

Internet Approaches for eHealth in Low Literacy Populations

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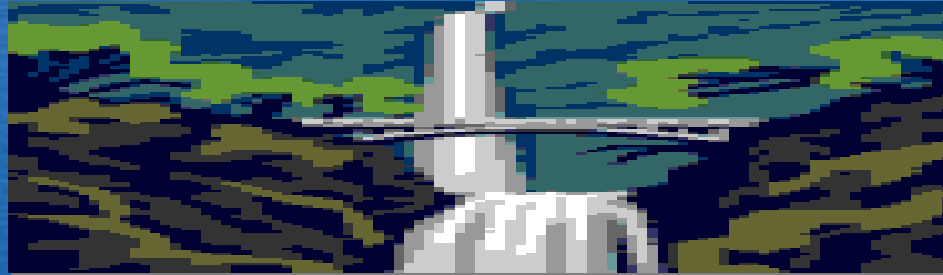


Presentation Overview

- § The Harlem Health Promotion “Digital Partnership” Project
- § What we learned about our community
- § The basis for the decisions we made
- § Current status and lessons learned to date

CDC-Prevention Research Centers

- § Established by Congress in 1984. 33 Centers located across the country, 3 in NYS
- § Serve as a bridge between science and practice, and between academia and vulnerable communities
- § PRCs work with communities to identify areas of concern and develop practical strategies to address these concerns





Background

§ HHPC- Working with community partners for 10+ years

§ Beginning 2004 Digital Partners in Health Project

Develop a health portal to provide consumers with low literacy, culturally – relevant health information and decision support



Background (con't)

- § Although national and regional data exist that describes technology use for people of color, specific community level data is often unavailable.
- § Additionally, little is known about the extent to which people of color have access to, or interest in, using the Internet for health-related activities.



Phone Survey

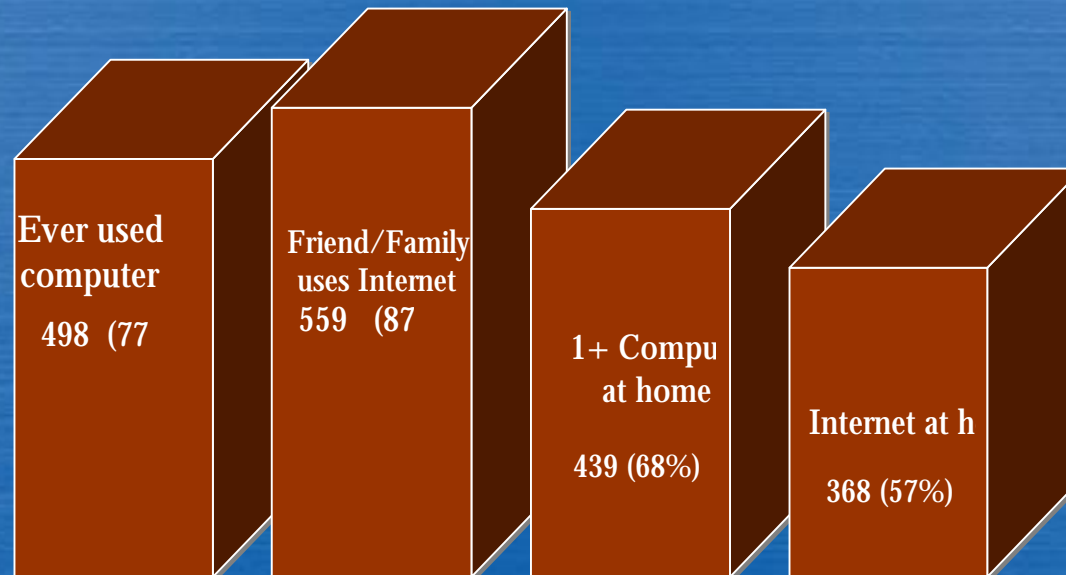
- § A random digit dial landline phone survey; English and Spanish speaking community members age 18 or older
- § N=646

Multiple topics were covered, including:

- § **Demographics**
- § **General Health**
- § **Health Information Seeking Behaviors:** Frequency, location and impact (i.e. changes in behavior) of health info seeking; ease of locating info; clarity and understanding of information; confidence in ability to find info; trust in various sources; Trust of and attitudes toward Internet as source of health information
- § **Access to Technology:** Forms of technology used; Friend and family use of tech.; Computers and Internet availability in home; Children's use of Internet; Availability of Internet in neighborhood; Ease of use; Length, frequency and location of Internet use; Frustrations with Internet use; Perceived access barriers; Future intentions for computer use, Internet and e-mail.



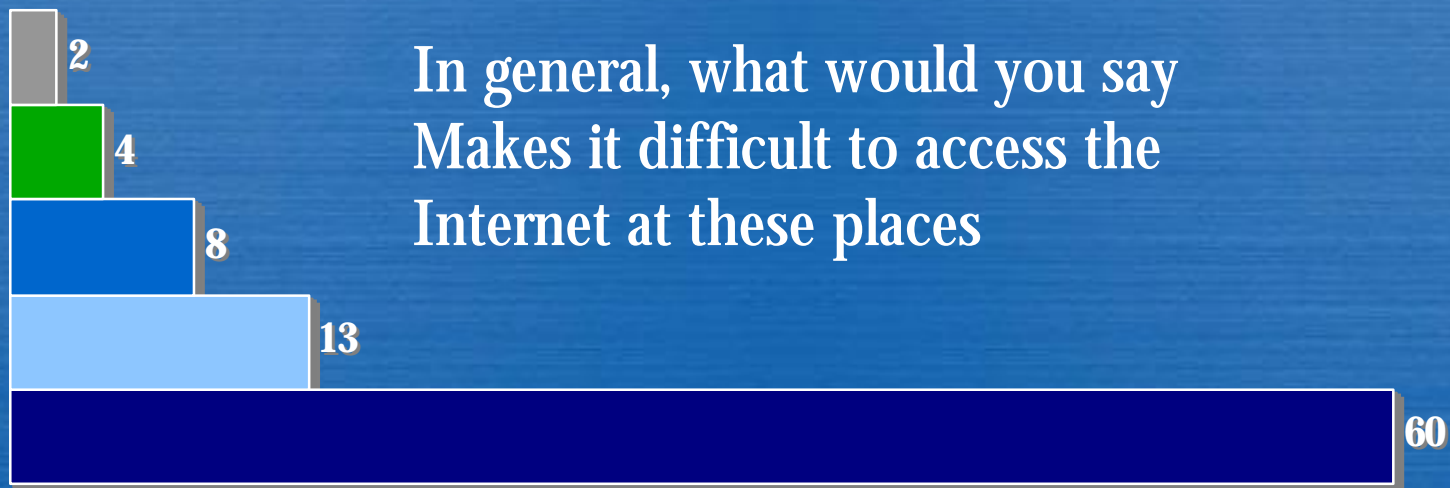
Technology Use in Harlem





Technology Use in Harlem

76% know a place where the Internet is publicly available



- Overcrowding
- Hours of Operation
- Location or Transportation
- Equipment Problems
- Cost



Demographics by Current Internet Use

	No. (%)	No. (%)	P Value
GENDER			
Male	107 (51.4)	101 (48.6)	0.97
Female	226 (51.6)	212 (48.4)	
AGE			
18-24	40 (69.0)	18 (31.0)	<0.0001
25-34	94 (66.2)	48 (33.8)	
35-44	104 (61.9)	64 (38.1)	
45-54	48 (47.1)	54 (52.9)	
55-64	30 (41.7)	42 (58.3)	
65 or above	14 (14.0)	86 (86.0)	
Language(s) spoken			
English or English + Other	315 (57.0)	238 (43.0)	<0.0001
Spanish or Other Only	16 (17.6)	75 (82.4)	
Race/Ethnicity			
African American / Black	186 (53.0)	165 (47.0)	0.0035
Hispanic or Latino	81 (40.1)	121 (59.9)	P-value comparing just Black with Hispanic. <0.0001
Caucasian or White	50 (74.6)	17 (25.4)	



Demographics by Current Internet Use

Educational Attainment			
Less than high school	15 (13.0)	100 (87.0)	<0.0001
High school diploma or GED	151 (47.0)	170 (53.0)	
Some college or more	162 (79.4)	42 (20.6)	
Employment status			
Employed	241(66.8)	120 (33.2)	<0.0001
Unemployed	35 (29.7)	83 (70.3)	
Homemaker/Student/Retired	52 (32.5)	108 (67.5)	
Yearly household income level			
Less than \$15K	30 (17.5)	141 (82.5)	<0.0001
\$15K to \$34,999K	86 (48.6)	91 (51.4)	
≥ \$35,000K	181 (80.4)	44 (19.6)	
Number of people living in home			
	Mean (SD)	Mean (SD)	0.1027
	2.85 (1.58)	2.64 (1.69)	
Health insurance coverage			
	299 (52.0)	276 (48.0)	0.26



Demographics by Current Internet Use

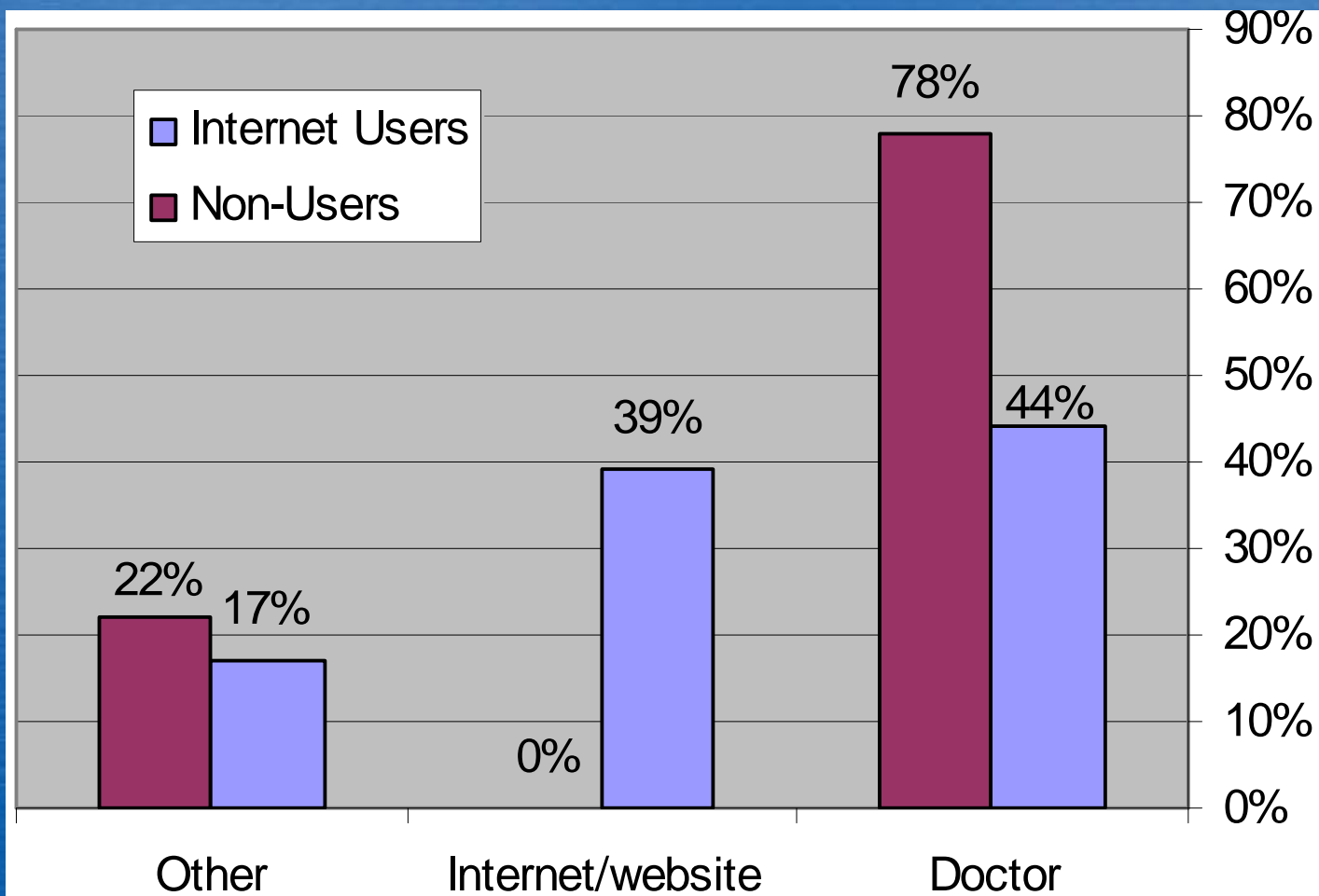
Self-rating of health (Scale of 1: Excellent to 5: Poor)	Mean (SD) 2.27 (0.95)	Mean (SD) 3.19 (1.15)	<0.0001
Self-Reported Health Status			
Excellent	80 (72.1)	31 (27.9)	
Very Good	117 (70.5)	49 (29.5)	<0.0001
Good	106 (51.5)	100 (48.5)	
Fair or Poor	30 (18.5)	132 (81.5)	



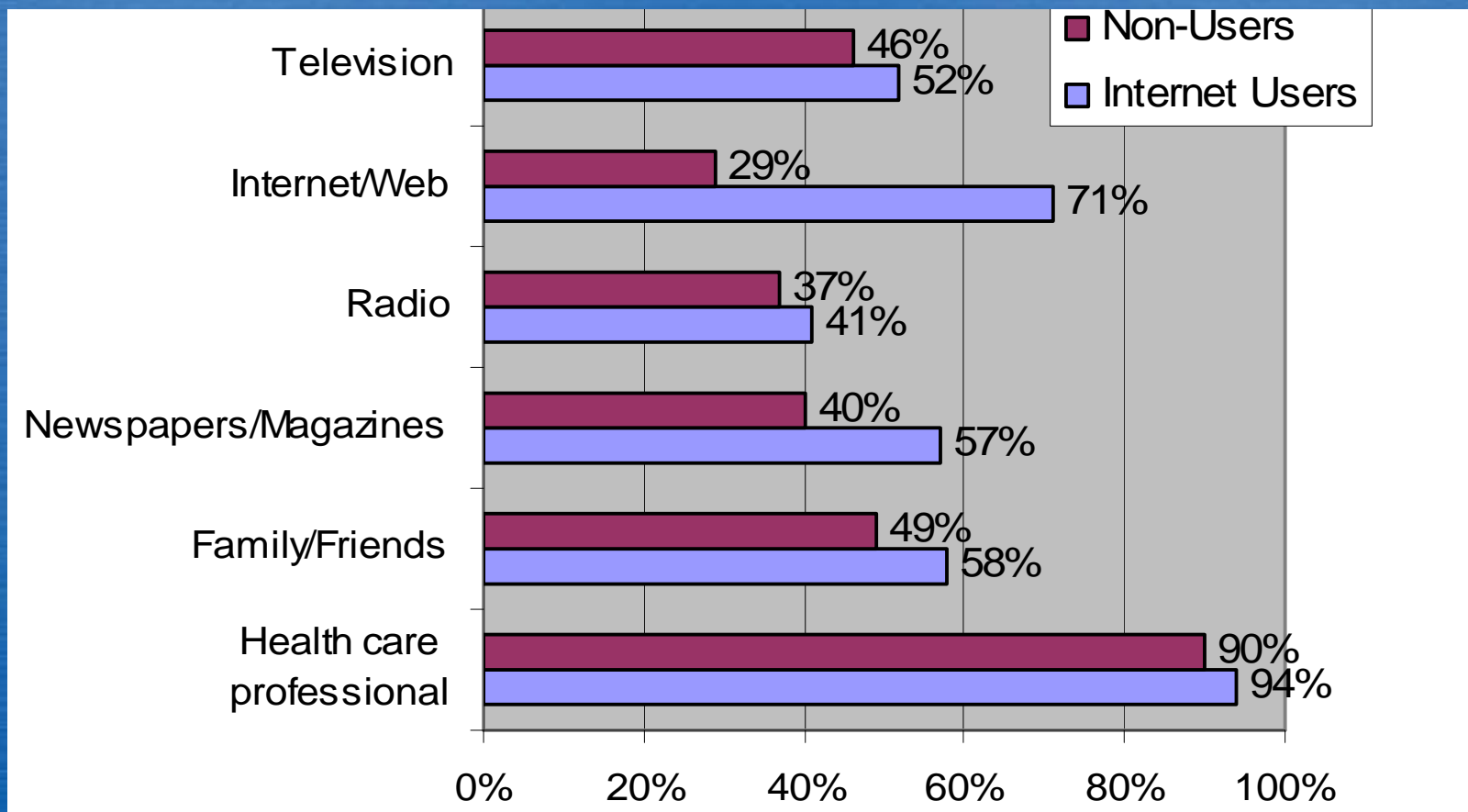
Health-information seeking by current internet use

	Internet Users	Non Users	P Value
“I have difficulty understanding a lot of the health information that I read.”	70 (21.2)	128 (42.0)	<0.0001
“When I read or hear something concerning my health care, I bring it up with my doctor.”	274 (83.3)	272 (87.7)	0.1101
“It is hard to find good answers to my health questions and concerns.”	90 (27.5)	142 (47.3)	<0.0001
“Very” or “Somewhat” confident in ability to get health advice or info if needed confident	290 (88.2)	247 (80.7)	0.0096
<i>OR</i> Confidence in ability to get health advice or info if needed confident	Mean (SD)	Mean (SD)	0.0014
<i>Scale of 1) Very confident 2) Somewhat confident 3) Slightly confident and 4) Not confident at all</i>	1.53 (0.77)	1.75 (0.92)	

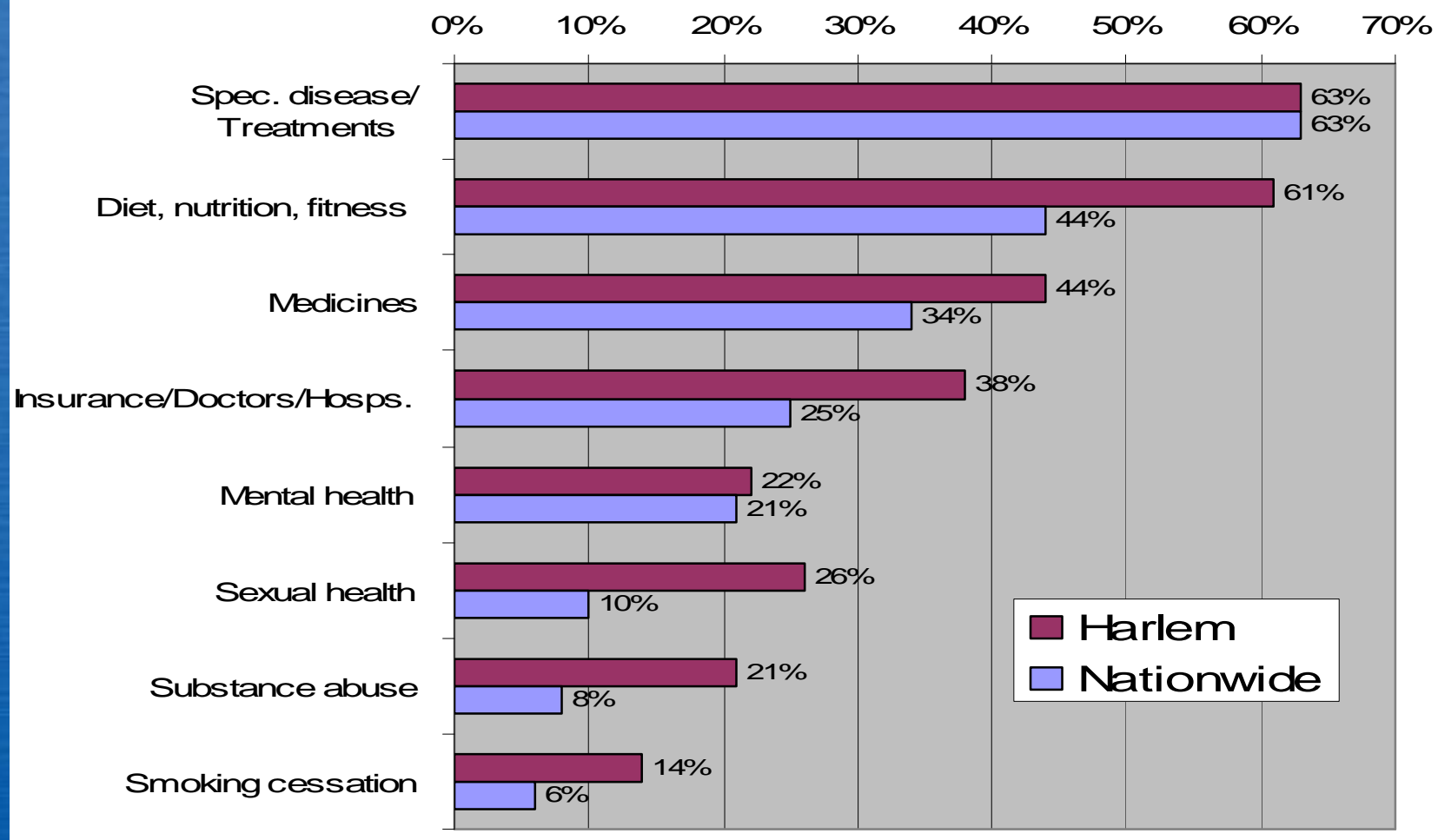
“The last time you needed information about a health issue, where did you go?”



“Generally speaking, how much would you trust health-related information from...?”



Topic of health information sought....





Barriers (non-users)

Reasons for non-use:	Major	Minor
Worried about porn, fraud	45%	15
Don't want or need it	33	17
Too expensive	33	14
No time	25	20
Too complicated & hard to understand	27	17



Attitudes (Non users)

The internet...	Agree	Disagree
Would help find out things easily	82%	10
Helps people keep in touch	79	11
Mostly entertainment	55	34
I'm missing out by not using it	54	39
Is a dangerous thing	51	41
Too expensive	50	31
Confusing/hard to use	38	29



Focus Groups

- § English- and Spanish-speaking Harlem residents.
- § Each participant self-selected into a “web user” or “non-web user” category.
- § Three focus groups were held per category with 6-8 participants in each group.



Focus Group Results

- § Web users and non-users both considered the Internet to be a legitimate source of health information.
- § Attitude prevailed even among those for whom the Internet was not the preferred source of information.
- § Internet users were likely to use the internet as a source of health information because of its convenience.
- § Although, respondents reported enjoying the freedom that the Internet allowed, many expressed difficulty understanding information found online and expressed a need for assistance in interpreting the health information.



Suspicion

“I think one of the keys is that there is money involved. It is all about greed”.



Suspicion

”those of us who are African-Americans are still grappling with the Tuskegee studies and the aftermath. So there are a lot of historical monsters with which we identify, when it comes to medical community treatment and medical residents here to, specifically to us.”



Suspicion

“Then that leads me to conclude that there is just a lot of general information that we are not getting. There seems to be a mainstream level of information which gives you stuff to lead you into drugs different things like that... **there is like a whole stream of other viable alternatives that could work but you don't even hear about because it will blow all the mainstream drugs out...**”.



Suspicion

§ “The pharmaceutical companies are in bed with the FDA.”



Folk/alternative medicine

- § Mentioned and trusted by many
- § Mother stated as first source; then folk medicine ('grandmother's cures'), healthcare providers, internet, in that order
- § Everyone aware of importance of lifestyle, diet, stress but frustrated in attempts to improve these



Web portal requirements

- § Some themes centered around disease – specific topics
- § Many themes centered around **distrust of medicine and medical institutions**
- § Conclusion: web portal platform would have to do more than deliver health information, even if it were at a lower health literacy level
- § Web platform would have to encourage a **level of trust and cultural relevance** as its foundation



The HHPC Web Portal

- § Goal is to facilitate an “architecture of participation” (Web 2.0, health 2.0, medicine 2.0)
 - ÿ Emphasize the pre-eminence of content creation over content consumerism
 - ÿ Information is liberated from the control of experts (often the source of mistrust) allowing community members to create, assemble, organize, locate and share content to meet their own needs or the needs of their community



Web 2.0 applications (medicine 2.0; health 2.0)

§ Services and tools to enable and facilitate social networking, participation, collaboration, and openness within and between user groups





Some of the technologies which constitute the Web 2.0

- ÿ Blogs- web pages which contain a service of frequently generated entries by an individual or a group.
 - § May contain, text, links, photos, audio files
- ÿ RSS Feeds- Syndication of web site content
 - § Contains web content or summaries of content together with links to the full versions of the content, and other meta data
- ÿ Wikis- web site that allows users to add, remove, otherwise edit and change most content very quickly.
 - § Example of self organizing structures where the principle of evolution leads, in the course of time, to correct and complete content.

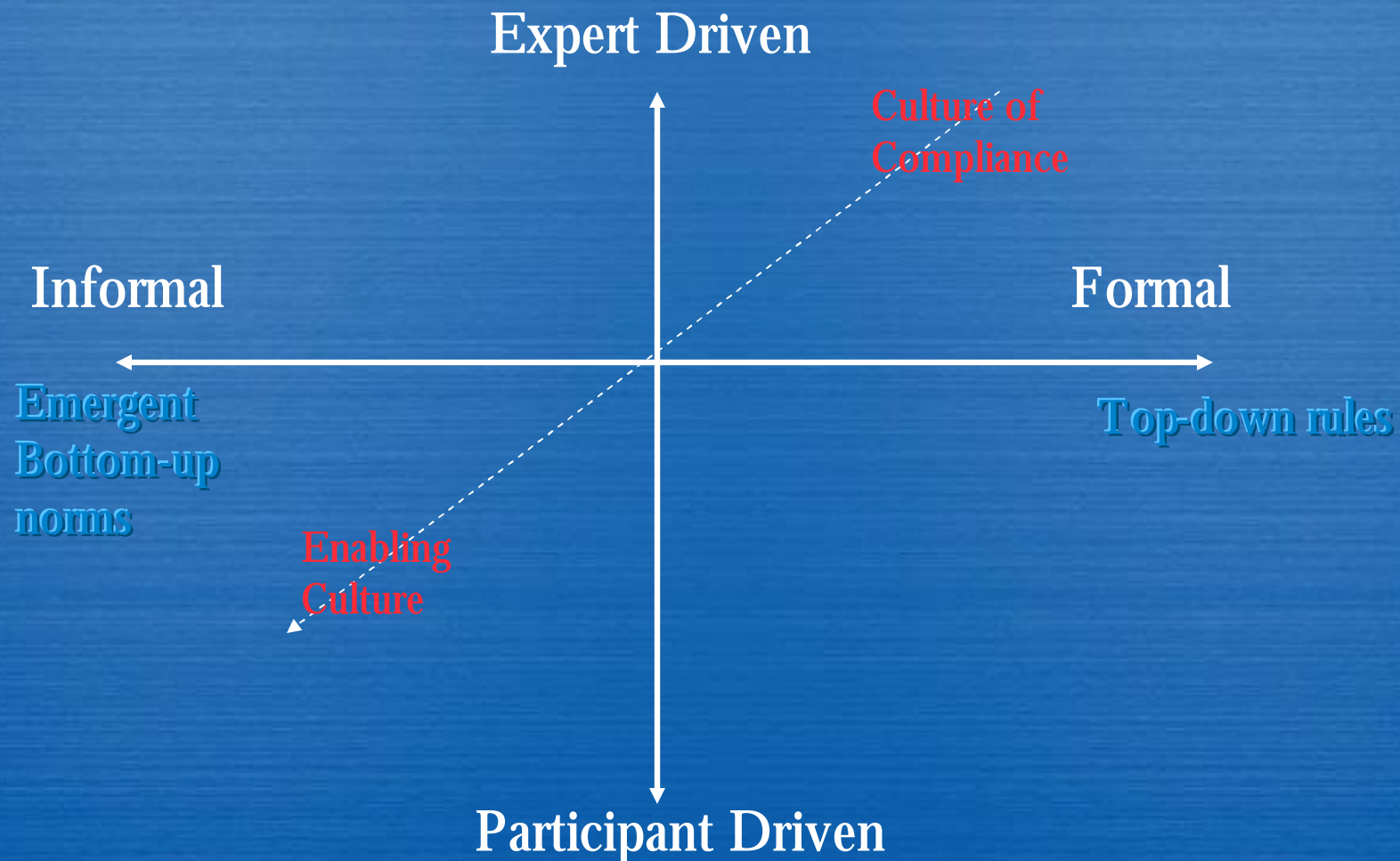


Overarching Principles of Web 2.0

Principle	Web 2.0	Traditional (Web 1.0)
Power	Decentralized (autonomy; information self sufficiency)	Centralized (experts); dependence
Priorities	Guided by community perspectives/norms, bottom up	Guided by technology developers
Filtering	Downstream (e.g, user ranking)	Upstream
Nature of information consumption	Co producers	Passive receivers- consumption
Learning	Collective- capacity building	Exclusive-
Content Credibility	Based on understandable language, experiential knowledge	Based on science
Culture	Enabling	Compliance



Priorities emerge in an enabling culture



Boosting Trust Through Web 2.0 Technology

§ Information is perceived as direct “unmediated”

§ more credible than mediated information because mediation through a gatekeeper brings opportunity to impute motives and intentions of the communicator *

§ Baldry et al. Health Professionals actively encourage patients to view their own health records can help to restore patient's trust in the medical system**

§ Users are not merely recipients of technology, but participate actively and equally in its ongoing development

•Gunther AC. et al. Attitude Extremity and trust in Media, Journalism Quarterly, 1988.

**Baldry M. et al. Giving Patients their won records in general practice: Experience of patients and Staff. British Medic Journal, 1986.

Parallels between Participatory Action Research Methods and Web 2.0



PAR Concepts

- § To produce knowledge and action directly useful to a group of people
- § To empower people at a second and deeper level through the process of constructing and using their own knowledge...

(Reason, 1998, p. 271)

Project Research Aim

- § Explore Web 2.0 technologies as an informatics approach to facilitate the principles and distinguishing characteristics of a PAR in disadvantages populations*

*Kukafka et al, "*Nothing about me without me*": Parallels between Web 2.0 and Participatory Action Research (Submitted)

■ ■ ■ Technical specification based on end user input

- § The website content can be viewed by anyone but users must register to post or comment on the site's content.
- § Registered users can submit their own blog (e.g., “how I quit smoking after ten failed attempts”) or create special interest groups and social networks, each with their own discussion forums.



Technical Specifications (Con't)

- § They can also post events of interest, links to useful health resources, or participate in several special programs, such as the Harlem YMCA sponsored “Fitness Challenge”.
- § Registered users can also rate posts made by other users or flag posts as inappropriate (community policing and appraisal).
- § An overall moderating team consisting of our experts as well as users will provide editorial control to ensure content quality.



Meet Luz

Article posted by Joe in Food 5 days ago



Hi, my name is Luz, and I am your GetHealthyHarlem.org virtual tour guide. You can go to my profile to learn more about me and how I use this website to get healthier. You'll find this is a great place to get connected to other people in Harlem who are interested in health—just like you! And yeah, read my latest blog today.

Community

New Members



Community activity



New group "Group Name" created by Joe User 10 minutes ago

Small group description in a sentence here.

[Read more](#)



Jane User joined the group "Group Name" 5 minutes ago

[Read more](#)



New group "Group Name" Link posted in Fitness 3 hours ago posted by The One

[Read more](#)

General Harlem News

- General News
- Health & Nutrition News
- Exercise News
- Obesity News





Featured Most Recent Most Viewed Recently Popular

Harlem Word: Sample Article Title

Article posted by Joe in Food 5 days ago



Today's article was written by my friend Mary Ellen Ricks, RYT, CMT who is the owner and director of The Awakening Point. The Awakening point is a wellness center located in Hackettstown, NJ. Hi, my name is Luz, and I am your GetHealthyHarlem.org virtual tour guide. You can go to my profile to learn more about me and how I use this website to get healthier.

Read more

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Read more

Events

Happening soon

Party in Harlem with Jay Leno

The party starts at 12PM in Agatha's Club

The Haleem's best days

The party starts at 12PM in Agatha's Club

Next Events Calendar

Past Events

General Harlem News

General News

Sample title or description for the last added feed/article under this category

Health & Nutrition News

Sample title or description for the last added feed/article under this category

Exercise News

Sample title or description for the last added feed/article under this category

Obesity News

Sample title or description for the last added feed/article under this category



Conclusions

- § Platform and tools presented has a clear fit to the goals of HHPC and the population it works with
- § Careful thinking, testing and evaluation research are still needed in order to establish best practice models for leveraging these emerging technologies and to boost our ability to support health improvement in our community

Conclusion



§ "If the living, experiencing being is an intimate participant in the activities of the world to which it belongs, then knowledge is a mode of participation, valuable in the degree in which it is effective. It cannot be the view of an unconcerned spectator." [*Dewey, J. (1916) Democracy and Education, p.338*]





Acknowledgements

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