

Patient and family engagement

Jackie Beckerman, MPH

Chief Patient Experience Officer and Senior Director ICARE Commitment, UPMC

Alvin Lin, MBA

VP of Ambulatory Transformation, SBH Health System

Agenda

- **Introductions**
 - HANYS AHEI team
 - AHEI faculty
- **Our partners**
- **Session 9:**
 - Patient and family engagement

HANYS AHEI team



Kathleen Rauch, RN, MSHQS, BSN, CPHQ

Vice President, Quality Advocacy, Research and Innovation and Post-acute and Continuing Care



Christina Miller-Foster, MPA

Senior Director, Quality Advocacy, Research and Innovation



Morgan Black, MPA

Director,
AHEI



Maria Baum, MS, RN, CPHQ

Project Manager,
Mohawk Valley



Rachael Brust, MBA

Project Manager,
North Country



Kira Cramer, MBA

Project Manager,
Downstate

HANYS faculty



Julia E. Iyasere, MD, MBA

Executive Director, *Dalio Center for Health Justice, NewYork-Presbyterian*
Senior Vice President, *Health Justice and Equity, NewYork-Presbyterian*
Assistant Professor, *Medicine, Columbia University Irving Medical Center*



Theresa Green, PhD, MBA

Director, *Community Health Policy and Education, Center for Community Health and Prevention, University of Rochester Medical Center*

Our funder and partner



Our funder

Funding from the [Mother Cabrini Health Foundation](#) allows HANYS to expand its capacity to provide education, direct support, tools and data to our members in a strategic way. With this learning collaborative, we strive to effect lasting change in health equity at the local level by engaging providers and community stakeholders to address health disparities.



Our partner

[DataGen](#) develops custom analytics for participants to help them understand how and where communities are affected by health disparities so they can develop tailored interventions.

Presenters



Jackie Beckerman, MPH

Chief Patient Experience Officer and Senior Director ICARE Commitment,
URMC



Alvin Lin, MBA

VP of Ambulatory Transformation,
SBH Health System

Every Patient Deserves a Voice:

Utilizing Patient and Family Advisory Councils in Health Equity Work

Jacqueline Beckerman, MPH

Chief Patient Experience Officer, University of Rochester Medical Center
Senior Director, Office of the Strong Commitment

MEDICINE *of* THE HIGHEST ORDER



Who We Are...



- ❑ Comprehensive health care delivery network in Upstate NY
- ❑ Anchored by Strong Memorial Hospital, an 897-bed, tertiary care academic facility
- ❑ Regional trauma and burn center
- ❑ Only comprehensive stroke center and cardiac transplant program
- ❑ Regional perinatal center
- ❑ 41,000 discharges annually
- ❑ Daily occupancy routinely 110%
- ❑ 130,000 emergency visits per year
- ❑ ~3 million outpatient visits per year



A Values-Driven Culture

- ❑ Revisit organizational values routinely

Inclusion

Integrity

Compassion

Accountability

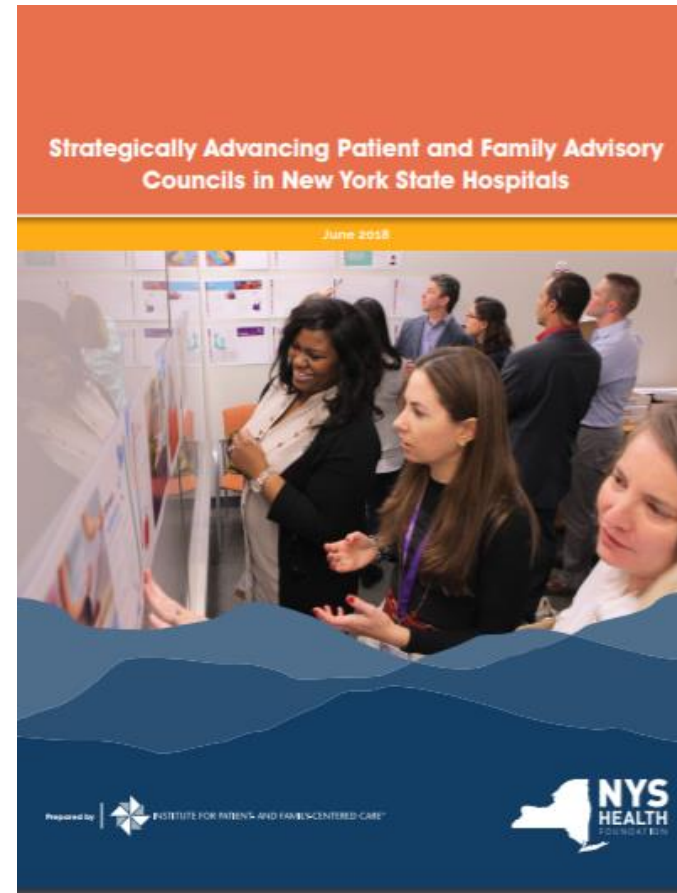
Respect

Excellence



Long History of PFACs

- ❑ Proud to be one of 3 hospitals in NY selected for a site visit regarding our Patient and Family Advisory Councils.
- * *Co-sponsored by: Institute of Patient and Family-Centered Care (IPFCC) and Healthcare Association of New York State (HANYS)*
- ❑ Initiated first PFAC over 20 years ago – continued to change our approach over time



Must-Haves for a Successful PFAC

Leadership

- Need the right person
- Community partnership
- Engage your senior leadership – truly listen

Transparency

- Share data freely
- Be open with the good the bad and the ugly
- Openly discuss the barriers to rapid change

Accountability

- Follow through on items
- Provide continuous feedback whenever input is given
- Publicly acknowledge and celebrate accomplishments

Influence

- Empower your Council to impact change
- Make their voices heard
- Emphasize their essential role in positive changes made

Role and Value of Patient/Family Advisors

- ❑ Great way to engage patient and families
- ❑ Essence of Patient and Family-Centered Care
- ❑ Advisors **always** need to be part of the discussion
- ❑ You have to be comfortable sharing your “dirty laundry”
- ❑ We were one of the early adopters, with a hospital-wide, PFAC in existence for over 20 years
- ❑ Added other “traditional” PFACs such as:
 - Cancer Center PFAC
 - Children’s Hospital PFAC



Issues Surrounding Traditional PFACs

- ❑ Ongoing challenge – ensuring that membership fully represents the broad spectrum of patients we serve
- ❑ Nationally, the answer has been to add diversity to these groups
 - I haven't ever really seen it be successful 😞
 - We've heard it from our patients and families



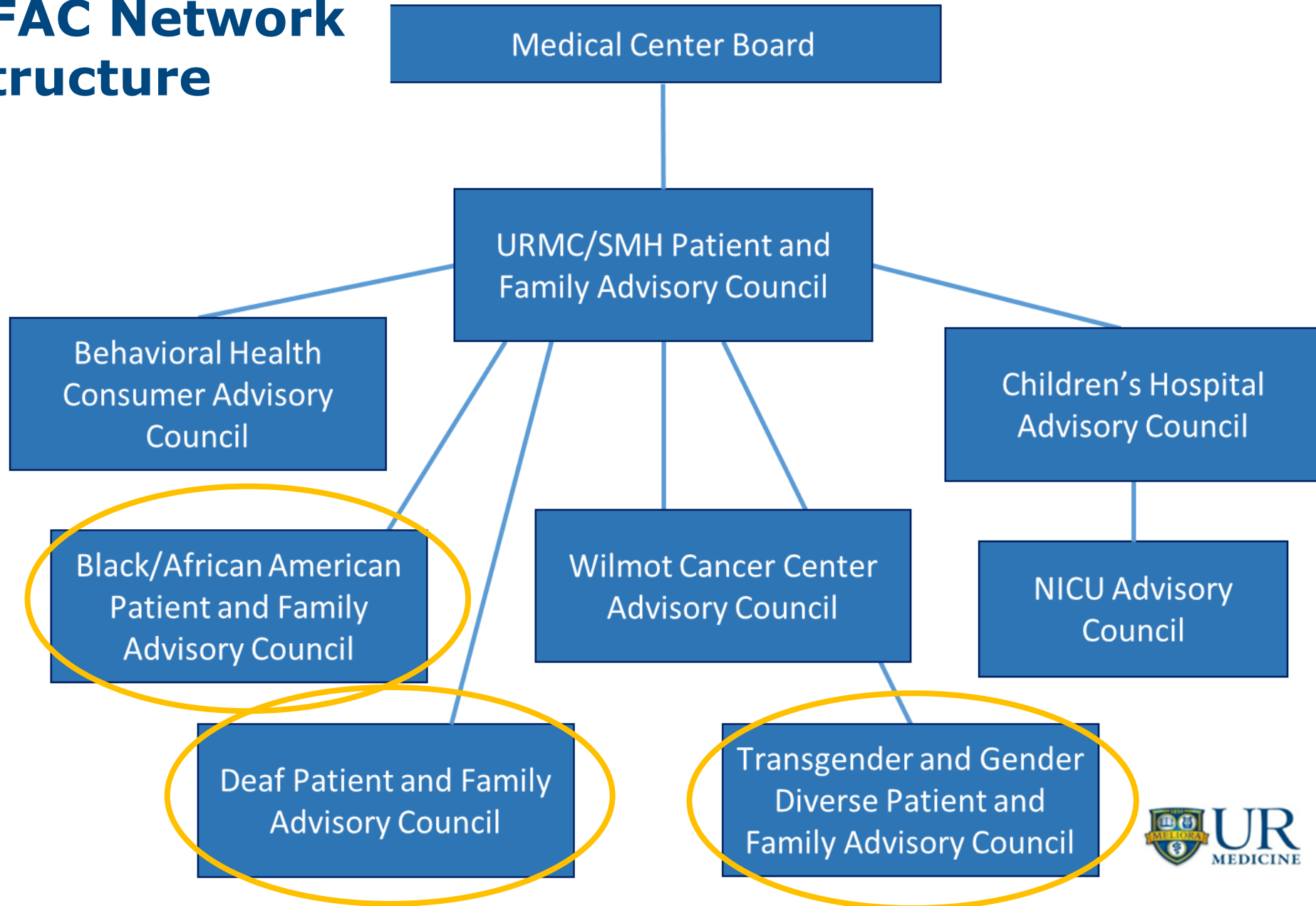
A Different Approach

❑ Decided to bring together groups of individuals with similar lived experiences

- Ensures greater equity in the voices of our patients
- Still need a broad enough perspective, even with a focused PFAC
- Included organizations within those communities
- Constantly looking around the table “Who is missing?”



Our PFAC Network and Structure



Why These PFACS?

- ❑ In many ways, they self-identified
- ❑ In our analytical survey data
 - Although, we know there is some bias in the data
 - Need to re-design the entire surveying process for these groups, and they want to help.
- ❑ But it's also the qualitative data
 - the stories of their experiences.
- ❑ They are often the hardest to hear....

Know Your Community

❑ Largest Deaf population per capita in the world

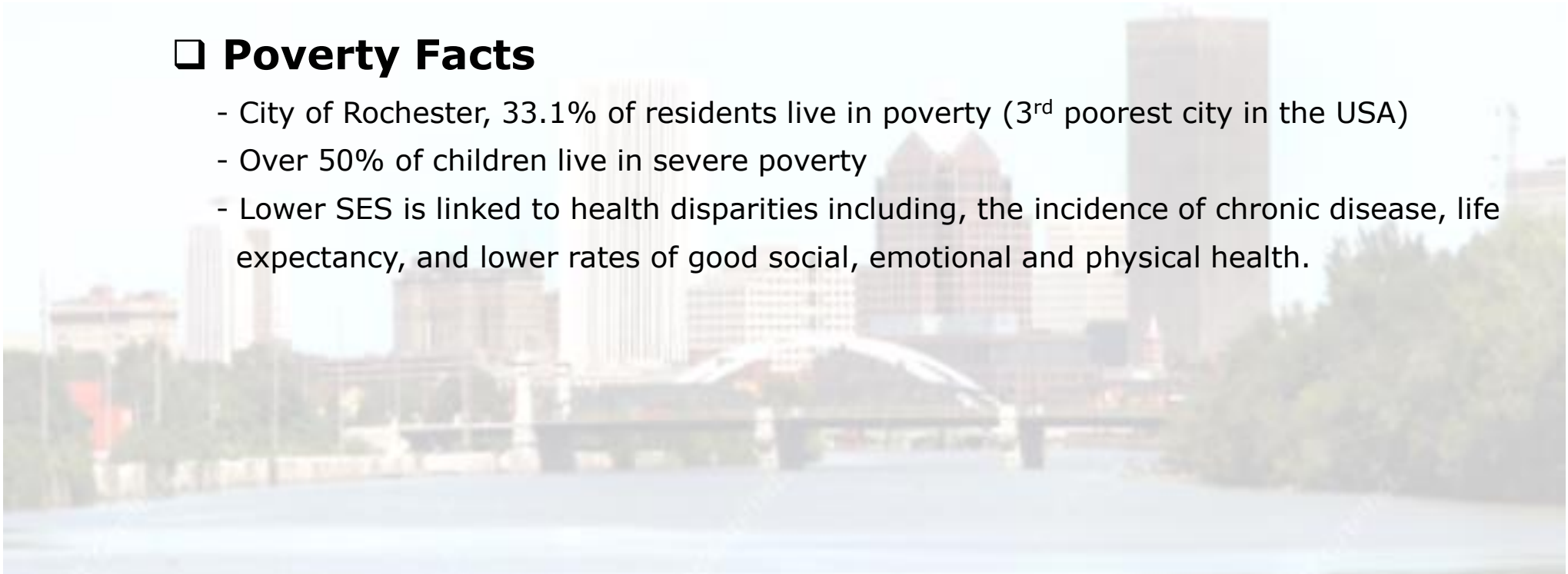
- We serve approximately 5,000 Deaf patients

❑ Transgender Facts

- Large LGBTQ population
- Estimated 60,000 transgender individuals in region
- We've become a safe haven for trans people

❑ Poverty Facts

- City of Rochester, 33.1% of residents live in poverty (3rd poorest city in the USA)
- Over 50% of children live in severe poverty
- Lower SES is linked to health disparities including, the incidence of chronic disease, life expectancy, and lower rates of good social, emotional and physical health.



Results have been Remarkable:

Actionable Efforts:

- ☐ Educational offerings
- ☐ Staffing needs
- ☐ Policy input
- ☐ Operational improvements
- ☐ Direct involvement in hiring process





OUR DEAF COMMUNITY

*The Deaf and Hard-of-
Hearing Patient and Family
Advisory Council*

Background

- ❑ Patient and family forum
- ❑ First known Deaf PFAC in the country
- ❑ Official kick-off in February of 2018



Recruitment and Meetings

- ❑ Membership
 - Community groups
 - Patients/family members
 - Deaf and signing staff
- ❑ Deaf Co-facilitator



Prioritizing Efforts

- ❑ Addressing data limitations
 - Deaf culture
 - Creating ASL video Press Ganey surveys
 - Developing real-time individual interpreter survey

- ❑ Staffing Needs
 - Increase in interpreters
 - Deaf Social Workers
 - Patient Relations Specialist



Educational

- ❑ Appropriate terminology
- ❑ Sharing experiences - patient panels, Grand Rounds
- ❑ Screensavers:

**Do Not Use the Term
'Hearing Impaired.'
This is often felt to be very offensive.**

Appropriate Terminology is:

- Deaf
- Hard of Hearing
- DeafBlind



When in doubt... ask – don't assume!

For More Information please contact the Office of Patient Experience or the Office of Equity and Inclusion.

MEDICINE *of*
THE HIGHEST ORDER



Deaf and Hard-of-Hearing Communication Toolkit

YOU ARE why ICARE



DEAF/ HARD-OF-HEARING COMMUNICATION TOOLKIT

Please return this kit to the nursing station.
For replacement kits or materials, please contact Patti Canne at 585-276-5746



YOU ARE why ICARE

COMMUNICATION ALERT



**I am Deaf.
Please face me.
I use sign language.**

☐ ASL
☐ Deaf Interpreter

Interpreter Services 585-275-2222

Thank You! Remember: Effective Communication = Patient Safety



YOU ARE why ICARE



We need an ASL Interpreter



**Please contact Interpreting Services
by calling the Page Office – 275-2222**

Available 24/7

Effective Communication = Patient Safety

MEDICINE of THE HIGHEST ORDER



YOU ARE why ICARE



Call Interpreter Services

For immediate needs:
Call (585)275-2222
24 Hours a day/7 Days a Week

To schedule in advance:
Contact (585) 275-4778
Email: Interpreter_Services@urmc.rochester.edu
Hours: 8 am to 5:30 pm M-F
Please page x5-2222 after hours for interpreter needs.

- physician rounds
- medical procedures
- medical history
- explanation of tests
- diagnoses
- imaging
- treatment planning
- therapy (PT,OT, or Chemo)
- family consultation
- discharge instructions
- scheduling of follow-up care
- as requested by the patient or their family

**In accordance with Federal Laws:
Section 504 of the Rehabilitation Act
and Title 2 of the Americans with
Disabilities Act (ADA) sign language
interpreters and/or auxiliary aids
must be provided for all Deaf/Hard of
Hearing individuals, family members,
or care givers.**


















**Patient
requires
Sign Language
Interpreter**

Interpreter Services 585-275-2222


If you would like to work
with our Deaf Social Worker,
Patti Canne – please
contact 585-286-4019, or
Patricia_Canne@urmc.rochester.edu

YOU ARE why ICARE

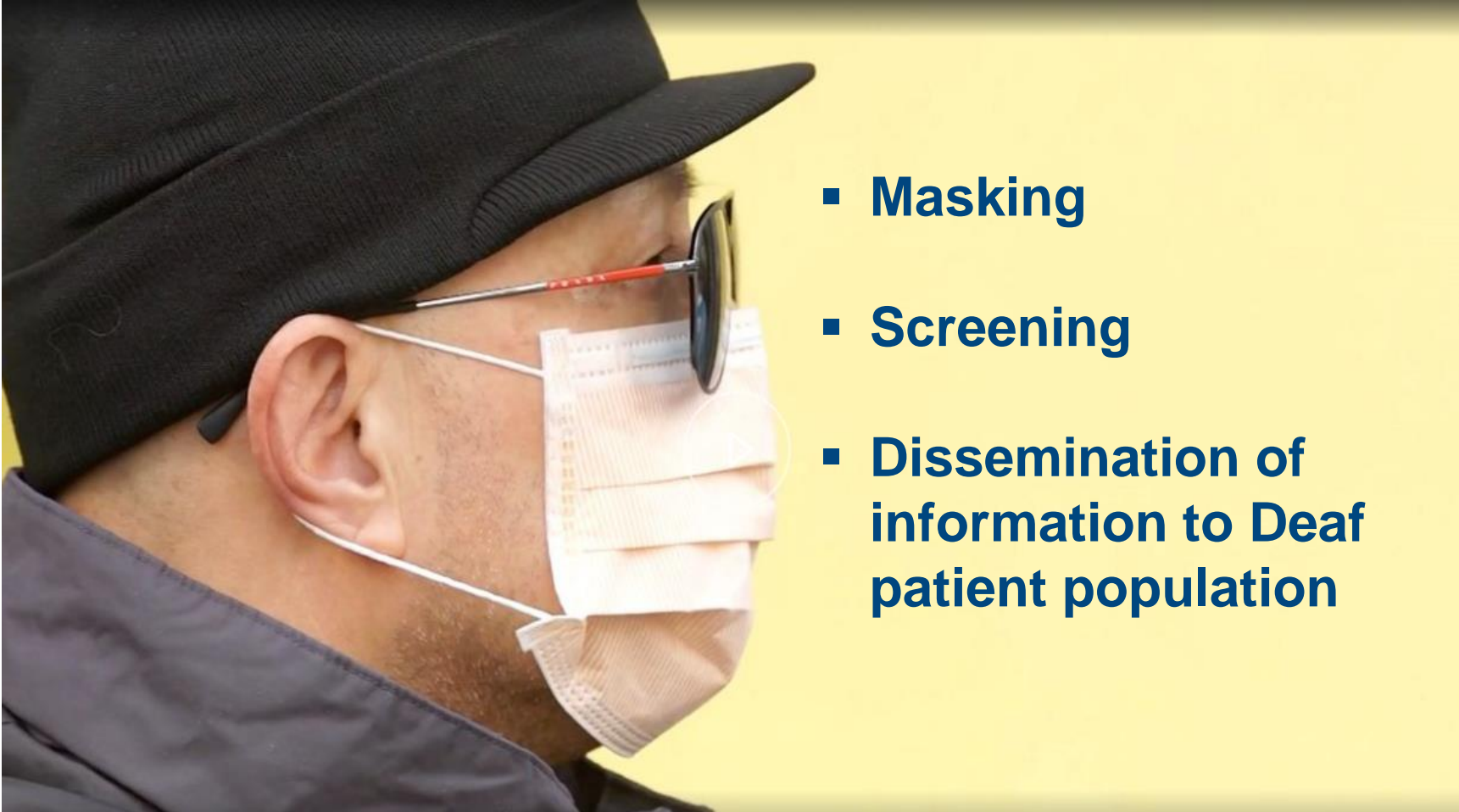
PATIENT MENU BREAKFAST DAILY SPECIALS

 Breakfast Sandwich <small>(Sundays / Wednesdays)</small>	 Cheese or Western Omelet <small>(Sundays / Saturdays)</small>	 Scrambled Eggs <small>(Thursdays)</small>
 Pancakes <small>(Sundays / Wednesdays)</small>	 Breakfast Scramble <small>(Sundays / Saturdays)</small>	 French Toast <small>(Tuesdays / Fridays)</small>
 Belgium Waffles <small>(Thursdays)</small>	 Chicken Sausage Link	 Sausage Patty
 Bacon	 Home Fries	 Cereal
 Fruit	 Yogurt	 Bake / English Muffin

Effective Communication = Patient Safety



Covid Brought New Challenges




- Masking
- Screening
- Dissemination of information to Deaf patient population

COVID-19 Symptom Screening Tool


COVID-19 SYMPTOM CHECKER

I have (symptoms):




Cough, shortness of breath or difficulty breathing

☐ YES ☐ NO




Fever or Chills

☐ YES ☐ NO




Vomiting or diarrhea

☐ YES ☐ NO



New loss of taste or smell

☐ YES ☐ NO




Muscle or body aches


☐ YES ☐ NO

*"Symptom" icons by CDC, from cdc.gov.

Have you been exposed to anyone who has COVID or have you been diagnosed?



☐ YES




☐ NO


Have you traveled outside NYS in the past two weeks?

☐ YES

☐ NO



We will take your temperature



Video Series for Deaf Community



Educational video series produced by Deaf PFAC members in partnership with URM:

- COVID visitation policy
- URM COVID screening Process
- Safety updates and suggestions





OUR TRANSGENDER COMMUNITY



*The Transgender and
Gender Diverse Patient and
Family Advisory Council*

Background

- ❑ A few significant complaints
 - public commitment to do better
- ❑ **THRIVE** – internal committee
 - educational needs
 - operations/eRecord changes
 - new policies
 - create transgender clinic
 - implementation of PFAC
 - staff pronoun badges
- ❑ **September 2019** -
Kicked-off Transgender
and Gender Diverse PFAC



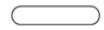
New pronoun badges for IDs:



Inclusion:

I will embrace diversity, be an ally for others, and acknowledge that everyone has their own story.

My Pronouns are She/Her



ICARE About Your Pronouns

- Be **Inclusive**, ask a person's name and pronouns - don't make assumptions.
- Practice **Integrity**, be an ally - speak up if you hear the wrong pronouns being used.
- Be **Compassionate**, use inclusive language.
- Be **Accountable**, pursue education about pronouns and gender inclusive language.
- Be **Respectful**, use the same language a person uses.
- Practice **Excellence**, if you slip up, apologize and ask what term is preferred.

TRUST IS EARNED WHEN
ACTIONS MEET WORDS.

~ Chris Butler ~

Recruitment

- ❑ Was a challenge getting transgender patients to join
- ❑ Transgender facilitator reached out to community organizations
- ❑ Parents of transgender children
- ❑ Currently:
 - 7 transgender individuals
 - 6 parents of trans teens
 - 1 gender diverse individual
- ❑ Ongoing recruitment

Patient and Family Advisory Council ... Do you want to make a difference?

The goal of the University of Rochester Medical Center (URMC) is to provide high quality, respectful, and compassionate care to all patients. We are expanding and accelerating our efforts to support transgender and gender nonconforming patients by starting a Transgender and Gender Diverse Patient and Family Advisory Council because we value patient and family feedback.

Mission of the Council: The Transgender Patient and Family Advisory Council is a group of transgender and gender diverse patients and their family members, who will provide ongoing feedback, guidance and recommendations to enhance the patient and family experience. The Council will provide URMC with first-hand knowledge from transgender and gender diverse consumers and their families, keeping the patient perspective and needs at the center of all improvement efforts.

Structure:

- Up to 20 members, with representation of patients, their families and URMC team members.
- Co-chaired by participating community members.
- Monthly meetings - 90 minutes (a meal or refreshments will be served).
- Best time and location to be determined.
- Interested members will participate in an interview process and will be asked to commit to serve for at least one year.

What will members be asked to do:

- Share personal insights and experiences.
- Listen with an open mind.
- Express their opinion collaboratively in a group setting.
- Provide constructive feedback on hospital initiatives.
- Provide input on ways to enhance the patient and family experience.
- Share a passion for improving healthcare!

For further information contact the **Office of the Patient Experience** at
585-275-8794



Projects

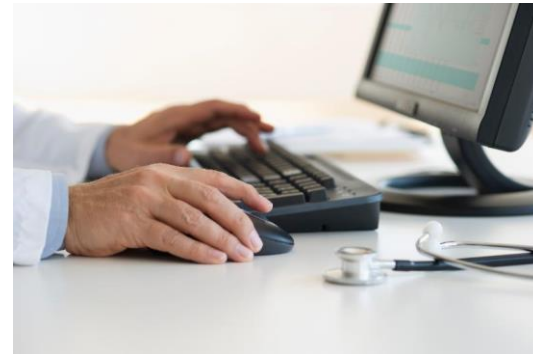
❑ Assisted with Operational eRecord Changes:

- removed gender markers
- affirming name - front and center
- overriding of default pronouns
- patients can change their pronouns in MyChart
- name changes

❑ Provided input:

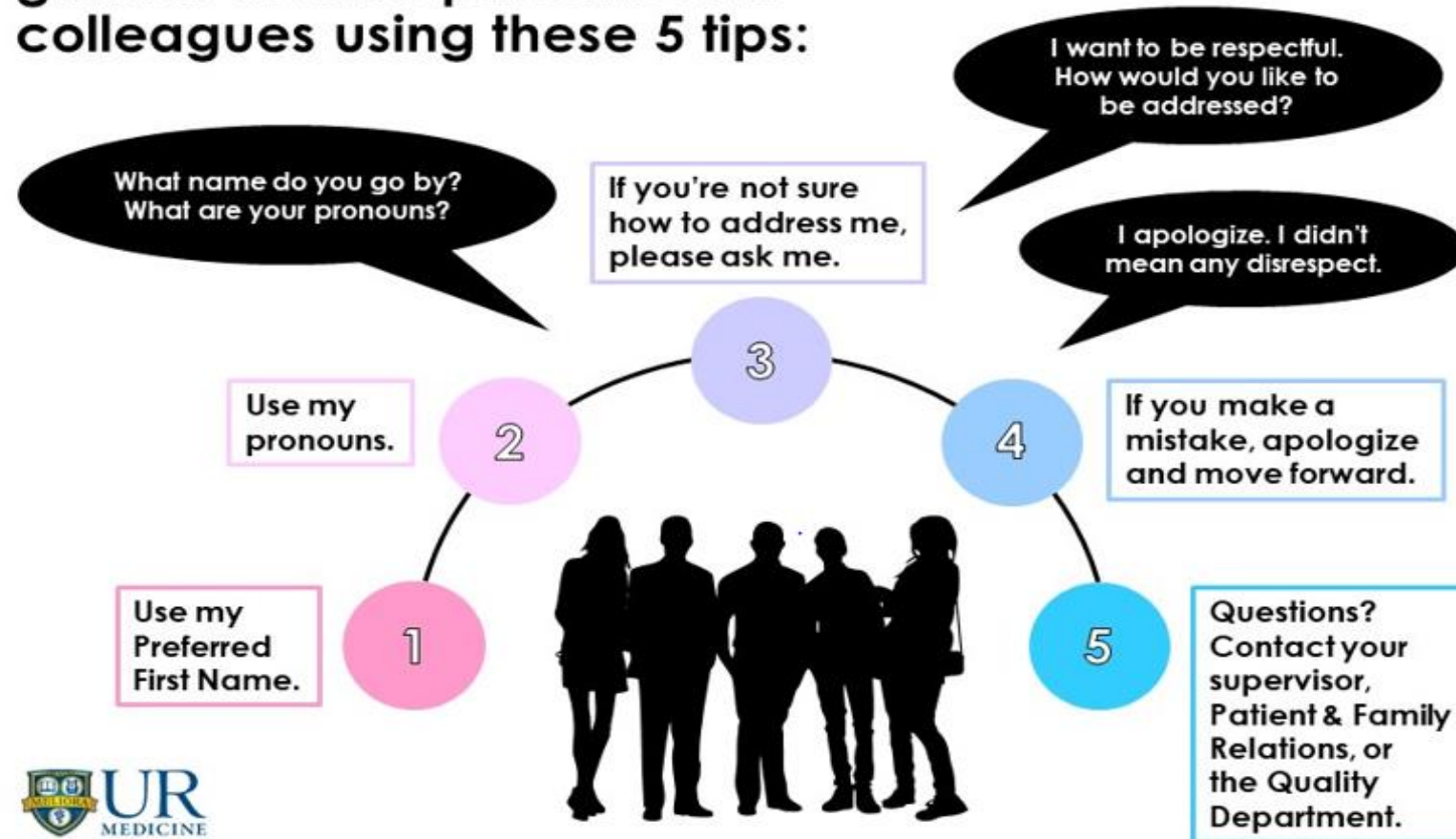
- on-line training module
- new name for Women's Health Clinic
- new rooming policy

❑ Wrote scenarios for guidance to accompany rooming policy



Educational Screensavers

Respect our transgender and gender diverse patients and colleagues using these 5 tips:





BLACK / AFRICAN AMERICAN PFAC

*Implemented in
Collaboration with Office of
Equity and Inclusion*

Getting Started

- ❑ Wanted input from the community beforehand
- ❑ Pulled together an Executive Group
 - Prominent members of the community
 - Asked “why now?”
 - Extremely supportive
 - Moved forward – needed good representation from this community
- ❑ Close collaboration with Office of Equity and Inclusion



Mission Statement

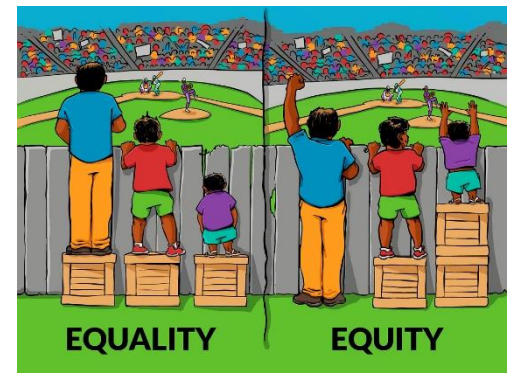
Our mission is to hold the University of Rochester Medical Center (URMC) accountable to Black and African American patients and families to ensure that they consistently receive compassionate, person-centered care from a workforce that is culturally competent and responsive. Further, we aspire to serve and heal those who have been disproportionately affected by Racism, poverty, and other forms of oppression. Building a culture of respect, safety, and advocacy for Black and African American patients and families will result in equitable patient care and positive experiences for all.

Providing Meaningful Input

- ❑ Reviewing Patient Experience Data by Race
 - analyzing the data through an equity lens
 - explore barriers and gaps
 - **working to improve methods/surveys for data collection**

- ❑ Re-imagining Public Safety
 - hired consultants to evaluate current status and propose recommendations for change

 - interviewed PFAC in detail to ensure patients' voice represented in their scope of work



Improving Access through MyChart

❑ MyChart Utilization and Education

- review of MyChart activation by race
- explored barriers within the community
- made recommendations for improvement



❑ Review of URMC Digital Health Literacy Initiative

- joined forces with PFAC to determine best approaches

❑ Compensation for Complex Medical MyChart Messaging

- looking at initiative through the health equity lens
- how best to convey the why, when, and how to patients

ED Patient Experiences

- ❑ Collaboration with ED Patient Relations Team
 - shared experiences and common themes
 - discussed ongoing issues of bias
 - potential plans for improvements
 - will utilize PFAC in action plan
 - meeting with ED Leadership

- ❑ Working on educational opportunities for staff



COMING TOGETHER IS A BEGINNING;
KEEPING TOGETHER IS PROGRESS;
WORKING TOGETHER IS SUCCESS.

HENRY FORD

[illegible]

Next as an Organization

- ❑ Expand our network of Councils
- ❑ Continue to build trust within the communities that face significant challenges with the healthcare system
- ❑ Assure equitable care through collaborative partnerships
- ❑ Develop better metrics to measure progress

Still have so much work to do...

Continue to LISTEN



I Encourage All of You

- ❑ Although hard work, some of the most rewarding
 - I can't begin to tell you how much I've personally learned from these individuals, who give so generously of their time, knowledge and expertise.
- ❑ Beyond humbling to work so closely with these remarkable Councils
 - Exciting to see trust begin to grow and silos broken down
- ❑ To achieve true equity in care and patient experience – we need to continue to change the way we do things, including how we engage our patients and families
- ❑ We need to fully understand the nuances between these populations and only by learning directly from those living these experiences, can we make the improvements needed...

Thank you.



Patient and family engagement: best practices for engaging patients and families in their care

Alvin Lin, VP Ambulatory Care Transformation and Innovation
SBH Health System

Tuesday, May 28, 2024

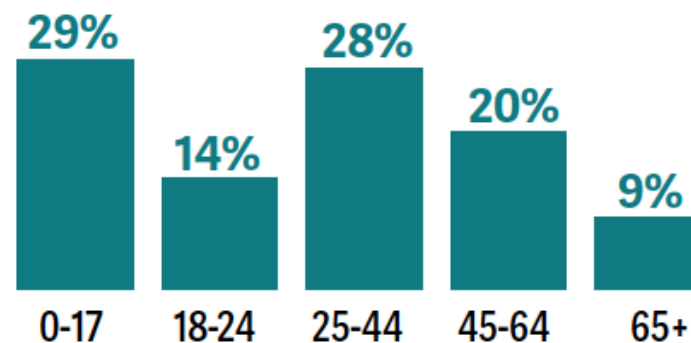
SBH Health System Overview

SBH Health System is a safety net community hospital serving the Bronx community.

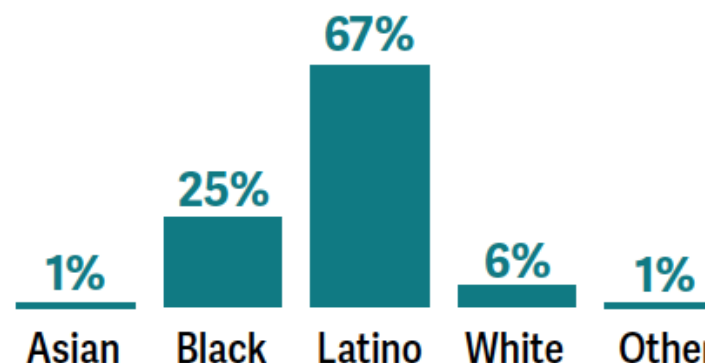
Statistics At A Glance

- 2500 Employees
 - 435 Licensed beds
 - 17,000 Hospital discharges
 - 88,000 Emergency room visits
 - 400,000 Outpatient visits
 - 160,000 Behavioral health visits
 - Payer Mix: 90% Medicaid/5% Medicare
-
- Founded in 1866
 - First US hospital for chronic diseases
 - Level 2 Trauma Center
 - Teaching hospital: 280 residents
 - NCQA NYS Patient Centered Medical Home

Population By Age

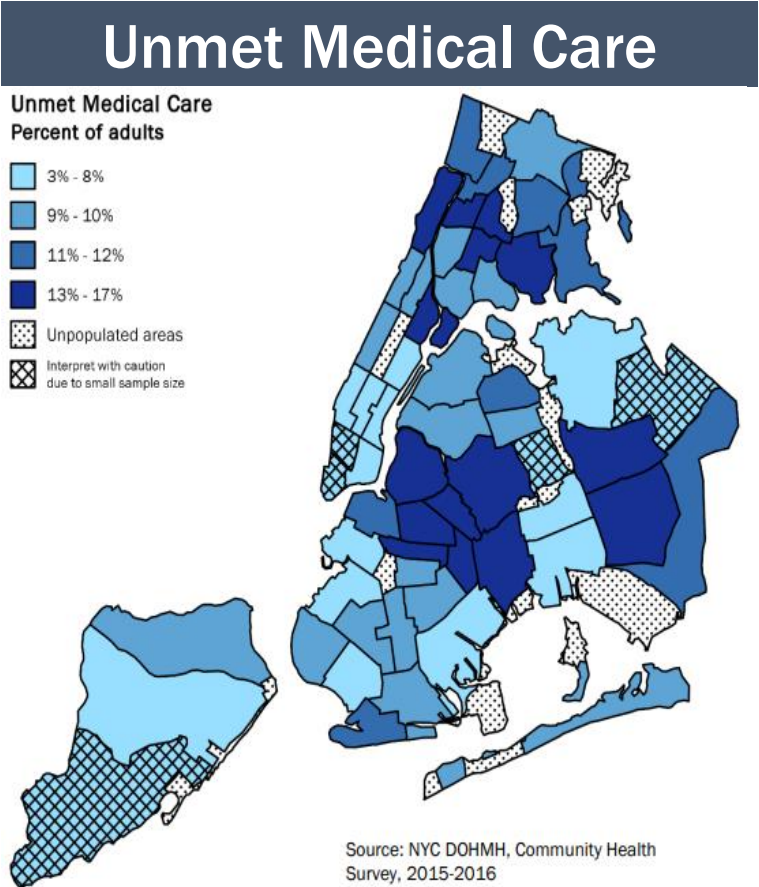
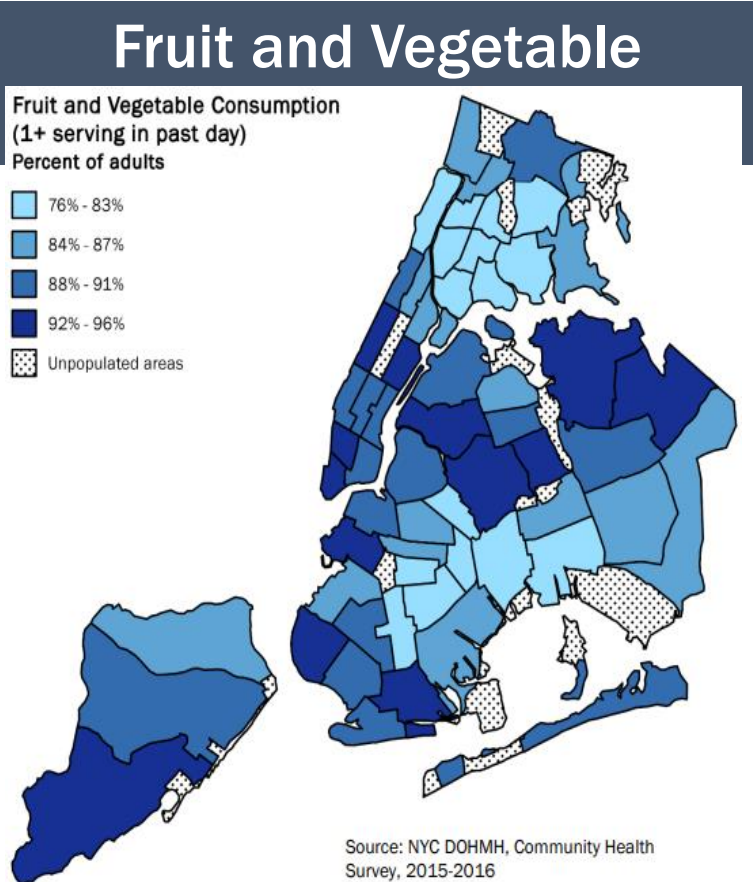
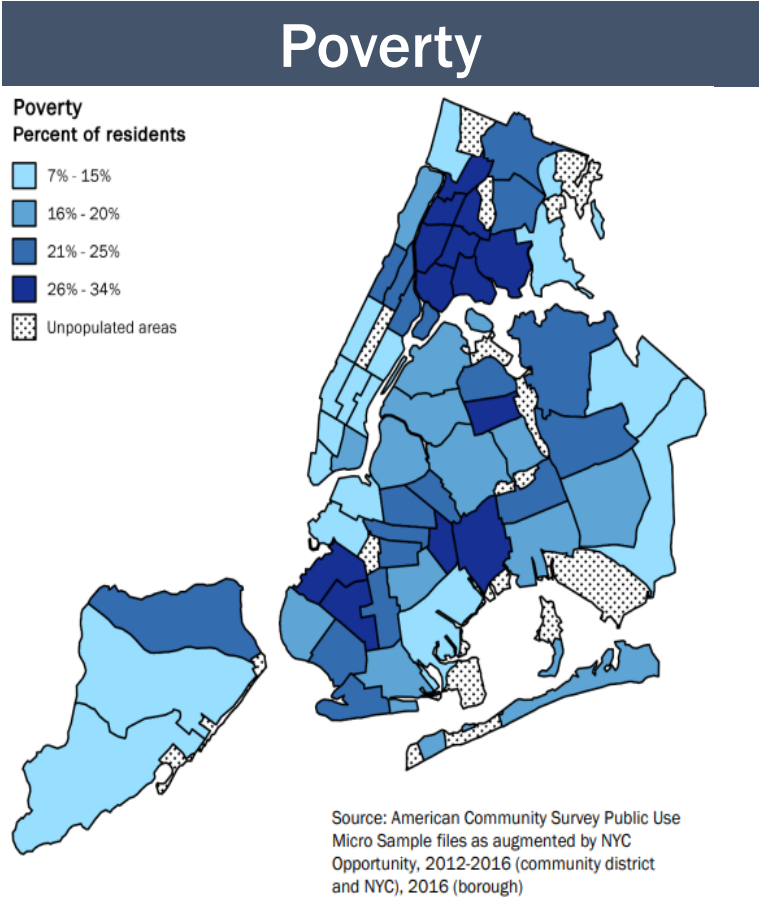


Population By Race / Ethnicity



Health Equity: Bronx vs. New York City Borough Comparison

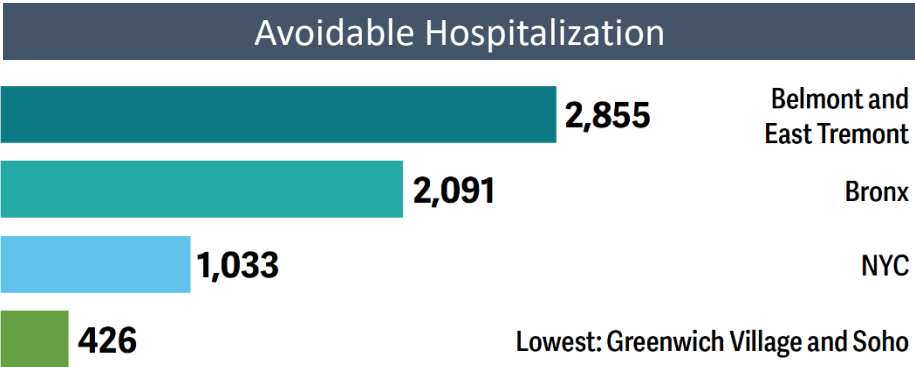
There is a large health disparity issue which is apparent when Manhattan (New York County) just across the Harlem River is one of the healthiest in the state.






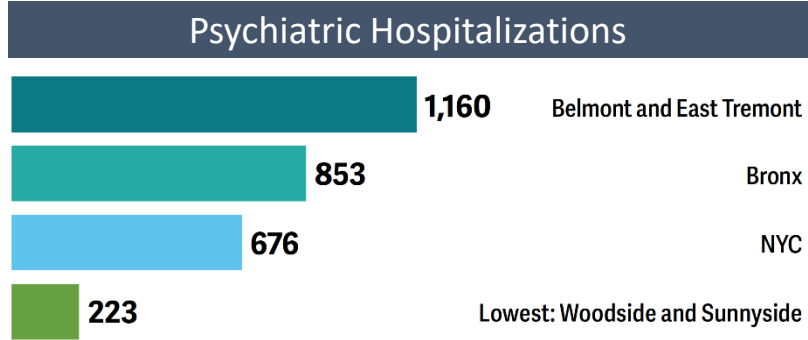
Health Equity: Belmont/East Tremont vs. Bronx Comparison

Our neighborhood is even more challenged when compared to other neighborhoods in the Bronx.

Economic Stress			
	Belmont and East Tremont	Bronx	NYC
Poverty (percent of residents)	31%	25%	20%
Unemployment (percent of people ages 16 and older)	16%	13%	9%
Rent Burden (percent of renter-occupied homes)	60%	58%	51%



Disease Prevalence			
	Belmont and East Tremont	Bronx	NYC
 Obesity	36%	32%	24%
 Diabetes	22%	16%	11%
 Hypertension	32%	36%	28%



Source: NYC Dept of Health and Mental Hygiene Community Health Profile: Belmont and East Tremont, <https://www1.nyc.gov/assets/doh/downloads/pdf/data/2018chp-bx6.pdf>

SBH Health and Wellness Overview

OUR MISSION STATEMENT

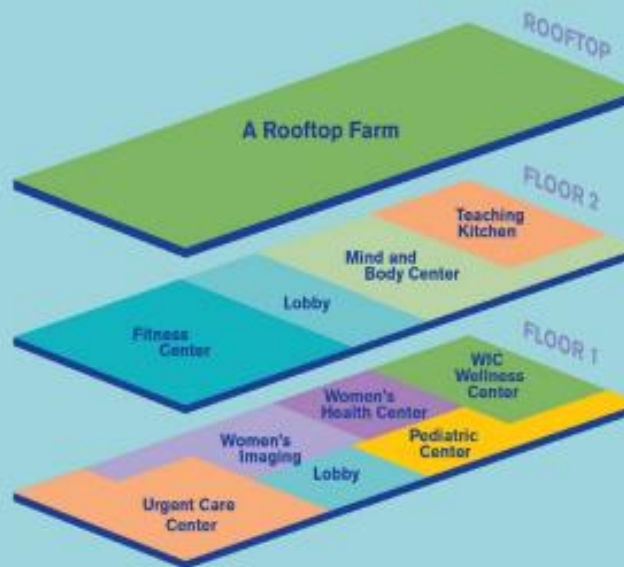
To develop an integrative health and wellness center which builds a culture of lifelong wellness and self-empowerment by offering innovative services and programs focused on prevention and healthy choices for the Bronx community.

THE PROJECT

This groundbreaking project will transform health care in the Bronx. The Health and Wellness Center at SBH will address food and housing insecurities, education, social support, and personal safety concerns – those social determinants that can ease the burden of the chronic diseases that plague our community.

The 50,000 square foot Health and Wellness Center at SBH is a part of mixed-use development that includes more than 300 units of affordable housing. The health and wellness space will feature:

- A fitness center
- A teaching kitchen that will be used as an education tool for community residents and healthcare providers



- An urgent care center
- Women's and children's health services
- A breast imaging center
- A rooftop farm

WHY IT'S SO IMPORTANT

A new paradigm is desperately needed in the Bronx. Consider the following:

- The Bronx ranks 62nd out of 62 counties in New York State in terms of health outcomes
- SBH serves a low income and ethnically diverse population with most of our patients covered by Medicaid or no insurance at all.
- The prevalence of preventable illness – obesity, asthma, diabetes and heart disease – are the highest in New York City, as is substance abuse, non-accidental trauma and behavioral health diagnoses.

HOW IT WORKS

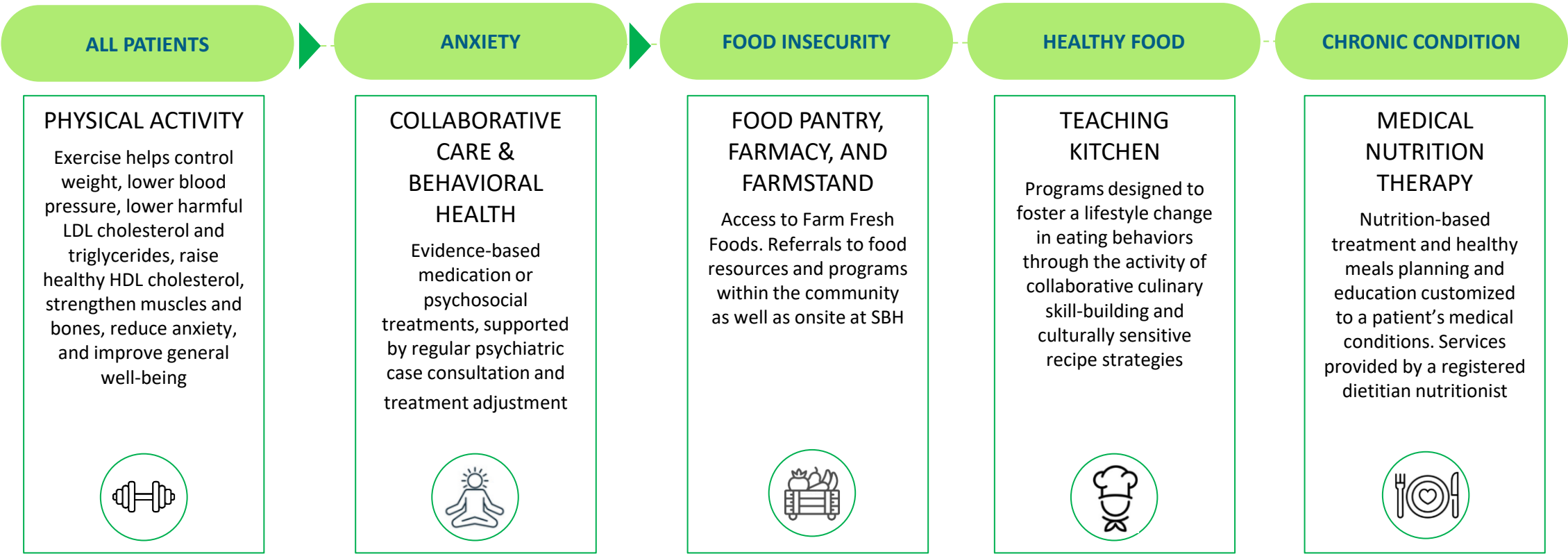
The transformation of health care in the Bronx depends on your help.

To hear more about our story, visit www.findthehealthieroneinyou.org



Incorporating Health and Wellness Programming Into Care Model

Our health and wellness programming combines culinary nutrition education with a medically-supervised exercise program. Our goal is to promote healthy, active lifestyles for members of the community with chronic conditions who experience barriers to food security.



Healthy Living Initiative



HANYS Collaboration: Healthy Food Education



PROJECT
E A T S
ART FOOD LIFE



HANYS Collaboration: Healthy Food Education



Healthy Living Initiative: Study Results

01

Strength Assessment

- ✓ Average strength improvements for lower body was 35%
- ✓ Average strength improvements for upper body was 30%
- ✓ 1.2% increase in skeletal muscle mass percentage
- ✓ 2.3% loss in fat mass percentage

02

Core Stability

- ✓ Patients performed front plank
- ✓ Average core stability improvements of 100%



03

Cardiorespiratory Assessment

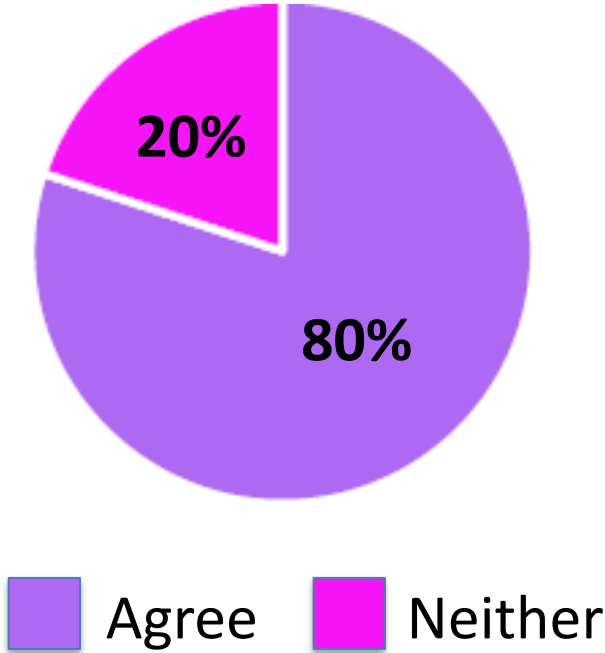
- ✓ Patients used the rowing machine
- ✓ Average cardiorespiratory improvements was 15%

04

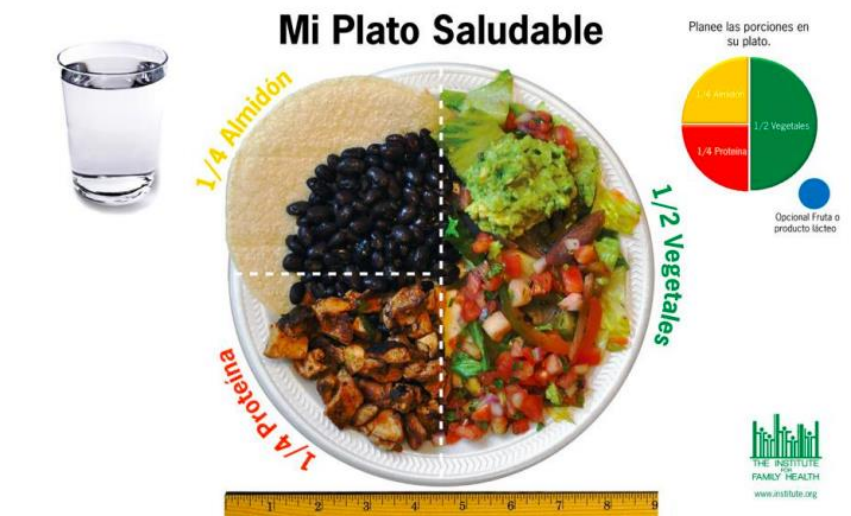
Healthy Food

- ✓ 52% would often select healthy ingredients at the supermarket (160% increase)
- ✓ 60% would often make a meal with vegetables (275% increase)
- ✓ 48% would often prepare fruits or vegetables to eat (500% increase).

Positive changes in my daily eating habit



Healthy Food Education



Mi Plan para Comer Saludable: Porciones Sugeridas

Escoja 1 almidón = 1 taza

Casabe (1 pedazo)	Cereal	Tuberos (3-4 pedazos)	Pan italiano (2 pedazos pequeños)
Manga	Avena	Plátano	Ensalada de papa
Arroz	Galletas de soda (5)	Pan integral (1-2 rebanadas)	Batata (1 mediana)

Escoja 2 o más vegetales = 2 tazas

Remolacha	Brócoli	Repollo	Zanahoria	Coliflor
Chayote	Pepino	Berenjena	Tierras verdes	Lechuga
Melondron/Quimbombó	Calabaza/Auyama	Pimiento rojo	Tomate	

Escoja 1 proteína = 4 onzas

Huichuelas (1/4 taza)	Carnes de res	Huevo hervido	Pollo	Queso bajo en grasa (2 onzas)
Pescado	Mantequilla de maní (1-2 cucharadas)	Nueces (1/4 taza)	Cerdo	

Opcional: Escoja 1 fruta o 1 producto lácteo = 1 pedazo pequeño o 1 taza

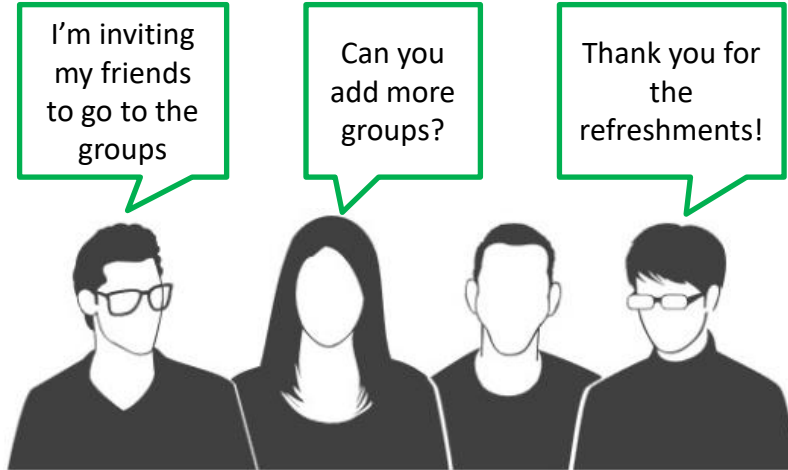
Banana	Mango	Lechosa	Piña	Leche 1%	Yogur de dieta o descremado
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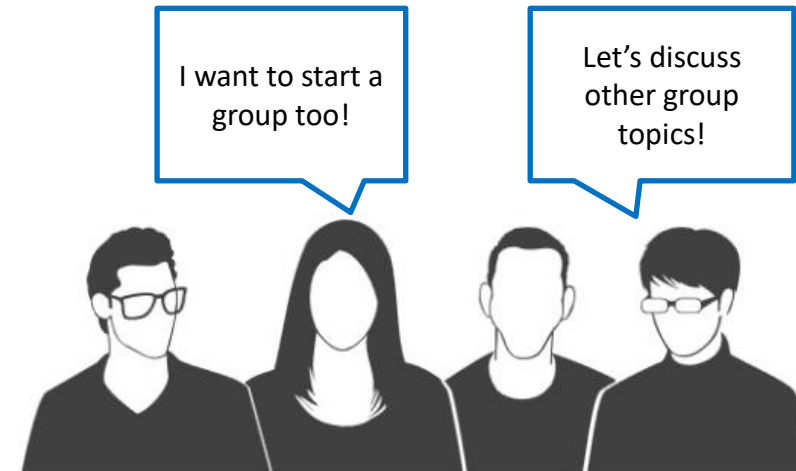


Addiction Medicine – Patients / Staff Asking for Group Sessions

Here are feedback from patients and staff on group sessions.



Patient Feedback



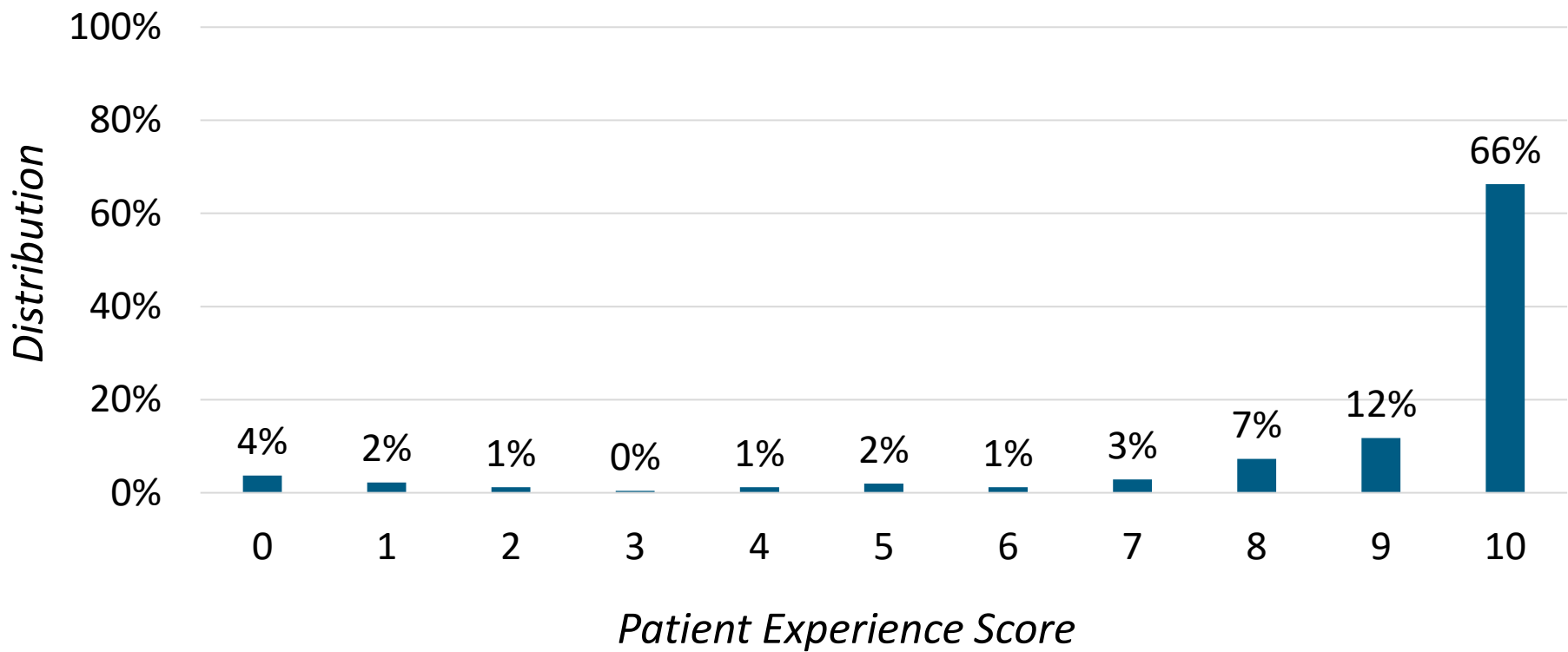
Staff Feedback

Patient Experience Survey After Every Visit

The average patient experience score for the baseline period is 8.74.

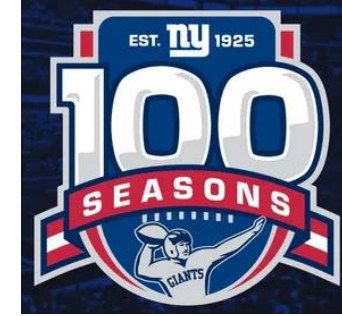


Baseline Patient Score Distribution



Source: NRC

NY Jets / NY Giants Football Camp with Bronx Middle Schools

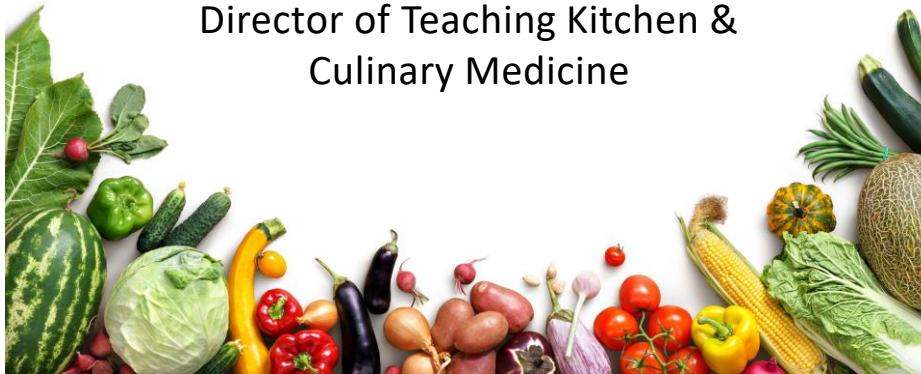


CHANGING THE CONVERSATION:

Culinary techniques to meet the needs of a client's diagnosis without sacrificing flavor for **Diabetes** and **Heart Disease**

Presented by:

Chef Abbie Gellman, MS, RD, CDN
Director of Teaching Kitchen &
Culinary Medicine



Learn how to make evidence-based nutrition education relatable to clients through “food talk”



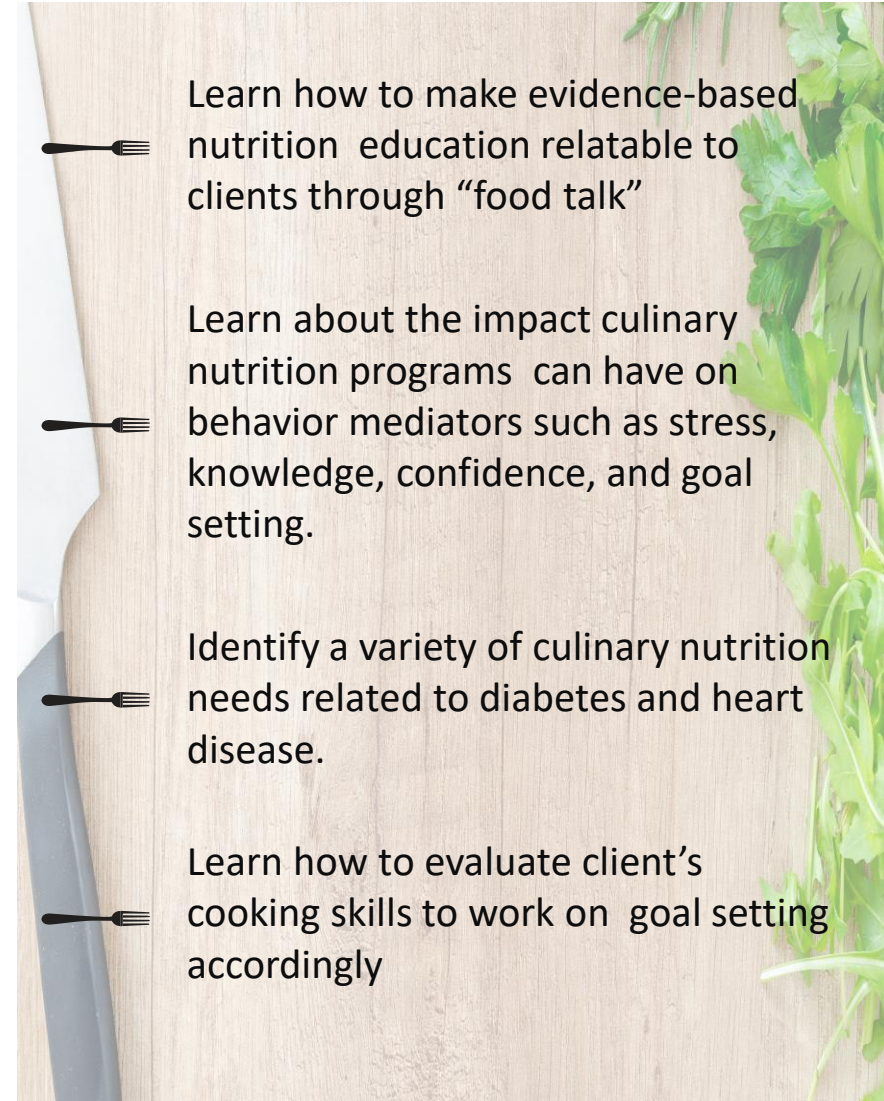
Learn about the impact culinary nutrition programs can have on behavior mediators such as stress, knowledge, confidence, and goal setting.



Identify a variety of culinary nutrition needs related to diabetes and heart disease.



Learn how to evaluate client’s cooking skills to work on goal setting accordingly



Contact

Alvin Lin

Vice President, Ambulatory Care Transformation and Innovation

SBH Health System

718.960.6836

alin2@sbhny.org

End of Year Showcase

December 3 & 5 | 9 a.m. to noon.

Our virtual showcase explores how AHEI hospitals are addressing disparities through targeted health equity work. Attendees learn how their peers are advancing health equity and how to apply these strategies to their own work.

Register [here](#).



ADVANCING HEALTHCARE
EXCELLENCE AND INCLUSION

Questions?

Morgan Black, MPA

mblack@hanys.org

AHEI Team

ahei@hanys.org