

Every Patient Deserves a Voice: Deaf, Behavioral Health and Transgender PFACs

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MEDICINE *of* THE HIGHEST ORDER



Objectives

- ❑ Learn how to create a successful Patient and Family Advisory Council focusing on giving a voice to specific patient populations
- ❑ Recognize the difficulties and challenges these, often marginalized, populations face throughout the healthcare system
- ❑ Identify best ways to fully engage diverse PFACs in ongoing improvement efforts
- ❑ Gain creative tools to help ensure a positive experience for the identified patient populations

Who We Are...



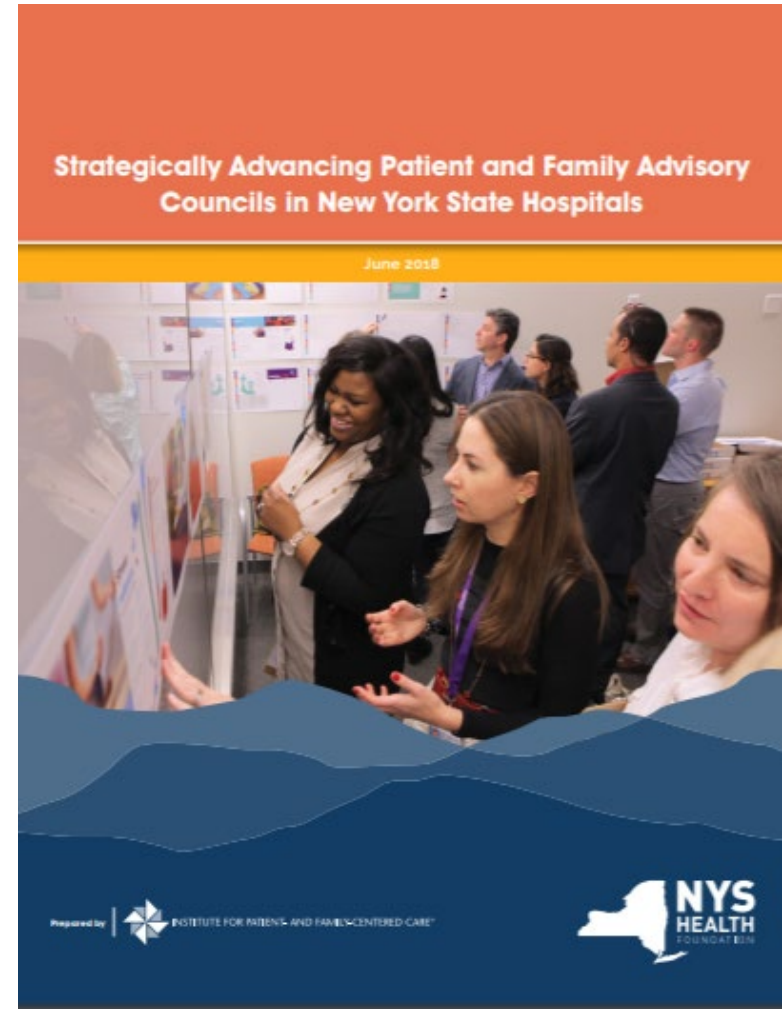
- ❑ Comprehensive health care delivery network in Upstate NY
- ❑ Anchored by Strong Memorial Hospital, an 850-bed, tertiary care academic facility
- ❑ Regional Trauma and Burn Center
- ❑ Only Comprehensive Stroke Center and Cardiac Transplant Program
- ❑ Regional Perinatal Center
- ❑ 40,000 discharges annually
- ❑ Daily occupancy routinely 100% - 112%
- ❑ 115,000 emergency visits per year
- ❑ 2.5 million outpatient visits per year



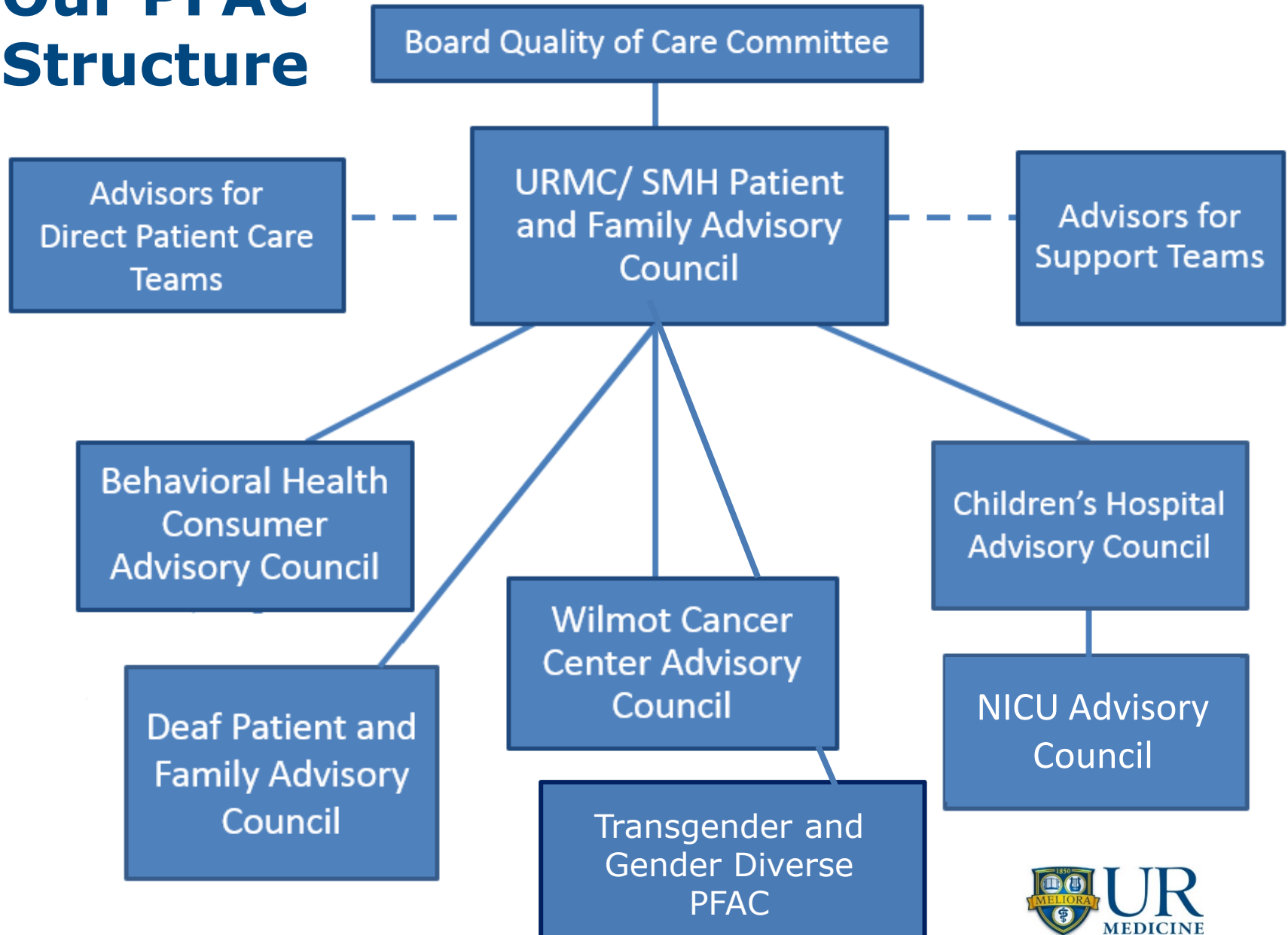
Long History of PFACs

- ❑ 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)*



Our PFAC Structure



Must Haves for a Successful PFAC

Leadership

- Need the right person (with thick skin and courage)
- Community partnership
- Engage your senior leadership

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 was given
- Publicly acknowledge and celebrate accomplishments

Influence

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

A Values-Driven Culture

- ❑ Revisit organizational values routinely

Inclusion

Integrity

Compassion

Accountability

Respect

Excellence



New Commitment



Inclusion:

I will embrace diversity, be an ally for others, and acknowledge the value that everyone's story brings.

- ✓ Be welcoming – invite everyone to be involved
- ✓ Address my own biases and behaviors – take responsibility for my actions
- ✓ Ask – don't make assumptions about others

Respect:

I will be open and accepting of others perspectives, and treat each person with dignity and cultural sensitivity.

- ✓ Treat all individuals fairly and equitably – always valuing personal identity
- ✓ Be courteous and friendly – to all colleagues, learners, patients, and families
- ✓ Speak positively – about colleagues, learners, departments, and the institution

Know Your Community

❑ **Largest Deaf population per capita in the country**

- We serve approximately 5,000 Deaf patients

❑ **Behavioral Health Facts**

- According to health survey conducted in the local region in 2018, 55% reported personally dealing with mental or emotional health issues
- We serve ~36,000 patients annually
- We provide ~300,000 Outpatient visits/year

❑ **Transgender Facts**

- Large LGBTQ population
- Estimated 60,000 transgender individuals in region

❑ **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 a higher incidence of chronic disease, short life expectancy and lower rates of good social, emotional and physical health.

I was extremely ill and told I couldn't have the first available visit because there wasn't an interpreter available. I was forced to wait an additional 3 weeks.

We waited for 3 days in the Psych ER to get our child admitted. It was awful for us and the staff.

In front of everyone the nurse asked me what people 'like me' like to be called

What These Patients are Telling Us

I was frightened after surgery and there was no interpreter there - I couldn't communicate with anyone at all!

There is no where for families to go when we have to leave the unit for safety reasons if a person is out of control. They send us out to wait by the elevators. This is scary and exhausting!

Even though I corrected staff 3 or 4 times, they repeatedly used my 'dead name', jeering as they kept mis-gendering me. Their rudeness was so blatant, I felt dismissed and totally unsafe. I will never go back!



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
- ❑ Monthly meetings – now zoom
- ❑ Further Deaf representation
 - Patient Engagement Committee
 - MyChart Operations Team
 - striving toward Deaf members on all PFACS



Video



Prioritizing Efforts

- ❑ 3 Areas of focus
 - Educational
 - Operational
 - Personnel/Staffing needs
- ❑ Address data limitations
 - Press Ganey surveys
 - Individual interpreter data
 - Deaf Culture



Added interpreter questions:

| | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 9. If you used an ASL interpreter, degree to which the interpreter helped you communicate with your caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. If you used other interpreters, degree to which the interpreter helped you communicate with your caregivers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Timeliness of response to your request for ASL interpreter services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Timeliness of response to your request for other interpreter services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Comments (describe good or bad experience): _____ | | | | | |
| _____ | | | | | |

Educational

- ❑ Appropriate terminology
- ❑ Sharing experiences - patient panels
- ❑ Screensavers:

Our Deaf Community

- Don't use the term "hearing impaired," this is offensive.
- Please use the terms "Deaf," "Deaf-Blind" or "Hard of Hearing."



- Ask me how I prefer to communicate instead of making assumptions

For more information, please contact the Office of the ICARE Commitment at 273-2215, or visit CultureVision™ online.

Operational Enhancements

- ❑ Improved timeliness of scheduling appointments
- ❑ Process to obtain patient feedback on individual interpreters
- ❑ Deaf Volunteer Visitation Program
- ❑ Communication Toolkit for Units/Departments
- ❑ 24/7 text message line for urgent interpreter needs
- ❑ Informational card with important interpreter services contact options

**Interpreter Services
Contact Information**

Monday-Friday 8AM-5PM
Voice: 585-275-4778
VP: 585-206-1922

24 Hours a day/7 Days a week
Text: 585-465-2565
Fax: 585-276-2856

Email: Interpreter_Services@urmc.Rochester.edu
Website: <https://interpreters.urmc.edu>



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

PATIENT MENU BREAKFAST DAILY SPECIALS

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

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.



YOU ARE why ICARE



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

COMMUNICATION ALERT



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

☐ ASL

☐ Deaf Interpreter

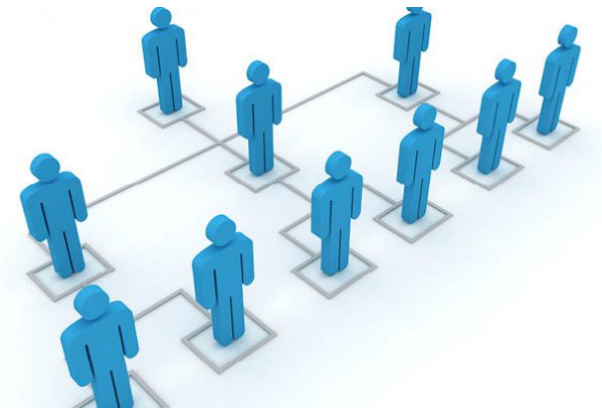
Interpreter Services 585-275-2222

Thank You! Remember: Effective Communication = Patient Safety



Personnel – Staffing Needs

- ❑ Single Patient Relations Contact
- ❑ New Deaf Social Worker
- ❑ Restructuring of Interpreter Services
 - additional interpreters hired
- ❑ PFAC members incorporated into interview process



Covid Brings New Challenges



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



Clear Masks are key

New Screensaver
underway to alert staff



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 C:

- COVID Visitation Policy
- URM C COVID Screening Process
- Safety updates and suggestions



What I've Learned

- ❑ The term hearing impaired is incredibly offensive
- ❑ ASL is its own language
 - not every Deaf patient speaks or reads English
- ❑ What is a Deaf Interpreter
- ❑ Understanding the Deaf culture
- ❑ We as hearing individuals are privileged



What's Next:

- ❑ Deaf Patient forum – hosted by the Deaf PFAC
- ❑ Interpreter Survey – produced in Sign Language
- ❑ Continuation of staff education
 - Grand Rounds
- ❑ Expand representation to include more diverse members!!!





BEHAVIORAL HEALTH...

*Department of
Psychiatry Advisory
Council of Consumers*

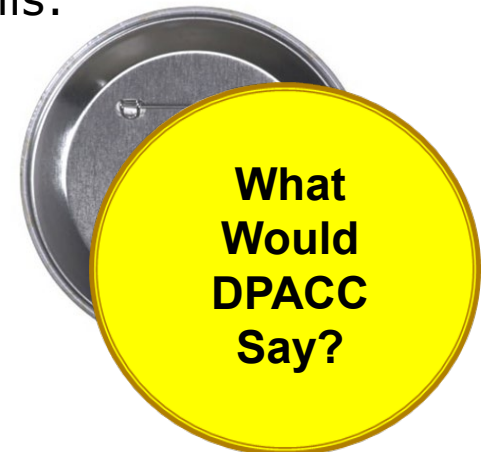
Listening to and learning from those we serve...



Background

In 2006, DPACC was initiated for Adult Ambulatory Services...

- ❑ First meeting, members let us know our focus was not their focus - so we changed. They were right!
- ❑ Broadened scope from narrow program perspective to continuum of care
- ❑ Ever since, their areas of focus have truly guided our PFCC initiatives.
 - Helped us understand importance of including their voice for guidance in all that we do
- ❑ Currently we have general DPACC and two sub-councils:
 - Family Advisory Board for C&A Psych Services
 - Strong Recovery Addictions Services
- ❑ Today members sit on Incident Review Committee and part of leadership interviewing process



Getting Started: Testing the Waters

-----Original Message-----

From: Nestro, Caroline

Sent: Wednesday, August 16, 2006 5:05 PM

Subject: Patient Advisory Council Member Recommendations Needed

Hello Everyone.

Please take a moment to consider whether or not you are currently working with a patient(s) who might have interest in being on an Ambulatory Patient Advisory Council. I'd like to have a first meeting of the Council in October and have already spoken with one consumer who is quite interested. If you identify anyone, please give them my office number so they can contact me and email me their names so I'll expect their call.

Here's an update on the process: The Ambulatory Leadership Committee is determining whether or not we'll have one larger council for all of Ambulatory Psych, a few site-specific councils, or a combination of both, e.g. quarterly or prn larger council meetings for the smaller councils to convene together if we're going to present/launch a major initiative that crosses all of Ambulatory.

Looking forward to hearing from you!
Caroline

P.S. FYI Amb. Leadership: I'm just seeking names from General Ambulatory staff in this email.

Subject: RE: Patient Advisory Council Member Recommendations Needed

Hello Again.

I have so far had contact with 3 enthusiastic individuals who are interested in becoming members of our Advisory Board (thanks [REDACTED]). We're aiming to have the first meeting in October but would like to have more members before we set a date. If you haven't already, please discuss this opportunity with some of your patients who you think might be interested and who would be able to help us get this off the ground. Give them my name and number (275-7418) and ask them to give me a call. Follow-up with an email to me with their name so I can expect their call.

We are now opening this up to all of our Adult Ambulatory Programs (not just General Adult) so if you'd like to send a rep from your program please do! For DWC patients who might be interested, I'm happy to correspond with them via email, TTY or relay (let me know your rec depending upon which patients might be contacting me). Program leadership, please forward this to your staff if there's interest in joining this effort.

Thanks!
Caroline

Current DPACC Membership & Member Criteria

Consumers(10)

Family Members(7)

Staff Members(3)

- ☐ Adults 18 and over
- ☐ Present or past recipient of our services
- ☐ Variety of mental health concerns
- ☐ Recommended for Council by a treatment team member or DPACC member
- ☐ Have or had a family member/significant other utilize our services
- ☐ Interest in advocacy and/or are concerned re: care quality

DPACC members need to have:

- The ability to share personal experiences in ways that others can learn from them.
- The ability to see the bigger picture.
- An interest in more than one issue.
- The ability to speak candidly in a group.
- The ability to listen and hear other points of view.
- The ability to connect with people.

From J. Conway, B. Johnson, S. Edgman-Levitan et al. (2006)

"Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System:
A Roadmap for the Future, a Work in Progress"

Benefits of Partnering with Patients and Families

We partner with patients and families in four general ways:

1. At the Individual Experience Level*
2. At the Practice & Policy Level
3. At the Community Partnership Level
4. At the Research Level

We have found that all levels are expedited through our patient/family advisory council partners.

These ways of partnering mirror our four core mission areas:

Clinical Care, Education, Research, and Community.

* Learning from patient/family reports of their experiences of us has offered many benefits. This differs from the “patient story” aimed at increasing our understanding of addiction or mental illness. Their stories in this instance reflect upon our care.

Accomplishments Include:

- ❑ Input provided on:
 - Discharge Instruction
 - Inpatient Treatment Plan
 - Treatment Agreement
 - Job Descriptions for Peer and Family Advocates
- ❑ Sensitive and Informative Signage
- ❑ Respectful Letters
- ❑ Parking Process Improvements
- ❑ Ceiling Mirrors, Tissues in rooms
- ❑ CPEP Suggestions for Therapeutic Milieu
 - Waiting Area Improvements
- ❑ Advocacy for Integrating Peer and Family Support

Informing patients & families about comfort items...



CPEP Patients and Visitors

We generally have the following items available to you. Please let staff know if you would like any of the following:

| | |
|-------------------------------------|---------------------------|
| FOAM EARPLUGS | BLANKETS |
| LIMITED SNACKS/BEVERAGES | PHONE AVAILABILITY |
| READING MATERIALS | GAMES/CARDS |
| LIMITED PERSONAL CARE ITEMS | TISSUE |
| HOSPITAL MAPS/DIRECTIONS | TOYS/ACTIVITIES |
| NICOTINE REPLACEMENT OPTIONS | |

If there is anything else that would be helpful to you, please let us know and we will do our best to accommodate you.

Helped 'soften' look of barrier-resistant doors



Family Lounge

sponsored by

Ronald McDonald House Charities of Rochester



- The 1st of its kind in the nation
- Grand Opening on 11/5/18
- Departmental Support
- Support from Friends of Strong
- Helped you feel more relaxed and rested
 - 67% strongly agree; 30% agree
- Enabled you to be better able to provide support to your child
 - 77% strongly agree; 17% agree



Advocacy for Comprehensive Psychiatric ED

- ❑ Letter sent to Leadership regarding need for more staffing to:
Increase efficiency; lessen wait times; improve quality of service

While commending CPEP's efforts to develop innovative and integrated care operations, there absolutely must be increased staffing within the CPEP unit. This increase in staffing must be prioritized as critical.

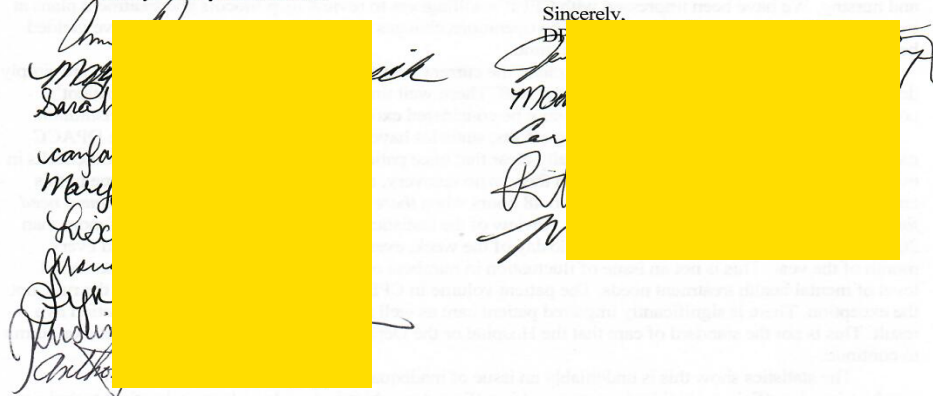
Based on discussions with CPEP about its shifts, staffing and patient volumes, it is clear in order to maintain basic clinical care, for the patients, their families and the community, the Unit must be staffed, for each 8 hour shift with:

**2 Psychiatrists
3 Psychiatric Social Workers
7 Psychiatric Patient Care Technicians
8 Psychiatric Nurses**

DPACC remains dedicated to the Hospital, the Department of Psychiatry and their patients and families. DPACC's commitment to support you, the staff, and the best care through CPEP remains "Strong".

Thank you for your attention.

Sincerely,



cc: Susan Parks McNally, URM Board Member
Mark Pagano, Director of Finance, SMH Psychiatry
Carole Farley-Toombs, Sr. Program Administrator, SMH Psychiatry
Jacqueline Beckerman, Sr. Director for Patient Experience, Director, Strong Commitment
Kristi Stockwell, CPEP Program Director, Sr. Social Worker
Aurelian Niculescu, CPEP, Medical Director, M&D Crisis Services

Education Highlights

- ❑ New Psychiatric Nursing Staff Orientations
- ❑ Professional & Academic Development Seminar for Postdoctoral Psychology Fellows
- ❑ Nazareth College Social Work Class
- ❑ Medical Student Practice Sessions
- ❑ Departmental Grand Rounds Presentations



Video





OUR TRANSGENDER COMMUNITY

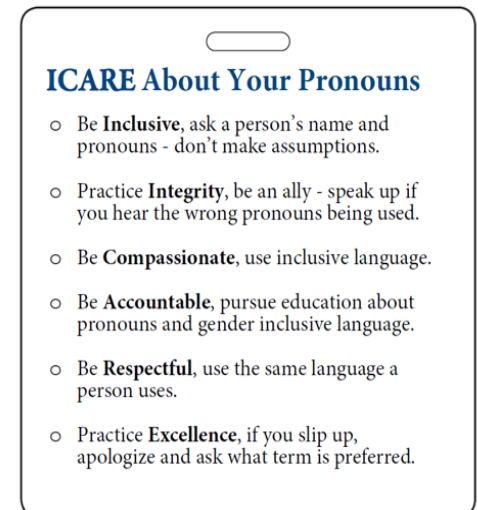
*The Transgender and
Gender Diverse Patient
and Family Advisory
Council*

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:



TRUST IS EARNED WHEN
ACTIONS MEET WORDS.

~ Chris Butler ~

Recruitment

- ❑ Been a challenge getting transgender patients to join
- ❑ Transgender facilitator reached out to community organizations
- ❑ Parents of transgender children
- ❑ Currently:
 - 6 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!

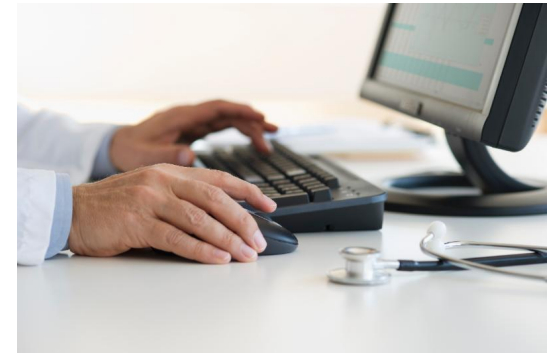
For further information contact the **Office of the Patient Experience at**
585-275-8794

Video



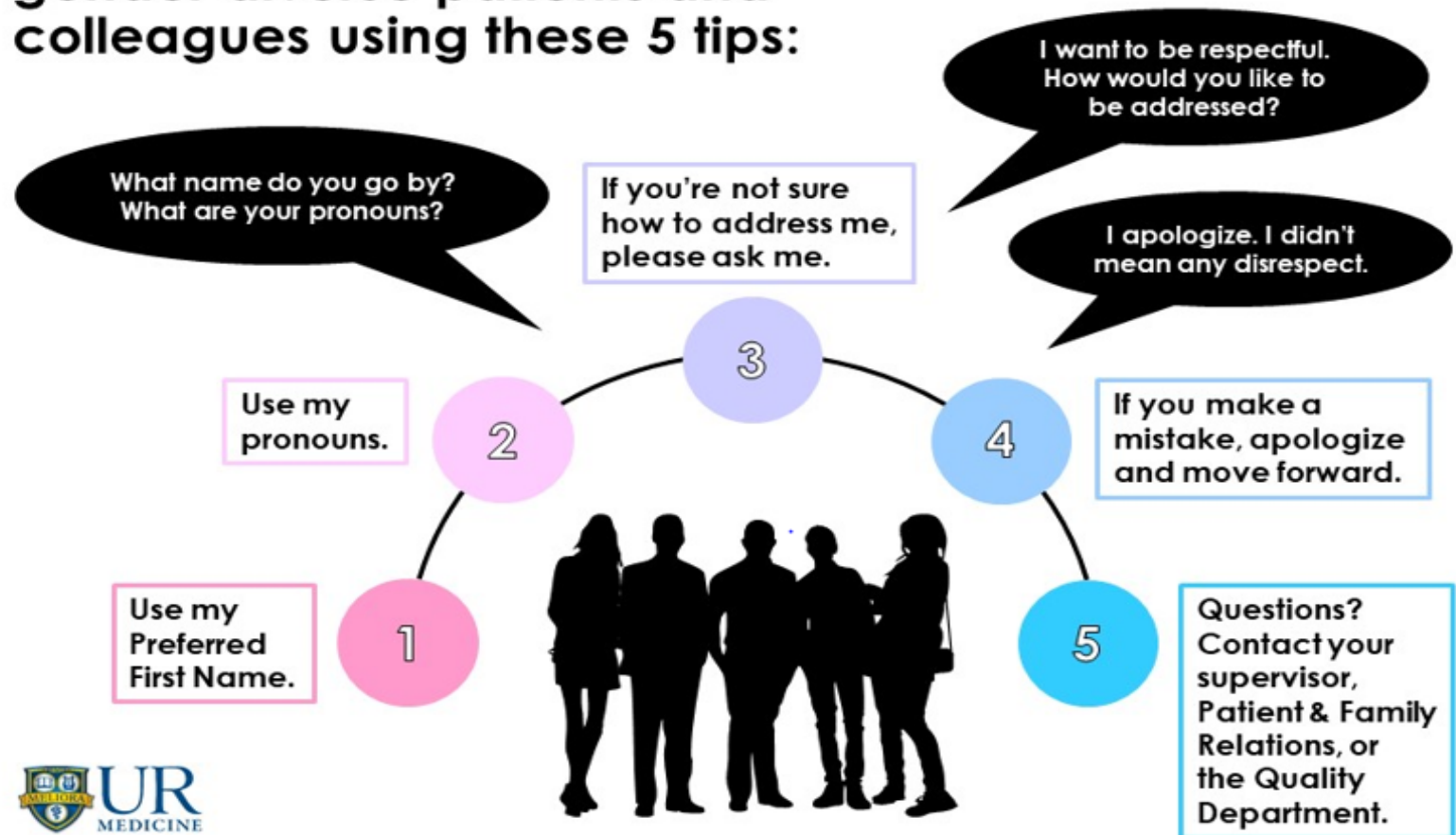
Projects

- ❑ Assisted with Operational eRecord Changes:
 - removed gender markers
 - preferred name - front and center
 - overriding of default pronouns
 - 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
- ❑ Created educational screensaver



New Educational Screensaver

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



What's next

Hello,

May this email find you well. As you may already realize, we are approaching our one year mark since the PFAC has been up and running. This year we have discussed infographics, rooming policies, language do's and don'ts, pronoun tags for staff to wear, and so many other important conversations.

As we approach the start of year two, we felt it important to learn from each of you your thoughts and feedback to help plan how we move forward. We want to understand from you what you need from this group to feel supported and heard, what agenda items may be of value to you moving forward, and where we've dropped the ball and could have done better. Ultimately, we want to check in and learn from you what matters most, because you are what matters most.

With all that said, I would like to invite you to a discussion via email, phone, zoom, or in-person. If you are comfortable with having a discussion, please respond with your availability and method of meeting preference so we can schedule a time. Make sure not to "respond all" to be respectful of others and not bulking up their mailbox.

I look forward to hearing from you so we can schedule something soon!

Sincerely,

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

HENRY FORD

Tips for Success and Sustainability

- ❑ Co-Facilitation for effective follow-through
- ❑ Engage Leadership
 - reminding leadership about their helpfulness
- ❑ Assure opinions are valued and acted upon
 - show them they are making a difference
 - acknowledge and celebrate what was accomplished
- ❑ Ongoing recruitment
- ❑ Not enough to invite to table, need to engage their participation
- ❑ Think out of the box
- ❑ **They help in more ways than we imagined...**



Next as an Organization

- ❑ Expanding the diversity on all of our PFACS – number one priority
- ❑ Exploring the creation of a Diversity, Equity and Inclusion PFAC
- ❑ Continue to identify metrics to measure progress
- ❑ Still have so much work to do...



Thank you.

