

Building Partnerships with Patients and Families to Improve Care

PCPCC Support and Alignment Network
Institute for Patient- and Family-Centered Care
September 11, 2018







Today's Speaker





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Senior Policy and
Program Specialist





Objectives

- Create common understanding of patient- and family-centered care
- Explore person and family engagement metrics and strategies to achieve them
- Learn about ways to engage patients and families in improvement work
- Discuss Colorado Retina
 Associates opportunities to
 partner with patients and families



Shared Goals: Meet the TCPI Aims



- 1 Support more than 140,000 clinicians in their practice transformation work
 - Improve health outcomes for millions of Medicare, Medicaid and CHIP beneficiaries and other patients
 - Reduce unnecessary hospitalizations for 5 million patients
 - Generate \$1 to \$4 billion in savings to the federal government and commercial payers
 - Sustain efficient care delivery by reducing unnecessary testing and procedures
 - Transition 75% of practices completing the program to participate in Alternative Payment Models
- Build the evidence base on practice transformation so that effective solutions can be scaled





The PCPCC SAN: What We Do

Primary Care
COLLABORATIVE

We promote deeper patient relationships and community engagement among care teams through technical assistance and other resources.

We offer the TCPI Community of Practice:

- Virtual and in-person learning events
- Scholarships to conferences and training events
- Coaching sessions for patient advisors and practices
- Choosing Wisely resources

- Expert faculty in the field of patient advocacy and community health to PTNs
- Online tools and resources
- PFCC.Connect: A virtual community for patient partners

Visit PCPCC for tools and Resources: http://www.pcpcc.org/tcpi





PCPCC SAN Message





Person and family engagement is a core element of effective and efficient clinical care.

When people and their families are engaged to become partners in health, it drives better outcomes, reduces costs, and improves clinician satisfaction.



Value of the SAN: We support PTNs and clinicians to develop person, family, and community engagement capability as a transformative activity and as a tactic to meet cost and quality goals.



Opportunity: PTNs can use SAN assets to accelerate initiatives targeting cost and quality improvement. It's not "another thing to do."

TCPI PFE Metrics are integrated into PTN transformation strategies to improve adoption among targeted practices.









A Strategic Framework



https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Pers on-and-Family-Engagement.html





- Patient- and Family-Centered Care
- Person and Family Engagement
- Patient Experience



Principles of PFCC

Dignity and Respect

Information Sharing

Participation

Collaboration





- Planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships.
- Engages patients and families at direct care and operationall levels to improve outcomes, reduce harm, and enhance experiences.
- Promotes empathic relationships that seek to understand "what matters".







Patient- and family-centered care is working "with" patients and families, rather than just doing "to" or "for" them.



Why Patient- and Family-Centered Care and not just Patient-Centered Care?

Individuals, who are most dependent on health care,

are most dependent on families...

The very young;

The very old; and

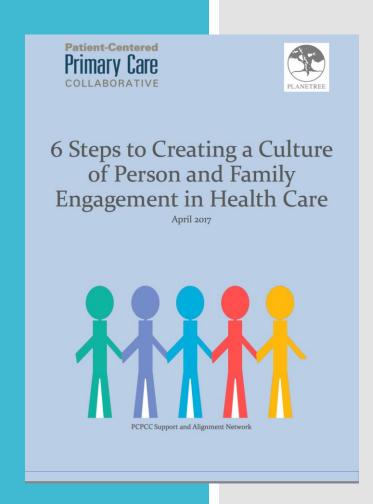
Those with chronic conditions.



Families can be allies for quality and safety; they often are the constant support across settings and assist with transitions of care. They can participate in the development of a care plan and support the patient in following the plan.



A Practical Resource: Continue the Conversation



www.pcpcc.org/resource/6-steps-creating-culture-persons-and-family-engagement-health-care

'Blockbuster Drug' Patient Engagement

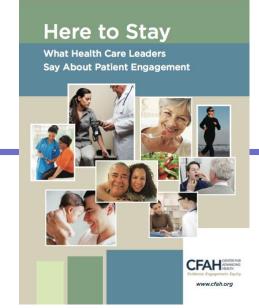


"Engagement broadly defined is an

active partnership

among individuals, families, health care clinicians, staff, and leaders to improve the health of individuals and communities, and to improve the delivery of health care."

Patient Engagement



"...actions individuals must take to obtain the greatest benefit from the health care services available to them."

Center for the Advancement of Health, 2010

http://www.cfah.org

http://www.cfah.org/fileCFAH_PACT_WhitePaper_current.pdf



Cindy's Story

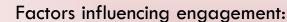
"Actively Engaged in Her Health"





Continuum of Patient Engagement

Depth of Engagement Partnership & Consultation Involvement **Shared Leadership** Co-Given **Asked** creates Info ?'s plan Co-**Provides** leads Survey input change



- Patient (beliefs about their role, health literacy, education)
 - Organization (policies and practices, culture)
 - Society (social norms, regulations, policy)







Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel and Jennifer Sweeney Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies doi: 10.1377/hlthaff.2012.1133 Health Affairs 32, no.2 (2013):223-231

Extensive Evidence on PFE



DISCUSSION PAPER

Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care

Susan B. Frampton, Ph.D., Planetree; Sara Guastello, Planetree; Libby Hoy, PFCCpartners; Mary Naylor, Ph.D., F.A.A.N., R.N., University of Pennsylvania School of Nursing; Sue Sheridan, M.B.A., M.I.M., D.H.L., Patient- Centered Outcomes Research Institute; Michelle Johnston-Fleece, M.P.H., National Academy of Medicine

January 2017

ABSTRACT | Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in partnership with patients and their families (as defined by the patient) in a way that integrates their preferences, values, and desired health outcomes. This vision represents a shift in the role patients and families play in their own care teams, as well as in ongoing quality im-





Compelling Evidence

- Improvement in staff experience, retention, reduction in job stress and burnout
- Improved transitions of care, decrease in unnecessary readmissions
- Increased patient and family success in self- management, improved quality of life, reduced illness burden
- Reduced rates of hospitalization, emergency room utilization, shorter LOS and cost per case



Download for free at NAM.edu/PFEC

Person and
Family
Engagement
Performance
Metrics

Governance

 Support for Patient and Family Voices

Point of Care

- Shared Decision Making
- E-tool Use

Policy and Procedure

- Patient Activation
- Health Literacy Survey
- Medication Management



Support for Patient and Family Voices

Are there policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making of the practice (Patient and Family Advisory Councils (PFAC), Practice Improvement Teams, Board Representatives, etc.)?

Intent: The intent of this metric is to include the perspective and voice of the patient and family in all aspects of the governance/operation of the practice.



Key Lever for Transformational Change

In a growing number of instances where truly stunning levels of improvement have been achieved...

Leaders of these organizations often cite—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.



Reinertsen, J. L., Bisagnano, M., & Pugh, M. D. Seven Leadership Leverage Points for Organization-Level Improvement in Health Care, 2nd Edition, IHI Innovation Series, 2008. Available at www.ihi.org

Have you considered...

Inviting patients and family to participate on an improvement team?

Establishing a Patient and Family Advisory Council?

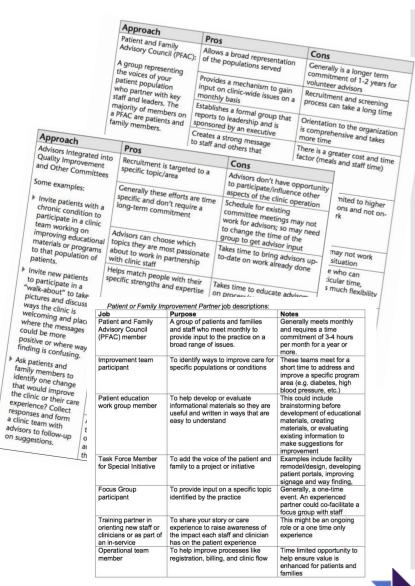
Inviting advisors to walk through the clinic and share observations of what engages them and what is not welcoming and supportive of their participation?

Polling patients and families about a change you are considering?

Seeking input on educational or informational materials?

Support for Patient and Family Voices





Patients and Family as Implementation Partners

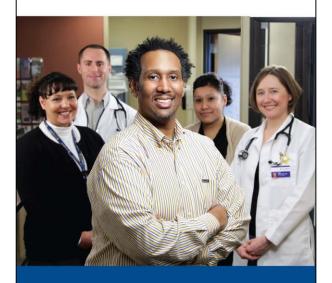




Patient-Centered Medical Home Brochure

- Created in partnership with Patient & Family Advisors, Providers, Health Educators
- Language is understandable, translated into 5 languages, has patients individual clinic information on the back





Your care Your voice Your team

Your Providence Patient-Centered Medical Home



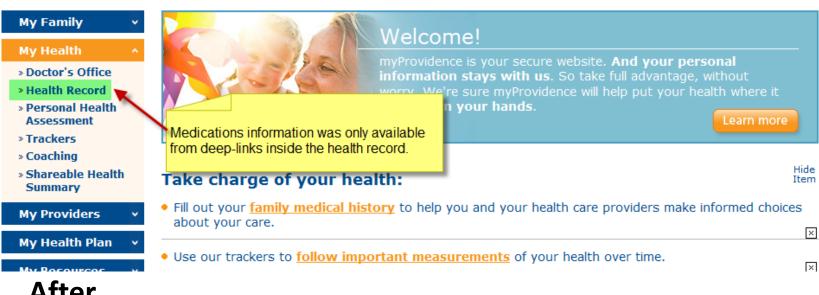


Access to Medications Info

PROVIDENCE

Medical Group

Before







Working in Partnership across Sites

Executive PFAC chartered subcommittee

Clinic PFAC members recruited to serve on subcommittee

Poster created out of subcommittee work to be used system-wide

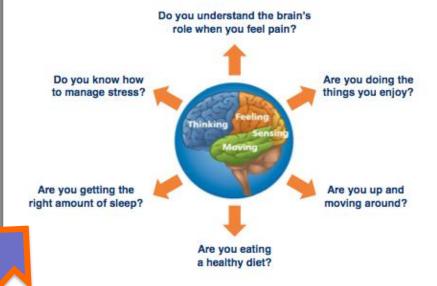




Many Things Affect Your Pain

Pain is complex and everybody experiences pain differently.

Here are some things to consider to help you reduce your pain:



Medication is only one part of your care plan.

Talk with your medical home care team about options for changing your pain experience.



Outcomes and Benefits

- Health care professionals & staff make fewer assumptions about what patients or families "want."
- Advisors "see things differently" and ask "why do you do it this way?"
- Advisors challenge what's possible.
- Patients/Families are motivators provide hope and dampens cynicism
- Reduces burden for healthcare team
- Creates better tools to meet patient needs and "activate" patients as full partners
- Provides information to help make better business decisions
- Broadens perspectives acting into new ways of thinking





Shared Decision Making

Does the practice support shared decision-making by training and ensuring that clinical teams integrate patient-identified goals, preferences, outcomes, and concerns into the treatment plan (e.g. those based on the individual's culture, language, spiritual, social determinants, etc.)?

Intent: The intent of this metric is to ensure that patients (and their families according to patient preference) are authentically part of the care team.

Shared DecisionMaking – Individual

- Set the stage by understanding and documenting patient preferences:
 - Preferred language
 - How to receive information
 - About loved one's involvement in care
- Invite patient participation
 - What are your priorities today?
 - What matters to you about this new diagnosis?
- Encourage family member presence at medical appointments
- Offer options in treatment approaches
- Show appreciation for their active participation

Study of
Communication
in
Outpatient Visits

When patients achieved common ground with physicians, health status improved, emotional health improved, fewer referrals and diagnostic tests needed two months after the visit.

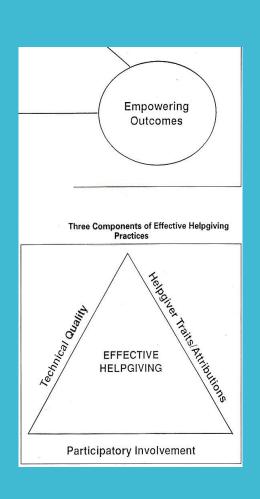
Stewart, M. A., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W., et al. (2000). The impact of patient-centered care on outcomes, *Journal of Family Medicine*, 49(9), 796-804.

Family Presence at Medical Appointments

Improved Outcomes

Medicare study compared experience of care for patients accompanied by family to unaccompanied patients. Positive observations included:

- Health care providers engaged in more biomedical information giving.
- Family facilitated communication, provided information on medical needs or conditions, helped explain physician instructions.
- Patients were more highly satisfied with physician's technical, information giving and interpersonal skills even though they had worst self-rated health.



Effective help giving is not simply a matter of whether the individual's needs are met, but is in the manner in which they are met.

Primary Care COLLABORATIVE

Studies have shown that 40-80% of the medical information patients are told during office visits is forgotten immediately, and nearly half of the information retained is incorrect.

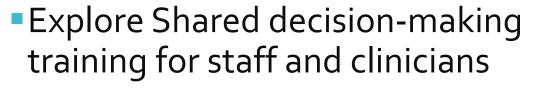
Communicating Via Decision Aids

A 2011 analysis of 86 randomized clinical trials concluded that decision aids make patients better informed, improve communication with doctors, and increase participation in decisions about their care.

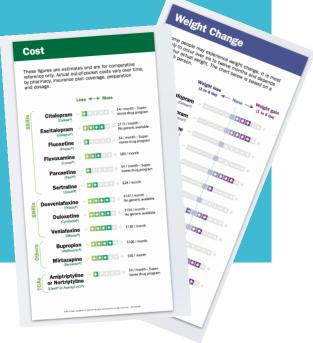
Stacey, D., et al. Decision aids for people facing health treatment or screening decisions. Chochrane Database Syst Rev, 2011.



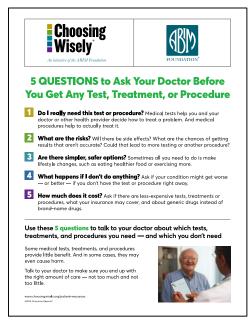
Shared DecisionMaking – Clinic Readiness

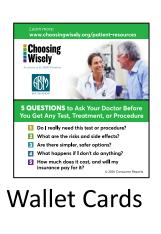


- Determine your top 3 clinical conditions
- Research available shared decision-making tools
- Invite patients and family with lived experience to share it and provide input about tools under consideration
- Develop a sustainable process that outlines team roles



Questions to Ask your Doctor: Several resources with similar messaging, and all easy to use.











Videos



Brochures / Posters



Inviting Patient and Family Participation

Patients and families bring insights about:

- How to introduce practice changes to better engage others
- What Choosing Wisely tools are most useful to them
- Where to place materials/tools to increase visibility
- Which messages will build shared decision-making partnerships
- How to evaluate success of implementation



Primary Care

Implementation
 of
Choosing Wisely
 with
 Patient and
 Family
 Participation

Inviting Patient and Family Participation in Implementation of Choosing Wisely® Tools

The mission of Choosing Wisely (CW) is to promote conversations between clinicians and patients that help patients choose care that is supported by evidence, not duplicative of other tests or procedures already received, and free from harm.

Participating clinicians have identified more than 540 tests, treatments, and procedures that are unnecessary and performed too frequently. The Choosing Wisely website www.choosingwisely.org has many tools available to support these important conversations with patients and their families.

QUESTIONS TO CONSIDER WHEN IMPLEMENTING CHOOSING WISELY

- · Which topics/tests/procedures are most relevant to our practice?
- How do we create a team-based workflow process that is efficient and effective in building partnerships with patients and their families? What is needed to make it sustainable?
- What CW tools (posters, brochures, rack cards, wallet cards, information on using the mobile
 phone app, etc.) should we select and how will they be used in the practice? Where should
 they be placed to achieve high impact and visibility?
- How can our clinic communicate our CW program to patients and their families?
- · What messages will help start meaningful conversations with our patients and their families?
- · How might we evaluate the success of our implementation efforts?

PATIENT AND FAMILY INSIGHTS CAN HELP YOU!

Patients and families can help answer the questions above and plan implementation strategies. Consider the ideas below to ensure that patient and family perspectives inform your implementation:

- Sit down with one patient and share a CW tool that is relevant to tests or treatments they have had. Ask whether and how the information could have been useful to them in making decisions.
- Provide a list of topics that could be addressed through CW, and ask patients to select items
 that would be most impactful from their perspective.
- Bring together a small group of patients and family members to review a small number of specific tools that could be implemented and ask them which they like best and why. Integrate that information into implementation decisions.
- Invite 2-3 patients or family members to join a workgroup planning the implementation of Choosing Wisely.
- Ask a few patient portal users to rate the value of receiving a Choosing Wisely link via the
 portal and to suggest what messages might engage other patients to review the information
 before an office visit
- Walk through the clinic with a few patients and ask for suggestions on where CW materials would be most visible and accessible to patients and families.
- Ask a few patients and family members to help you develop scripts/messages for clinicians to
 use when they talk about the CW program to other patients and families.

licit input from patients on how to customize patient education on CW materials so they tter reach/match your patient population.

ainstorm with patients and families the best ways to get feedback from patients about their perience with the CW tools during implementation.

tablish a project advisory group of patient and family advisors to participate throughout the pject — in the planning, implementation, and evaluation.

ite patient and family advisors to role play with staff and clinicians and serve as coaches to actice how to have a conversation about CW with patients and families.

GETTING STARTED

Determine which of the ways listed above you will use to involve patients/families. Ask staff and clinicians to help identify potential patient and family advisors—individuals who can listen and share their thoughts effectively, are naturally curious, can see more than one side of an issue, and want to make a difference who will partner with clinic on this effort. Create information for potential patient and family advisors about what you are hoping to accomplish, why it's important and how they can help you. This information can be shared in a flyer/brochure posted in exam rooms or in a short letter/email.

Select those individuals whose experiences and interests match your goals for CW implementation.

LEARN HOW OTHER PRACTICES INVOLVE PATIENTS AND FAMILIES AS PARTNERS IN TRANSFORMATION

Quality Counts first incorporated Choosing Wisely into its Patient Centered Medical Home re as part of the Aligning Forces For Quality (AF4Q) project. The strategic emphasis was on t engagement and establishment of patient advisory groups and patient advisors at the selevel. Four pilots in primary care practices had great success in recruiting patient advisors k with the practices specifically on creating tangible ways to engage patients in their own rough Choosing Wisely. Read more about their efforts at:

http://ipfcc.org/bestpractices/maine-quality-counts.html.

e information about working with patient and family advisors to improve your practice is available at www.pcpcc.org/tcpi.









E-Tool Use

Does the practice use an e-tool (patient portal or other e-connectivity technology) that is accessible to both patients and clinicians and that shares information such as test results, medication list, vitals, and other information and patient record data?

Intent: The intent of this metric is to have an electronic tool that allows patients to access their medical record and have an easy, direct way to communicate with providers.

How Well Is Your Portal Utilized?

- Designate staff to act as Patient Portal Champions
- Identify a portal technical support who available to patients
- Set goals between teams on portal usage and make progress transparent

If adoption is low, consider increasing functionality!

Access to Information Patient Portals





Studies have shown that 40-80% of the medical information patients are told during office visits is forgotten immediately, and nearly half of the information retained is incorrect.

Patient Activation

Does the practice utilize a tool to assess and measure patient activation?

Intent: The intent of this metric is to use a standard method to measure a patient's activation level.

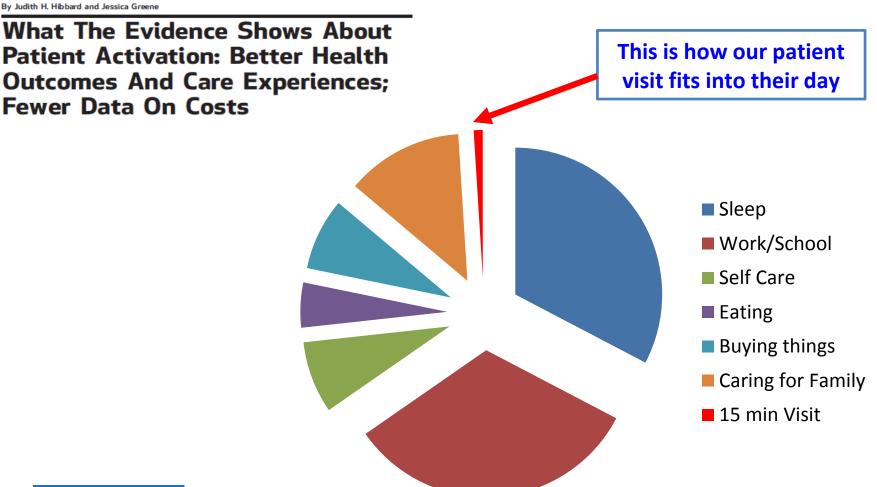
Patient Activation

An individual's overall knowledge, skill, and confidence for self-management.

Studies have shown that activation scores are predictive of outcomes within specific patient groups



Why Care Plans?







Care Plan Goals

- Understand where patients are in managing their health
- Understand patients' priorities for their health (what matters to you?)
- Create shared goals
- Develop an action plan <u>WITH</u> the patient
- Customize care interventions
- Identify and address strength and challenges
- Build skills needed to reach the goal
- Leverage team-based care model

All teams work from the same care plan, for care coordination, shared goals, and communication between teams. Plan is printed and given to patient.

Stanford Chronic Self-Efficacy Scales

Resources

Patient Health Engagement Scales



Self-Efficacy for Diabetes

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

- How confident do you feel that you can eat your meals every 4 to 5 hours every day, including breakfast every day?
- 2. How confident do you feel that you can follow your diet when you have to prepare or share food with other people who do not have diabetes?
- How confident do you feel that you can choose the appropriate foods to eat when you are hungry (for example, snacks)?
- 4. How confident do you feel that you can exercise 15 to 30 minutes, 4 to 5 times a week?
- 5. How confident do you feel that you can do something to prevent your blood sugar level from dropping when you exercise?
- How confident do you feel that you know what to do when your blood sugar level goes higher or lower than it should be?
- How confident do you feel that you can judge when the changes in your illness mean you should visit the doctor?
- How confident do you feel that you can control your diabetes so that it does not interfere with the things you want to do?

not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
not at all confident	1	2	3	4	5	6	7	8	9	1 10	totally confident
not at all confident	1	2	3	4	5	6	7	8	9	1 10	totally confident
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not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
not at all confident		2	3	4	5	6	7	8	9	10	totally confident

1

Health Literacy

Is a health literacy patient survey being used by the practice (e.g., CAHPS Health Literacy Item Set)?

Intent: The intent of this metric is to ensure that practices are systematic in addressing health literacy issues.

Health Literacy Impacts Engagement

"Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information, and services needed to make appropriate health decisions." NAM report Health Literacy: A Prescription to End Confusion 2004

- Assume most patients may have difficulty comprehending health information and accessing health services
- Implement universal precautions
- Ask patients about their experiences:
 - Were the results of your test easy to understand?
 - Did this provider use medical words you did not understand?

Spotlight on Health Literacy:



- Improvement Aim: Increase the follow-up appointments with patients whose HgbA1c are above 9
- Response rate to traditional letters or patient portal messages was poor
- Small team of LAPTN QI Advisor, Population Coordinator and Education Department formed
 - Coordinated with diabetes providers re: input and clinical language
 - Analyzed current letter and identified gaps related to best practice for health literacy
 - Utilized http://thewriter.com as a resource



Changes

Venice Family Clinic

- 5-6 grade language
- Shared the patient's current/last known HA1c
- Used a common
 "stoplight" visual to place
 their HA1c in context
- Built on the doctor/patient relationship
- Identified a specific person to call
- Created in both English and Spanish



02/01/17

Estimado/a «New_Name»,

Nuestros registros indican que necesita una visita con su equipo médico junto con una prueba de A1C actualizado.

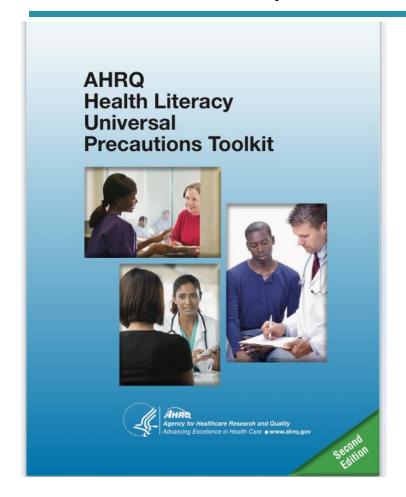
La A1C es una prueba de sangre que demuestra el promedio de azucar en su sangre durante los últimos tres meses. Ser conciente de su nivel de A1C ayuda a dar retroalimentación sobre qué tan bien ha funcionado su manejo de la diabetes. En general, se recomienda tener un nivel de A1C menos de 7%. . A partir de «A1c_Date», su A1C es «A1c_Result». La diabetes es una condición que usted puede manejar y su equipo médico está preparado para ayudarle.

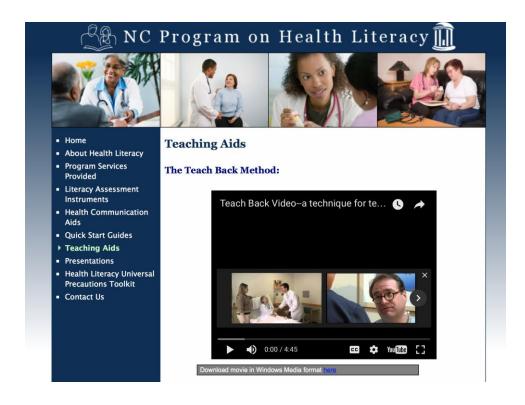


Por favor comuniquese con Jonathan Vargas al (310)664-7537 para programar su cita.

Atentamente, «Usual_Provider» Equipo Medico de Venice Family Clinic

Health Literacy Practices Improves Engagement





https://www.ahrq.gov/professionals/qualitypatient-safety/qualityresources/tools/literacy-toolkit/index.html

http://nchealthliteracy.org/teachingaids.html



Medication Management

Does the clinical team work with the patient and family to support their patient/caregiver management of medications?

Intent: The intent of this metric is to ensure that all patients and/or their family are being supported to safely manage their medications.

Patients do not take their medicine as prescribed 50% of the time.

Over 25% of initial prescriptions are never filled.

Inappropriate medication use leads to increased complications and hospitalizations, costing the United States an estimated \$100 billion to \$290 billion annually.





Collaborative Approaches Improve Outcomes

There is significant evidence that a more collaborative medication management strategy that actively engages patients and families results in improved outcomes.*

^{*}Advances Volume 22 No. 4 in Therapy® July/August 2005 Medication Adherence and Persistence: A Comprehensive Review Kem P. Krueger, PharmD, PhD Bruce A. Berger, PhD, RPh Bill Felkey, MS;

Tran, V.T., et al. Taxonomy of the burden of treatment: A multicountry Web-based qualitative study of patients with chronic conditions. BMC Med, 2015. 13: p. 115.

Building Partnerships for Medication Safety

- Develop a blame-free environment and a positive, trusting relationships with patients and families.
- Partner with patients to determine current medication list and management process.
- Motivate patients by building on their successes and positive experiences.
- Address the burden of treatment.
- Tailor the approach to individual patients and their situations.



What direct care PFE opportunities can you imagine?

What are you currently working to improve where patient and family input could be of value?



Previously Suggested Opportunities:

- Work with the Inherited Retinal Disease Clinic Team on specific projects
- Sub-specialty care team care coordination
- Improvement to Post-Surgical Experience
- Work with the Lean Consultant on integration of patient and family voices into the work underway

Questions?







Webinars, Tools, Resources to Strengthen Your PFE Efforts!



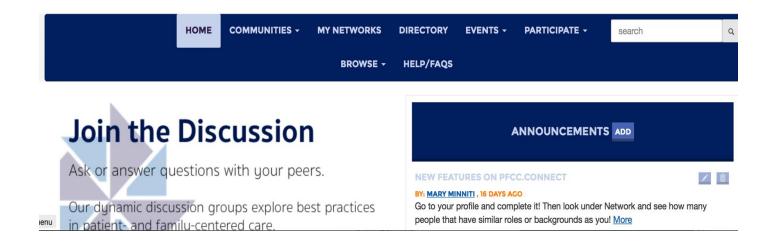


https://www.pcpcc.org/tcpi



A free on-line learning community dedicated to partnerships with patients and families to improve and transform care across all settings.







http://pfcc.connect.ipfcc.org/home



THANK YOU!



www.ipfcc.org

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