

Complexities of Community-Based Participatory Research (CBPR)

Earnestine Willis, MD, MPH

Kellner Professor in Pediatrics
Director, Center for the Advancement of Underserved Children
Medical College of Wisconsin & Children's Hospital of Wisconsin

9/23/2016



Disclosures

- Research reported in this presentation was supported by the National Institute on Minority Health and Health Disparities of the National Institutes of Health (NIH) under award number R24MD001812
- Content is solely the responsibility of the authors and does not necessarily represent official views of the NIH
- No Other Financial Disclosures

OBJECTIVES

- Understanding of the principles of community-based participatory research (CBPR) approach to address health disparities.
- Recognition of complexities to effectively engage community sectors.
- Consideration of the benefits of the CBPR approach or similar processes for sustaining population health improvement.





CHIMC CBPR Principles

(Israel et al, 2003)

- Recognizes community as a unit of identity;
- Builds on strengths and resources within the community;
- Facilitates collaborative, equitable involvement of all partners in all phases of the research;
- Integrates knowledge and action for mutual benefit of all partners;

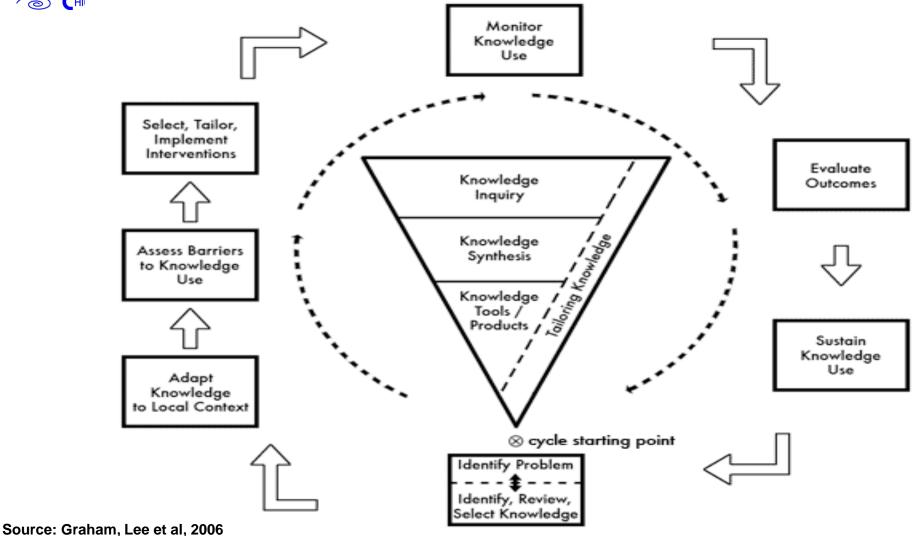
CHIMC CBPR Principles

(Israel et al, 2003)

- Promotes a co-learning and empowering process that attends to social inequalities;
- Involves a cyclical and iterative process;
- Addresses health from both positive and ecological perspectives;
- Disseminates findings and knowledge gained to all partners; and
- Involves a long-term commitment by all partners.



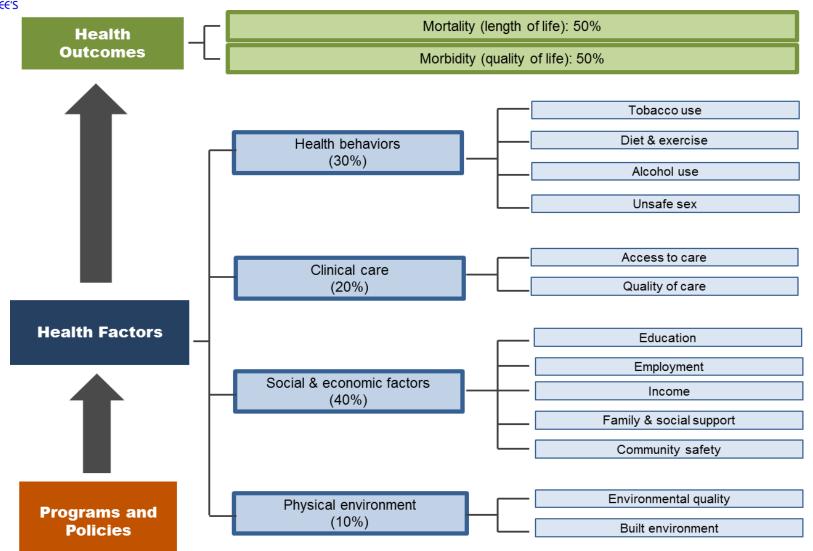
Knowledge to Action Framework





Factors Beyond Clinical Care Impact Health Outcomes

(Source: County Health Rankings 2014)



ACTION CYCLE

Source: County Health Rankings & Roadmaps, 2016

(CBPR: Seeks balance between research and action; and Foster colearning, collaborative and equitable power sharing and capacitybuilding among all partners)





CHIMC: CBPR Case Study Overview

Phase I: Community Assessment, 2005-2008

Planning Phase



Phase II: Interventions, 2008-2013

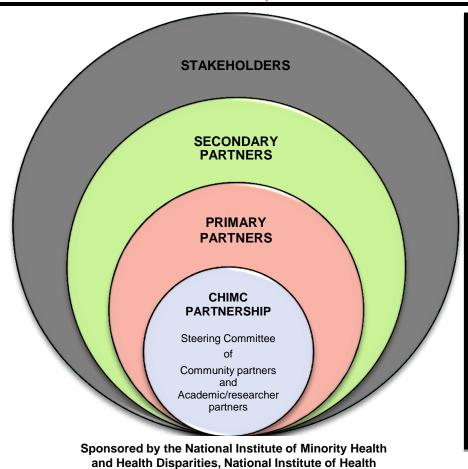
Phase III: **Dissemination Plan,** 2013-2016

- Education
- **Social Marketing Campaign**
- **Planned Behavior Change**
 - Web-based platform for enrollment, intervention, and evaluation
 - **CHIMC Toolkit**
 - e-Learning Café

Community Health Improvement for Milwaukee's Children (CHIMC) Infrastructure, 2005-2016

Primary Partners

- CommunityParents/Caregivers
- Children's Hospital of Wisconsin
- Children's Hospital of Wisconsin-Immunization Committee
- Marquette University
- Medical College of Wisconsin
- Milwaukee County WIC
 - Aurora Health Care
 - Northwest Health Center
 - Wee Care-Capital Dr
 - Wee Care-North Ave
 - Wee Care-Teutonia Ave



Primary Partners

- Milwaukee Health Department
- State of Wisconsin
 Immunization Program
- United Neighborhood Centers of Milwaukee
 - Children's Outing Association (COA)
 - Neighborhood House of Milwaukee
 - Next Door
 - Northcott Neighborhood House
 - Silver Spring
 Neighborhood Center

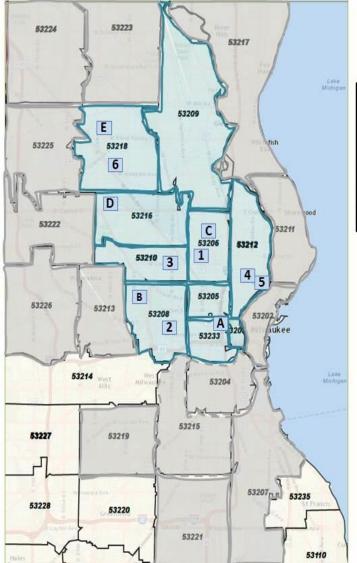
Secondary Partners

Black Health Coalition of Wisconsin; Milwaukee County Department of Human Services; Immunize Milwaukee! Coalition; Hmong American Women's Association; Social Development Commission

Stakeholders and Supporters

Milwaukee Mayor's Office; Milwaukee Common Council; Milwaukee Public Schools; Member of Congress; Member of Wisconsin State Senate





Satellites Locations



UNCOM Family Resource Centers (6)

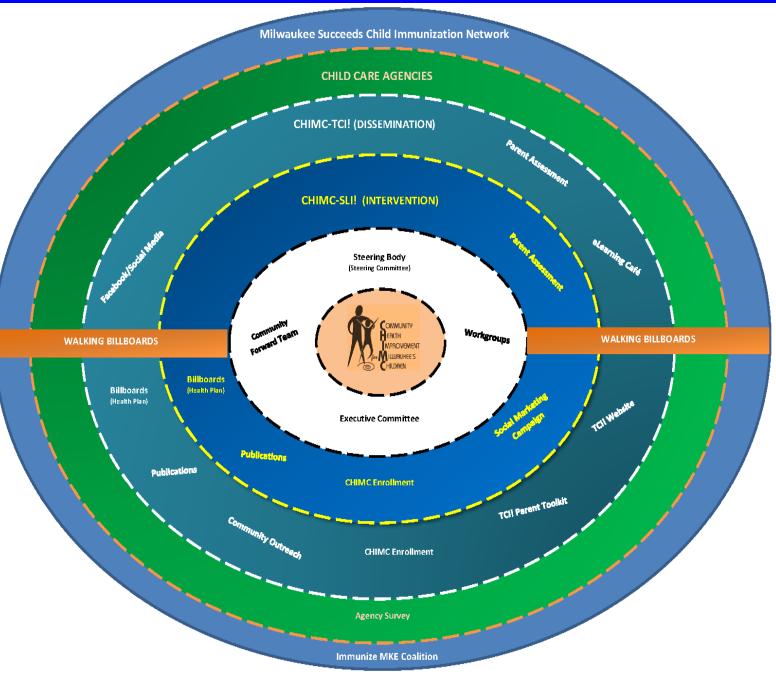
- COA-Goldin Center Youth and Family Centers
- Neighborhood House of Milwaukee (NHH)
- 3. Nextdoor (ND)
- 4. Northcott Neighborhood House (NNH)
- COA-Riverwest Center Youth and Family Centers
- 6. Silver Spring Neighborhood Center (SSNC)

WIC Sites (5)

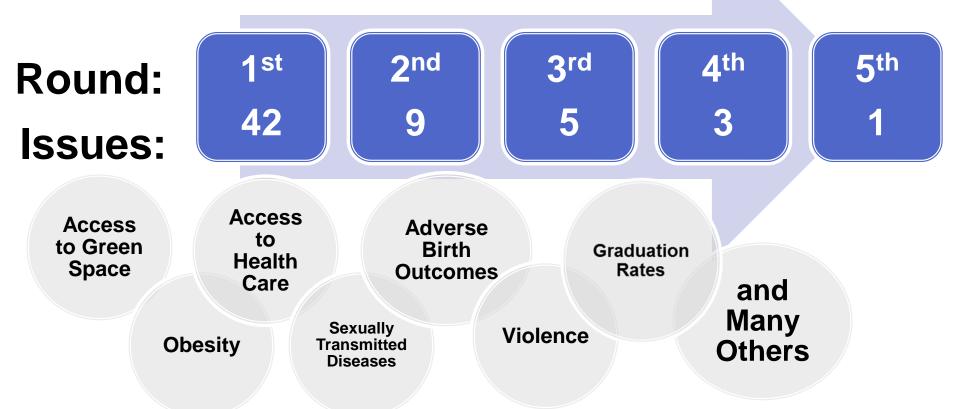
- A. Aurora WIC (AW)
- B. Northwest Health Center (NWHCW)
- C. Wee Care North (WCN)
- D. Wee Care Capitol (WCC)
- E. Wee Care Teutonia (WCT)

(CBPR Principle: Community as a unit of identity.)





Health Disparities Selection after a Windshield Community Health Assessment



CBPR Principle: Addresses Problems that are of Local Relevance Using an Ecological Approach

Immunizations



Tools and CBPR Process Timeline

CHS= Community Health Specialist and CFT = Community Forward Team

Enrollment Process	Roles	Timeline
Parents/Caregivers Outreach	CFTs/CHS	March 2014- ongoing
Verification of Eligibility & Consent	CHS/Research Coordinator	March 2014- January 2016
Parents/Caregivers Assessment Survey	Parents/Caregivers	March 2014- December 2015
Quarterly WIR Record Reviews (Baseline & Follow-up)	CHS/Research Coordinator	March 2014- January 2016
CHIMC-TCI! Enrollment	CHS/Research Coordinator	June 2014- February 2016

CBPR Principle: Integrates knowledge and action for mutual benefit of all partners.



Self-Assessment by Partners, 2013-2015

Questions	Median 4 (3-Agree to 4 Strongly Agree) (Interquartile Range 25%-75%)
Communicate openly and honestly	
Comfortable expressing points of view	All Results: Median response
Comfortable bringing up new ideas	for academic (26) and community (52) partners were rated as
Opinion is listened to and considered	4 (Strongly Agree) for all eight (8)
Feel that I have a voice	self-assessment survey items.
Satisfied with how CHIMC operates	
Feel a strong sense of loyalty	
Communication is effective	



Self-Assessment by Partners, 2013-2015

	Response	Academic (n=26)	Community (n=52)	AII (n=52)
Questions		%		
Benefits outweigh costs	Yes	92	76	81
Provided adequate knowledge	Yes	96	94	95
Taught me about community health disparities	Yes	100	96	98
Responsible for activities, would not have occurred otherwise	Yes	100	90	94
Brought benefits to my community	Yes	92	96	95
Ranges		92-100	76-96	81-98



Capacity-Building & Training

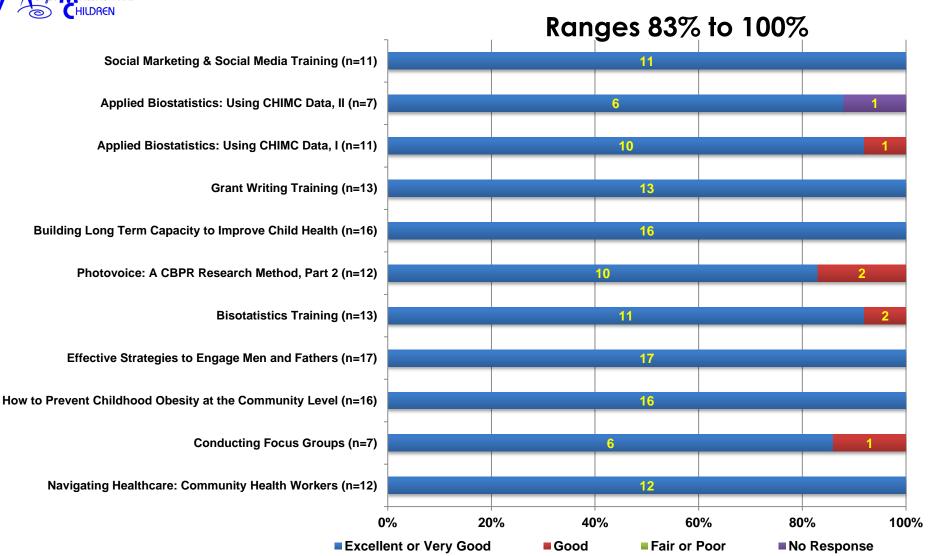
TOPICS					
1. Navigating Healthcare and Social Services: 211 IMPACT Training	2. Photovoice: CBPR Research Method				
3. Navigating Healthcare: Community Health Workers	4. Use of Technology: Social Marketing to Social Media Communication				
5. Conducting Focus Groups	6. Wisconsin Immunization Registry				
7. Childhood Obesity Prevention	8. Community Health Assessment				
9. Strategies for Engaging Men and Fathers	10. Grant Writing Training				
11. Mental Health/Parenting Stress*	12. Applied Biostatistics (3)				

• Training conducted by academic experts (58%); community experts (33%) and 7% nationally recognized expert in community health assessment and partnerships.

(CBPR Principle: Fosters co-learning, collaborative and equitable power sharing and capacity-building among all partners)



Co-Training Satisfaction: Dec 2014 - Feb 2016





Range of Community Engagement by Community Forward Team Members

Health Disparities

- Food Insecurity (5)
- Infant Mortality (3)
- Mental Health (2)
- Breast Cancer (2)
- Tobacco Prevention (2)
- Violence Prevention (2)
- Healthy Babies
- Immunizations
- Breast Feeding
- Women's Health
- Cancer
- Asthma
- Diabetes
- Blindness
- Lead Toxicity
- Safe Water Advisory Committee

Social Determinants of Health

- Outreach/Social Services (13)
- Leadership (8)
- Community Development (5)
- Advocacy (5)
- Health Education (4)
- Elderly/Aging (4)
- Healthy Neighborhoods
- Fatherhood Initiative
- Nursing
- Cultural Health
- Health Fair
- Housing
- Human Trafficking
- Homelessness
- Living Wills/Estate Planning
- Financial Literacy

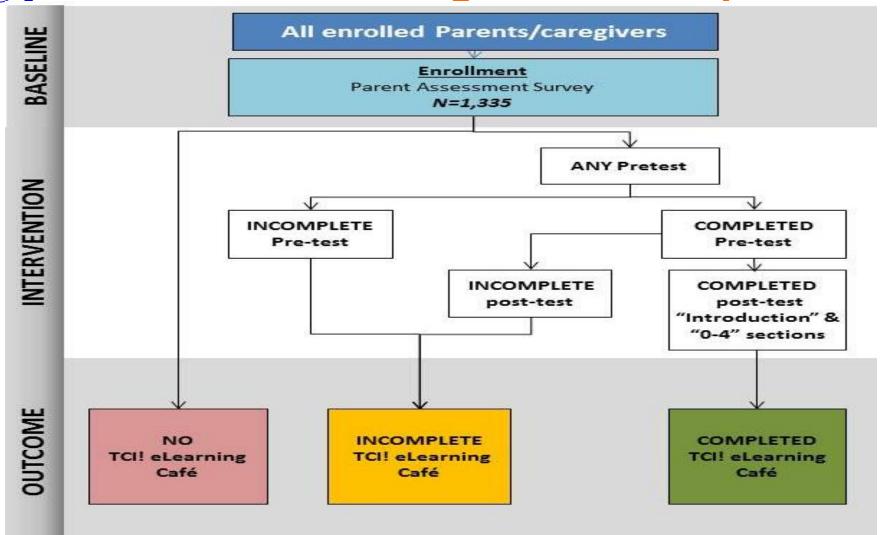
Systems Impact

- Community Health Worker (9)
- Human Research
 Protection
 Programs (2)
- CommunityEngaged Research
- Public Health
- Health Policy
- Medicaid
- NAACP
- 2-1-1 IMPACT
- Prison After-Care
- Child Care
- Foster Care

CBPR Principle: Addresses health from both positive and ecological perspectives.

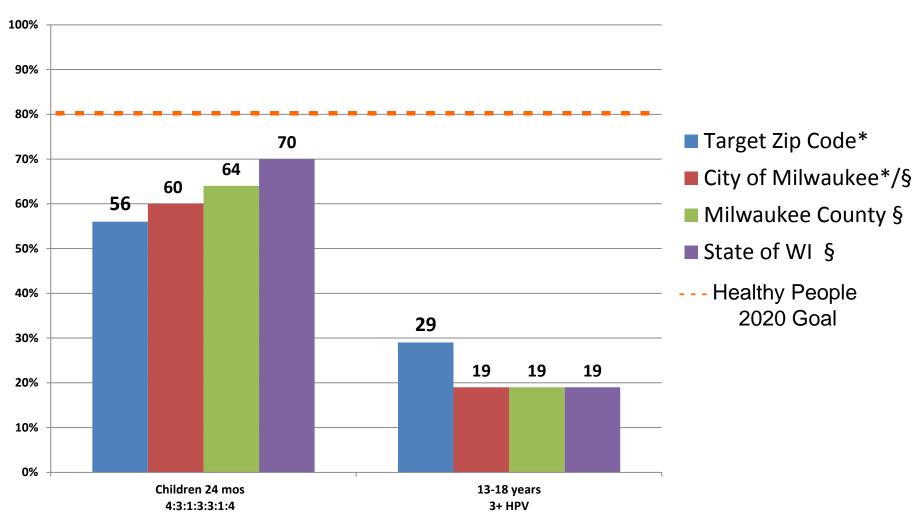


Data Analysis Algorithm: TCI! eLearning Café Participants





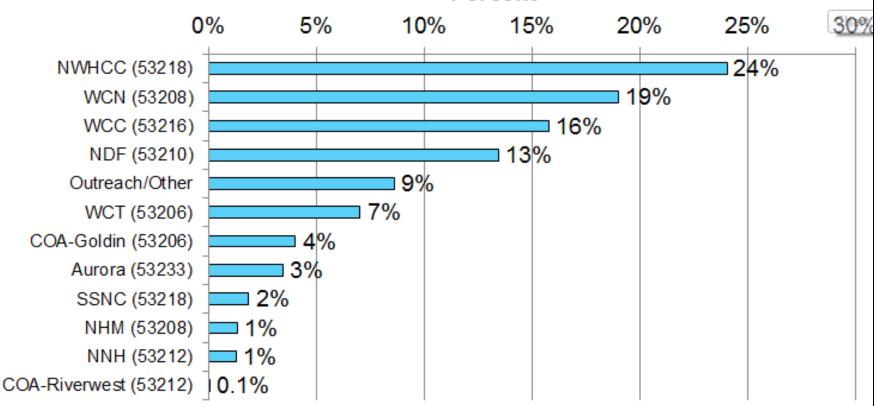
Baseline Proportions of Immunization UTD Status for Age-Appropriate Antigen Series, 2013





Proportion of Enrollment by CHIMC-TCI! Sites

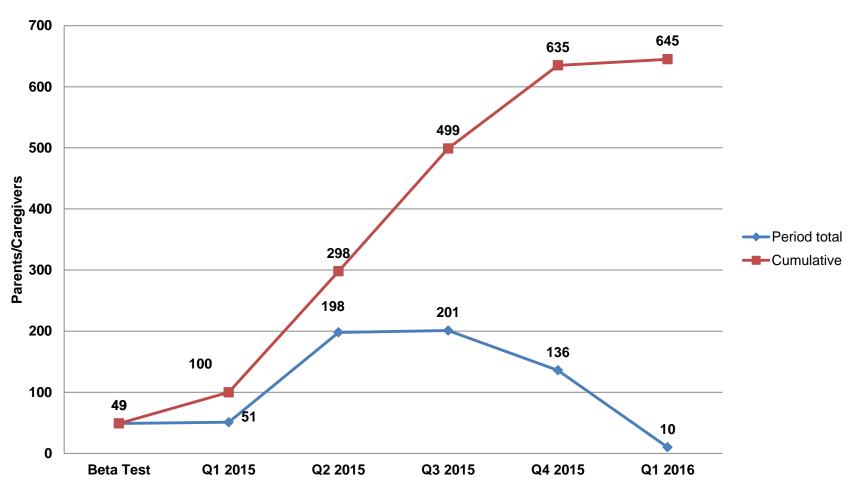
Percent



Key: NWHCC=Northwest Health Center WIC, WCN=Wee Care-North, NDF=Next Door Foundation, WCC=Wee Care-Capitol, WCT=Wee Care-Teutonia, Aurora=Aurora WIC Clinic, NNH=Northcott Neighborhood House, SSNC=Silver Spring Neighborhood Center, NHM=Neighborhood House of Milwaukee



Enrollment in TCI! eLearning Café by Quarters





TCI! eLearning Café Pre/Post Knowledge Survey by Exposure

eLearning Café Participation Status	Pre Test			Post Test	Total Modules Enrollees	Cumulative Enrollment	%		
		Required Optional Modules Modules							
NO Incomplete Complete		Intro	0-4	Catchup	10-18				
Number of Questions:	15	5	6	2	2	15			
NO eLearning	0	0	0	0	0	0	690	690	52
	0	0	0	0	0	0	33	723	3
INCOMPLETE eLearning		0	0	0	0	0	58	781	4
		0	0	0	0	•	26	807	2
COMPLETED eLearning				0	0		528	1,335	39



Population Demographics Comparisons: TCI! eLearning Café Exposure

	COMPLETE (%) (n=523)	INCOMPLETE (%) (n=117)	NONE (%) (n=684)	p values
Parents/Caregivers (Mother)	92	91	93	p=0.75
Gender F>M	95	96	88	p <u><</u> 0.001
Median Age	28 yrs.	27 yrs.	26 yrs.	p <u><</u> 0.001
Employment	38	43	47	p<0.01
Communication Access Internet	58	53	49	p=0.008
Transportation for all CHIMC-TO Bus/Public-(25% vs. 5%); Ride v Estimation all range 5-25%		p <u>≤</u> 0.001		

Chi Square Test

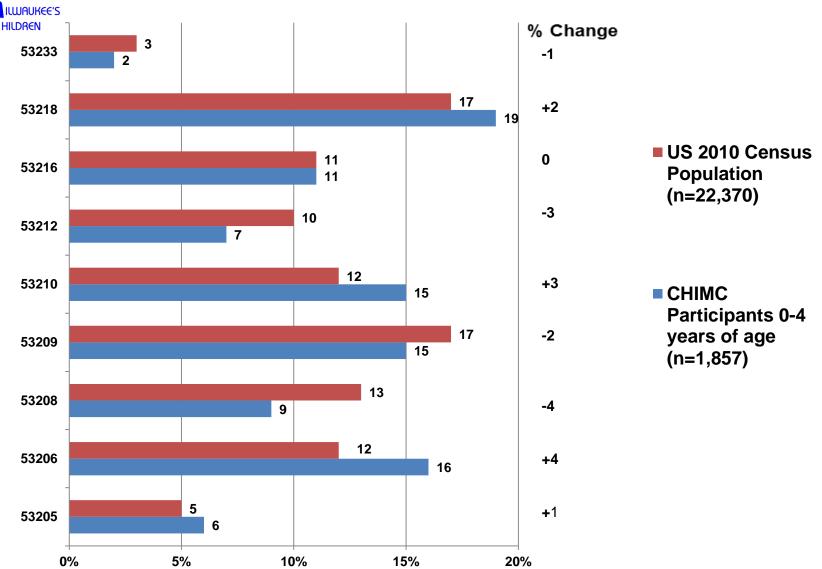


Population Demographics: TCI! eLearning Café Exposure

	COMPLETE (%) (n=523)	INCOMPLETE (%) (n=117)	NONE (%) (n=684)	p values
Income (<\$15,000)	61	54	58	NS
Education Attainment (HS or GED)	39	45	42	NS
Duration in Employment (< 2yrs)	25	22	24	NS
Race/Ethnicity (Black/African American)	82	87	83	NS
Transportation Access (Own Car)	49	44	44	NS
Decision-maker Immun. (Mother)	92	93	88	NS
Locations for Health Care (Doctors' Office)	87	82	87	NS
Perceptions of Immun. (UTD Status)	84	86	84	NS

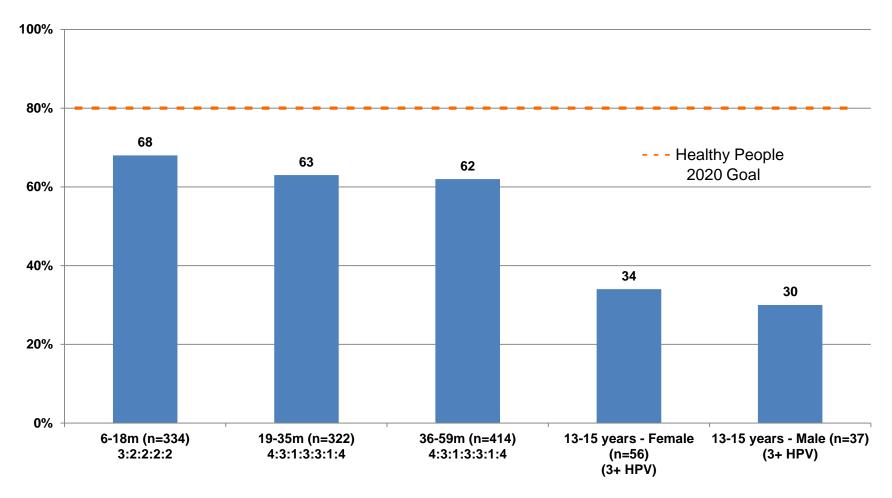


Distribution of Child(ren) (0 to 4 yrs.) by Zip Codes Compared to 2010 US Census Data





Baseline Immunization UTD Status for Children/Youth, 2013



Parents'/Caregivers'Attitudes/Beliefs and Efficacy on Immunizations



If child is not vaccinated he/she may get a preventable disease

Confident in safety of routine childhood immunizations

Good relationship with healthcare provider(s)

Need to know about health issues to keep healthy

Vaccines are necessary to prevent certain diseases

Could contract serious infectious disease if not vaccinated

Important to vaccinate to protect spread of disease in my community



Enjoy learning about health issues

Those in charge of vaccinations have child's best interest at heart

Can figure out if child is up-to-date on immunizations

Confident in ability to check and follow immunization status

Neutral

Know how to go online to Wisconsin Immunization Registry & find child's record



Screenshots of CHIMC-TCI! Toolkit

HOME

PARENT TOOLKIT

FACES OF CHIMC

HOW TO FIND US & ENROLL

THE CHIMC STORY

AGENCY STAFF INFO

Welcome to the CHIMC Parent Toolkit



Recommended Immunization Schedules



Look Up Your Child's Immunization Record



Free and Low-Cost Milwaukee Clinics



Health Care Appointment Checklist



Immunization Websites



Frequently Asked Questions (FAQs)

Sponsored by the National Institute on Minority Health and Health Disparities of the National Institutes of Health



CHIMC Social Marketing Intervention



Intercept respondents (n=406), 85% reported that they recognized this message with visual prompting.



Theory of Planned Behavior Change (PBC) Intervention Sessions

- 1. Orientation
- 2. Health Care System Navigation
- 3. Communicating with HealthCare Providers
- 4. Accessing Immunization Records through the Wisconsin Immunization Registry
- 5. Social Networking
- 6. Action Planning for Immunization Compliance
- 7. Next Steps and Wrap-Up



Focus Groups on Messages and Social Media Preferences (n=21)

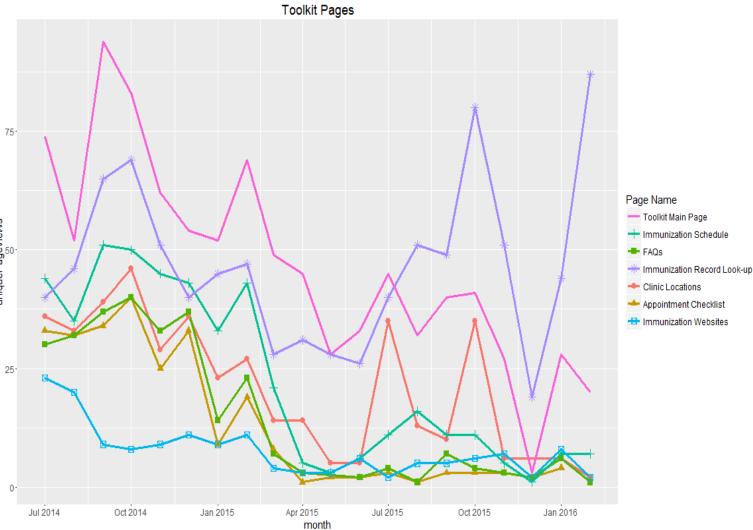
- Well distributed across 8 of 10 of the zip codes.
- Older population cohort: focus group median age 36 yrs. verses CHIMC-TCI! enrollees median age of 28 yrs.
- Social media message agreed upon with responsibility for childhood immunization shared by primary caregivers, community and multiple players. (Hospitals, health care professionals, policymakers, etc.)
- Preferences of communication access included internet and Facebook.



CHIMC Parents/Caregivers Toolkit Unique Page Views (July 2014 - Feb 2016)

Early use:

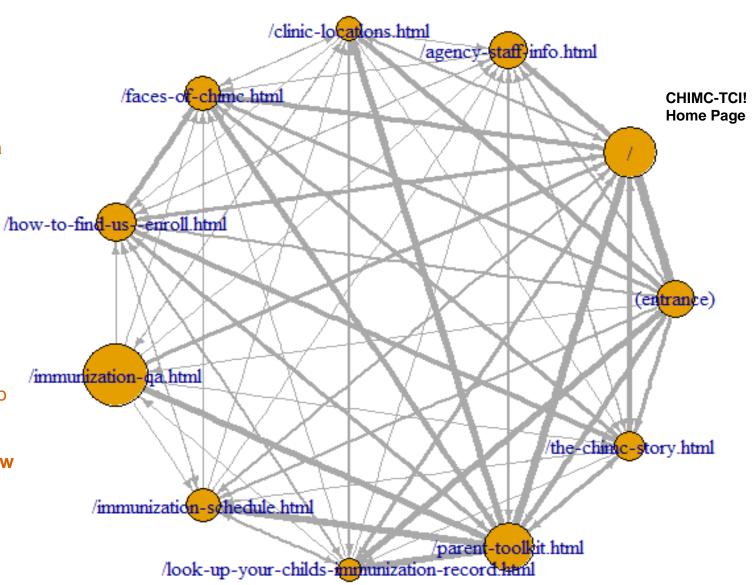
- Frequently Asked Questions; Recommended Immunization Schedules;
- Free and Low-Cost Milwaukee Clinics; and
- Health Care
 Appointment
 Checklist webpages,
 which tapered off by
 April 2015.
- Look Up Your Child's Immunization Record peak increases in utilization in October 2015 and February 2016.





Circle represents a single webpage; size of circle is proportional to how many other pages are visited from that page.

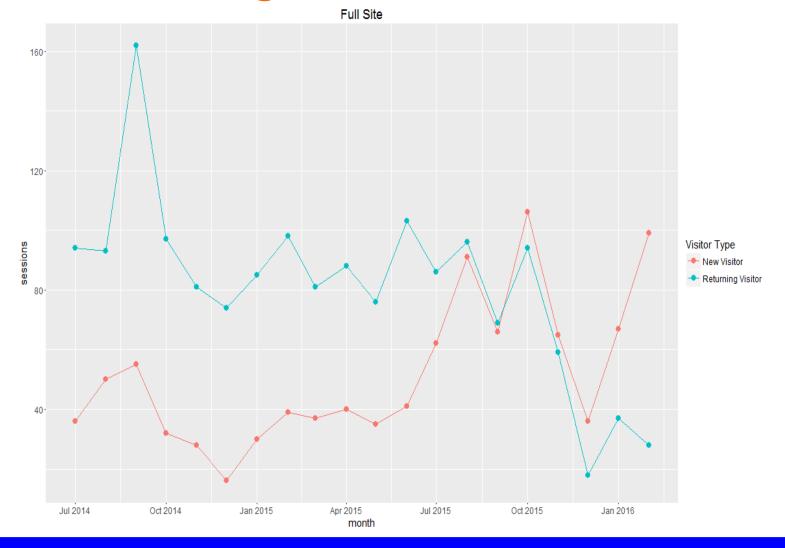
Lines between circles represent traffic between two pages and thickness is proportional to how much traffic.





CHIMC Website New and Returning Users (July 2014 - Feb 2016)

Early,
majority of
sessions
were from
returning
users,
but after
October
2015 new
visitors
became the
majority.

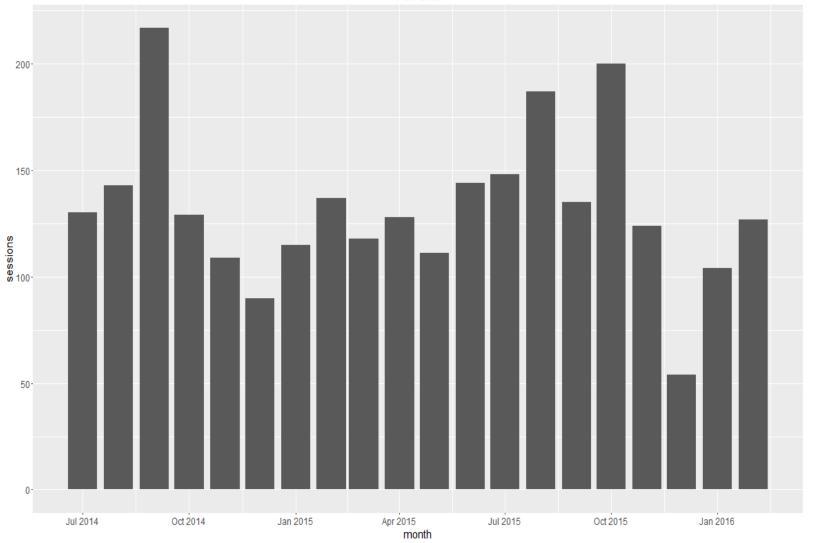




CHIMC Website Sessions by Month

(July 2014 – Jan 2016)
Full Site







Screenshots of CHIMC-TCI! Childcare Agency Resources





Selected CHIMC MKE Facebook Photo Posts, 2015-2016



Did you complete a survey about immunizations with CHIMC Take Control Immunize?

If so, you have a chance to win a prize and learn more about the immunizations that protect your children from preventable diseases by completing the online eLearning Café

Contact the CHIMC Community Health Specialist

to sign up!

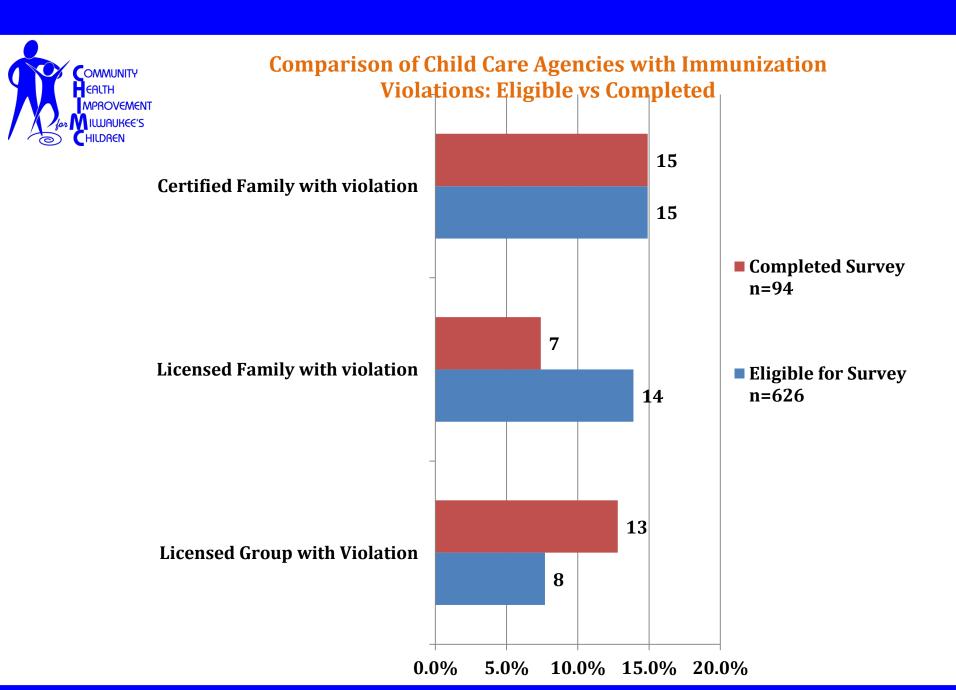


Fue Xiong
Community Health Specialist
(414) 978-2025
fxiong@uncom-milw.org



CHIMC is a partnership with community residents and organizations including the Medical College of Wisconsin, United Neighborhood Centers of Milwaukee (UNCOM), Milwaukee County WIC program, Milwaukee Health Department, WI Department of Health Services-Immunization Program, and the Marquette University Diederich College of Communication.

Sponsored by the National Institute on Minority Health and Health Disparities of the National Institutes of Health





Child Care Agencies Awareness of WI Immunization Requirements

Questions	Yes
n=94	%
Aware that WI Student Immunization Law Requirement Can Be Waived	
for only medical, religious, or philosophical reasons.	80
Recognize Different Rules for Different Ages. (missing 6)	26
Immunization Requirements are Stricter for Younger Children. (missing 6)	24
Can children who are not UTD on vaccines obtain them on site.	4
Aware of any changes to Immunization Requirement or Laws for school	
or Child Care entry during the present school year. (missing 1)	4
Does your agency receive Vaccine For Children (VFC) (missing 1)	3



Child Care Agencies Immunization Violation Rates by Types

Agency Type	Unweighted Violators (%)
Certified Family	
n=21	14 (67)
Licensed Family	
n=22	7 (32)
Licensed Group	
n=51	12 (24)
Total	
n=94	33 (35)



Child Care Agencies Estimations of Enrolled Children Immunization UTD Status by Age Cohorts

Age	0-4 mos. n= 49	5-15 mos. n=67	16-23 mos. n=61	24-59 mos. n=78	5-9 yrs. n=75
% UTD	82	73	69	74	77



Child Care Agencies Select Components of CHIMC-TCI! Toolkit as Useful Resource

CHIMC-TCI! Toolkit Resources	Yes
n=94	%
Healthcare Checklist (missing 6)	75
Free and Low-Cost Immunizations (missing 6)	72
CoCASA (missing 4)	64
Wisconsin Immunization Registry for Look-up (missing 6)	48



Publications:

Local, Regional, and National with PMCID

- Gray-Murray J, Leary M, Watts M, Xiong F, WILLIS E. Field Methods for Discovering Practical Wisdom: The Microdynamics of Going Beyond Technical Rationality in Real-World Practice. Int Q Community Health Educ. 2012-2013;33(1):39-53. <u>DOI:10.2190/IQ.33.1.d.</u>
 PMID:23570827
- Ngui EM, Hamilton C, Nugent M, Simpson P, WILLIS E. The Effect of a Social Marketing Campaign to Increase Awareness of Immunizations for Urban Low-income Children. <u>Wisconsin Medical Journal</u>. February, 2015;114(1):10-15. PMCID:PMC4390996
- **WILLIS E**, Svapna S, Hamilton C. Improving Immunization Rates through Community-Based Participatory Research: Community Health Improvement for Milwaukee's Children Program. Progress in Community Health Partnerships: Research, Education, and Action. 2015. **PMCID:PMC4869973**
- WILLIS E, Ngui E, Chen V, Cronk C, Meurer J, Shankle S, McManus P, Harvieux A.
 Navigating the Complexity of Relationships in Community-based Participatory Research
 (CBPR) In: Uncharted Path from Clinic-based to Community-based Research. Nova
 Science Publishers, New York. Chapter 9, pp 161-182. October 2008. NLM ID:
 101478480



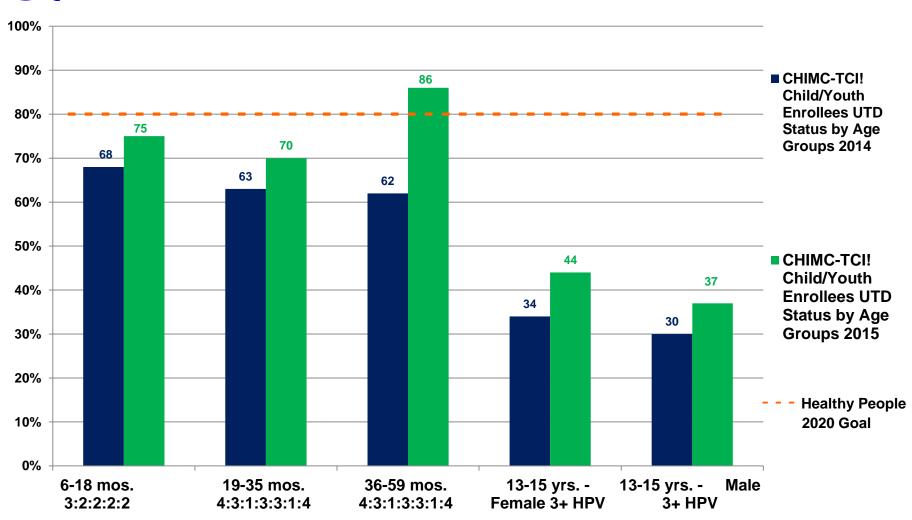
Reported UTD Immunization Status: Perceptions vs Actual wir-verified

Cohorts by Age for Youngest Child-Adult Pairs	Parents'/Caregivers' Perceptions (%)	Actual WIR-Verified (%)	Variance (%)
Youngest Child 0-4 yrs. (n=1,335) (3:2:2:2:2 children 6-18 mos.) (4:3:1:3:3:1:4 children 19-59 mos.)	82 (n=1,096)	71 (n=948)	-11
Youngest Youth (n=194) (3+ HPV for youth >11 yrs.)	94 (n=183)	26 (n=51)	-68



Comparisons of Child/Youth UTD Status by Age-Cohorts for Age-Appropriate Antigen Series

(May 2014 to December 2015)





Pre/Post Knowledge of Parents/Caregivers Exposed to TCI! eLearning Café

	Questions	% Correct Pre	% Correct Post	Variance	p-value
	Immunizations work by increasing child's body's ability to protect them from diseases, also called immunity. (n=548)	95	97	+2	p=0.296
Introduction	If most people in a community get their immunizations, others who have not been vaccinated will be shielded from getting diseases. (n=547)	28	53	+25	p≤0.001
onpo	Getting immunized against measles will not give you that disease. (n=547)	53	69	+16	p≤0.001
Intro	Multiple immunizations given at the same time do not increase the risk of minor side effects, such as fever and sore arms or legs, compared to a single immunization. (n=547)	37	72	+51	p≤0.001
	The Wisconsin Immunization Registry provides secure access to your child's immunization records. (n=547)	93	98	+5	p≤0.001



Pre/Post Knowledge of Parents/Caregivers Exposed to TCI! eLearning Café

	Questions	% Correct Pre	% Correct Post	Variances	p-value
	The first vaccin e given to a newborn is Hepatitis B . (n=529)	80	90	+10	p≤0.001
	Children at high risk for the seasonal flu should be immunized yearly , starting at six months . (n=527)	80	90	+10	p≤0.001
yrs.	The MMR vaccine prevents against measles, mumps, and rubella. (n=527)	77	95	+18	p≤0.001
Children: 0-4	Delayed pneumococcal vaccines are not protected against serious infections such as pneumococcal pneumonia and meningitis. (n=525)	49	70	+21	p≤0.001
O	Research shows that immunizations cause certain illnesses like autism . (n=523)	57	72	+15	p≤0.001



Pre/Post Knowledge of Parents/Caregivers Exposed to TCI! eLearning Café (Optional)

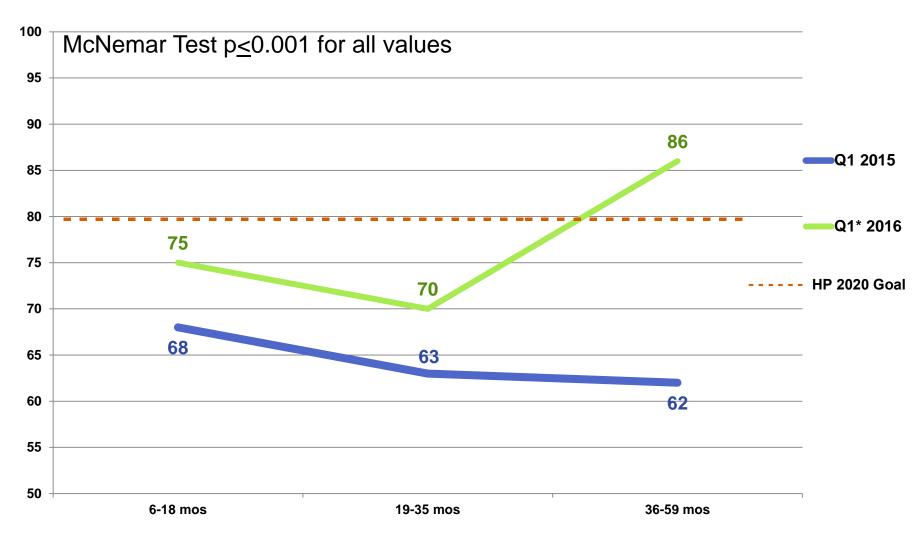
	Questions	% Correct Pre	% Correct Post	Variances	p- value
dn-	If child has the appropriate amount of time, or interval, between doses, they will have appropriate protection from the disease. (n=180)	63	88	+25	p≤-0.001
Catch-up	If child is BEHIND on immunizations, it's too late to catch up. (n=180)	96	91	-5	p=0.096
10-18 yrs.	The Human Papilloma Virus, or HPV vaccination protects against some forms of cancer. (n=212)	54	84	+30	p≤0.001
Youth: 10-	If your teen or pre-teen steps on a rusty nail, they should get a Tetanus booster , such as TdaP , if more than five yrs . since the last booster. (n=212)	86	96	+10	p≤0.001



TCI! eLearning Café Satisfaction Results

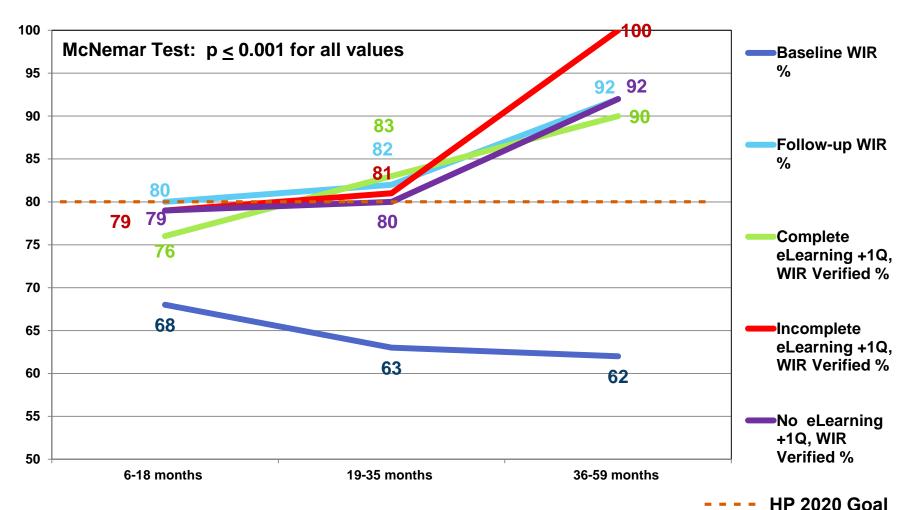
The TCI! eLearning Café	Strongly Agree/ Agree (%)	Neutral/ Disagree (%)
is easy to use.	95	5
has components that are interactive with me.	91	9
has attractive features that appeal to me.	88	12
provides information that is easy to understand.	93	7
provides enough information for me about immunizations.	95	5
provides information that is relevant to my child's immunizations.	92	8
provides information that is exactly what I need.	93	7

Community Health IMPROVEMENT Comparison of Children's Immunizations (UTD) Status by AgeMILLIANDIKEE'S Children Cohorts at Enrollment; Follow-up* (+1 Q); and HP 2020 Goal





Children's Immunization UTD Status Stratified by TCI! eLearning Café Exposures





Tracking BEHIND Status for Children/Youth, WIR-Verified

(Antigen series completion 3:2:2:2:2 for children 6-18 months; 4:3:1:3:3:1:4 for children 19-59 months and Youth 10-18 yrs. for 3+HPV)

	Enrollees	BEHIND	% BEHIND
Children (6 – 59 mos.)	5,908*	1,315*	22
Youth	1,547*	1,111*	72

^{*}This number is greater than the total number of children enrolled (not representing unique individuals) since some children/youth were identified as BEHIND multiple times throughout the Project



Best Practices and Lessons Learned

- (a) Parents/Caregivers perceptions of childhood immunization rates are significantly higher than actual documented rates.
- (c) Capacity-building to enhance skills development (e.g. data collection, data analysis, and, more generally, soft skills) can result in personal and professional growth.
- (d) "Take Control" message was essential to foster collaboration among the community-academic partnership, contributing to the success of this Project.
- (e) Increased knowledge across all partners of health disparities balanced with action guided the research agenda.
- (f) Health disparities can be eliminated with broad partners participation and building of trust.
- (g) Priority of time commitment to secure buy-in and perspectives of all partners is essential.

Acknowledgements

Academic Partners

- Earnestine Willis, MD, MPH
- Sheri Johnson, PhD
- Pippa Simpson, PhD
- Svapna Sabnis, MD
- John Meurer, MD, MBA
- Chelsea Hamilton, MS
- Melodee Nugent, MA
- Norma Magallenes
- Tiffiney Gray, MMS

Community Agency Partners

- Black Health Coalition
- · Children's Hospital of Wisconsin
- COA Youth and Family Centers
- Marquette University Diederich College of Communication
- Medical College of Wisconsin
- Milwaukee County WIC Program
- Milwaukee Health Department
- Neighborhood House of Milwaukee
- Next Door
- Silver Spring Neighborhood Center
- State of Wisconsin, Immunization Program
- United Neighborhood Centers of Milwaukee



Community Forward Team

- Darnell Bowles
- Yolanda Hamilton
- Talya Hicks
- Joyce King
- Carolyn Pridgeon
- Dorothy L. Smith
- Ben Watson

- Alesia Gray
- Janice Harrell
- Donna Johnson
- David Orley
- · Dorothy G. Smith
- Christal West
- Ida Winters



