role playing. Drawing from a cast of characters modeled after real, albeit exaggerated family members, I designed skits and scenarios that were funny, silly, but within the range of possible, to mimic what might or could happen and how to handle such situations. Students were introduced to and role played such characters as Amiable Aunt Agnes, who

never let you finish a sentence but would agree and sign anything if she thought it would make you happy. Paranoid Patty, who knew for a fact that the government had placed robot bugs in everybody's house so they could spy on all of us cause she saw it on "60 Minutes", Uncle Mo who rode his lawnmower to the corner liquor store and always had a snoot full, Granddaddy Don who wouldn't agree with anyone much less to anything, Brother Joe who would participate if you promised to clean his room for a month, and Momma, who kept everyone out of trouble and under control.

I became a 'mad scientist' researcher and gave all the students terrible diseases to test my newly developed drug, which caused some to have crippling side effects. Students were wearing swimming goggles to mimic eye damage, rubber gloves to mimic neuropathy, slings to mimic strokes and loss of the use of a limb. I withheld information, broke every ethics rule and violated every right, and then made them use their skills and knowledge of ethics to help build a case to bring charges against me and my Pharmaceutical company, while identifying what principles were violated.

But no matter what crazy way we presented and practiced each new concept and process of implementing this program, it was all designed to follow the same format which was a designed step by step checklist that students used to make sure no procedure or process was overlooked. This transformed what was a rote process to something that was memorable because students had practiced it as various crazy characters while learning how to deal with awkward situations that could present certain barriers.

The reasons for my passion to see this program be successful were many but centered in that I knew there was so much untapped potential in our communities, and I love to teach, be creative and have fun. It was the excitement and pride I witnessed in the faces of students, when they rose to the occasion and excelled at something most believed they could not do. They understood research and more importantly how to use it to bring about change. They were health advocates in their families and vectors of change.

The energy was contagious and it spread through all of us including the family members. When they realized that together they could address issues they had researched and were important to them, their loved ones, and their communities the projects took on a life of their own. It suddenly was as if they found a key to open the door and had a way to make a difference. This ownership was empowerment and a gateway to get others involved. My role evolved and changed to that of the coach and mentor. I brought together community resources and groups. I reassured, encouraged and was a sounding board and guide for proposed interventions and projects. Sometimes I nudged, but rarely because for so many of those participating, it was if they were finally able to 'get in the game' and were not just sidelined waiting for that unknown someone or something to get things started and done. It is how the role of Community Research Associate began, and is still evolving.

In addition to preparing the young investigators and their club teachers, the essential infrastructure for the study conduct had to be provided. This included developing standard operating procedures (SOP) so that each club would perform the study with the same quality. In order to ensure integration of activities between clubs, we were fortunate in the existing HSTA regional, county and club levels of structure and prior experience in conducting community projects. We did have to formulate the structure of the questionnaire and ensure its easy conversion from paper to electronic format, centralize flow of data and provide appropriate management of identified (kept in West Virginia) and de-identified information (organized and curated in Pittsburgh). The resource base and information technology capability at the University of Pittsburgh were essential in planning, design and execution, but the activities provided a tremendous opportunity for the community to achieve more than they believed possible. It is worth emphasizing that these behind the scenes activities were vital to a successful outcome and could not have been done at the community level within a short time without the outside expertise available from Pitt.

5. The magnitude of the problem of obesity and diabetes in individuals in rural Appalachia

Our experience provided proof of principle that education can be extended to action to conduct CBPR in the community. It also provided an opportunity to the students to give back the information to the community. In the first year of this initiative, we trained and certified 210 HSTA club teachers and club members in the ethics and principles of clinical research. We developed a paper based questionnaire with the students transferring paper data to an electronic format. The DPD study used appropriate assent/consent and achieved HIPAA compliance in use of identified and de-identified data. Over a 6 month period, 989 subjects were recruited to a baseline evaluation of the extent of the problem by responding to this obesity, diabetes-based questionnaire. The cohort in HSTA-linked family members was enriched in poor and minority participants that reflected outreach into the community, and covered a wide age-range. Enrollment of subjects across the state reflected the distribution of 18 clubs participating in this survey (*Figure 2*). It shows a rural distribution that represented the poorest communities targeted by the HSTA Program.

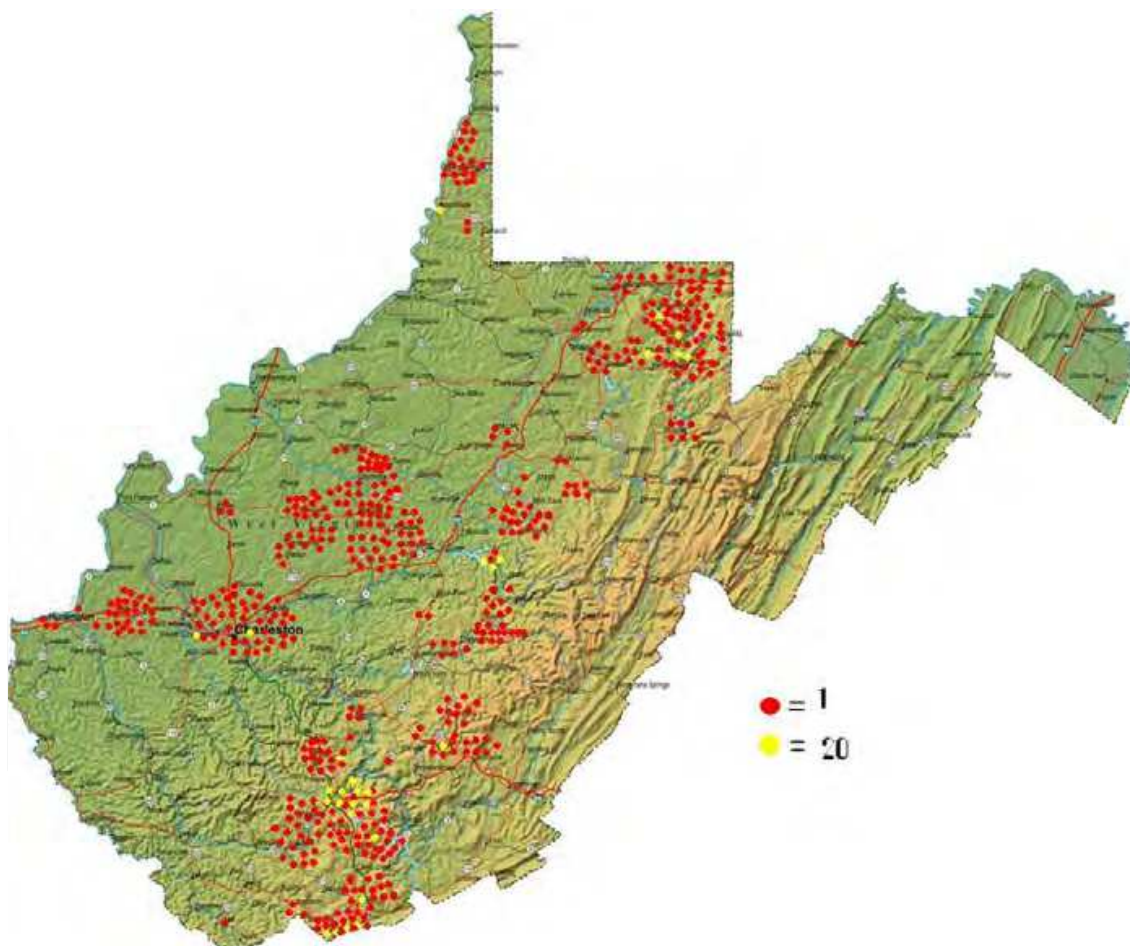


Fig. 2. Geographic location of study participants. (Bardwell et al., 2009)

The students have been successful in enrolling an even distribution of family members over a wide range of 8-80 years old. (Pancoska et al., 2009) The results were appalling and worse than anticipated from other studies. In subjects over 20 years, the mean was at a BMI of 30 (i.e. over

50% were already obese. (Figure 3) In subjects under 20 years, there was the expected relationship of age with BMI. Using the regression of this relationship to identify its mean as a correction factor, and linking the two age groups, the age corrected BMI had a similar distribution about the mean in all age groups. Thus, the problem of obesity being shown equally prevalent at all ages. The adolescents already had as much of a problem as their elders.

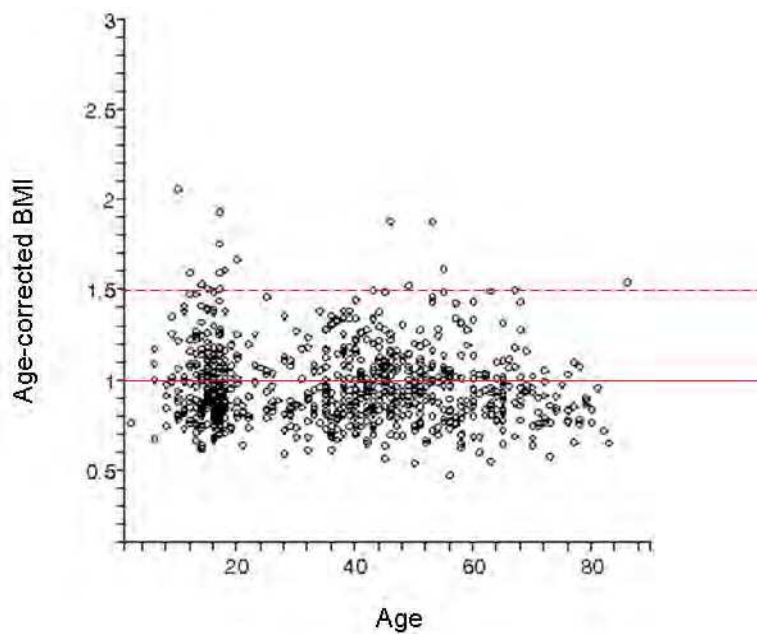


Fig. 3. Age-corrected BMI normalized for mean of BMI which is 30 in subjects > 20 years. (Pancoska et al., 2009)

When all subjects were considered together, the prevalence of diabetics was 10.6%. When only adults were considered, it rose to 16%, and when BMI was subdivided into cohorts of 5 BMI units, there was an exponential relationship of BMI to diabetic frequency, approach 50% with BMIs over 55. (Figure 4)

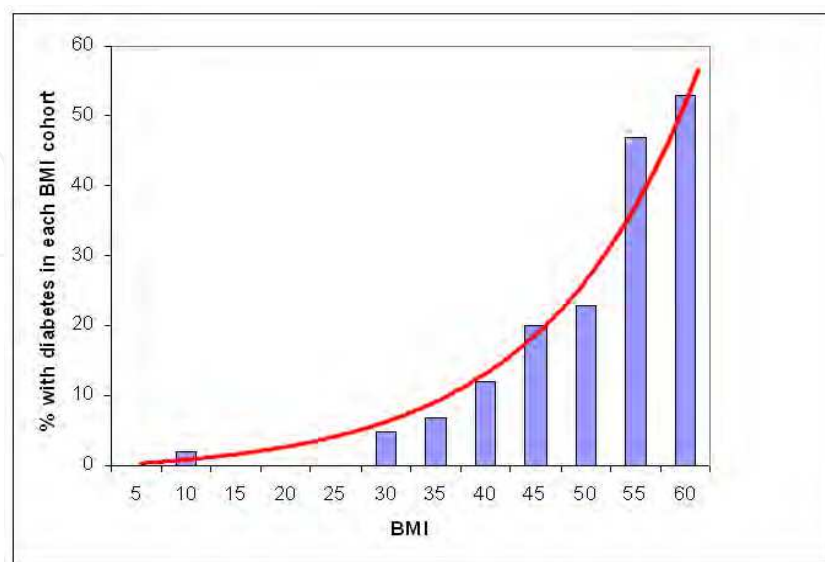


Fig. 4. The change in frequency of diabetes with increasing BMI in rural Appalachia in 2008. (Pancoska et al., 2009)

6. The HSTA cohort in context of obesity: Diabetes epidemic

This region is known to be at the epicenter of an evolving epidemic where the prevalence of obesity has increased by 61% in the last decade in the US, and is mirrored by the prevalence of diabetes, which has increased by 50% within the same period.

Childhood and adolescent obesity has more than doubled in the last decade. In West Virginia, over 43% of children had been classified as at-risk of becoming overweight, or are overweight. Unless these trends are reversed, it has been suggested that a third of all children today will develop Type II diabetes during their lifetime. The impact of this impending epidemic is not only a community health care burden but a financial disaster for an already overstretched, undermanned and under-funded local healthcare system.

The major complications of obesity in adults are DM and CD in mid-life. In the last decade, West Virginia has reported the highest premature death rate in the nation. (WVFAHC, 2008) These diseases also contribute immensely to morbidity, mortality, and health care costs. An illustration of the magnitude of this impact is the recent report that when 2% of counties with the lowest life expectancy are compared with the 2% of counties with the highest life expectancy in Appalachia, the difference in life expectancy for men is 10 years and in women 7.5 years. The counties with the lowest life expectancy are the rural West Virginia communities of the HSTA families.

The 1998-2009 Behavioral Risk Surveillance System (BRFSS) files compiled annually by the Center of Disease Control provides the most detailed information of rate of change. (USBRFSS, 2002) The objectives, design and structure of this report are different from the CAIRN study, but does provide interesting complementary information. This organization uses random digit phone calls for 1000 subjects who respond per state to collect self reported data including height and weight used to calculate BMI, the index of obesity. This system is known to reflect an approximate 10% underreporting, but is considered to yield comparative data between years to look a trends. Using this conservative approach between 1989 and 2008 the national prevalence of obesity has risen from 12% to 27% (with West Virginia being 10 points higher in 2008).

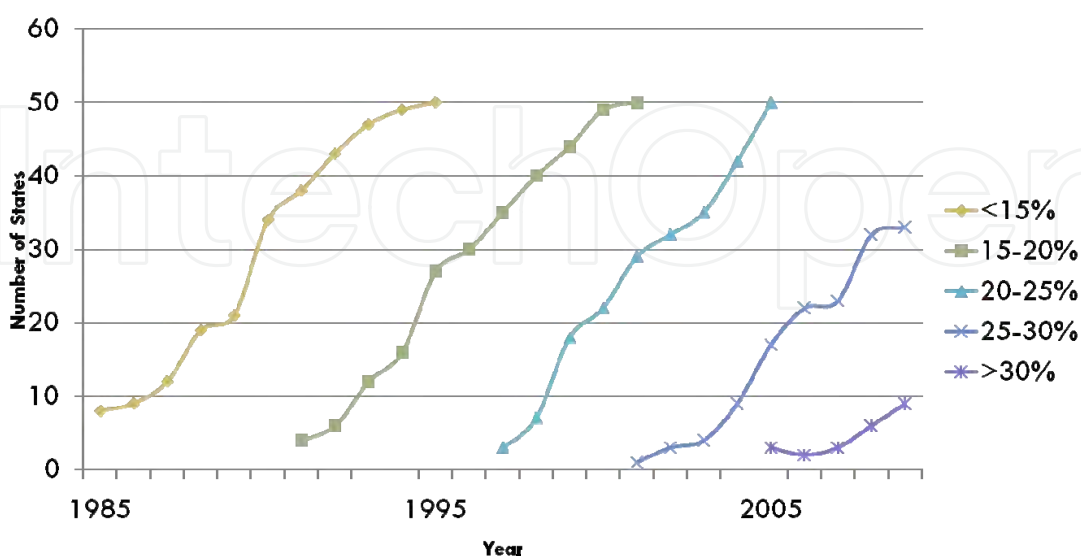


Fig. 5. The number of states in the US that have achieved a prevalence of obesity (BMI>30). Adapted from BRFSS report.

We have adapted the detailed CDC presentation of individual states obesity prevalence rate to illustrate the number of states that achieves an obesity prevalence threshold rate in increments of 5% from 15-35% over the years. This format of presentation reinforces the CDC year by year mapped prevalence to emphasize the problem is national and not local, with all 50 states participating in the epidemic. (Figure 5) (USBRFSS, 2002) It is mirrored by similar trends in Europe, the Middle East, India and more recently China. Figure 5 also emphasizes that the rate of new states reaching the next threshold has been linear over the years of monitoring, with only a possible slowing down in the last 5 years. The state of West Virginia has been at the forefront of States reaching each threshold (Figure 6). When the date that each threshold for obesity prevalence in WV is plotted against the year the threshold was exceeded, the result can be fitted equally well to a linear regression, or a more recent exponential increase. (Figure 6) If the >50% results of HSTA survey are added, the last data point can be considered as either a part of the exponential increase, or a high outlier to the linear increase. In either case, the implications for the future are ominous.

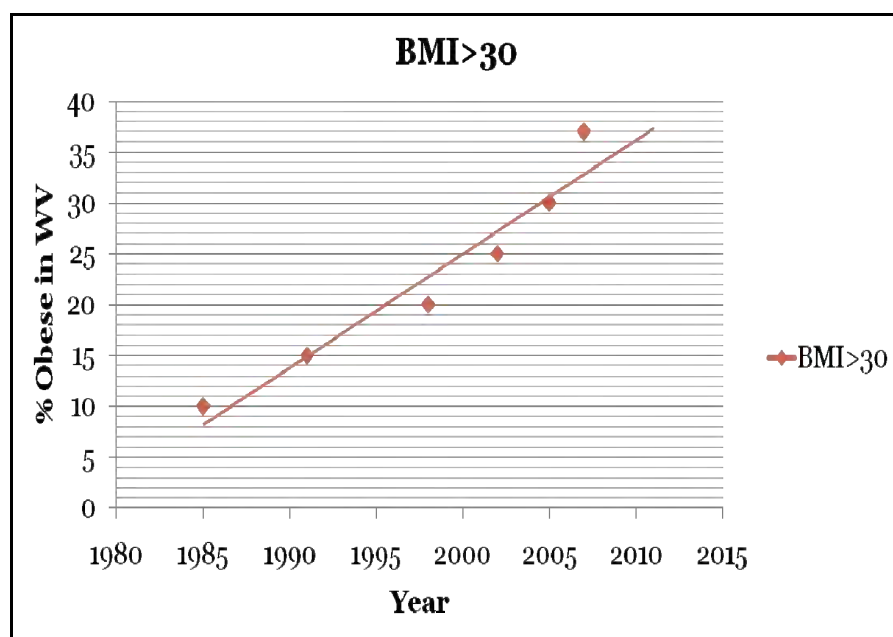


Fig. 6. Linear progression of obesity incidence in West Virginia based on BRFSS data.

At the present time, we favor the idea that the differences in subject selection identify different subsets of the population with the BRFSS random digit dialing in WV favoring population centers, and our study, the more dispersed rural population (Figure 2). Longitudinal follow up from both sources will allow us to discriminate based on the slopes of rate of change from each source in the future.

We are aware that in the majority of longitudinal studies of individual subjects, BMI tends to increase with aging. We were, therefore, surprised that age-corrected BMI had no change with aging (Figure 3). We reason that if we consider the older cohort in Figure 3, that it is likely, based on the BRFSS trend (Figure 6) that when this cohort was in their adolescence, that their mean BMI was substantially lower than the mean of today's adolescents. We have modeled this slope (Figure 7), and projected the same slope to the future projections of change in BMI based in the assumption that the rate of increase in BMI in these adolescents continues to be linear (Figure 6). The results are truly frightening in that in 20 years the mean BMI in adults will be 42 unless we change this rate of progression. (Figure 7)

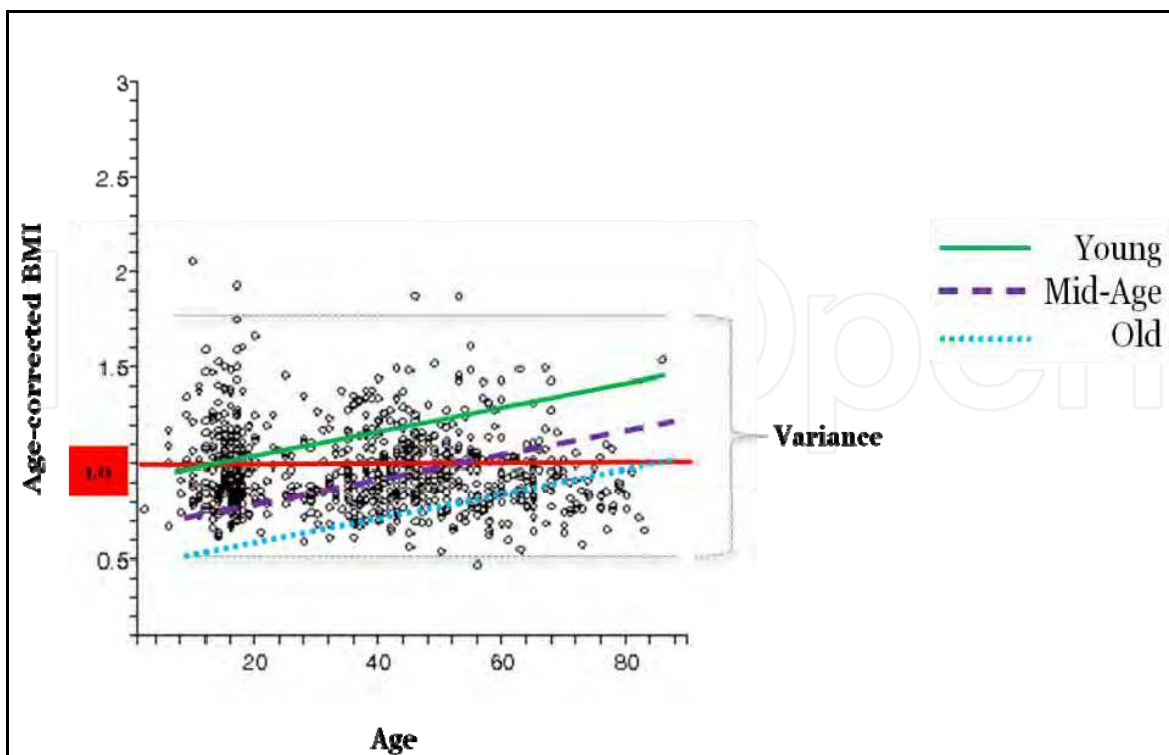


Fig. 7. Projected changes of BMI in HSTA family sample populations of West Virginia in subjects as they age from the present time.

We have, therefore, identified a community at the center of the US Obesity epidemic, and have further identified that the apex and most at risk is in the adolescent within this community. We consider that this is the most vulnerable group to target our interventions.

7. The family as the target for intervention within the HSTA community

We suggest that the primary goal of the HSTA organization has been successful because a subsection of the community has recognized that escape from a cycle of poverty is through education. These adult family members have nominated their children to participate in science club activities. They drive them to activities, provide computers, laptops and smart phones to help their self-confidence and aspiration to seek college education. These families are open to change and to exposure of new ideas. They, by choice, have become part of a HSTA community in which their adolescent family member has become a point person in the inclusion of the whole family.

This position has been strongly reinforced in local discussion and focus groups; it reinforces central themes of West Virginia culture of self reliance and strong family closeness.

Dr. K. Bhat-Schelbert, MD: In 2009, I joined the team as a family physician and researcher with expertise in obesity management, in adolescents, and qualitative methods. I was fascinated by the great potential of this program in motivating activated adolescents to become health advocates for their families and communities. I realized that as adolescents develop their position in the family shifts. They learn a great amount from their peers and teachers, and are personally invested in the welfare of their families. Soon after joining the team, I helped devise focus group discussions to guide the direction of the project and evaluate how teenagers can learn best, then transfer what they have learned on to their families. In 2010, a set of informal groups were conducted when parents and

children were present. These groups helped us realize the true potential and value of the club structure, and the level of commitment these teenagers bring to improve their families' lifestyles. Moreover, we came to find that most of these teenagers had access to internet, and that their parents were committed to promoting the education of their children. These statements helped guide our decision to develop a web-based portal as a viable tool for education delivery. The focus groups also helped to assess the level of commitment and involvement of both HSTA students and parents in attempting behavior change in their diet and exercise habits. Recently, a set of formal focus groups were conducted to understand how teenagers communicate with their families, help them change behavior, and tell us how receptive families are to receive this communication. As part of the group HSTA project, they asked their families to perform one simple behavior change, which was decided by the students (reduce soda consumption, monitor pedometer steps or eat wheat rather than white bread). How they promoted and sustained change was decided by the student. Preliminary results of the focus groups suggest that a significant portion of the interviewed families were successful in implementing and sustaining behavior change although little guidance was given as to how to do this. Parents almost unanimously stated that they attempted the behavior change to support their children's desires and education, even when they would not do so by recommendation of their physician. And as a bonus, participation in the behavior change became a venue for adolescents to spend time with their families. These results strongly suggest that and that adolescents can be trusted to translate their knowledge of health-related behaviors, and family members can support one another in their pursuit of a healthy lifestyle.

These focus groups have been of great value because it has led us to identify a central theme of our program. This is for the whole family to be involved in family self-help rather than the isolated family member with the disease entity, in this instance obesity, DM and CD. In this model, all members have value in participating in whole family involvement of lifestyle choices, supporting health care/patient interactions and enhancing patient compliance with health care recommendations as the healthcare consequences of obesity, diabetes and cardiovascular disease, are in practice carried by the whole family, not just the target member. This is of major relevance in these disadvantaged, isolated, rural families.

7.1 Family network analysis

In order to obtain baseline information about family structure, and also to appeal to the curiosity of HSTA club members in their individual heritage in conducting this project, we structured our survey to have the student initially identify a family tree, and then request the family members to complete the individual questionnaire.

The family tree was restricted to living members within a family unit, i.e. those who could be expected to influence each other's behavior. This included only siblings in their own generation (not cousins), parents, uncles, and aunts in the parental generation and only grandparents in the generation above. This information included position in the family, age, gender, and zip code, but did not include any confidential health care information. Consenting individuals in the family tree were then individually approached to request their assent/consent, depending on age, to respond to confidential health care-related questions that enquired about self-reported height and weight, in order to compute Body Mass Index (BMI) and self-reported history of known DM or CD.

A family group was defined as a group in which complete data were available that comprised at least a boy or girl, their mother and their father. All additional members of the family with complete reported data were included in the analysis of that family. Our approach in using graph-based network analysis was made possible by Petr Pancoska PhD, a mathematician in our team.

Dr. P. Pancoska, PhD: I am a mathematician in the Center for Clinical Pharmacology at the University of Pittsburgh. I originally received my Ph.D. in experimental physics at Charles University, Prague. I spent twelve years intensely involved in conducting and teaching mathematical modeling and simulations in chemical physics in Prague. I then spent the next 10 years working in the Department of Chemistry at the University of Illinois, Chicago, where I focused on discrete mathematics. In 2003, I made a major career decision to move from fundamental mathematics as it relates to physical applications in chemistry, to biological applications. I moved and worked at Stony Brook University; trained myself in biology, and became deeply involved in using physicochemical modeling of DNA, using Eulerian graph representation to develop algorithms that predict functional consequences of single nucleotide polymorphisms of allelic gene variants and k-partite graph theory to analyze complex phenotype data sets and disease states. My familiarity in mathematical modeling and network analysis is well illustrated by the innovation applied to the preliminary data in formulating the family diabetes risk potential as a novel single family based metric. I have been instrumental in study design and will be responsible for the analysis of data acquired by the HSTA network and have developed the modeling algorithms.

The family-based approach brought several challenges to the data collection and processing together with development of data-driven descriptors of features we needed to capture, analyze and interpret. Families are social units with different sizes. Our family descriptor has to be therefore designed with ability to compare quantitatively different size families. Our next challenge was to extend from prior approaches characterize the family social structure using only topological indices of the family network graph. (Knowler et al., 2002) We realized that by annotating the family structure graphs by quantitative vertex potentials and edge weights, derived from the family member's clinico-demographic data, the rigorous mathematical tools of extremal graph theory can be used to find a family diabetes risk descriptor with the properties we were seeking. (Pancoska et al., 2009) Another challenge was how to deal with trends in the collected data, which were related to disease and clinical heterogeneity in the population from those that were normal consequences of an age range in the population (from young to elderly). While finding the tool for age correction was a matter of proper data visualization, the identification of heterogeneity required a combination of several complex algorithms, brought from different disciplines. With experience gathered in spectral data processing, we chose to extract and evaluate the information about the structure of data about obesity in our population in rational and efficient way using minimal number of variable parameters. This approach increases the power of the derived conclusions, as well as optimizes the data-driven intervals of age-corrected BMI used for classification of family members. These are used to derive vertex potentials and edge weights in the double-weighted family graphs. While non-linear transformation of newly derived obesity categories into disease risk potentials followed conventional practice, the conversion of them into family risk potential is novel. A deterministic algorithm was used for finding the maximal flow sub graph in the double-weighted graph, representing the obesity and key features of social relationships in every participating family. This approach allows a single value, "obesity-related diabetes risk flow" per family as the final analytical tool. This integration of tools, algorithms, facts and approaches from different disciplines, that are not normally used together providing an intellectually satisfying motivation for me. This approach has the additional appeal in that it can be applied to other diseases.

We based the selection of mathematical tools for quantitative characterization of the family group as a basic, single informational unit upon the following requirements: (1) the ability to quantitatively capture both the network of social relations in the family, the age-corrected BMI and presence or absence of diabetes for individual subjects. (2) Provide a mathematically rigorous way of combining the age-corrected BMI information for individual family members into a (single) numerical family-based descriptor, without losing

network information, while capturing individual information explicitly and quantitatively in a full family context. (3) Define a quantitative descriptor for comparisons of families or larger social units with diverse sizes and social structures. The quantitative mathematical tool, which satisfies the above criteria, recruits from discrete mathematics and is the weighted graph for the family. (Figure 8) In this graph, each vertex represents one family member weighted (in diameter) for age corrected BMI and the edge connecting two vertices, represents the edge as the social relationship between the two subjects. Each edge has been assigned as the mean of the age-corrected BMI-derived number of the two vertices for that edge. The methods have been described in full in Pancoska et al., 2009.

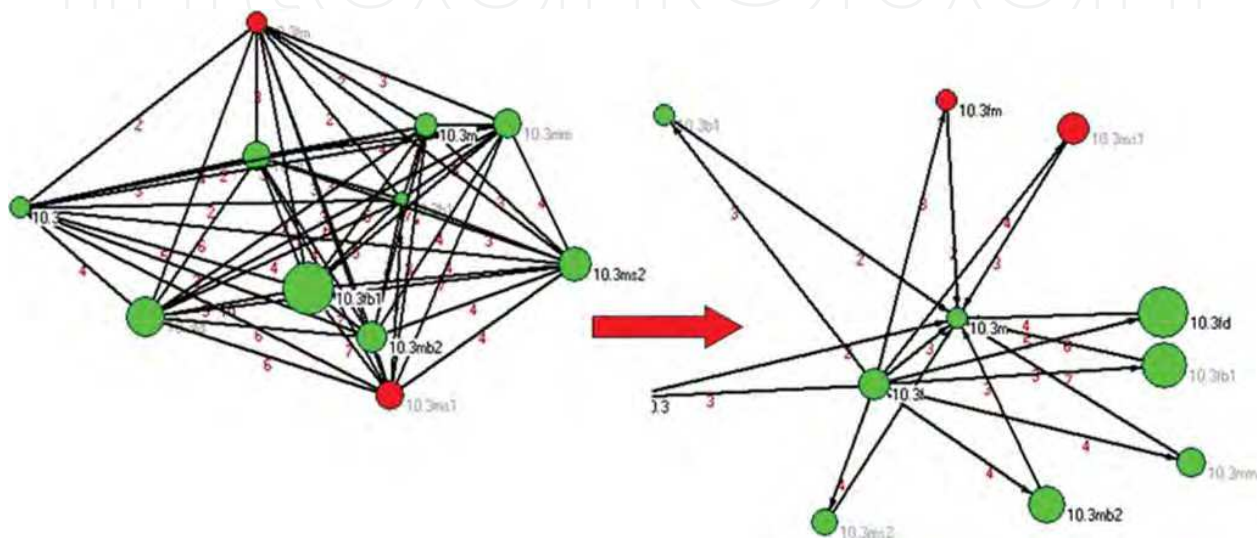


Fig. 8. Examples of (A) full family tree represented as weighted un-oriented graph for family with two incidences of diabetes (red vertices) and (B) corresponding maximal flow oriented sub graph. The size of each vertex is proportional to age-corrected. (Pancoska et al., 2009)

7.2 Family Diabetes Risk Potential (FDRP)

Having analyzed the cohort of participants in this study as individuals, we next proceeded to an analysis of the family as the unit of interest. Within this cohort, there were 142 families with at least an adolescent, a mother, and a father. The majority of families had one or more additional members of their families (average 6.5 members per family). Figure 8, Left Panel, illustrates a representative example of a full weighted for a family with two members having diabetes. The complexity of this network is substantially simplified by using an oriented, maximal flow sub-graph. (Figure 8, Right Panel) In the family diabetes risk potential (FDRP) analysis, we identified 53 families with at least one report of diabetes.

When the family diabetes risk potential was compared between families with and without diabetes, there was a clear difference between diabetic and non-diabetic containing families (Figure 9). The frequency distribution profile fell into three clusters. In the lowest and most common family cluster the proportion of families with diabetes was less than those without diabetes (43%). In the second cluster the proportion of diabetic families was 69% while in the highest cluster, 100% of families were diabetic.

Using a simpler topographic approach, evidence has been recently been presented to indicate that there is a communicable component to the prevalence of obesity. (Krummel et al., 2001) In the Framingham Heart Study, network analysis suggested that chance of

becoming obese increased if an individual had a friend who had previously become obese. We reasoned that in the context of rural Appalachia, the strength and importance of the family as a unit would be equally or more important. It is reasonable to suggest that if the communicable component is perception, then modification of this perception through interactive feedback communication that takes these networks of relationships into account could slow the spread of obesity, and thereby reduce the prevalence of diabetes. We suggest that the FDRP provides a new tool to use in intervention studies that target families at greater risk. This approach has the advantage it frames the starting point for optimizing an intervention in a resource efficient way.

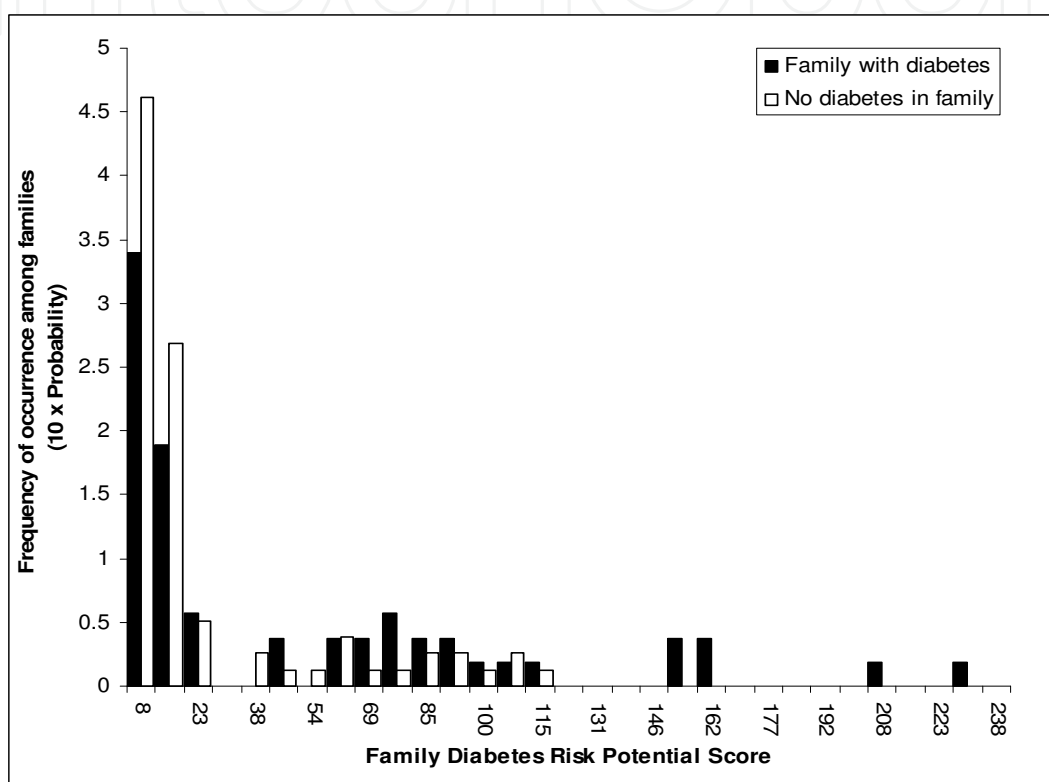


Fig. 9. The frequency distribution of family diabetes risk potential in 55 non diabetic families (open bars) or 87 families (solid bars) with diabetic members. Occurrence frequency of each group has been normalized within rural Appalachia. (Pancoska et al., 2009)

8. The value of decentralized community networking: The spring HSTA symposium

A further major learning experience in our early experience was best illustrated by the symposium in Spring of 2008 when all 800 HSTA club members, and their club teachers assembled for a one day session in which each club community project was presented by the responsible group in a series of parallel group sessions at a centrally located high school. One objective was for every student to have to stand before an audience and publicly speak, even if for a short time. A second objective was to share ideas, and the third was for the students to take ownership and pride in their own clubs' achievements.

As in prior years, the enthusiasm, ingenuity in presenting styles, and use of audio-visual aids was outstanding. What was particularly impressive was that a CBPR activity on obesity

that started from 22 students attending the summer course extended to 18 clubs for club projects and resulted in 40 individual group presentations at the symposium that shared an innovative range of ideas that extended from one subject who generated the Google map shown in *Figure 2* to an intervention in which the local high school agreed to modify the lunch program for all students at that school for a semester. In the following year, 30 clubs made the effort to join the CBPR activity and over 300 students were trained in CBPR. In 2011, this is extending further to all 79 clubs with approximately 800 students.

9. Building the Infrastructure: The CAIRN model

The mission of the CAIRN partnership interaction is to increase health knowledge in a culturally sensitive way that lifestyle choices, expectations in health care needs and choices in disease management result in improved community and family health. (*Figure 1*)

We are well aware that in the instance of obesity, knowing what to do is insufficient to change behavior patterns in a sustainable way. Conventional paternalistic health care teaching has repeatedly led to un-sustained change in weight. (*Figure 10*) The prototypic model of the 'Diabetes Prevention Program' that did reduce new onset of diabetes (Orchard et al., 2005; Lachin et al., 2007; DPP Research Group, 2006; DPP, 2000) and influence other components of the metabolic syndrome in high risk subjects (Knowler et al, 2002) has proved hard to replicate in a cost effective way. Two of its core elements, a modest diet reduction and modest increase in exercise are easy to say but hard to sustain. It appears that the other two key components of the program, a personal health coach and a tool kit for maintaining compliance and introducing new interests over time, are also essential. (Brimson, 2009)

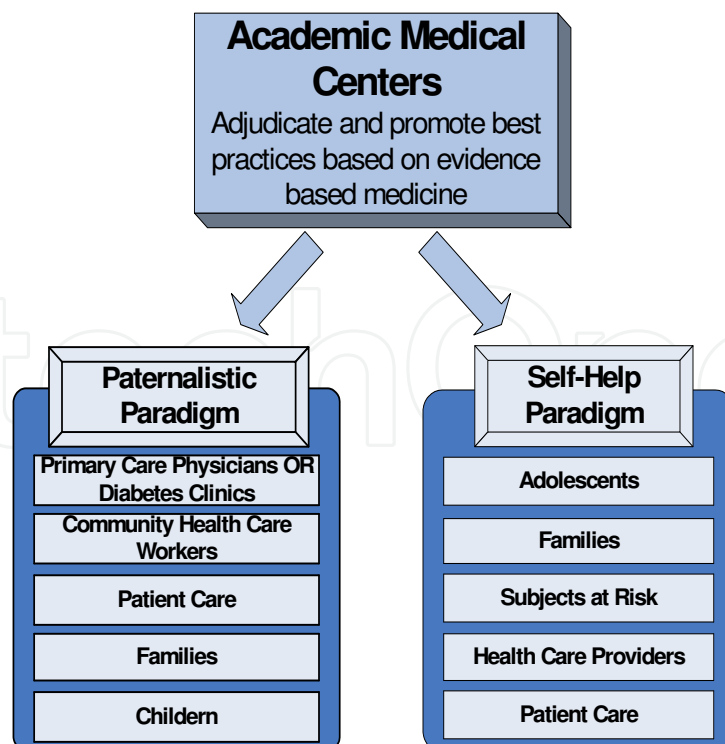


Fig. 10. A changing paradigm of information flow for obesity and diabetes prevention and management.

Our contention is that we can address each of these requirements within the CAIRN partnership by creating a community self-help paradigm in which trained adolescents play a pivotal role in family education to focus on learning (*Figure 10*) and an educated patient presents to health care providers at a time when prevention and early care can be better managed:

- Diet Modification
 - Dietary education
 - Food label reading competitions
 - Club cook off's
- Exercise Modification
 - Individual activities
 - Group activities
 - Electronic games like Wii
- Health coaching
 - Trained HSTA club member as the coach
- Tool Kit
 - Weight monitoring
 - Diet and exercise diaries
 - Movement monitors (arm bands)
 - Knowledge based games and quizzes competition
- Support Groups
 - HSTA family and community
 - HSTA family
 - HSTA club

We also recognize that we do not know what works best or how best to sustain activity within this community. Thus, Investigation and Research (components in the acronym CAIRN) are essential elements to be built into the program to critically assess progress.

In an ongoing dialogue, we have carefully considered the additional elements that would help us create an effective, cost efficient and sustainable program and apply this in a pilot model as an overlay to an existing learning program. Our underlying assumptions in our model are:

1. It builds on community based self-reliance, in which educational information and health care services are external inputs, but the program itself is community driven and not school or health provider driven. The goal is to learn why and how to change behavior. This requires a changing paradigm of paternalistic advocacy to the self-help active paradigm of assuming responsibility. (*Figure 10*) We have found the community is willing and eager to take on this challenge if provided the tools in an organized way.
2. The community itself is geographically dispersed, uniformly poor and medically underserved. This implies that a network of communication has to be provided as a resource base.

Three major new innovative features to promote change have been identified, that with the help of an infrastructure grant from the National Institute of Health are now in place within CAIRN and being further developed. These are:

- Community Research Associates (CRA) as a community education and research leaders.
- Learning Paradigm as contrasted to a teaching program.
- Communication Network for coordination.

9.1 CAIRN Community Research Associate (CRA) Network

In our preliminary experience over three years, the essential ingredient for success has been the willingness of the two experienced educators in high school science for HSTA to assume a double work role and invest their time and energy in developing the prototype of the CRA as a new community career track. (Bardwell et al., 2009) These individuals have responded extremely quickly and effectively to mentoring and training in CBPR from the University of Pittsburgh team and defining the potential in the community for this new career track. Our CRA network consists of a veteran leader, and the three CRAs, who report to her, live in the community and act as science educator liaisons between the clubs and scientists. Our model for this new career track is for senior science teachers to become full time committed individuals. They already have the skills of a science educator, and need to express a willingness to learn the principles of CBPR, disease domain specific medical information and background related science fields for the disease topic. They communicate and teach these ideas to club mentors and science teachers who have no training in these fields, who manage club students, who in turn educate HSTA-related families. We have elected to recruit senior educators rather than health care providers or citizen activists without teaching experience as their orientation to the program is more in line with the mission of the program. They also are ideally situated to know and be able to direct the resource capacity of CAIRN program, to where it can be used most efficiently in the community. Each position is embedded in the local community, so that they play a critical liaison role in interactions with the community. They are also ideally situated to play a mentoring role in college interactions for HSTA club teachers and the placement of HSTA graduates into WV colleges after HSTA matriculation.

In our opinion this CRA network provides the vital integrating element within the community that is enhancing the dynamics and excitement created by self-empowerment across this broadly dispersed region.

9.2 CAIRN Learning Paradigm

Our experience in the 2007-08 year provided us clear evidence that enthusiasm and access to tools for research is not sufficient to effect sustained change in culture. The symposium at the end of the year, and interactions throughout the year indicated the need for a theoretical frame work or pedagogy to build upon.

The CAIRN learning paradigm that we have elected to build has been based on 40 years of science teaching by our education collaborator, P. Brimson PhD.

Dr. P. Brimson PhD: I am an unusual educator in that I acquired my PhD only after retiring from a 40 year teaching career. The motivation to pursue this late dissertation arose from an academic frustration over contemporary methods being applied in adult science education in England, and my interest in enhancing the pedagogical approach of my colleagues. After 20 years of teaching science in the English equivalent of high school, I spent 20 years in adult science education in which I was faced with the challenge of mature students with limited, often misinformed conceptual understanding on the topics of interest. Based on the work arising in psychology, educational theory and science, my approach focused on the root cause of confusion, a clash of community and science cultures. (Patton, 1990; Ausubel, 1962; Novak et al., 1984) In my opinion this conceptual framework provides a sound basis for the CAIRN learning paradigm.

Our assumption is that learning (as opposed to teaching) involves a complex sequential process by which each individual acquires new information, integrates it with prior knowledge and builds a conceptual baseline framework by assimilation. There is a reorganization of understood information and concepts built into revised comprehension

and understanding. This consolidated base is a spring board for abstract conceptual expansion. It provides a platform for action and is the motivation for behavior. In this process health learning requires a process of individual discovery and construction that can be sustained by motivation if relevant to the individual.

We also assume that knowledge is being sought as a way of finding novel and productive ways of interacting with a complex world. Thus, simple concepts need to evolve into more complex concepts. We recognize that a challenge arises when new and more complex information is presented to an individual. When the new information is consistent with a preconceived concept, then concept building is emotionally acceptable. In contrast, if a preconceived model is misconceived or incorrect, when new valid, but more complex information is provided, the emotive response is either outright rejection or early 'forgotten learning'. This conflict is fundamental to Patton's 'mutually exclusive competing paradigms of enquiry' and a root cause for the clash between science and culture. Our approach is to adopt methods to bridge the divide that have been proposed by David Ausubel in his cognitive model of the assimilation theory of meaningful learning, (Ausubel, 1962; Novak et al., 1984) and extended into the practical use of concept mapping which in essence asks the learner to examine their prior concepts and evaluate them in the context of the new information. (Branch et al., 2009)

These theoretical constructs are relevant to our program in three major ways. We consider poorly formally educated adults in rural Appalachia have highly developed cultural explanations for their world. However, many such explanations are built on misconception or oversimplification. They are, therefore, predisposed to be resistant to new more complex ideas. In contrast, adolescents are less 'imprinted' with culture and from their concurrent exposure to new ideas in high school, are more open to scientific enquiry and more complex conceptualization. The second implication is that new information is less emotionally challenged if the information is provided by members of that culture even if they happen to be adolescents. The third implication is that learning and assimilation are active process that requires extensive discussion and dialogue in which the learner has to have time and feel comfortable to ask their own questions. This opportunity is available in a family setting. The CAIRN learning paradigm applies this philosophy of learning to the Appalachian community.

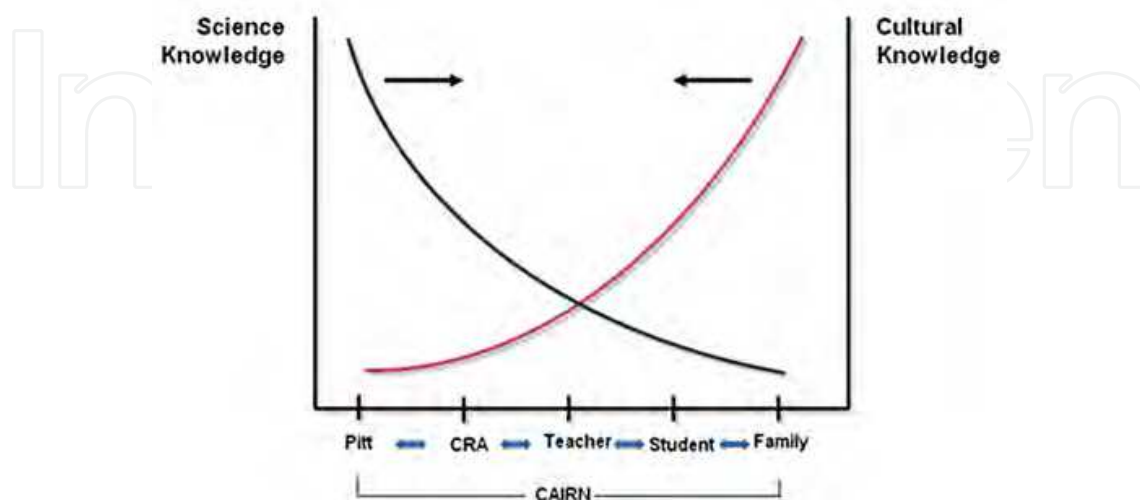


Fig. 11. A schematic representation of the CAIRN tiered, diffusion model of science and cultural learning.

The learning paradigm involves a tiered diffusion structure. It is designed with the premise that transfer of new knowledge embedded in complex concepts is difficult. It involves the sharing of preconceptions, an understanding of the implications of these 'perception of reality' when presented with new information and the willingness to change perception. However, once managed, the changes have the potential to result in a new set of perspectives to influence behavior that if reinforced can be permanently sustained. The tiers of levels of knowledge and of prevailing culture and the diffusion are via the intermediary steps in the exchange of concepts and information. (Figure 11) At each level of bi-directional information transfer, the amount of meaningful learning is a fraction of the information provided, and the barrier to learning is dependent on extent of cultural resistance to the new information. The expectation is that the level of sophistication of and differences between perception of conflicts of concepts on science and culture will be more similar between each step of the interactive transition process. Our goal in having a tiered structure is two-fold. The first is to move the shape of the science and cultural curves in Figure 11 to become more congruent, the second is to construct a logistically feasible model in which amplification from a few with initial knowledge can influence the many who potentially can benefit from it.

Scientific Disciplines	Physiology	Disease Understanding	Disease Intervention
<ul style="list-style-type: none"> • Clinical Translational Research • Epidemiology • Sociology • Psychology • Medicine • Economics 	<ul style="list-style-type: none"> • Energy Balance • Hormonal Regulation • Platelet and Endothelial Cell Interaction • Lipid Dynamics 	<ul style="list-style-type: none"> • Obesity • Diabetes • Dyslipidemia and Cardiovascular Disease 	<ul style="list-style-type: none"> • Prevention • Diagnosis • Non-drug Interventions • Drug Therapy • Surgery

Table 1. Some of the factors that interface between scientific disciplines, understanding of normal physiology, disease and disease interventions in the present proposal.

The range and depth of expertise in disciplines at a major AMC, such as the University of Pittsburgh, can offer is broad. (Table 1) It is realistic to anticipate considerable transfer of health care relevant knowledge in a limited health care domain to the CRAs as they are highly motivated, experienced and intelligent science teachers, only lacking a formal training in health care. They can be expected to have the learning skills, potential for critical thinking and motivation to acquire equivalent knowledge to their university specialist counterpart. Thus, it is reasonable to anticipate that the CRAs will not only understand and be able to use concepts (as illustrated in the example of a concept map Figure 12), but be able to develop and expand each topic area into its own concept map, with an ability to self-select and self-direct further in depth learning in conjunction with experts in each field.

The CRA role as a high level community health science teacher, in a CRA network of 4 individuals is the key linchpin to the overall program. Each CRA manages activities at approximately 20 HSTA clubs and is in daily and weekly contact with the individual HSTA club teachers.

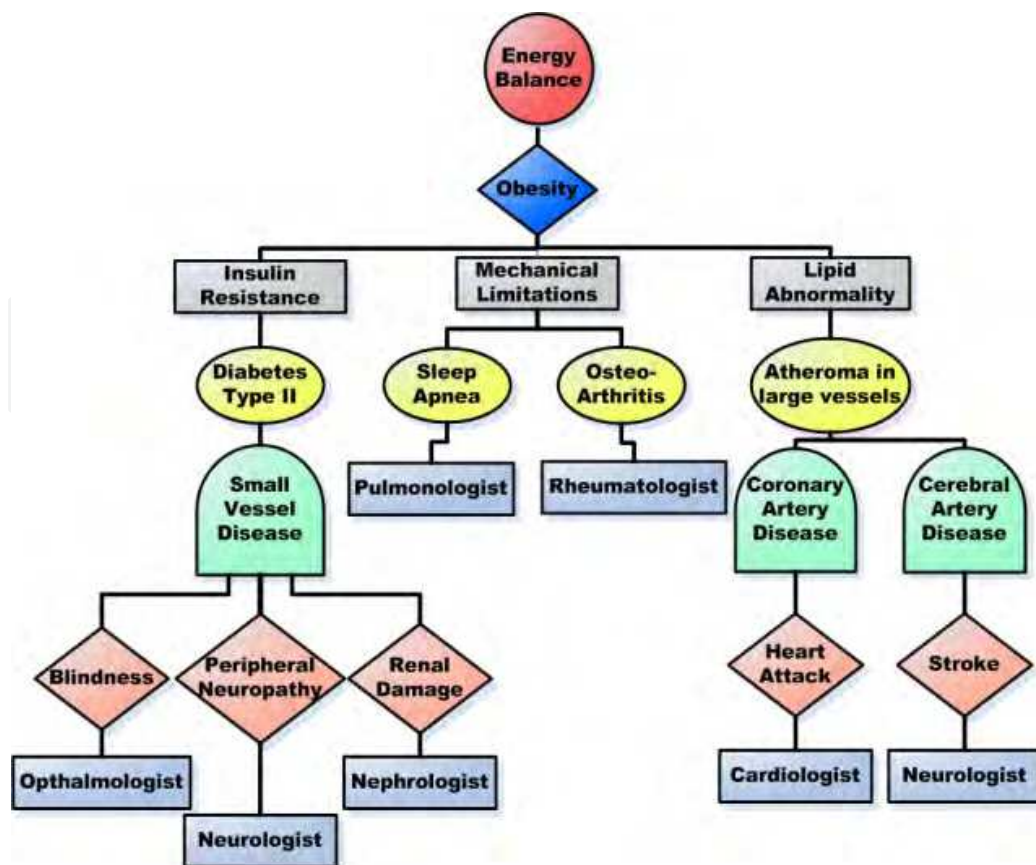


Fig. 12. An example of a concept map that links large and small blood vessel disease and mechanical complications of obesity to the broad range of clinical expertise that can be involved in patient care.

These teachers, once educated in health, use club activities to excite students with science, in health care, and become role models for striving to meld culture and science. It is with these students that the real family learning starts. To be a teacher is a powerful incentive to learn concepts to be shared amongst the adolescents. It will be the ability of HSTA mentors and mentees to provide an informal, unstructured discovery and learning process to families. This is where the success or failure of this strategy will take place.

Concept mapping is a tool for HSTA teachers to use in local club projects design. (Edwards & Fraser, 1983)

Collectively we use concept mapping for:

- Learning how to learn as a life skill
- Quality control of projects
- Extending range of concepts developed

We consider these tools add value to the CAIRN program.

Let us suppose that a HSTA club has decided on a club project that proposes a specific question, from this question frames a hypothesis: Recent examples illustrate the range a variety of topics.

- The frequency of diabetes, type II is more common in African American families than Caucasian families when matched for BMI.
- HSTA students can teach their parents to interpret grocery product labels to improve food selection choices for eating at home.

- A HSTA club can design and implement a nature walk that has callisthenic exercise stops in their district to provide a venue for exercise.
- A HSTA club can interact with clubs within their region and present a newssheet for local distribution in the community to promote HSTA activities.
- A HSTA club can interact with the high school dietary program to enhance selection of food options in its cafeteria.
- HSTA club members can collect saliva samples for genetic studies in family homes that are of analyzable quality, de-identified using bar coding, and arrange the transportation to a genetic laboratory.

To answer any of these topics, the student investigators and teachers need to understand and relate a number of concepts (formulate ideas). This includes general knowledge domains such as ethics, informed consent, CBPR research. It also includes health domain specific topics such as energy balance, dietary food constituents, principles of aerobic and anaerobic exercise, obesity, diabetes, dyslipidemias, and cardiovascular disease. Despite the diversity of projects many of these concepts are common to each hypothesis. In addition, further concepts can be selectively relevant to individual hypothesis, such as migration out of Africa for the ethnic question, dietary equivalents, quantitation of energy expenditure for different exercises, editing and marketing, negotiating skills and genetics for the subsequent hypotheses respectively. Thus, the initial core series of concepts rapidly becomes expanded with the diversity of club projects.

Each concept is developed as a written statement using a Wikipedia™ format, and each written statement can be overwritten or customized for project use, with the CRAs providing editorial control. The organization of concepts within a concept map can be modified as project design evolves; the outcome of the project becomes a new concept for each project conclusion. In this way we are teaching the clubs how to guide their own track of learning for each and every project. The concept map created at a local level, for one project, can be extended to address the additional self-selected topics within a common framework.

Concept mapping can also be seen as a first step in ontology-building, and used flexibly to represent a formal argument. Ontology is a description (like a formal specification of a program) of the concepts and relationships that can exist for an agent or a community of agents. This definition is consistent with the usage of ontology as set of concept definitions. Ontology allows converting the concepts (once mapped) into meaningful quantitative descriptors of that knowledge to describe the social network topology. Each concept in turn becomes a vertex of a network and the position of each vertex defines the edges of juxtaposition of concepts. Thus, cumulative concepts become a HSTA-pedia for the students to develop and write and for CAIRN to curate. When a HSTA-pedia concept has been developed by one group and is being used by another, it becomes open to be updated and made relevant to both topics. In this way concept mapping becomes a cross disciplinary tool to cover our overall initiative and help with integration of ideas.

Each concept is also a starting point for a more in depth organization of ideas for a concept map that can drill down and expand on the primary idea. The curation is important in creating an appropriate hierarchy and to maintain quality control for the CRA so they can follow activity. Quality of study design also offers a metric for project concept evaluation. A further advantage of this approach is that the CRA has an opportunity to encourage the project team to innovate and explore further concepts relevant to the project and identify key concepts have been overlooked.

9.3 CAIRN Communication Network

The information technology (IT) network has been critical to the success of our pilot studies. It also helps to integrate of geographically disparate groups. The IT resource, initially built to support Type I clinical translational research (CTR) at the University of Pittsburgh, (Branch et al., 2009) has proved flexible and scalable for CBPR using a three hub integrated system.

9.3.1 The Hub

The hub provides a flexible, efficient, centralized management system to support team assembly; whereby, individuals with different skill sets have complementary roles to come together to plan and organize the project, from concept to implementation. This is particularly challenging in a dispersed community: academia interaction extends to CRAs as they travel to HSTA clubs and to HSTA family homes. (Figure 13)

CAIRN Communication System

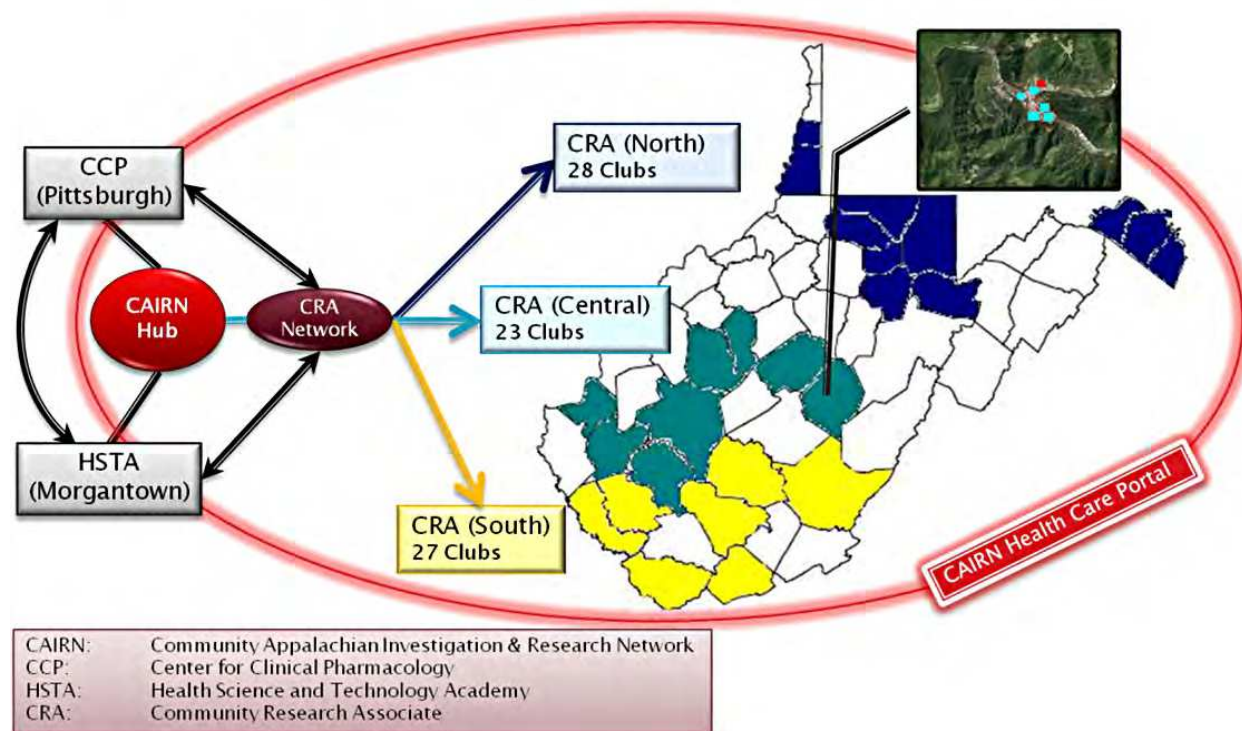


Fig. 13. A schematic illustration of the CAIRN Family Network that helps coordinate activities.

Tools that are to help this process are: distance person to person visualization by video conferencing; audio communication by teleconferencing; computer desktop sharing; scheduling; and tracking. In addition it provides data organization, storage and management. Tools include: central easy access; user friendly data input; capability of handling multiple formats; version control; relational data-based organization; quality assurance; data extraction; tracking of users; security and back-up.

9.3.2 Family health portal

This is a newly created internet portal across the hub for HSTA family members to network their health maintenance and disease prevention strategies through access connected to a private HSTA space (Figure 15). The portal is hosted by the University of Pittsburgh via a link to a private password protected URL. Students and families involved in this study use their computers (either laptop or desktop) to connect to the portal. Computers at homes or schools thus provide research related information to the hub. The HSTA Family Health Portal is designed to be a private single point destination for HSTA students and their families who are involved in the HSTA studies. Advice and personalized consumer health information (educational materials) for HSTA students, their clubs, and their families can be delivered via this portal. Among the consumer health information provided through the portal is information pulled together by students and curated by CAIRN, which relates to healthy lifestyle and diabetes and cardiovascular disease prevention and management. The portal provides facilities for students and families to enter their physical activities and nutrition intake, as well as baseline health records, such as height and weight that have been collected in the preliminary study. It provides an interface between the portal with self-monitoring devices such as pedometer and exercise game consoles such as Wii™ and exercise monitoring arm bands. Automatic capture would allow participants to record their diet history and physical activities with minimal effort. The users are able to track the progress of their diet and exercises, compare them with their own targets or with those of other club members and provide individual risk assessment (for diabetes, etc) to portal users based on the preliminary study data. The baseline data from the family and club social tree that have been gathered in the preliminary studies and formulated as family graphs, BMI scores and the family diabetes risk potential, is used to generate feedback to the families and clubs so that they can visualize their risks and communicate the risks with their family members.

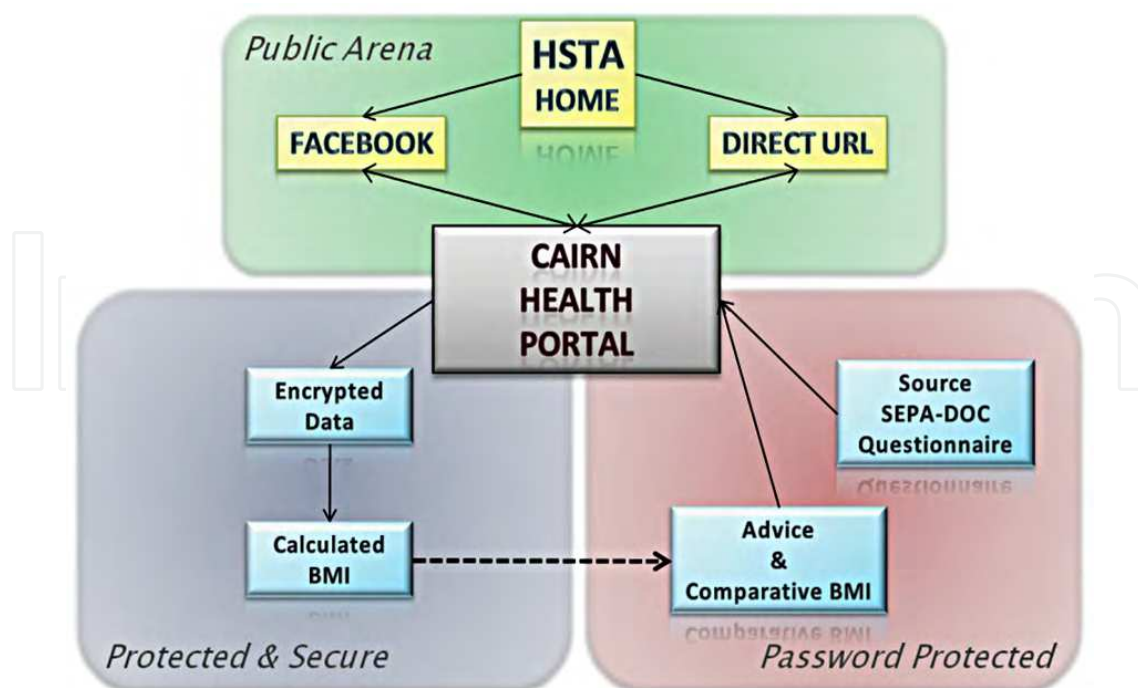


Fig. 15. A schematic representation of the data hub for the HSTA Family Network information technology system linked to the community.

The portal also allows students and families to connect to club mentors and to each other within each group to share tips on health, exercise, and nutrition and keep abreast of progress within their own groups.

9.3.3 Low risk web based surveys

Our initial experience in conducting research surveys in dispersed communities was a cumbersome paper trail of signed informed consent and completed paper-based questionnaires. For surveys and questionnaires that are self-reported and where information content is considered by an Institutional Regulatory Board as low risk, research regulations permit exempt consent. Full consent/assent is provided by a participant using a check box in an electronic form. This is considered to provide a valid full consent without the need for a written signature. The challenge in family strategies, such as we use, is the hurdle of how to differentiate consent, required by adults for themselves and their children, and assent for their children which can only be provided after parental consent. Using well designed software, we have successfully negotiated these hurdles and now have web-based questionnaires that both West Virginia University and the University of Pittsburgh IRBs have approved. A further feature added to the questionnaire is to provide instant feedback of the BMI, set in the context of their family, their club, and their region, together with individualized lifestyle choice advice given with a touch of humor. This new approach is having a dramatic impact on enhancing the study participation of family members from their homes. Using this strategy, we have now offered a 50 question survey designed to enquire about weight, obesity and its complications, attitudes to lifestyle behaviors in families to other research groups interested in using a similar strategy to acquire baseline information in their community before and if needed after launching an intervention.

9.3.4 Collection of Bio-samples

We consider that the high prevalence of obesity in this community reflects a complex interaction between genotype, phenotype and environment. In order to better understand the vulnerability of this population, we have initiated genotyping of community members to relate to phenotypic and environmental descriptors. However, the logistics of conducting CBPR on genetic information in a dispersed rural community, while maintaining quality control and confidentiality are not trivial.

For example, in a pilot study to obtain genotype: phenotype data, our requirements included management of:

1. Full signed written consent forms for obtaining and handling the identified bio-sample for genotyping.
2. Exempt consent for a questionnaire to define phenotype
3. Obtain a quality sample of saliva from study participant in the home.
4. Obtain and route an identified questionnaire for de-identification and data placement in the database.
5. Bar code the bio-sample at the site of collection and collection of multiple samples at one location.
6. Mail trans-state shipment of the bio-sample to the genetic laboratory at the University of Pittsburgh.
7. Laboratory coordination of samples for analysis of de-identified, coded samples.

8. Linkage of laboratory acquired data to the questionnaire via the two coded sources of de-identified information for data analysis.
9. De-identified data analysis by our statistician.
10. Return of data in an integrated de-identified format that is comprehensible to the participants.

In contrast to most research, best practices of CBPR require two way flow of information. This demands the added complexity of having in place a process to pass back down the chain to share with the community, not the raw data, but data that is placed in a lay context to endpoint data providers, with customizing for the individual, the family and the club. The design to respond to these logistical needs was met by Shama Buch PhD (Figure 16).

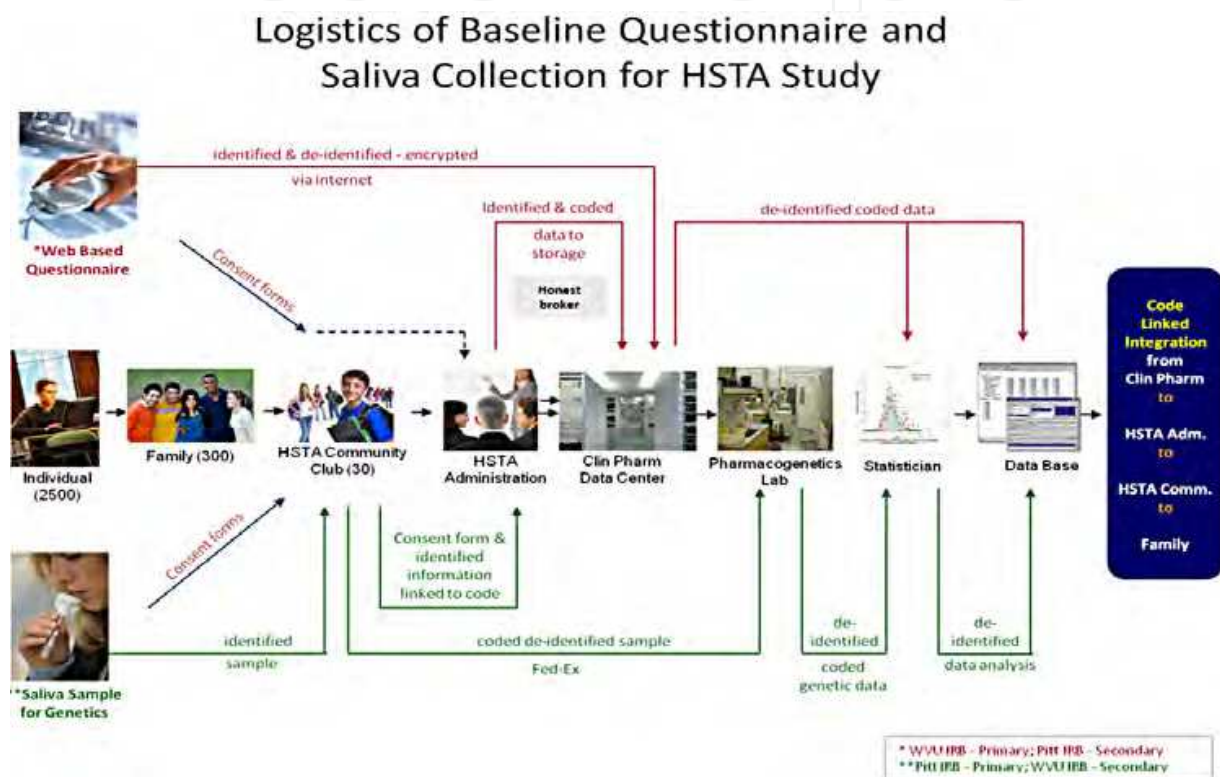


Fig. 16. Logistical schematic of conducting CBPR with genetic information.

Shama Buch, PhD: I am a geneticist trained at the Tata Memorial Center in Mumbai, India. My long term interest has been in investigating the contribution of genetic variance on cancer risk and I am currently working on genetic risk factors for lung cancer, head and neck cancer and melanoma in the US. My first exposure to CBPR was in epidemiological studies of workers in the tobacco processing industry in India who were at a higher risk for the development of head and neck cancer. The exposure of these workers to tobacco carcinogens was particularly high both due to occupational exposure as well as their habitual intake of tobacco and betel nut. Most of these individuals were from an underprivileged socio-economic background. The most challenging aspect of this study much to my surprise was not the complexity of the genetic studies but the ability to obtain individual written informed consents. There was a profound distrust of the written word among these individuals, most of whom were illiterate. I found that despite their eagerness to participate in the study, they refused to sign individual consent forms as they were afraid they might be signing away property and possessions. In order to obtain biological samples for a genetic risk assessment study, I had to have one consent form for a group of at least 20 individuals or sometimes an entire village! The head of the

village or community would read out the informed consent and be the first person to sign the document. After this reassurance, each subject who agreed to participate would sign the same piece of paper and in this way share the risk. (Buch et al.,2002) I was, therefore, intrigued by the challenge of obtaining written consent in a comparably poor population in rural Appalachia. In addition, as a geneticist, I am acutely aware of the privacy issues relating to genetic studies and the need for quality control if samples are to be collected in the home. The practical design of a process that is feasible enough to be conducted in the home by adolescents was also an intellectual challenge that I had great pleasure in resolving.

We now have trained HSTA students as investigators to collect and handle saliva samples in their homes. The logistical operation has been field tested and shown to be efficient in a field trip led by Tomoko Nukui PhD.

Tomoko Nukui, PhD: I am involved in research which focuses on the evaluation of genetic factors associated with multiple different common human diseases including cancer at the Center for Clinical Pharmacology, University of Pittsburgh. My initial involvement with this study was to introduce to the HSTA students and teachers the process for onsite saliva collection to help them to develop the next steps for home saliva collection/shipping for genetic analysis. Since the students and teachers live in regions that have a significantly higher incidence of obesity and type 2 diabetes and have a disadvantage in access to comprehensive health care, their interest and motivations in preventing the metabolic syndrome is high. The identification of individuals falling in to a genetically high risk group will dramatically improve the power of both disease prevention strategies and treatment efficacy. I was, therefore, delighted to be invited to help implement the plan for collecting saliva samples from this high risk population and to be able to evaluate unique patterns of genetic makeup which increase the risk of these metabolic syndromes in addition to multiple environmental and lifestyle factors (Figure 16). This study also has given me an opportunity to introduce both the concepts of personalized medicine and prevention, an important future direction in health care, as well as cutting edge technologies in biomedical research to these young and talented students who will be leaders in health care and/or science in their communities.

There are number of key factors necessary for the collection of biological samples from a large study population including non-invasive sample collection, ease of sample processing and transportation and low cost. The overall objective is to be able to generate high quality and quantity of genomic DNA samples for genotyping assays to be performed at some time in the future. There were three major goals of the feasibility field trip: 1. Determine the best way to collect biological samples in rural Appalachia and to be able to transport them to the Center for Clinical Pharmacology lab at the University of Pittsburgh, 2. Introduce and familiarize HSTA students to the process of collecting saliva samples and 3. to determine the approximate quantity and quality yields of DNA from saliva. We successfully collected and transported the saliva samples. The average yield was more than 200µg of genomic DNA with A260/A280 ratio of 1.88, which is a sufficient amount of DNA for the downstream application, the microarray based assays.

We plan to use the Cardio-MetaboChip Consortium designed “MetaboChip” to be analysed with the Illumina BeadStation platform (Illumina Inc., San Diego, CA). This 217,697 SNP array was designed by the Cardio-MetaboChip Consortium which includes representatives of several GWAS meta-analysis Consortia including CARDIoGRAM (coronary artery disease), DIAGRAM (type 2 diabetes), GIANT (height/weight), MAGIC (glycemic traits), Lipids (lipids), ICBP-GWAS (blood pressure) and QT-IGC (QT interval). This MetaboChip includes the SNPs with high significant association ($p < 1 \times 10^{-3}$) to metabolic and atherosclerotic-cardiovascular endpoints in these GWAS analyses. It also includes SNPs for

a detailed fine mapping of loci validated at genome-wide significance from these meta-analysis; all SNPs associated at genome-wide significance with any human trait; "wildcards" selected by each meta-analysis Consortium for Consortium-specific purposes; and other useful content, including SNPs that tag common copy number polymorphisms, HLA region SNPs, SNPs marking the X and Y chromosomes and mtDNA, and for sample fingerprinting.

10. Future directions

As stated at the outset, this is a presentation of a conceptual approach which is being applied in practice. We believe that our work in progress can lead to a transformational change. Even though obesity is a highly complex problem, it is of sufficient relevance to this community to merit a determined response by the community itself, supported by a sophisticated, well organized infrastructure with academic guidance. The value of the program is being continuously evaluated from our existing measured baseline. The range of relevant outcome measures includes tracking:

- The pipeline of students going to college and their subsequent careers.
- The weight of the adolescents over time.
- The weight of their family members over time.
- Diabetes and Cardiovascular Disease prevention.
- The use of health care resources by family members
- Compliance in disease management such as frequency of health care visits and health care interventions used.

Additional outcomes of value also include the intangible variables of changes in self-esteem, family cohesiveness and overall self-control that comes with health learning and acquisition of an adequate knowledge base to inform behavior and create a true change in culture.

There are two major challenges to this approach. The first challenge to the program will be sustainability. In the long term, this will have to be addressed in economic as well as social and health domains. From the outset, we plan to prospectively evaluate the underlying thesis that from a societal perspective a shift of resources from both health care and education targeted dollars to the community health learning initiatives in families is cost efficient. If we can provide proof of principle of this strategy, maybe we can persuade legislatures of its merit to create a transformational change for a new line item budget mechanism. This would reinforce and maintain the transformation.

The second challenge will be to maintain its vitality; for the kids to enjoy taking a responsible role in the health of their community, the families to listen to their kids and for each generation to take ownership of their program. This is where the cultural sensitivity and addressing tangible problems they can see and the role of continuing self-appraisal through investigation and research are such important components of the CAIRN strategy.

11. Acknowledgements

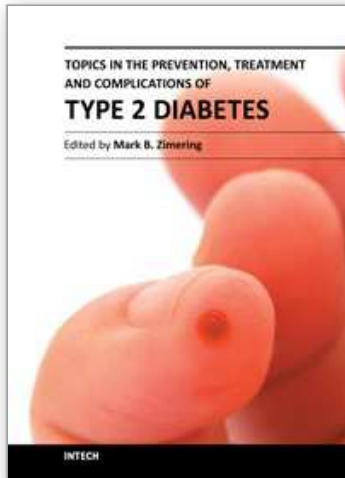
We would like to thank the enthusiastic HSTA students and their families without whom none of this would have been possible. We would like to thank the HSTA teachers for their dedication and long hours they have volunteered to enhance the lives of the children they influence. Also we wish to thank the National Center for Research Resources of the National Institutes of Health for its support through a Science Education and Partnership Award (SEPA) to HSTA, 99001382-005, two supplemental grants to the SEPA award, one to build

the Web Portal 3 R25 RR023274-04SI and the other for the web-based, SEPA-DOC questionnaire 3 R25 RR023274-05SI and an RC4, Community Based Participatory Research Infra-structure grant to CAIRN 1RC4RR031433-01. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NCCR or the National Institute of Health. Additional support for the program has been received from the Howard Hughes Foundation and the Claude Worthington Benedum Foundations. We also acknowledge the encouragement and guidance offered by the HSTA Joint Governing Board.

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Topics in the Prevention, Treatment and Complications of Type 2 Diabetes

Edited by Prof. Mark Zimering

ISBN 978-953-307-590-7

Hard cover, 340 pages

Publisher InTech

Published online 04, November, 2011

Published in print edition November, 2011

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Robert A. Branch, Ann Chester, Cathy Morton-McSwain, Soleh Udin Al Ayubi, Kavitha Bhat Schelbert, Philip Brimson, Shama Buch, Yvonne Cannon, Steve Groark, Sara Hanks, Tomoko Nukui, Petr Pancoska, Bambang Parmanto, Stephanie Paulsen and Elaine Wahl (2011). A Novel Approach to Adolescent Obesity in Rural Appalachia of West Virginia: Educating Adolescents as Family Health Coaches and Research Investigators, Topics in the Prevention, Treatment and Complications of Type 2 Diabetes, Prof. Mark Zimering (Ed.), ISBN: 978-953-307-590-7, InTech, Available from: <http://www.intechopen.com/books/topics-in-the-prevention-treatment-and-complications-of-type-2-diabetes/a-novel-approach-to-adolescent-obesity-in-rural-appalachia-of-west-virginia-educating-adolescents-as>

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