HAUTE AUTORITÉ DE SANTÉ

Colloque **HAS**

La dynamique patient innover & mesurer

16 novembre 2016 PARIS

Traduction / *Translation*

Channel 1 English

Canal 3 Français

Please, switch off during the lunch

Merci d'éteindre votre casque durant le déjeuner

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Du recueil de l'expérience des patients au partage de la décision

Animatrice
Maud GUILLAUMIN, journaliste

Grand témoin
Angela COULTER, directrice des initiatives mondiales, Informed Medical Decisions Foundation, États-Unis

Intervenants

Martine BUNGENER, économiste, sociologue, directrice de recherche émérite, CNRS − CERMES3

Arlene BIERMAN, directrice, Center for Evidence and Practice Improvement, Agency for Healthcare Research and Quality, États-Unis

Philip VAN DER WEES, chercheur, Scientific Institute for Quality of Healthcare (IQ healthcare), Radboud University Nijmegen Medical Centre, Pays-Bas

Karen SEPUCHA, professeur adjoint de médecine, Harvard Medical School, Massachusetts General Hospital, États-Unis

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Catherine GRENIER, directrice de l'amélioration de la qualité et de la sécurité des soins, HAS

Catherine CERISEY, vice-présidente, Association Cancer Contribution − administratrice, Europa Donna − membre de la commission information des patients, HAS

Écouter ce que dit le patient : apports d'un recueil qualitatif

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Martine BUNGENER

Économiste, sociologue,
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01

Une parole et une écoute inscrites dans un contexte

Une écoute socialement déterminée

Les effets d'un contexte historique :

1. Essor de la médecine
2. Invisibilisation des soins profanes
3. La maladie chronique et la « démocratie sanitaire »
4. Participation aux soins (dire et faire) des patients et proches : des acteurs de l'ombre parmi d'autres !
5. D'une parole contrainte, enclavée, à une parole libre et signifiante

Un contexte historique déterminant : des patients entre invisibilité et ombre

- Rupture durable formelle et symbolique depuis les années soixante, entre médecine efficace et soins profanes (patients et proches invisibles puis maintenus dans l'ombre)
- Représentations sociales pérennes ; perceptions hiérarchisées (compétences -/pertes de chance +)
- Perte de confiance entre les acteurs : disqualification, méconnaissance (MG ? - patients, familles ?)
- Peu d'écoute de part et d'autre : questions d'outil de communication et de contenu (que partager avec qui ?)

Des patients entre invisibilité et ombre : interventions négligées - avis enclavés

Un cheminement de travaux sur cette invisibilité

- Soins profanes à domicile : invisibilité économique, sociale et médicale
- *Unafam* : rendre visibles les soins des proches dans la maladie psychique (fermeture de lits spécialisés)
- « *Années sida* » : revendiquer l'intervention et la parole des patients
- Une parole « enclavée » : les consentements, questionnaires de satisfaction et de qualité de vie
- Des récits, une prise de parole associative (*Gram Inserm*) et une écoute qualitative scientifique (*Alzheimer à domicile*)

02

Les apports d'une approche qualitative

Les apports d'une approche qualitative

Une approche inductive : sortir des catégories médicales ; entendre les catégories des patients

- Une démarche compréhensive à partir de récits
- Une recherche du sens pour les personnes
- Une médecine narrative (*savoirs d'expérience*)

Une parole pour pouvoir choisir et agir ***(approches d'Amartya Sen, prix Nobel)***

- Ecouter ce qui importe et est « choisi » (*capabilités*)
- Déplacer le regard sur les *façons de faire* (résultats global/final)

Ecoute et résultat global / final

- Obtenir un résultat final est insuffisant : pas un indicateur de liberté de choix, ni l'assurance de valeur acquise pour la personne

- Les façons d'obtenir un résultat (à négocier) sont aussi importantes que le résultat final obtenu

- La capacité individuelle à décider ne suffit pas à garantir la liberté de choix : existence d'options, pouvoir dire, se faire entendre et négocier

Conclusion : s'affranchir des représentations pour écouter et donner sens à ce que disent les patients

- Rompre avec cinq décennies d'implicite, d'impensé des acteurs de l'ombre : malades, proches ou MG, (tâches, besoins, savoirs, « *savoirs d'expérience* », compétences)
- Reconnaître comment cet impensé influe *encore* sur les façons d'être, de faire, de penser, de dialoguer et de coopérer entre divers acteurs du soin, malades et proches (*virage ambulatoire*)
- Restaurer volontairement confiance, écoute qualitative et dialogue avec patients et proches sur attentes, choix de vie et façons de faire

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Évaluer l'expérience des patients : mesure de l'expérience (PREMs) et des résultats de santé perçus (PROMs)

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Arlene BIERMAN

Directrice,
Center for Evidence and Practice Improvement,
Agency for Healthcare Research and Quality, États-Unis

Prems and Proms

- Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcome Measures (PROMs) are complimentary approaches to engaging patients in improving health care quality
- The CAHPS® family of surveys ask about patients' experiences with their health care. CAHPS surveys are based on what patients say is important to measure
- PROMs foster the incorporation of patient goals an preferences into shared-decision making and care planning

01

Patient Reported Experience Measures

What is CAHPS®?

- Consumer Assessment of Healthcare Providers and Systems (CAHPS) Program
  - CAHPS is a "family" of surveys and supplemental item sets that measure patient experience in health care settings
  - Develops standardized surveys and related products according to established principles
  - Surveys assess quality of care from the patients' point of view
  - Publishes guidance on reporting of CAHPS scores
  - Studies use of CAHPS data for quality improvement purposes

Core CAHPS Design Principles

- Focus on topics for which **patients are the best or only source** of information
- Include **patient reports and ratings** of experiences – not “satisfaction”
- Include questions and domains for which the facility/provider is accountable, or for which we can risk adjust
- Question items and survey protocols are developed and tested with **rigorous scientific methodology**
- Incorporate extensive stakeholder input
- Questions are based on current practices and standards of care

CAHPS Surveys

Include the following:

- Facilities - Hospitals, Hospice, In-Center Hemodialysis, Outpatient and Ambulatory Surgery, Nursing Homes, Home Health
- Health Plans - Commercial Health Plans, Medicare Advantage, Prescription Drug Plan, Medicare Fee-for-Service, Medicaid Adult and Child
- Providers - Clinician and Group, Accountable Care Organizations, Patient-Centered Medical Homes

Hospital CAHPS (HCAHPS)

- Measures experience of care in most inpatient hospitals. In 2015, 4,167 hospitals reported CAHPS scores on more than 3.1million surveys.
- Contains 25 items covering communication with doctors and nurses, responsiveness to patient needs, pain control, communication about medicine, care from doctors, transition to post-hospital care, cleanliness, quiet, and global ratings. 7 “About You” questions.
- Provides objective and meaningful hospital comparisons on topics that are important to patients and consumers.

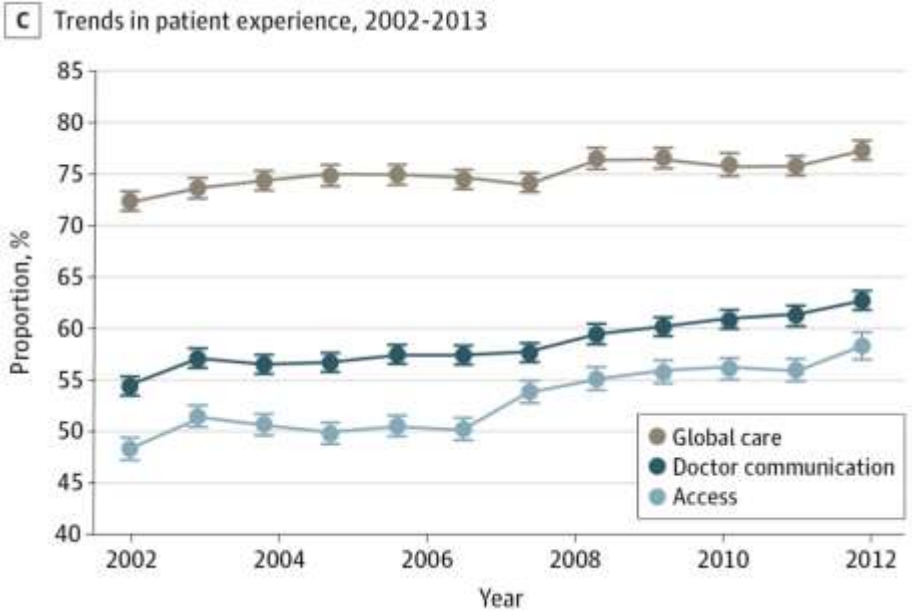
HCAHPS Survey Uses

- Required by the Centers for Medicare & Medicaid Services (CMS) for value-based purchasing – 25 percent of the “Total Performance Score” in 2016. HCAHPS scores are used to measure improvement and achievement
- HCAHPS scores are publically reported for consumer choice on www.medicare.gov/hospitalcompare

Improvement in HCAHPS Scores

- Measure HCAHPS improvement in 2nd-5th years of public reporting. 3,451 hospitals, 4.8 million surveys of adult inpatients.
- HCAHPS summary scores increased overall 2.8% in the most positive response category. Greatest improvement in for-profit and larger hospitals.
- Builds on earlier research showing small but significant improvement during years 1-2 of reporting.
- Improvement greatest for hospital types initially scoring the lowest.
- Similar results to prior studies documenting greater improvement in clinical measures in lower performing hospitals.

Improvements in Patient Experience

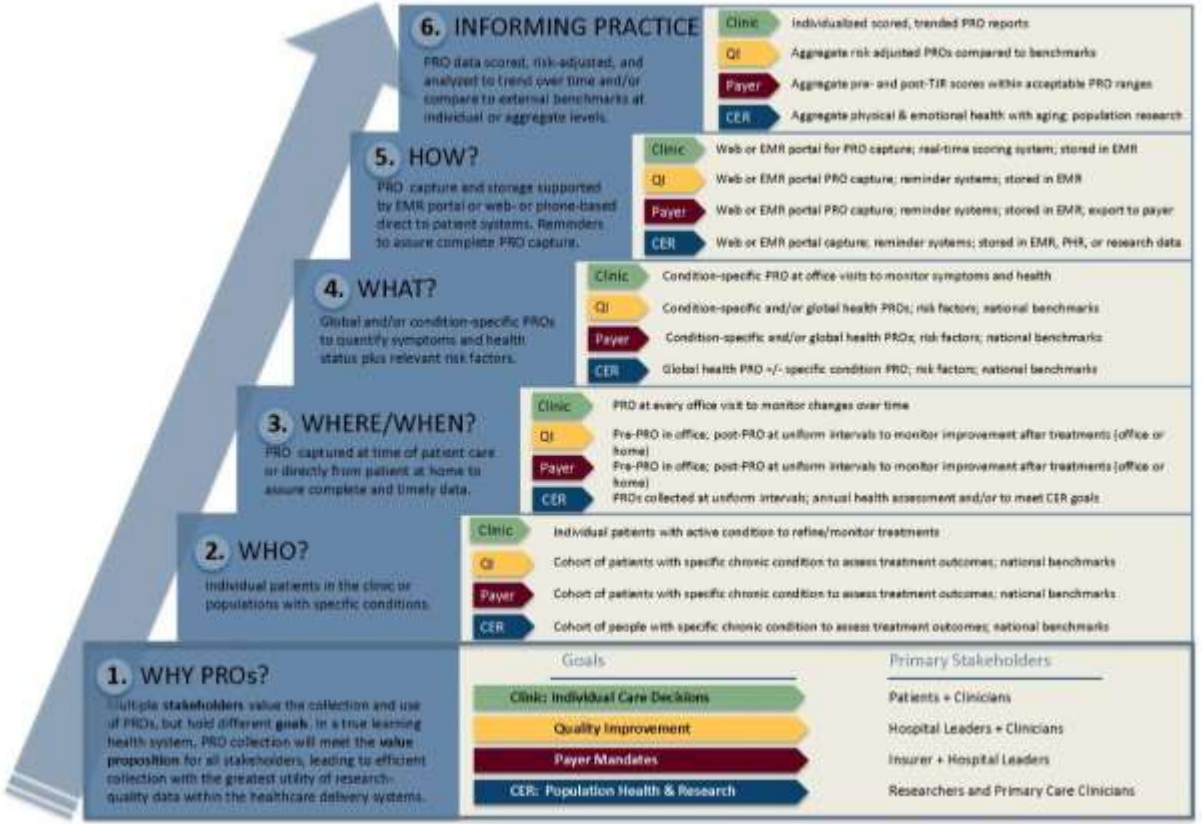


Levine DM, Linder JA, Landon BE. The quality of outpatient care delivered to adults in the United States, 2002-2013. JAMA Int Med. Published Online October 17, 2016.

02

Patient-Reported Outcome (PRO) Measures

Collection and use of Pros in the Learning Healthcare System



Patient-Reported Outcomes and Patient-Generated Data

Stakeholder	Primary PRO Goal
1. Patients and Clinicians	***Individual patient care decisions*** Patient-centered decisions to prioritize, treat, and monitor symptoms and health status
2. Hospital leaders and Clinicians	***Quality Improvement*** Monitor and improve aggregate patient outcomes as compared to national best practice/ benchmarks
3. Insurers and Hospital Leaders	***Value-based reimbursement*** Measure outcomes as compared to costs and utilization to optimize healthcare value
4. Researchers, primary care and public health	***Population health and research*** Generate new evidence for best clinical practices to achieve optimal health status

Implementing PROMs in Routine Care

- PROMs in standard care:
  - Potential to improve care by orienting clinicians and clinical teams to the outcomes that matter most to patients
  - Facilitates the prioritization and ultimate effectiveness of care
- Especially relevant for patients with multiple chronic conditions (MCC)
  - MCC patients often receive care that is fragmented, inefficient, and ineffective
  - Clinical care guidelines typically focus on single conditions without recognizing the potential contraindications or appropriate prioritization of treatments for MCC
- Understanding patients' and families' life circumstances, preferences, and values is essential in making shared decisions about care and in the larger process of care planning

AHRQ Technical Expert Panels on PROMs and EHRs: Challenges and Opportunities

Challenges

- Clinicians' lack of knowledge on how to interpret and apply scores for SDM
- Too many PRO measures to choose from
- Gathering, importing, and presenting PRO measures in a usable way

Opportunities

- Develop appropriate criteria/cutoff points and an action plan on how to interpret scores
- Identify PRO measures that add most value to clinical care
- Develop and test strategies to maximize collection and use of PRO measures within clinical practice

PRO Measure Implementations

- Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR)
  - Surgeons and health systems contributing to a registry that collects and shares real-time PRO data to improve care following joint replacement surgery
- Comparative Effectiveness Research Translation Network (CERTAIN)
  - Program called ‘PROs in Practice’ that provides a convenient and systematic platform for directly collecting PROs (i.e., pain, quality of life, health-related habits, and wellbeing) from patients
- Distributed Ambulatory Research in Therapeutics Network (DARTNet)
  - Completed a comparative effectiveness research project on major depression that built an informatics infrastructure to collect patient-reported data on a large scale via the PHQ-2/PHQ-9

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Résultats de santé rapportés par les patients (PROMs), expérience en cabinet paramédical

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Radboudumc

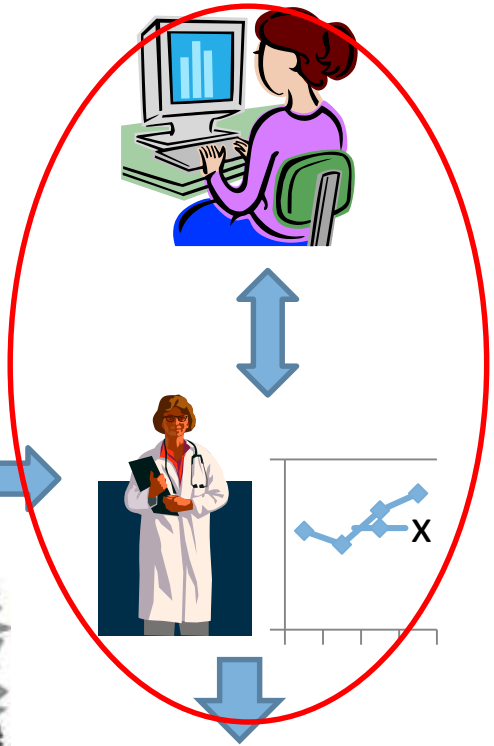
Chercheur, Scientific Institute for Quality of Healthcare (IQ healthcare),

Radboud University Nijmegen Medical Centre, Pays-Bas

Concept	Patients with osteoarthritis
PRO (patient-reported outcome)	Functional limitations
PROM (questionnaire, single-item measure)	Hip Disability & Osteoarthritis Outcome Score (HOOS)
PRO-PM (PRO-based performance measure)	Percentage of patients with >20 points difference in pre- and postoperative HOOS score

Purposes of PRO measurement in healthcare

1. **In patient-provider interaction (clinical practice)**
   - Goal setting
   - Monitoring and evaluation of treatment
2. **At organizational level (quality improvement)**
   - Quality improvement
   - Management information
3. **At (inter)national level (performance measurement)**
   - Comparing quality of providers
   - Reimbursement (P4P) by health insurers

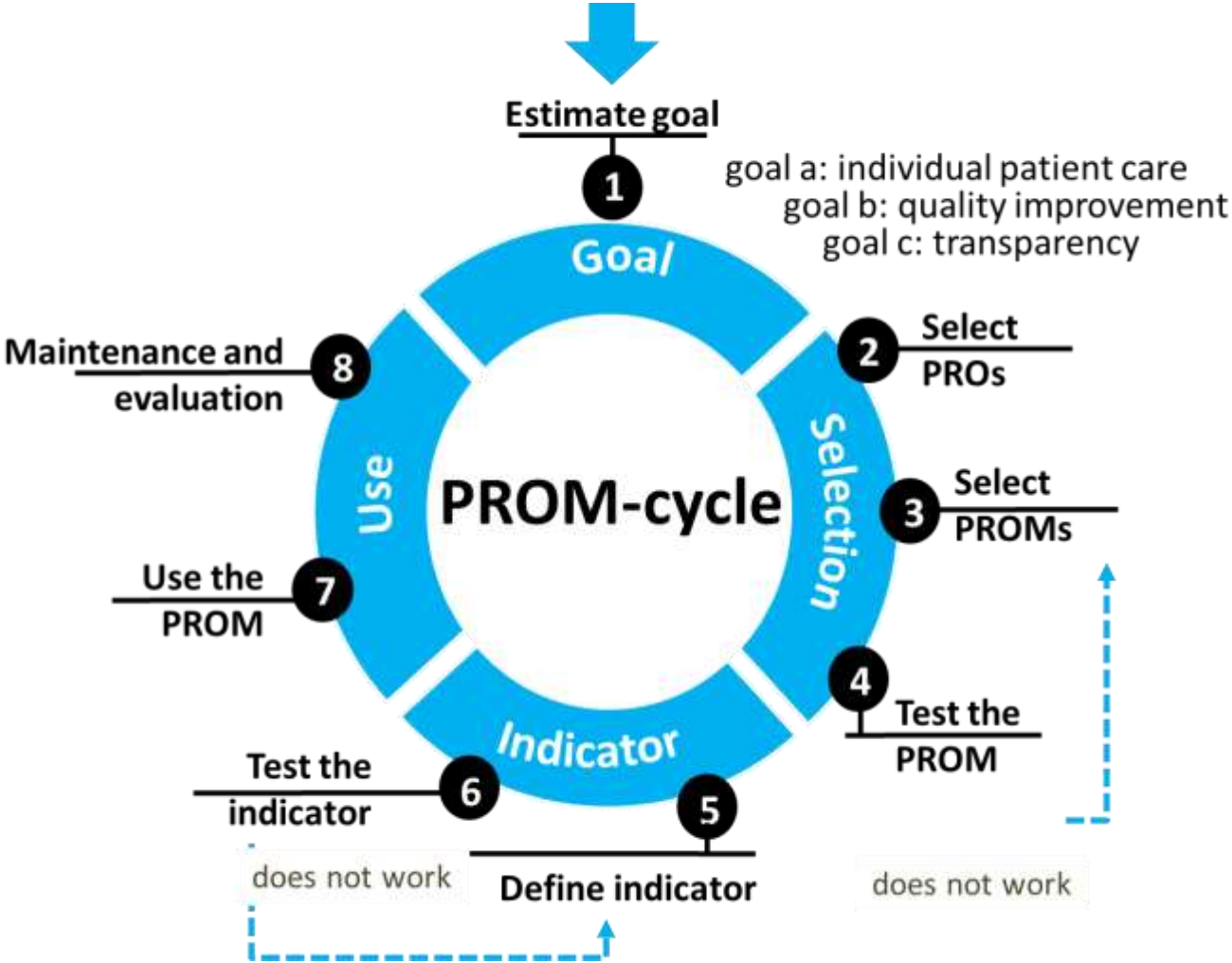

X


FEEDBACK
FEED BACK

Data collection for different purposes

Is it possible to establish data collection for integrated use in clinical practice, quality improvement and performance measurement?

Can we develop valid outcome indicators to measure the quality of physical therapist care?


Estimate goal
1
goal a: individual patient care
goal b: quality improvement
goal c: transparency
Goal
2
Select
PROs
Selection
3
Select
PROMs
4
Test the
PROM
does not work
Indicator
5
Define indicator
6
Test the
indicator
does not work
Use
7
Use the
PROM
8
Maintenance and
evaluation
PROM-cycle

Pilot projects in primary care physical therapist practices

- Measuring process and outcomes of care
- PRO measurement in five main orthopedic health conditions: low back, neck, shoulder, hip, knee
- Data collection in national registry
- Quality improvement based on peer assessment and audits

Pilot	Completed	Current	Practices	PTs
Fysiocare	2013-2014	2015 – 2016	33	180
Fysio Omni	2013-2014	2015 – 2016	23	80
Fysio10IJsselland	2014-2015	2015 – 2016	10	103
Rugnetwerk NH	2014-2015		57	100
FGH	2014-2015		40	68
SKFN		2015-2016	16	60
Total			179	591

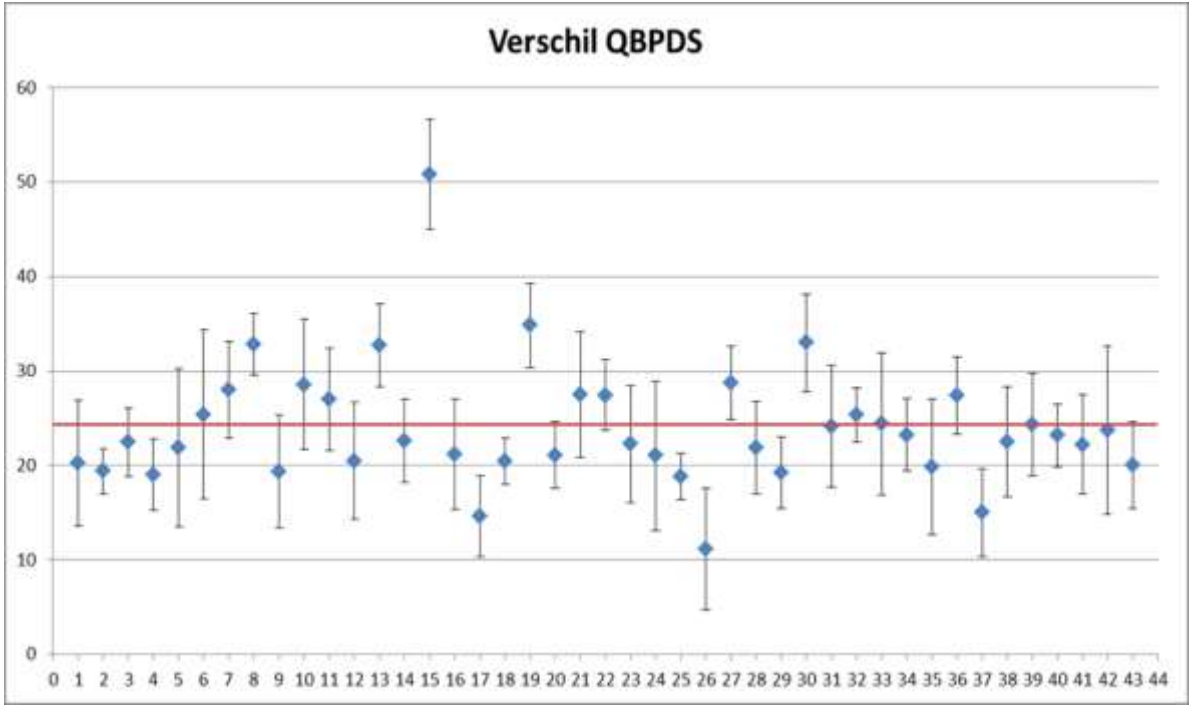
National registry (January 2016)

	N	(%)	Patient age (sd)	(Sub)acute (%)
Low back pain	57.025	(22)	51.0 (18.2)	74.1
Neck pain	47.084	(18)	48.5 (18.0)	73.7
Shoulder injury	34.268	(13)	52.9 (17.3)	68.5
Knee injury	24.066	(9)	47.3 (21.3)	70.8
Hip injury	19.096	(7)	54.9 (21.7)	71.2
Other	80.045	(31)	49.8 (22.1)	69.0
Total	261.583	(100)	50.1 (20.4)	69.3

Transparency of outcomes

PROM	N	Clinically relevant difference	Patients with clinically relevant difference (%)
Pain (NPRS)	N=11545	≥2 points	81.9
Low back disability (QBPDS)	N=1604	≥15 points	66.2
Neck disability (NDI)	N=1025	≥7 points	61.8

Differences between practices



Peer Assessment

Peer (n=5-7) provide each other feedback on their quality of care based on process and outcomes data

- Participants reflect on feedback and discuss potential for improvement
- Meetings supervised by a coach

Audits of primary care PT practices

Auditors assess the quality of primary care PT practices based on process and outcomes data.

- Self evaluation report of PT practrice
- Audits executed by trained peer auditors

Can we measure the quality of physical therapist practice?

- Transparency (public) of outcomes at national and network level
- At PT practice level database is still too small for public reporting
- Interpretation of outcomes at early stage
- Peer assessment and practice visitation highly appreciated after initial reluctance of participants
- Further data collection and analysis for establising quality indicators

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Décision médicale partagée, expérience du Massachusetts General Hospital

Karen SEPUCHA

Professeur adjoint de médecine,
Harvard Medical School,
Massachusetts General Hospital, États-Unis

Massachusetts General Hospital

- First and largest teaching hospital for Harvard Medical School
- 18 adult primary care practices
- Developed the first patient decision aids in 1980s
- Shared Decision Making Program started in 2005

Mission

To promote conversations and systems of care that value the expertise of patients and families, expertise of clinicians and the best available clinical evidence in medical decisions.

Implementation into routine care

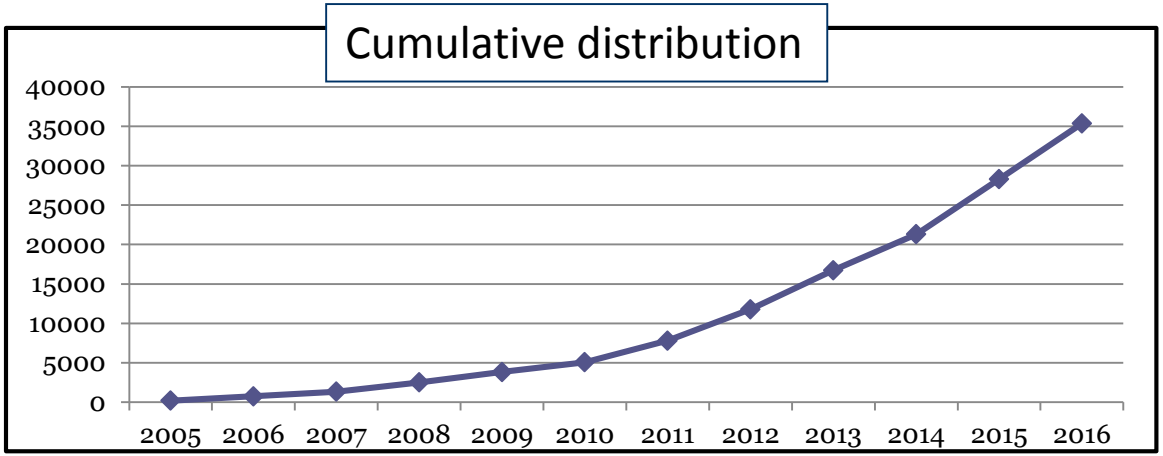
What is needed?

- Receptive culture (physicians, staff, administration)
- Engaged and informed patients and families
- Supportive systems (infrastructure and resources)

Patient decision aids

- Educational materials that focus on decisions, present options, pros and cons, and help patients clarify their preferences
- Available in different media (paper, online, video)
- 2014 Cochrane Collaborative systematic review contains 115 RCTs and shows increase knowledge, reduce decisional conflict, increased participation, reduced surgical rates

Snapshot of the program



Most Popular Topics Last Year:

1. Insomnia 2. Anxiety 3. Chronic low back pain
4. Knee Osteoarthritis 5. Prostate cancer screening

Some numbers:

35,000+ decision aids distributed

~ 1000 orders/month

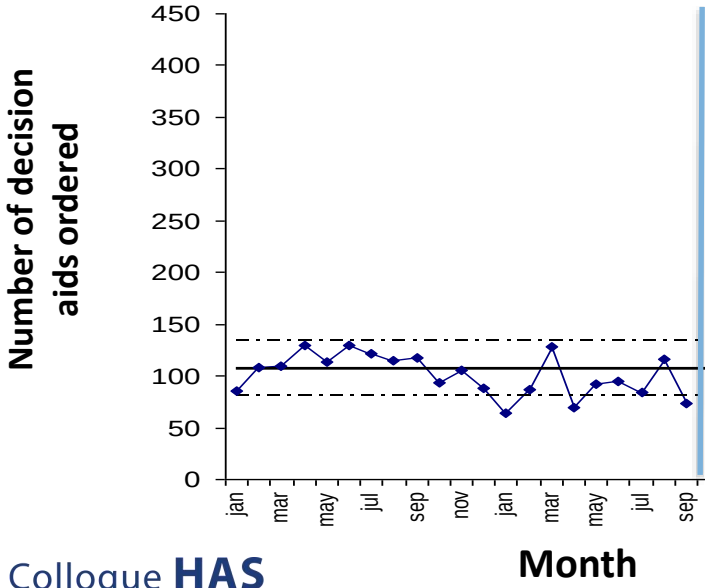
>900 unique clinicians and staff have prescribed programs

Challenging situations

- Patients with a LOT of questions about an issue you thought was more straightforward.
- Patients not asking ANY questions and now you wonder whether you are on the same page.
- Discussing probabilities for risks and benefits of treatments without confusing patients.
- Many patients don’t want to be involved, and want you to tell them what to do.
- There’s no time!!

Learning from the Bright Spots

Monthly rates of decision aid orders



- Stable, but low use
- 10 physicians accounted for 40% of all orders
- Developed training session for practices
- Watched decision aid
- Reviewed data
- Discussed experiences

Lessons learned

- Comfort with patient decision aids is important
- Comparative data is good motivator (for our clinicians)

→ New barrier, “I forget to prescribe, can someone else do this?”

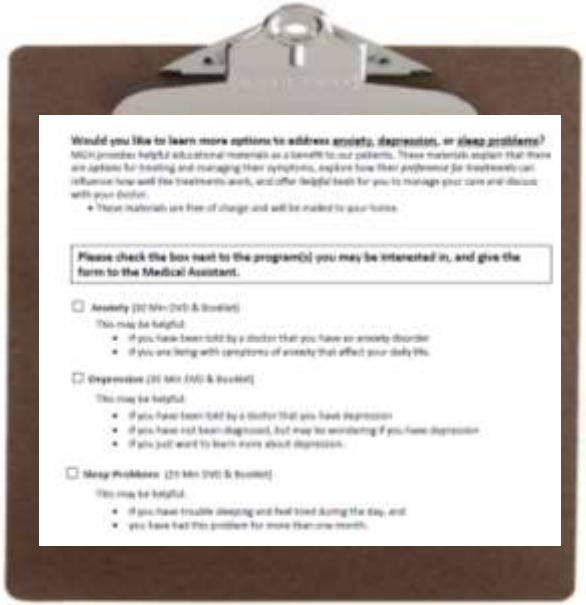
Harnessing the patient's power

- Context: hospital-wide effort to improve depression screening and management in primary care practices
- Setting: community-based health center; ~10 physicians, work in partnership with medical assistants
- Champion: nursing leader invested in improving patient education processes

Decision aids and PROMs

Workflow:

1. Medical assistants (MAs) administered PHQ-2
2. If PHQ-2 results were positive for depression, patients were offered order form for mental health programs (depression, anxiety, and insomnia)
3. MA would place order for programs to be sent to patient



Results

- Few patients (~5%) screened positive,
  → 19 programs ordered by patients in one month

- MAs began offered order form to ALL annual visit patients, with the PHQ-2 questionnaire…
  → 203 mental health programs ordered in one month
  (62 anxiety, 60 insomnia, 47 depression)

Lessons learned

- A provider-dependent workflow may limit patient access to decision aids
- Patients can/should be active participants in the decision aid ordering process
- All members of the clinical care team can participate in workflow; medical assistants took ownership of process and were crucial to suggesting improvements

Feedback

Patients love it and want more…

- "This helped me a lot, because I was & still feel a bit nervous, but will get checked! Thank you." *(colorectal cancer screening)*
- "Thank you very much for the web site you sent me, I read its cath section with great interest. I understand the process better." *(Treatment Choices for Coronary Artery Disease before a cardiac catheterization)*

Providers are positive about the use…

- "Great for both high and lower functioning patients" Behavioral health specialist
- "This has completely changed my conversations with patients about their back pain—from one driven by fear to one focused on what we can do to help with their pain." Physiatrist with spine service
- "The list of resources at the end of the anxiety program is helpful—one of my patients was lost with Google/Amazon and was so happy to have list to focus on." Primary care physician

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