

Patient Reported Outcome Measures et PR Experience M

X. de Béthune

CIPIQ-S

12 10 2012

Définition

- Broad definition (FDA) : any report made by patient about:
 - Health condition and treatment
 - symptoms (pain, fatigue, and energy,...)
 - functioning and well-being in physical, mental and social domains of life (i.e., health-related quality of life)
 - Health behaviors
 - adherence to medicines, tobacco use, and participation in exercise programs
 - Preferences for different types of care and desire to participate (or not to participate) in care
 - Satisfaction with the care and patient–clinician communication, coordination of care, and access to care

Fung CH, Hays RD. Prospects and challenges in using patient-reported outcomes in clinical practice. *Quality of Life Research* 2008; 17: 1297-302

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3119524/pdf/nihms-293919.pdf>

Origine

PROM surtout utilisés en recherche clinique, mais évolution en cours vers utilisations épidémiologiques et pour évaluer la qualité des soins.

Table 3 Measurement focus and associated outcome constructs

Measurement need	Primary outcome construct
Diagnosis	Impairment
Disease severity	Impairment
Treatment toxicity	Impairment
Patient functioning	Disability (activity)
Rehabilitation planning	Disability (activity)
Social service planning	Handicap (disadvantage)
Overall impact of disease and its treatment	Quality of life

In clinical settings the International Classification of Functioning is used for functional status assessment, goal setting & treatment planning and monitoring, as well as outcome measurement.

McKenna SP, Doward LC, Integrating Patient-Reported Outcomes. Value in Health 2004; 7(S1): S9-S12

<http://www.who.int/classifications/icf/appareas/en/index.html>

Objectifs possibles

- Sensibiliser les cliniciens aux attentes/soucis des utilisateurs des services de soins
- Améliorer la communication entre patients et cliniciens (p. ex. en oncologie)
- Screening de pathologies ou infirmités latentes (p. ex. santé mentale)
- Information de patients potentiels pour le choix de soins et/ou de prestataires
- P4P (NHS)

Steps of a patient–clinician encounter

IDEAL

- (1) Identify/elicit the problem(s);
- (2) Discuss with the patient about planned action(s);
- (3) Enact action(s)/cocreate plan(s);
- (4) Action(s); and
- (5) Learn about the effects

Measurements

- (1) Assessing baseline health-related quality of life
- (2) Patient's report about care (e.g., communication)
- (3) Engage the patient in a discussion
- (4) Patient's report of adherence
- (5) Satisfaction with care and change in health-related quality of life

Nederland

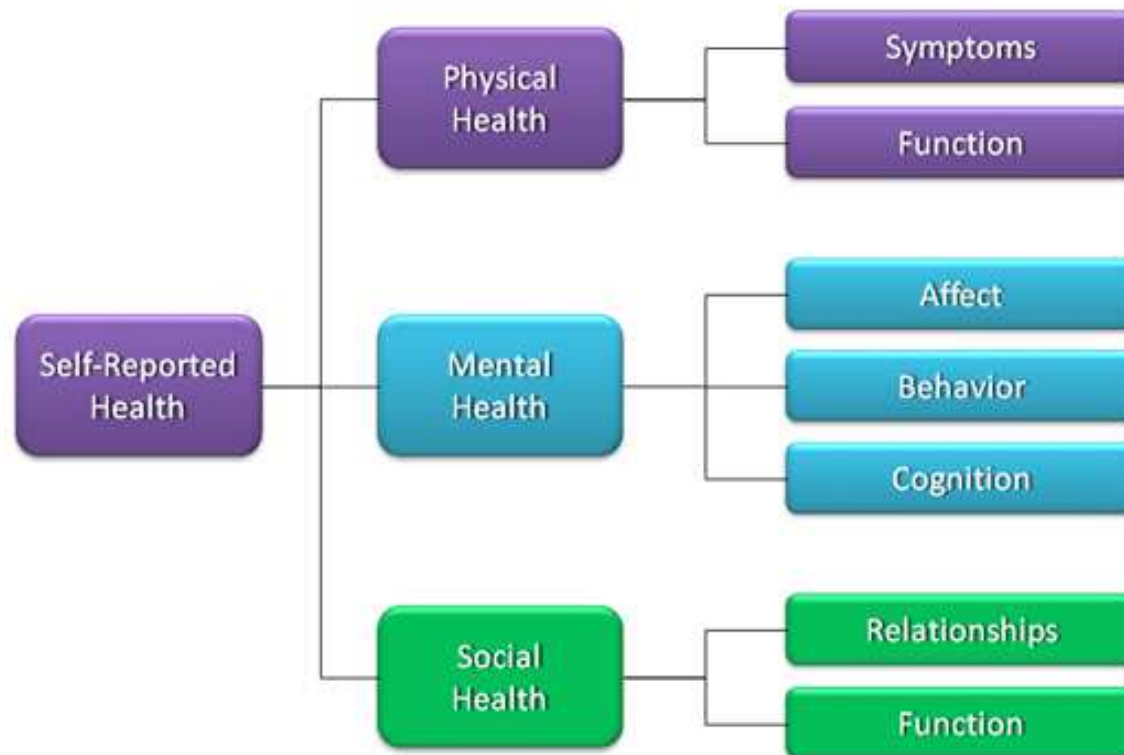
- Uiteindelijk is de combinatie van praktijkvariatie gegevens met patient-reported outcome measures (PROMS) de meest krachtige manier om scherp te krijgen of de praktijk van indicatiestelling ook de meeste toegevoegde waarde voor de patiënt levert.

IGZ

- Prioriteitenbepaling: vijf D's
 - *death (dood)*,
 - *disease (ziekte)*,
 - *disability (gebrek, functiebeperking)*,
 - *discomfort (ongemak) en*
 - *dissatisfaction (ontevredenheid)*

Examples

PROMIS Domain Framework



PROMIS

- Instruments
 - pain, fatigue, physical function, depression, anxiety and social function
 - short forms (typically requiring 4-10 items per concept)
 - computerized adaptive testing (CAT; typically requiring 4-7 items per concept for more precise measurement)
 - Peu de problèmes de santé spécifiquement
 - Cancer : les mêmes aspects que ci-dessus
 - Pathologies gastro-intestinales (en dvt)
 - Vie et pathologies sexuelles

NHS

- Patient Reported Outcome Measures (PROMs) measure quality from the patient perspective. Initially covering four clinical procedures, PROMs calculate the health gain after surgical treatment using pre and post operative surveys.
- The four procedures are
 - hip replacements
 - knee replacements
 - hernia
 - varicose veins
- short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time

Harris Hip Score

(With the permission of the Journal of Bone & Joint Surgery)

Clinician's name (or ref) _____

Patient's name (or ref) _____

Please answer the following questions

Section 1	
<p>Pain</p> <ul style="list-style-type: none"> <input type="radio"/> None, or ignores it <input type="radio"/> Slight, occasional, no compromise in activity <input type="radio"/> Mild pain, no effect on average activities, rarely moderate pain with unusual activity, may take aspirin <input type="radio"/> Moderate pain, tolerable but makes concessions to pain. Some limitations of ordinary activity or work. May require occasional pain medication stronger than aspirin <input type="radio"/> Marked pain, serious limitation of activities <input type="radio"/> Totally disabled, crippled, pain in bed, bedridden 	<p>Support</p> <ul style="list-style-type: none"> <input type="radio"/> None <input type="radio"/> Cane/Walking stick for long walks <input type="radio"/> Cane/Walking stick most of the time <input type="radio"/> One crutch <input type="radio"/> Two Canes/Walking sticks <input type="radio"/> Two crutches or not able to walk
<p>Distance walked</p> <ul style="list-style-type: none"> <input type="radio"/> Unlimited <input type="radio"/> Six blocks (30 minutes) <input type="radio"/> Two or three blocks (10 - 15 minutes) <input type="radio"/> Indoors only <input type="radio"/> Bed and chair only 	<p>Limp</p> <ul style="list-style-type: none"> <input type="radio"/> None <input type="radio"/> Slight <input type="radio"/> Moderate <input type="radio"/> Severe or unable to walk
<p>Activities - shoes, socks</p> <ul style="list-style-type: none"> <input type="radio"/> With ease <input type="radio"/> With difficulty <input type="radio"/> Unable to fit or tie 	<p>Stairs</p> <ul style="list-style-type: none"> <input type="radio"/> Normally without using a railing <input type="radio"/> Normally using a railing <input type="radio"/> In any manner <input type="radio"/> Unable to do stairs
<p>Public transportation</p> <ul style="list-style-type: none"> <input type="radio"/> Able to use transportation (bus) <input type="radio"/> Unable to use public transportation (bus) 	<p>Sitting</p> <ul style="list-style-type: none"> <input type="radio"/> Comfortably, ordinary chair for one hour <input type="radio"/> On a high chair for 30 minutes <input type="radio"/> Unable to sit comfortably on any chair

To score this section all four must be 'yes', then get 4 points. Nb. Not 1 point for each four or nothing.

Section 2

Does your patient have ALL of the following: -

- yes
Less than 30degrees of fixed flexion
Less than 10 degrees of fixed int rotation in extension
- no
Less than 10 degrees of fixed adduction
Limb length discrepancy less than 3.2 cm (1.5 inches)

Section 3 - Motion

Total degrees of Flexion

- None
- 0 > 8
- 8 > 16
- 16 > 24
- 24 > 32
- 32 > 40
- 40 > 45
- 45 > 55
- 55 > 65
- 65 > 70
- 70 > 75
- 75 > 80
- 80 > 90
- 90 > 100
- 100 > 110

Total degrees of Abduction

- None
- 0 > 5
- 5 > 10
- 10 > 15
- 15 > 20

Total degrees of Ext Rotation

- None
- 0 > 5
- 5 > 10
- 10 > 15

Total degrees of Adduction

- None
- 0 > 5
- 5 > 10
- 10 > 15

Print page

Close Window

Reset

To save this data please print or

Save As CSV

The Harris Hip Score is

0

Note: This page cannot be saved due to patient data protection so please print the filled in form before closing the window.

Grading for the Harris Hip Score

Successful result

=post operative increase in Harris Hip Score of > 20 points + radiographically stable implant + no additional femoral reconstruction

Or

<70 Poor

70 - 79 Fair

80-89 Good

90-100 Excellent

Reference for Score: Harris WH. Traumatic arthritis of the hip after dislocation and acetabular fractures: treatment by mold arthroplasty. An end-result study using a new method of result evaluation. J Bone Joint Surg Am. 1969 Jun;51(4):737-55. Link

Varicose veins surgery NHS

Post-operation

- Questions on home circumstance
- Questions on general health
- Questions on present state of varices and legs
- Questions on impact of varices on daily life
- Symptoms related to varices
- Present treatment
- Idem for **hernia repair**, but with much less detail

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf

Validated questionnaires

Table 4.1 – Health status measures used in the PROMs questionnaires

Procedure	Condition-specific	Generic
Unilateral Hip Replacement	Oxford Hip Score	EQ-5D*
Unilateral Knee Replacement	Oxford Knee Score	EQ-5D*
Groin Hernia Surgery	None	EQ-5D*
Varicose Vein Surgery	Aberdeen Varicose Vein Questionnaire	EQ-5D*

*: EQ-5D™ is a trademark of the EuroQol Group (www.euroqol.org)

Contenu

- Recueil de PROMs et PREMs
 - Pour aspects hôteliers de séjours hospitaliers
 - Pour qualité de vie en général
 - Pour pathologies sélectionnées
 - Identifiables par le biais des pseudo-DRGs
 - Suffisamment fréquentes
 - Suffisamment graves (chirurgie, maladies chroniques)
 - Médecine ambulatoire et hospitalière
- Combinaison de méthodes
 - Validation par groupes focaux p. ex.
- Collaborations avec autres acteurs du système de santé

Barrières

- Qualité de vie dépend de beaucoup plus que les soins de santé
- Un feedback PROM/QOL risque d'avoir peu d'impact sur les prestataires
- L'organisation d'une enquête PROM est lourde, puisqu'elle
 - Doit se réaliser idéalement après le retour à domicile
 - Demande un consentement éclairé du patient (NHS)
 - Nécessite des données standardisées pour un nombre important de facteurs liés au patient et externes
- Représentativité de l'échantillon
 - Accès Internet
 - Multiculturalité
 - Taux de réponse (seuil minimal = 80% (NHS))
- Il y a une courbe d'apprentissage pour ce type d'activité
- Le choix entre PROM générique ou spécifique n'est pas simple
- Les coûts peuvent devenir élevés.

Choix à faire

- Administration du questionnaire
 - Interview, papier ou électronique
 - Avec aide ou non
 - Trusted Third Party?
- Enquête pré- et/ou post-interventionnelles
 - Repose sur la collaboration des prestataires de soins
- Questionnaire QOL ou par problème de santé
- Résultats
 - Analyse standardisée en fonction des risques, de critères socio-économiques, culturels (langue) et démographiques
 - Présentation
 - Publication transparente à destination de qui
 - Collaboration avec institutions/prestataires
- Conséquences
 - Preferred Provider Organisation
 - Pay 4 Performance
 - Labelisation

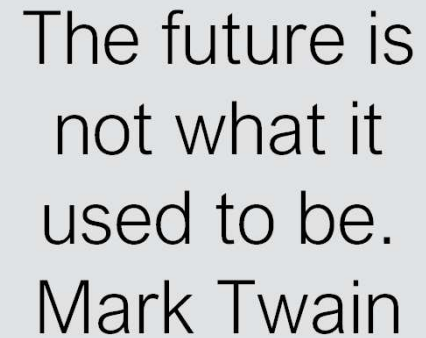
PREM

- Recueil des expériences et perceptions
- Enquête de satisfaction
- www.pickereurope.org

Alternatives ou compléments

Une autre vision du futur

- Blog santé
 - Membres peuvent y rapporter leurs expériences
 - Forum de discussion sur des sujets spécifiques
- Conditions de succès
 - Contenu intéressant pour les membres
 - Confidentialité
 - Facilité d'utilisation
 - Modération active et continue
 - Solutions interactives pour problèmes en cours (gains de temps et d'efficacité)
- Exemple
 - www.doctissimo.fr, mais sans bénéfiques opportunistes, taillés selon les besoins immédiats des internautes



The future is
not what it
used to be.
Mark Twain

Internet

- <http://www.gezondheidsweb.eu/gezondheid-tot-z/internet-grote-uitdaging-voor-dokters-pati%C3%ABnten-zoeken-zelf-informatie>
- Overheen alle aandoeningen die in kaart gebracht werden is er één duidelijke constante: zodra men ziek wordt, is de kans significant groter dat de patiënt eerst zelf informatie opzoekt over zijn/haar conditie en pas in een volgende stap een arts raadpleegt

www.doctissimo.fr

Santé et bien être avec Doctissimo - Windows Internet Explorer

http://www.doctissimo.fr/

File Edit View Favorites Tools Help

Favorites Free Hotmail Personnaliser les liens

Forum ressources - Internati... CollaboRhythm | MIT Media ... Our Products - BMJ Group Lifelong Kindergarten | MIT ... Santé et bien être avec ... Le Journal du médecin

Club Doctissimo | Devenir membre | Se connecter | Forums | Chat Doctissimo Momes.net

Doctissimo.be

un article un médicament

Santé Médicaments Grossesse / bébé Psychologie Famille Nutrition Beauté Mode Forme Sexualité Recettes Vidéos Test - Quiz

Accidents domestiques Arrêter de fumer Chirurgie esthétique Contraception Diabète Dépression Grossesse mois par mois Marquillage Minceur Médecines douces Programmes minceur Santé dans l'assiette Santé dentaire Soins de bébé Sommeil Thalasso Troubles de l'érection **Forums**

Rechercher

un article

un médicament

Votre santé

- Votre fiche santé
- Affaire Mediator
- Prothèses PIP
- Grippe
- Encyclopédie médicale
- Atlas du corps humain
- Dictionnaire médical
- Principales maladies

Sélectionnez

- Dossiers santé

Sélectionnez

Grossesse

- Dico de la grossesse
- Enceinte
- Grossesse mois par mois

Sélectionnez

- Grossesse semaine par semaine
- Dossiers grossesse

Sélectionnez

Mieux soigner son coeur



Santé dentaire

La gingivite en 10 questions



Une gencive qui saigne facilement ? La gingivite, bénigne, ne doit pas être négligée sous peine de se transformer en parodontite. [Lire notre article](#)

Beauté

Ma rehab beauté de la rentrée



Après avoir peaufiné votre bronzage, les bobos post-soleil débarquent. Peau zébrée, cheveux de paille... Nos conseils pour y remédier ! [Voir les images](#)

Cannabis

Les dommages d'une consommation régulière



L'attention, la mémoire et l'intellect sont perturbés chez les fumeurs réguliers de cannabis. Des dommages accentués chez les ados. [Lire notre article](#)

Les blogs de la rédaction

- Le blog Bien-être
- Le blog bébé

Inscrivez-vous à nos newsletters, c'est gratuit !

your email

Magazine (hebdo) Recettes (quotidienne)

Beauté (hebdo) Grossesse (hebdo)

[Gérer mes newsletters](#)

➔ Rechercher dans nos articles

Vos programmes minceur recommandés par Doctissimo

Tous les programmes minceur

Vos espaces communautaires

Tous nos forums :

- Forum Santé
- Forum Beauté
- Forum Famille
- Forum Cuisine
- Forum Nutrition
- Forum Psychologie
- Forum Loisirs
- Forum Vivanes
- Forum Mode
- Forum Sexualité
- Forum Vie pratique
- Forum Médicaments
- Forum Forme et sport
- Forum Grosse et bébé
- Forum People
- Forum Animaux

Error on page.

21

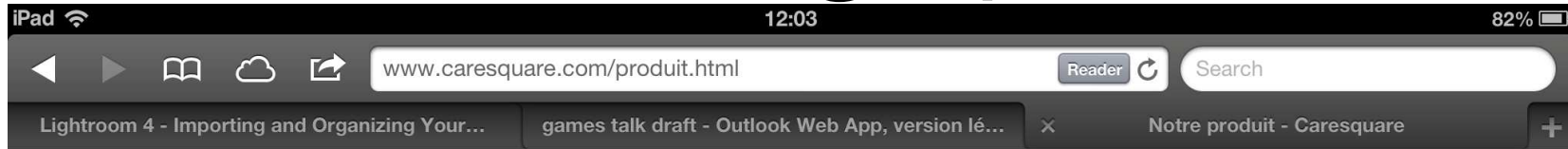
Internet | Protected Mode: On

Start bib in Personal Fo... Calendar - Micros... RIC - meeting - 1... 2 Reminders MCM|7514060 on... PROM PREM fiche... 3 Internet Exp... Microsoft Excel - ... Windows Task Ma... 16:51

mHealth

- use of mobile devices
 - in collecting community and clinical health data
 - delivery of healthcare information to practitioners, researchers, and patients
 - real-time monitoring of patient [vital signs](#), and direct provision of care (via mobile telemedicine)
- mHealth summit 2012
 - **New for 2012!**
 - **Health and Healthcare Delivery** Track will showcase the use of mHealth technologies to improve health and healthcare delivery at all income levels globally. From reducing costs, increasing access, quality, patient care coordination and engagement to the management of specific disease states, population health and self-health management this section will highlight emerging best practices.

En Belgique



[Pourquoi ?](#) [Fonctionnalités](#) [Bénéfices](#) [Où et comment se le procurer ?](#)



CollaboRhythm software platform

- CollaboRhythm is a platform that enables patients to be at the center of every interaction in their healthcare with the goal of empowering them to be involved, reflective, and proactive.
- support can be provided in real-time in the real world instead of through inconvenient doctor's office visits
- through cell phones, tablets, televisions, and computers automatically populated by devices such as glucometers and blood pressure cuffs
- Although the hub of CollaboRhythm is located in the doctor's office, the system's goal is to connect with the patient from any place at any time.

Failure of Google Health

- Few consumers are interested in a digital filing cabinet for their records. What they are interested in is what that data can do for them. Can it help them better manage their health and/or the health of a loved one? Will it help them make appointments? Will it save them money on their health insurance bill, their next doctor visit? Can it help them automatically get a prescription refill? These are the basics that the vast majority of consumers want addressed first and Google Health was unable to deliver on any of these.
- John Moore

BMJ

Medical and Healthcare iPhone Apps from the BMJ Group — BMJ Group - Windows Internet Explorer

http://group.bmj.com/products/mobile-apps

File Edit View Favorites Tools Help

Keynotes — International Fo... collaborhythm software platf... Medical and Healthcare i...

Doctors Toolbag - Just launched

The Doctors Toolbag app provides healthcare professionals with smart and easy to use clinical prediction rules at the touch of a button, providing everything that is needed effective day to day practice.

[Click here for further information >>](#)

Available on the App Store

Best Practice decision support for the iPhone

Check clinical guidelines and research evidence, and consult expert opinion with the new Best Practice app. It structures authoritative decision support information around the patient consultation and includes 20 free sample topics.

[Click here for further information >>](#)

Available on the App Store

Child Health app from Best Health

The child health app from Best Health allows you to check the symptoms of your child's illnesses, find out which treatments work and don't work and highlights key questions to raise with your doctor - all in plain English.

[Click here for further information >>](#)

Available on the App Store

Depression app from Best Health

The depression app from Best Health provides you with up-to-date, reliable, plain English information about depression. It includes suggested questions to ask your doctor, to enable you to make more informed choices about your treatment.

[Click here for further information >>](#)

Available on the App Store

Type 1 Diabetes app from Best Health

The type 1 diabetes app from Best Health explains, in plain English, how to manage your diabetes and keep it under control. It includes information on healthy living and checking your blood glucose levels to help you make more formed choices about your care.

[Click here for further information >>](#)

Available on the App Store

26

Internet | Protected Mode: On

Start | Inb... - Microsoft Outlook | Calendar - Microsoft Outl... | ACHG | PROM PREM fiche projet ... | Medical and Healthca... | 12:17

Quantified self

- N=1 studies, long period (diary) notification of
 - person's daily life
 - inputs (e.g. food consumed, quality of surrounding air)
 - states (e.g. mood, [arousal](#), [blood oxygen levels](#))
 - activity (e.g. pedometer with altimeter for stairs)
 - performance ([mental](#) and physical)
 - health care encounters
 - With or without technology (fi. Geolocalisation)
- data collection, followed by visualization, cross-referencing and the discovery of correlations
- Issues of privacy when data are sent to a website
 - Cfr. www.fitbit.com (with iPhone and Android apps)

Fitness
Weight control
Chronic disease
management

MedLion, Inc. Silicon Valley

- Their breakthrough model is enabled by disintermediating insurance companies from their encumbrance of day-to-day healthcare.
- insurance-centric primary care is the norm today
- For only \$49 per month and \$10 per visit, MedLion is able to provide high quality medicine at a price point nearly any family can afford.
- For the same amount they may pay in co-pays with an insurance policy, we can offer complete primary care without the added cost burden of insurance.
- more than half of their patient interaction is via electronic means

Future : P. A. C.

- Patient-centered, Accountable and Coordinated
 - Patient Centered Medical Home (PCMH)
 - Accountable Care Organizations (ACO)
- vs
- Fee for service, face to face based reimbursement