PREMs Observatory

Systematic digital use of PREM for quality enhancement in Italian Hospitals.

Milena Vainieri and Sabina De Rosis, Ph.D.
Laboratorio Management e Sanità,
Scuola Superiore Sant'Anna di Pisa

Sant'Anna School

Sant'Anna School of Advanced Studies is a **PUBLIC UNIVERSITY** institute - **with special autonomy –, vocated to research** and education in an international environment, working in the field of **applied sciences.**

Laboratorio Management e Sanità

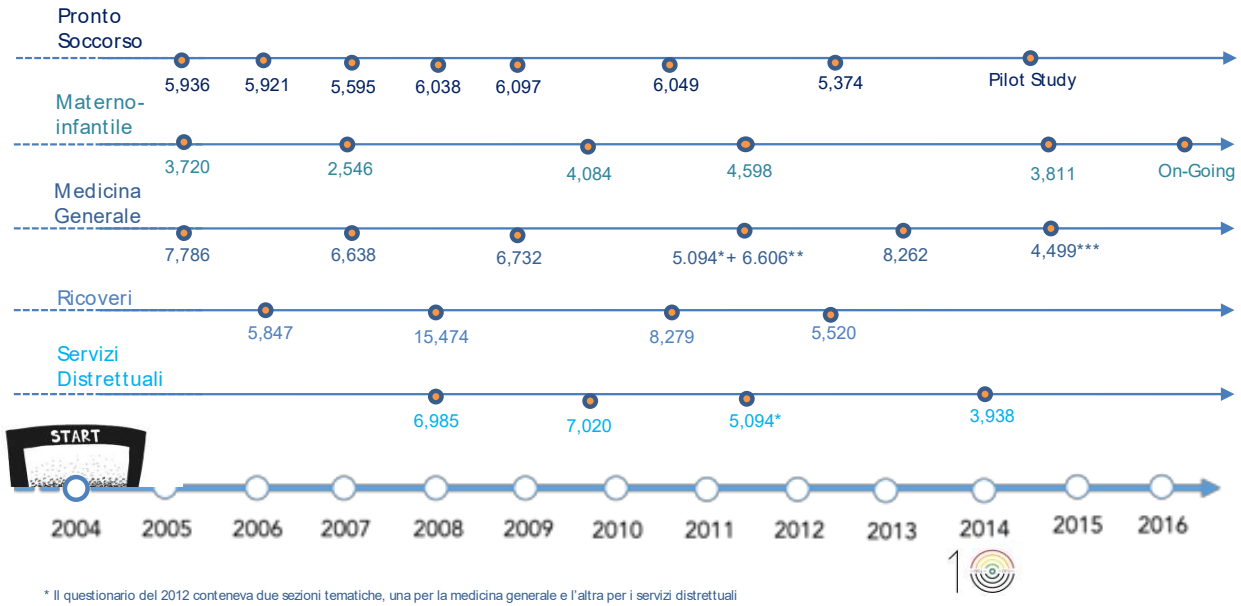
A multidisciplinary team working on:

- Research
- Healthcare performance
- evaluation
- Professionals & Users' participation
- Behavioural economics
- Training

Once upon a time

The multi-year experience of the MeS Lab investigating patients' views

The multi-year experience of the MeS Lab. investigating patients' views



* Il questionario del 2012 conteneva due sezioni tematiche, una per la medicina generale e l'altra per i servizi distrettuali
** Indagine dedicata alla Sanità di iniziativa (pazienti cronici)
*** La survey ha interessato gli adolescenti toscani tra i 16 e i 17 anni, coinvolgendo più di 5.000 rispondenti.

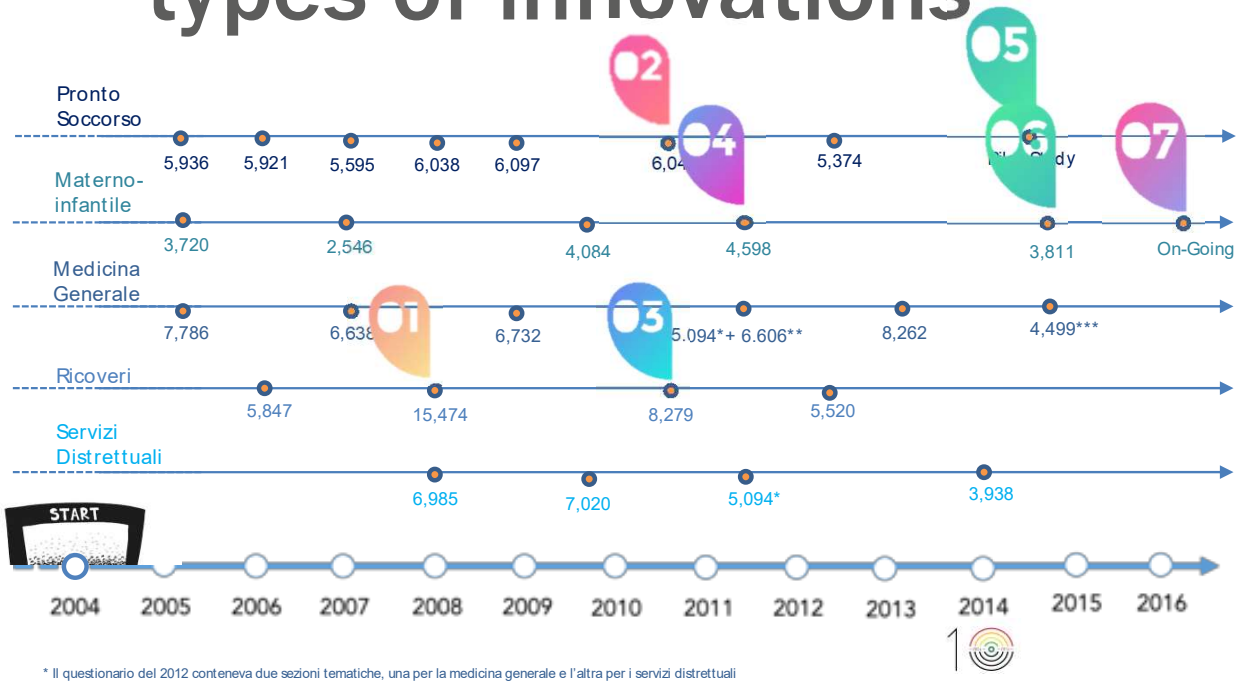
Periodic surveys

Different services and pathways

Over 170,000 QUESTIONNAIRES collected in 10 years

The Figure summarizes the surveys carried out between 2004 and 2016, in the various settings / care pathways. The figures under the points indicate the number of questionnaires collected.

Introduction of different types of innovations



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01 **THE FIRST PATIENT REPORTED EXPERIENCE SURVEY in Tuscany** (from satisfaction to experience)

02 The assessment bands are defined after correcting for the patient's characteristics and on the basis of the benchmarking

03 **THE FIRST MULTICHANNEL SURVEY** (postal, CATI and CAWI)

04 **THE FIRST COMPLETELY ONLINE SURVEY,** which all women who gave birth in Tuscany were invited to

05 The first feasibility study of a survey only via SMS.

06 **THE FIRST LONGITUDINAL SURVEY** with follow-up from the moment of delivery to one year of the baby's life

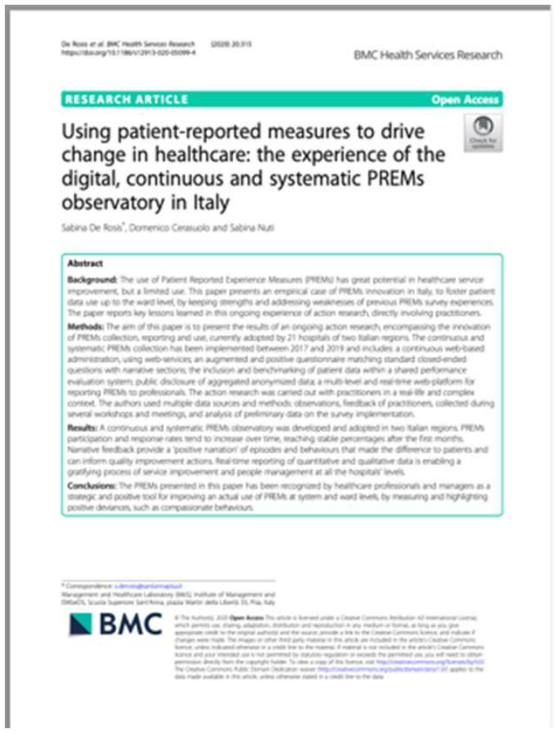
07 **THE FIRST SURVEY VIA MOBILE APPs** in Tuscany, hAPPyMamma (and webAPP – beFood on lifestyles)

The new generation surveys

EACH PATIENT can take part to the survey, after the healthcare service use

The survey is an **INTEGRAL PART** of the service provision

Using **WEB SERVICES**, the patient voice is a **IN CONTINUOS AND REAL TIME DATA FLOW**



BMC Health Services Research

RESEARCH ARTICLE Open Access

Using patient-reported measures to drive change in healthcare: the experience of the digital, continuous and systematic PREMs observatory in Italy

Sabina De Rosis*, Domenico Cerasuolo and Sabina Nuti

Abstract

Background: The use of Patient Reported Experience Measures (PREMs) has great potential in healthcare service improvement, but a limited use. This paper presents an empirical case of PREMs innovation in Italy, to foster patient data use up to the ward level, by keeping strengths and addressing weaknesses of previous PREMs survey experiences. The paper reports key lessons learned in this ongoing experience of action research, directly involving practitioners.

Methods: The aim of this paper is to present the results of an ongoing action research, encompassing the innovation of PREMs collection, reporting and use, currently adopted by 21 hospitals of two Italian regions. The continuous and systematic PREMs collection has been implemented between 2017 and 2019 and includes a continuous web-based administration, using web-services, an augmented and positive questionnaire matching standard closed-ended questions with narrative sections, the inclusion and benchmarking of patient data within a shared performance evaluation system, public disclosure of aggregated anonymized data, a multi-level and real-time web-platform for reporting PREMs to professionals. The action research was carried out with practitioners in a real-life and complex context. The authors used multiple data sources and methods: observations, feedback of practitioners, collected during several workshops and meetings, and analysis of preliminary data on the survey implementation.

Results: A continuous and systematic PREMs observatory was developed and adopted in two Italian regions. PREMs participation and response rates tend to increase over time, reaching stable percentages after the first months. Narrative feedback provide a 'positive narration' of episodes and behaviours that made the difference to patients and can inform quality improvement actions. Real-time reporting of quantitative and qualitative data is enabling a gratifying process of service improvement and people management at all the hospitals' levels.

Conclusions: The PREMs presented in this paper has been recognized by healthcare professionals and managers as a strategic and positive tool for improving an actual use of PREMs at system and ward levels, by measuring and highlighting positive deviances, such as compassionate behaviours.

BMC

- **IN CONTINOUS**
- **IN REAL TIME**
- **PREMs, PROMs & Longitudinal PREMs**
- **Patients' narratives**

De Rosis, S., Cerasuolo, D., & Nuti, S. (2019), **Using patient-reported measures to drive change in healthcare: the experience of the digital, continuous and systematic PREMs observatory in Italy**. BMC health services research, 20, 1-17.

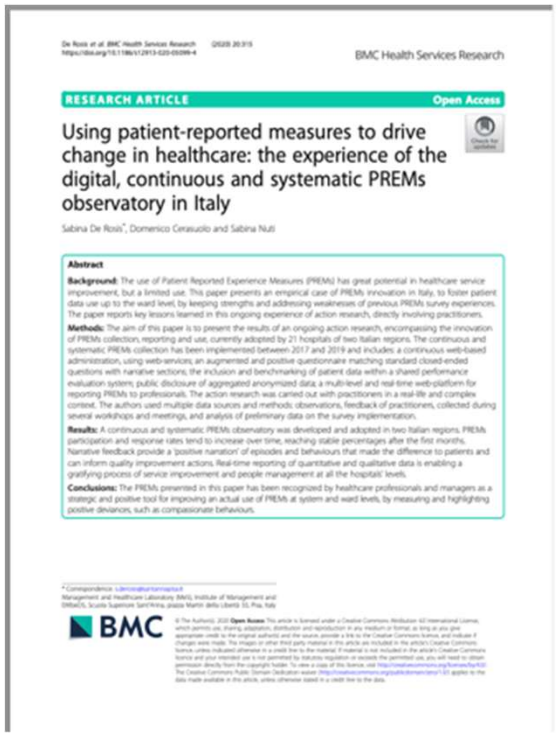
The new generation surveys

A **DIGITAL, CONTINUOUS, AND SYSTEMATIC** PREMs observatory was developed and adopted in Italy.

1 Data collection

2 Type of data

3 Data reporting



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De Rosis, S., Cerasuolo, D., & Nuti, S. (2019), **Using patient-reported measures to drive change in healthcare: the experience of the digital, continuous and systematic PREMs observatory in Italy**. BMC health services research, 20, 1-17.

1

Data collection

Sample surveys	**The whole population of patients using a certain service or in a specific pathway**
Biennial surveys	**In continuous surveys**

- High number of questionnaires collected with a quasi-census survey allows for A MICRO-LEVEL DATA REPORTING.
- This allows a MICRO-LEVEL USE OF DATA.

1 Data collection

MeS Lab ICT system

MeS Lab ICT system

Hospital Electronic Health Record

Continous Enrolment

WEB SERVICES

Personalized link by e-mail or SMS

Online questionnaire

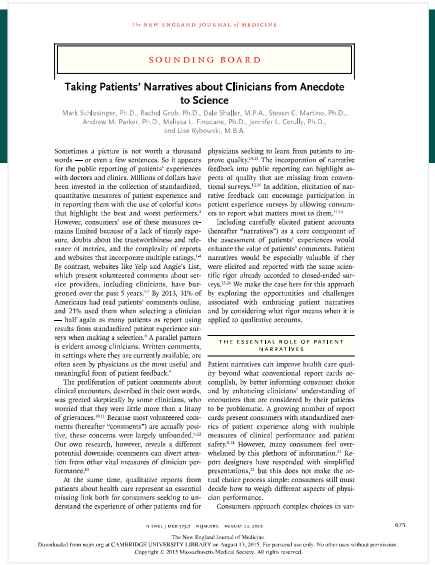
WEB SERVICES

Real-time data reporting web platform

2

Type of data

Experience	**Experience**, satisfaction and outcome measures
Only quantitative questions	More **narrative surveys**



The NEW ENGLAND JOURNAL of MEDICINE

SOUNDING BOARD

Taking Patients' Narratives about Clinicians from Anecdote to Science

Mark Schlesinger, Ph.D., Rachel Grob, Ph.D., Dale Shaller, M.P.A., Steven C. Martino, Ph.D., Andrew M. Parker, Ph.D., Melissa L. Finucane, Ph.D., Jennifer L. Cerully, Ph.D., and Lisa Rybowski, M.S.A.

Sometimes a picture is not worth a thousand words — or even a few sentences. So it appears for the public reporting of patients' experiences with doctors and clinics. Millions of dollars have been invested in the collection of standardized, quantitative measures of patient experience and in reporting them with the use of colorful icons that highlight the best and worst performers.[1] However, consumers' use of these measures remains limited because of a lack of timely exposure, doubts about the trustworthiness and relevance of metrics, and the complexity of reports and websites that incorporate multiple ratings.[2-4] By contrast, websites like Yelp and Angie's List, which present volunteered comments about service providers, including clinicians, have burgeoned over the past 5 years.[5-7] By 2013, 31% of Americans had read patients' comments online, and 21% used them when selecting a clinician — half again as many patients as report using results from standardized patient experience surveys when making a selection.[8] A parallel pattern is evident among clinicians. Written comments, in settings where they are currently available, are often seen by physicians as the most useful and meaningful form of patient feedback.[9]

The proliferation of patient comments about clinical encounters, described in their own words, was greeted skeptically by some clinicians, who worried that they were little more than a litany of grievances.[10,11] Because most volunteered comments (hereafter "comments") are actually positive, these concerns were largely unfounded.[5,8] Our own research, however, reveals a different potential downside: comments can divert attention from other vital measures of clinician performance.[12]

At the same time, qualitative reports from patients about health care represent an essential missing link both for consumers seeking to understand the experience of other patients and for physicians seeking to learn from patients to improve quality.[13-15] The incorporation of narrative feedback into public reporting can highlight aspects of quality that are missing from conventional surveys.[16-18] In addition, elicitation of narrative feedback can encourage participation in patient experience surveys by allowing consumers to report what matters most to them.[17,19]

Including carefully elicited patient accounts (hereafter "narratives") as a core component of the assessment of patients' experiences would enhance the value of patients' comments. Patient narratives would be especially valuable if they were elicited and reported with the same scientific rigor already accorded to closed-ended surveys.[8,20] We make the case here for this approach by exploring the opportunities and challenges associated with embracing patient narratives and by considering what rigor means when it is applied to qualitative accounts.

THE ESSENTIAL ROLE OF PATIENT NARRATIVES

Patient narratives can improve health care quality beyond what conventional report cards accomplish, by better informing consumer choice and by enhancing clinicians' understanding of encounters that are considered by their patients to be problematic. A growing number of report cards present consumers with standardized metrics of patient experience along with multiple measures of clinical performance and patient safety.[5,8] However, many consumers feel overwhelmed by this plethora of information.[21] Report designers have responded with simplified presentations,[22] but this does not make the several choice process simple: consumers still must decide how to weigh different aspects of physician performance.

Consumers approach complex choices in var-

N ENGL J MED 372;7 NEJM.ORG FEBRUARY 12, 2015

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The New England Journal of Medicine

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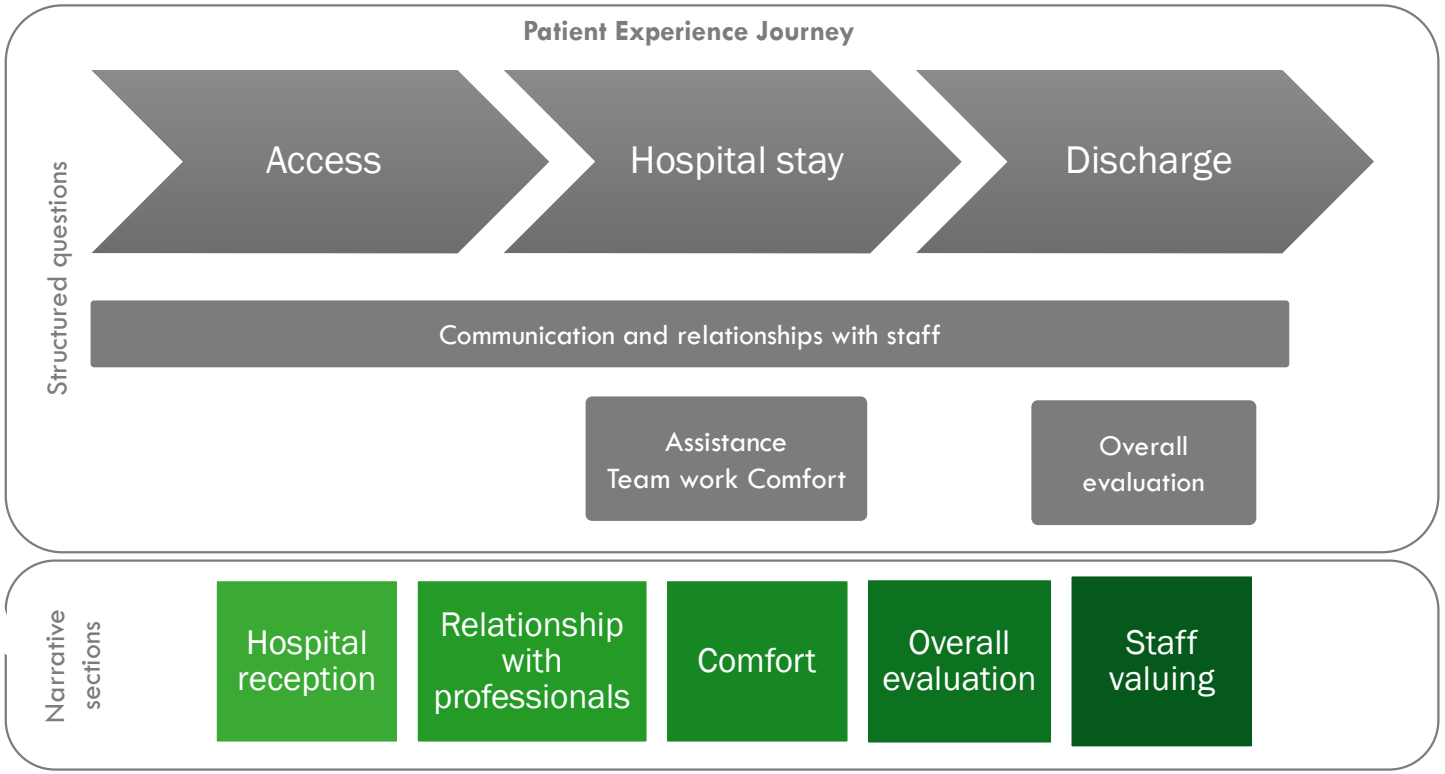
Listening to patients' stories is important, but the challenge for health professionals is to **find ways of using these narratives** to improve practice and the patient experience

(Buckley A et al (2016) Patient narratives 1: using patient stories to reflect on care. *Nursing Times*; 112: 10, 22-25.)

The quali-quantitative questionnaire follows the process of hospitalization - PREMs

The **narrative sections** (additional to the closed questions) allow patients to reports relevant aspects of their experience (what is value to them)



3 Data reporting

Results available in several months

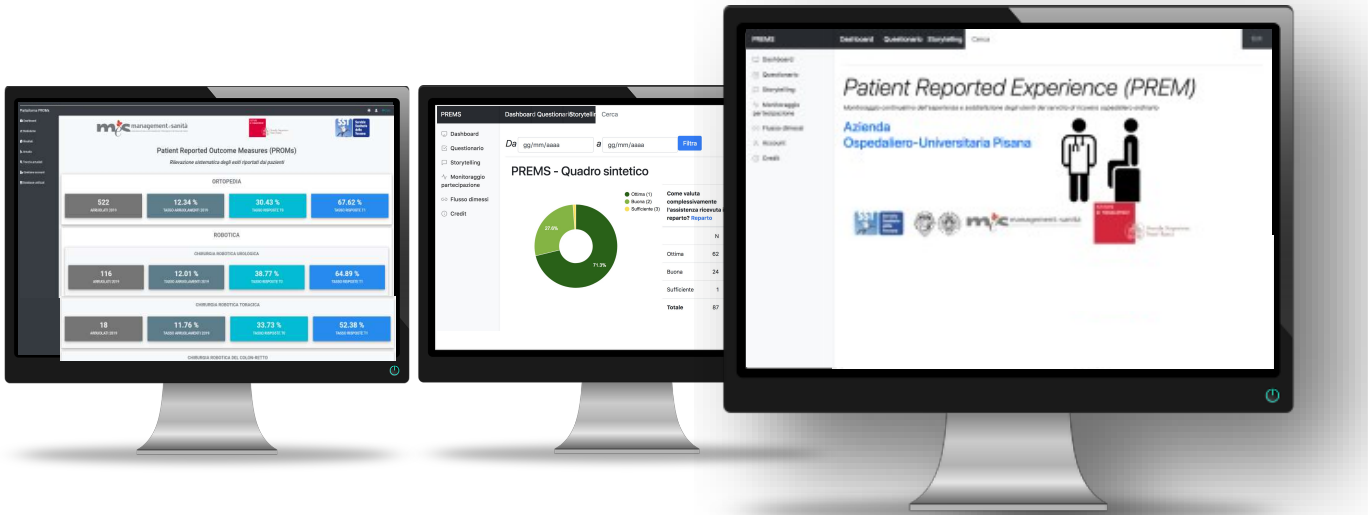
Real-time updated results

From Experience and Outcome Measurement to the Health Professionals' Engagement

Sabina De Rosis, Francesca Pennucci and Sabina Nuti

Abstract

Relationship and stakeholder marketing suggest that the environment in which an organization is embedded is very complex and that the value created through its activity is affected by several internal and external stakeholders. This is particularly true in the public healthcare sector, where behaviors and decisions of healthcare professionals and patients, who are key stakeholders, significantly determine the value created to each patient and to the entire population. Engaging healthcare professionals and patients represents a keystone of improvement processes and value co-creation. However, the service-orientation has been not substituted by a client-orientation, for improving value to patients, organizations and the whole system. Stakeholder marketing has considerable potential in public healthcare contexts. The paper addresses the question of how to successfully engage key stakeholders in healthcare in a systematic and continuous initiative of patient feedback collection, reporting and use for co-producing value in healthcare. The paper describes an empirical ongoing initiative (PREMs and PROMs Observatory) of patients' engagement into a retrospective healthcare services' co-assessment, and healthcare professionals' engagement in the prospective use of real-time patient-reported measures. The paper reports preliminary results of stakeholders' participation. A case study design was used, with on-field



De Rosis, S., Pennucci, F., & Nuti, S. (2019). From experience and outcome measurement to the health professionals' engagement. *Micro & Macro Marketing*, *28*(3), 493-520.

Multi-level use of data

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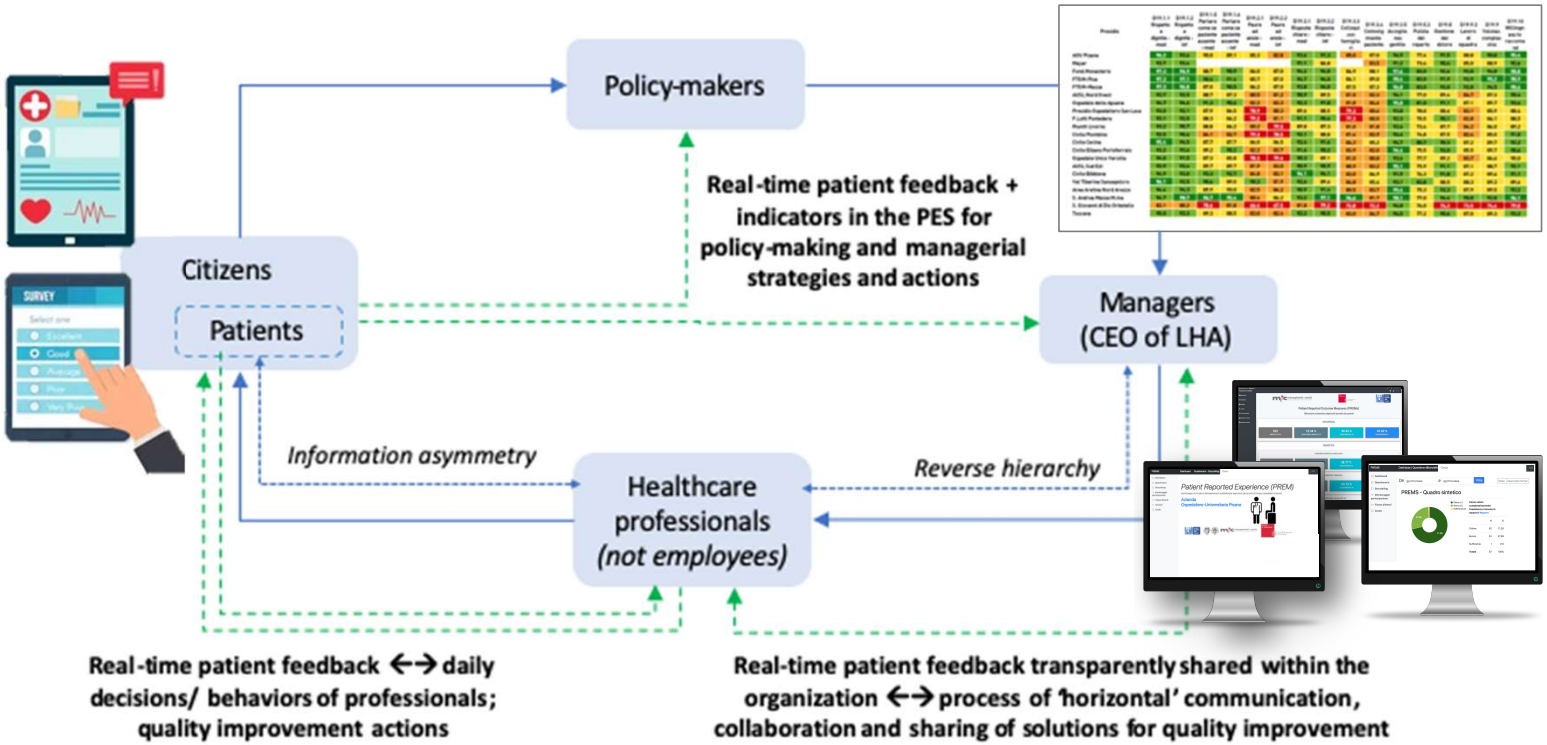


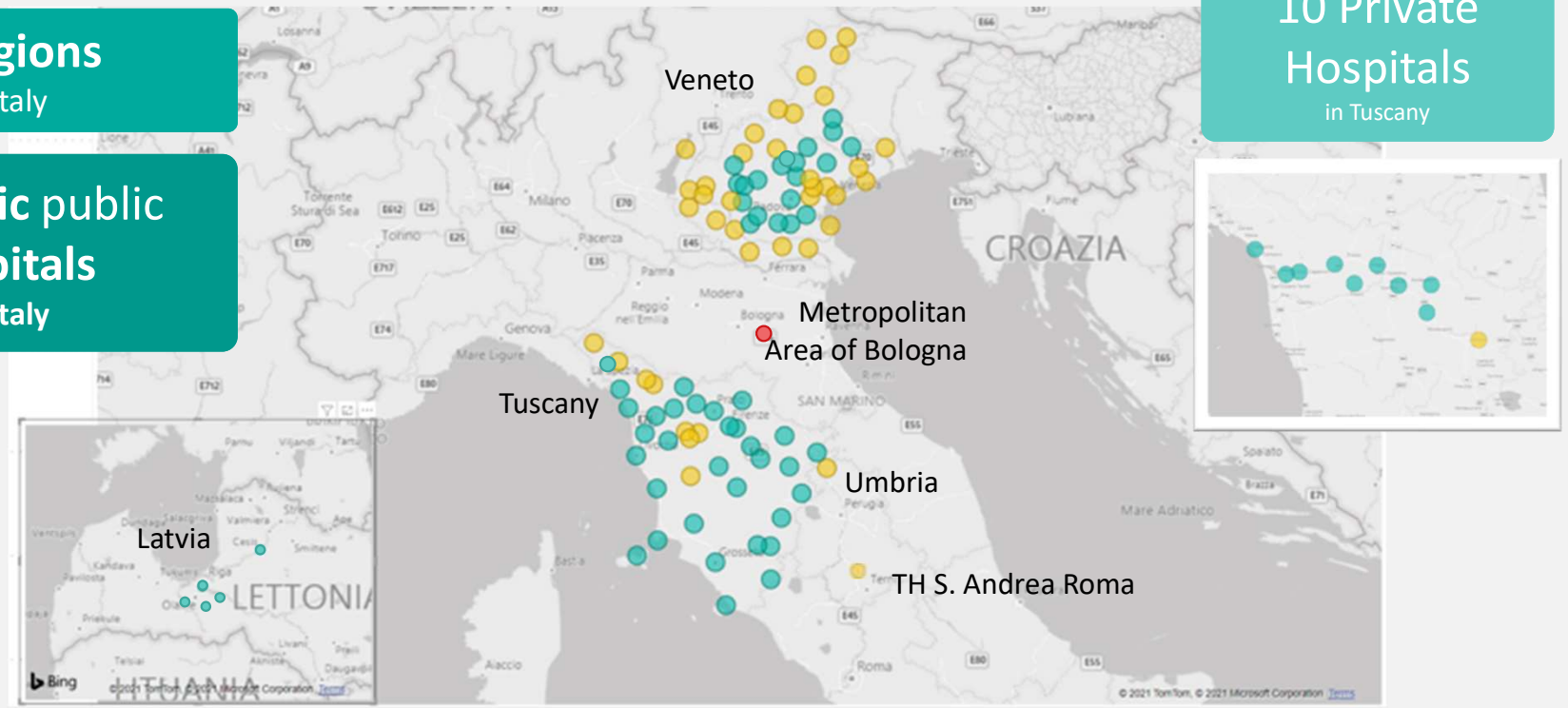
De Rosis, S., Pennucci, F., & Nuti, S. (2019). From experience and outcome measurement to the health professionals' engagement. *Micro & Macro Marketing*, *28*(3), 493-520.

2 Countries
Italy and Latvia

3 Regions
in Italy

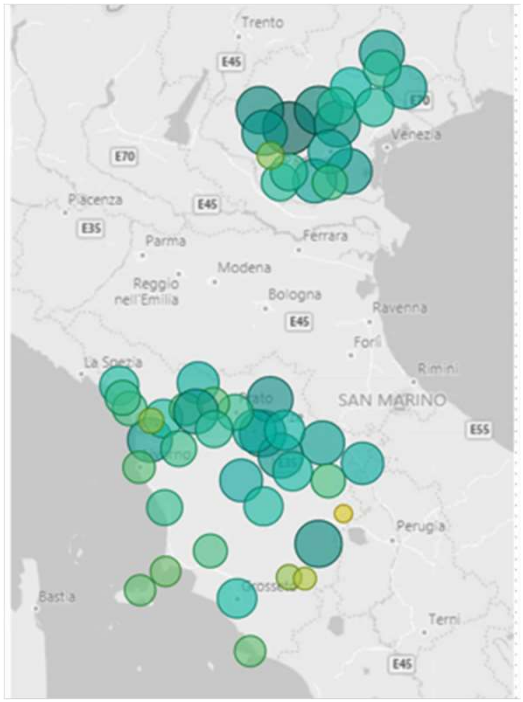
67 public public hospitals
In Italy

10 Private Hospitals
in Tuscany

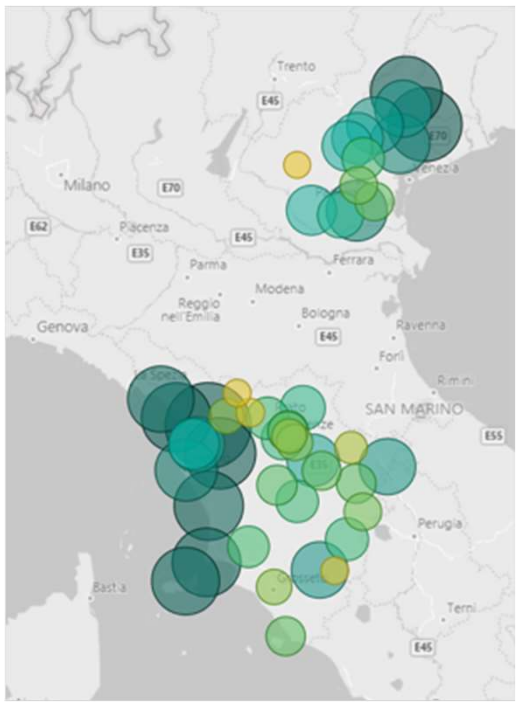


From the end of 2018 to September 2022

PARTICIPATION RATE



RESPONSE RATE



All patients, always, can participate

More than **350,000** contacted patients

BIG DATA

More than **101,000** patient responses

RESPONSE RATE estimated on average

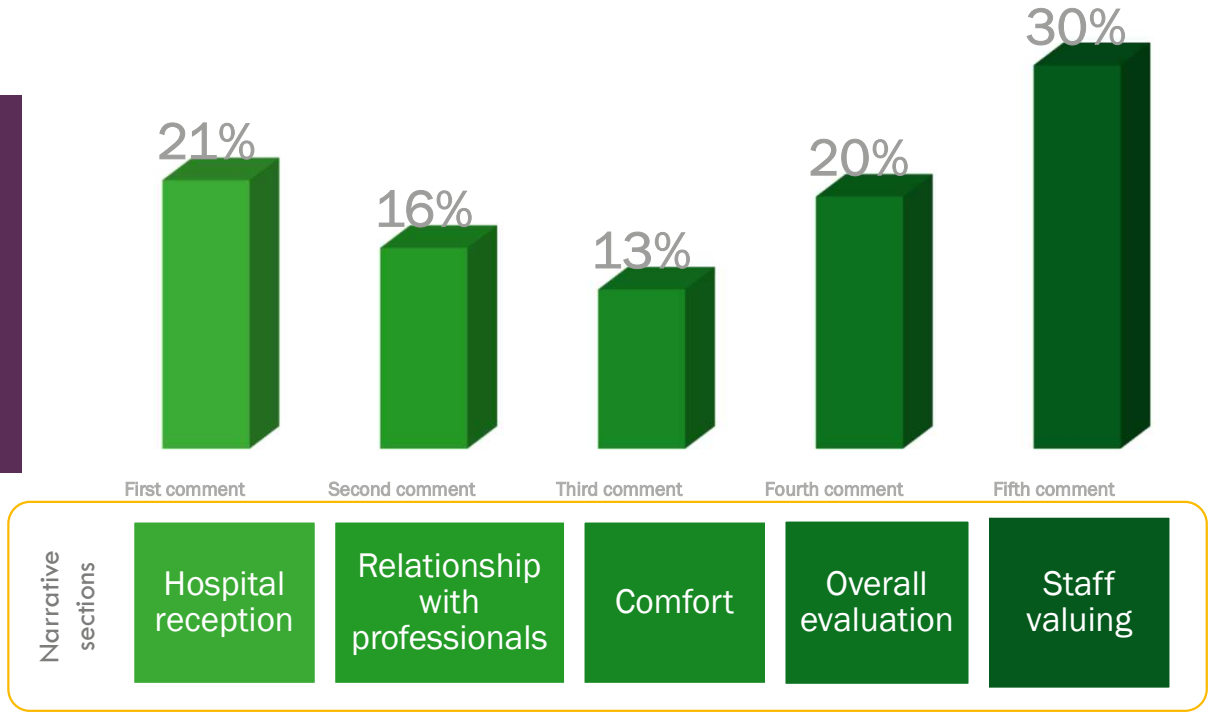
> 33%

De Rosis, S., Cerasuolo, D., & Nuti, S. (2019), Using patient-reported measures to drive change in healthcare: the experience of the digital, continuous and systematic PREMs observatory in Italy. BMC health services research, 20, 1-17.
Coletta,L., Murante, A,M., & Nuti, S. The continuous collection of user experience for timely addressing critical factors of the hospital journey. Excellence in Services 22nd International Conference, Thessaloniki (Greece) - Conference Proceedings ISBN 9788890432798

...the patients' stories

Percentage of completion of open-ended questions on the total number of respondents

More than 250,000 stories collected



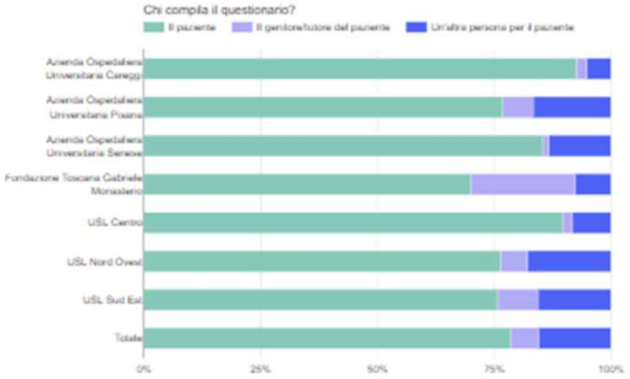
Data monitoring and return platform

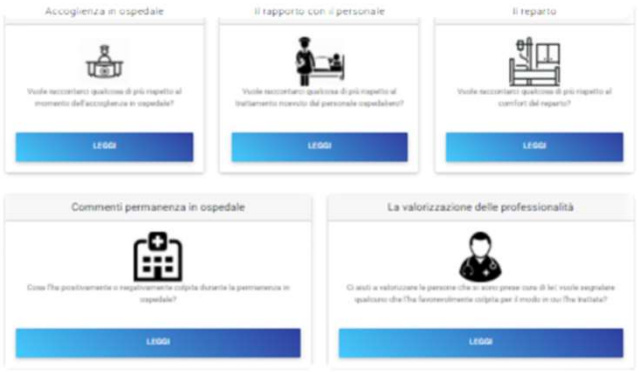
PREMs

Toscana

- Dashboard
- Adesione
- Partecipazione
- Storytelling
- Profile
- Credits

Exit





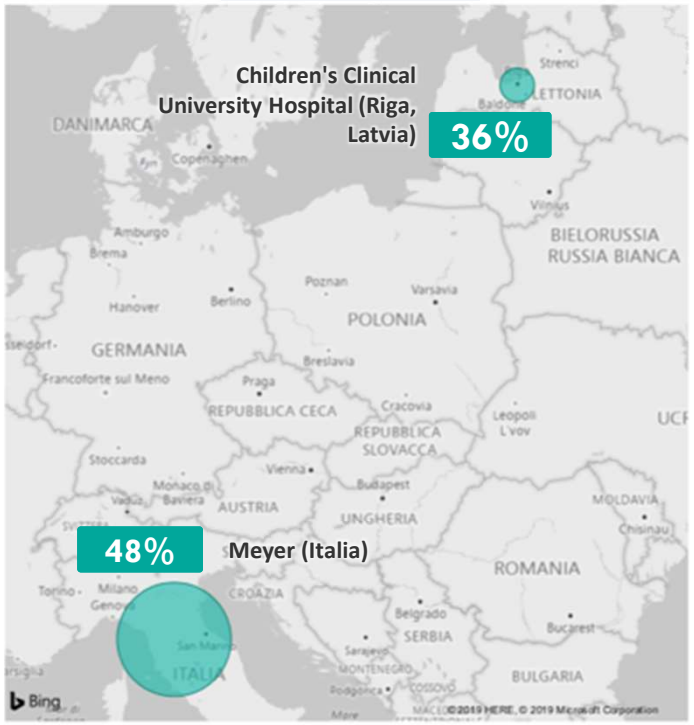
...for peadiatric patients

The voice of <u>paediatric</u> patients

More than 23.200 CONTACTED FAMILIES

More than 8.500 RESPONDENTS

RESPONSE RATE



In two years...

Corazza, I., Gilmore, K. J., Menegazzo, F., & Abols, V. (2021). Benchmarking experience to improve paediatric healthcare: listening to the voices of families from two European Children's University Hospitals. BMC Health Services Research, 21(1), 1-13.

...for peadiatric patients

Value of including the Children Experience for improving their rightS during hospitalization

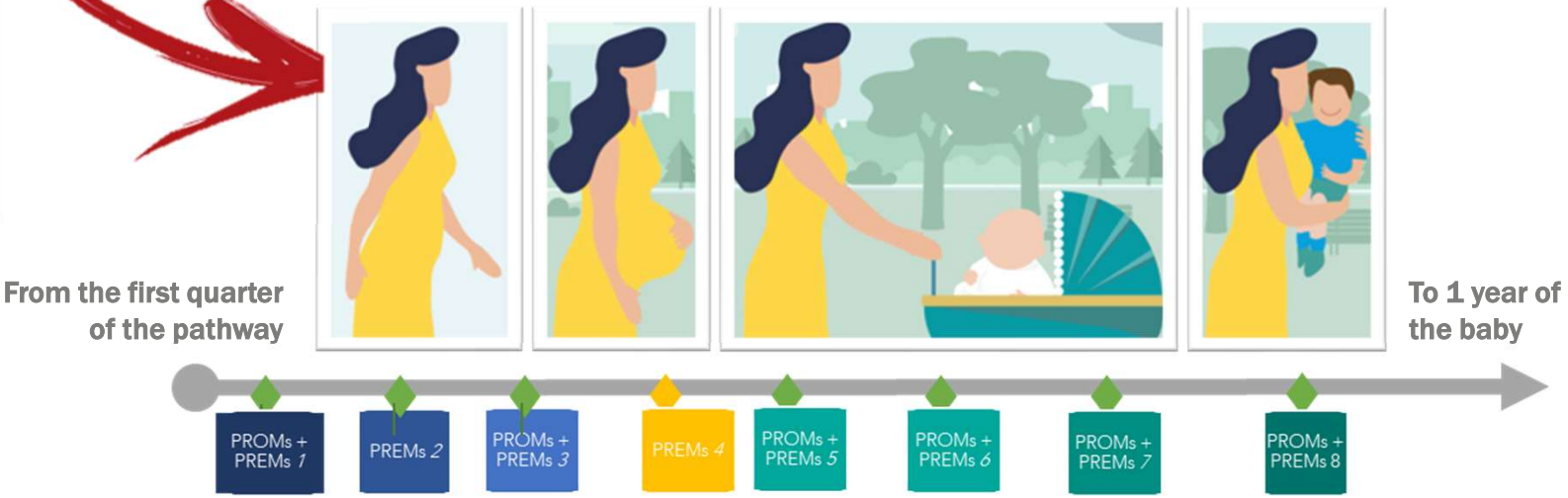
The European VoiCEs project aims to strengthen children's involvement in evaluating and improving the quality of care in children's hospitals.

The VoiCEs project will lead to the development of a **European Observatory** of the children voices, which would represent a fundamental step towards the improvement of the children's awareness of their rights, as well as of the practitioners' attention on their young patients' rights.

De Rosis Sabina, Manila Bonciani, Veronica Spataro, Ilaria Corazza, Barbara Sibbles, Jan A. Hazelzet, Pekka Lahdenne, Katariina Gehrmann (former Silander), Francesca Menegazzo, Michela Sica, Vita Šteina, Guna Esenberga, Stefania Solare, Milena Vainieri (2022). Value of including the Children's Experience for improving their rightS during hospitalization: protocol of the VoiCEs project; JMIR Preprints. 19/09/2022:42804

...for women in the maternal-pathway

The **longitudinal PREMs and PROMs survey** is integrated with the **MOBILE APP hAPPyMamma** that contains the digitized version of the pregnancy booklet, allows you to have an updated agenda of appointments and allows you to book visits and tests, as well as provide validated information on the care pathway and information on the facilities and services to contact.



Bonciani, M., De Rosis, S., & Vainieri, M. (2021). Mobile Health Intervention in the Maternal Care Pathway: Protocol for the Impact Evaluation of hAPPyMamma. JMIR Research Protocols, 10(1), e19073.

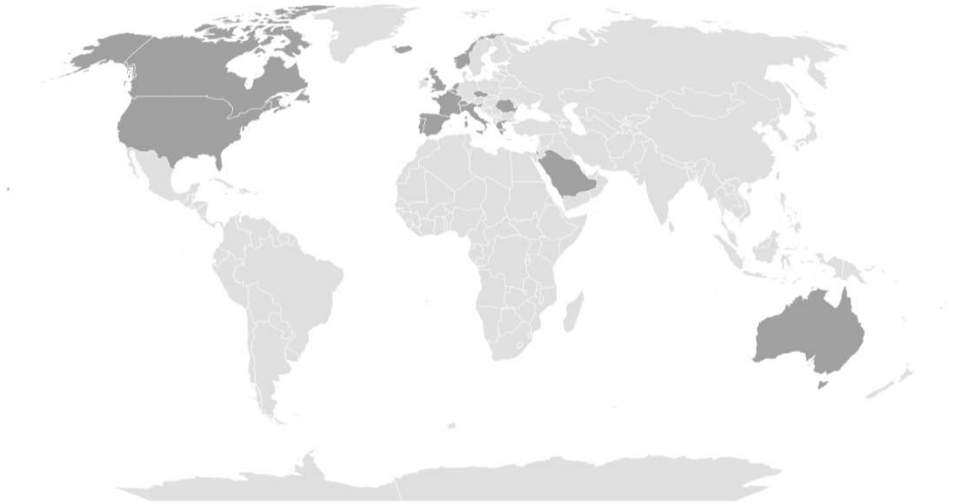
What's next?

PREMs and PROMs on primary care and chronic diseases….

PaRIS

Patient Reported Indicator Survey

Observatory on PREMs and PROMs about primary care



Vainieri, De Rosis, Nuti, Spataro, Bellentani, Carbone, Quattrone, Visca, Urbani (2022) Da un'iniziativa internazionale a un osservatorio nazionale per monitorare l'esperienza dei pazienti cronici in Italia. Sistema Salute n.2/2022

PaRIS

Patient Reported Indicator Survey

PC PROVIDER QUESTIONNAIRE
+
PATIENT QUESTIONNAIRE

ONE-TIME surveys

Benchmarking

Observatory on PREMs and PROMs about primary care

PC PROVIDER QUESTIONNAIRE
+
PATIENT QUESTIONNAIRE
+
QUESTIONNAIRE FOR DISTRICT DIRECTORS

PANEL for periodic surveys

Monitoring of PNRR investments

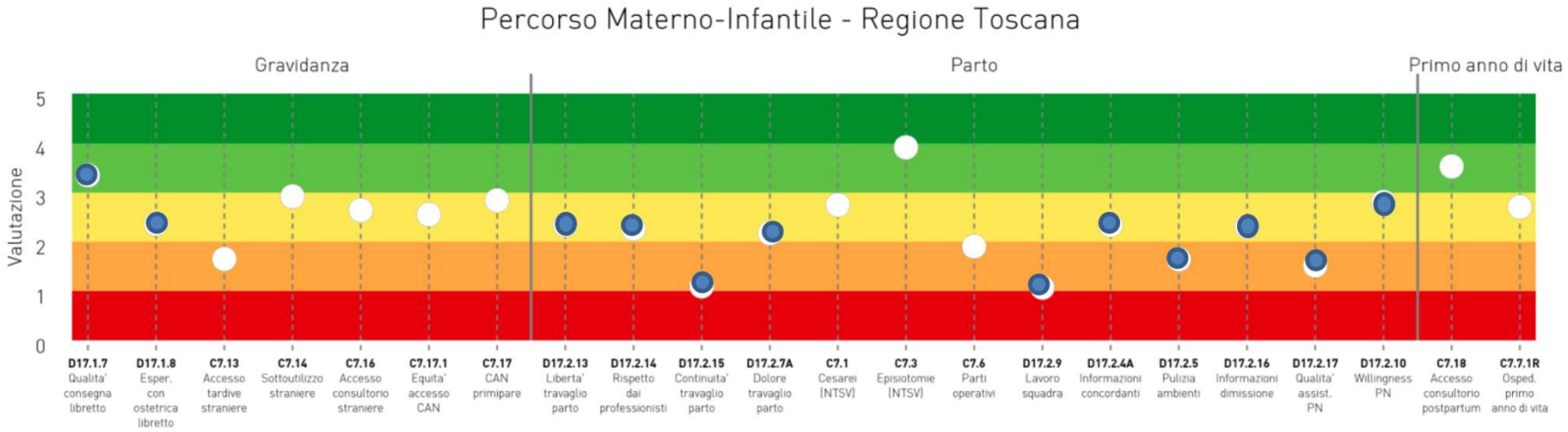
Vainieri, De Rosis, Nuti, Spataro, Bellentani, Carbone, Quattrone, Visca, Urbani (2022) Da un'iniziativa internazionale a un osservatorio nazionale per monitorare l'esperienza dei pazienti cronici in Italia. Sistema Salute n.2/2022

Are they used?

...something happened...

Integrare la valutazione della performance con indicatori calcolati a partire dalle indagini agli utenti

Indagini di Esperienza Longitudinale – Pentragramma percorso nascita
Regione Toscana – Anno 2019

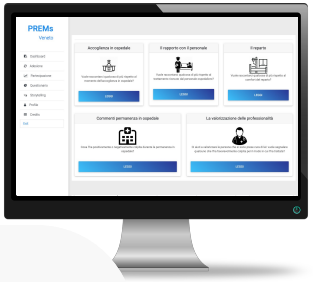


Integrazione di indicatori calcolati dai flussi amministrativi (Certificato di Assistenza al Parto e flussi consultoriali) e dai dati raccolti attraverso l'indagine alle utenti

Fonte: Piattaforma del sistema di valutazione della Toscana
https://performance.santannapisa.it/pes/start/home.php

Dare valore alle single storie dei pazienti sia per le azioni di quality improvement, sia per valorizzare il personale

ASPETTI ORGANIZZATIVI DA MIGLIORARE



COMPORTAMENTI CHE FANNO LA DIFFERENZA E RICONOSCIMENTO DEL RUOLO DEI PROFESSIONISTI

Sono rimasta positivamente colpita dall'amore e la professionalità da parte dei medici nel svolgere non un semplice lavoro ma una missione! Negativamente colpita dalla scarsa pulizia del reparto, poiché dopo un intervento il paziente è molto più esposto a rischio di infezioni.

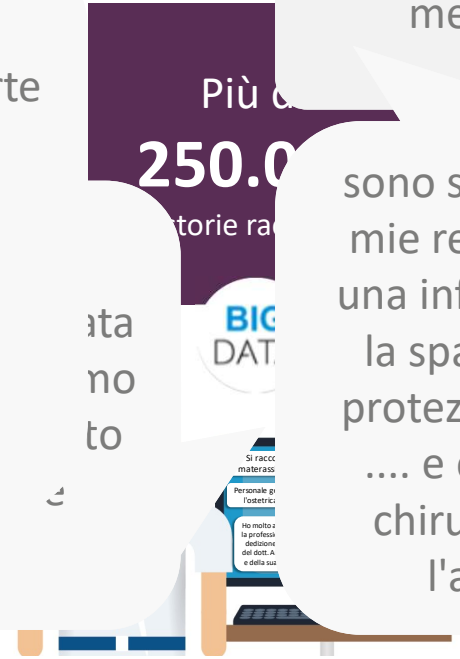
preoccupaz

…Nonostante l'emergenza del Coro irus e i medici e infermi veramer

感谢意大利政府和医院各 至的关照 o italiano e ospedalieri neticolosa!)

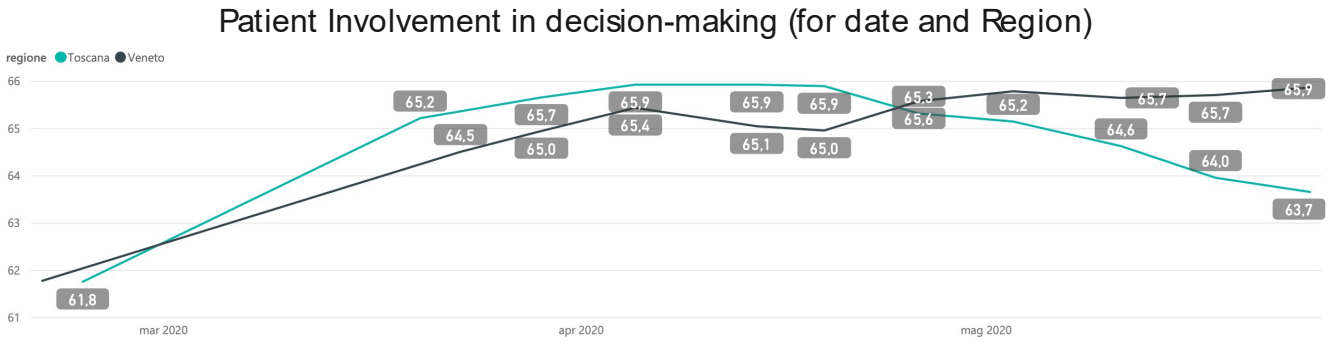
sono stati tutti molto attenti alle mie reazioni e ansie; addirittura una infermiera mi ha accarezzato la spalla con modo di affetto e protezione.... e la ringrazio tanto .... e c chirur l'altro mi faceva parlare

Ci vogliono bene a noi bambini



...during the COVID-19

The PREMs and PROMs Observatory measured the effect of crisis on patient experience



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Evaluating organizational models

The PREMs and PROMs Observatory can evaluate Organizational Models of service delivery, or organizational change/innovations

Survey on the Organizational Climate

PREMs

	Mi ritengo soddisfatto di lavorare nella mia struttura	Consiglierei ad un altro di lavorare nella mia Struttura/Unità Operativa	Posso svolgere il mio lavoro con ritmi sostenibili	Penso spesso di cambiare lavoro	Mi trasferirò in un'altra struttura o unità della mia Azienda appena possibile	La mia Azienda incoraggia cambiamenti ed innovazioni
Q1- Lavoro per compiti			-0,138			
Q2 - Prendere le decisioni				-0,061	-0,081	
Q3 - Infermiere unico					0,063	
Q4 - Continuità dopo l'evento acuto	0,17	0,188	0,107			0,132
Q6 - Team ben definito			-0,156			-0,185
Q7 - Supervisore	-0,097	-0,091				
Q9 - Sinergia con OSS						0,163
Q10 - Flessibilità	-0,076	-0,104		0,058	0,06	-0,089
ETA'						
GENERE						

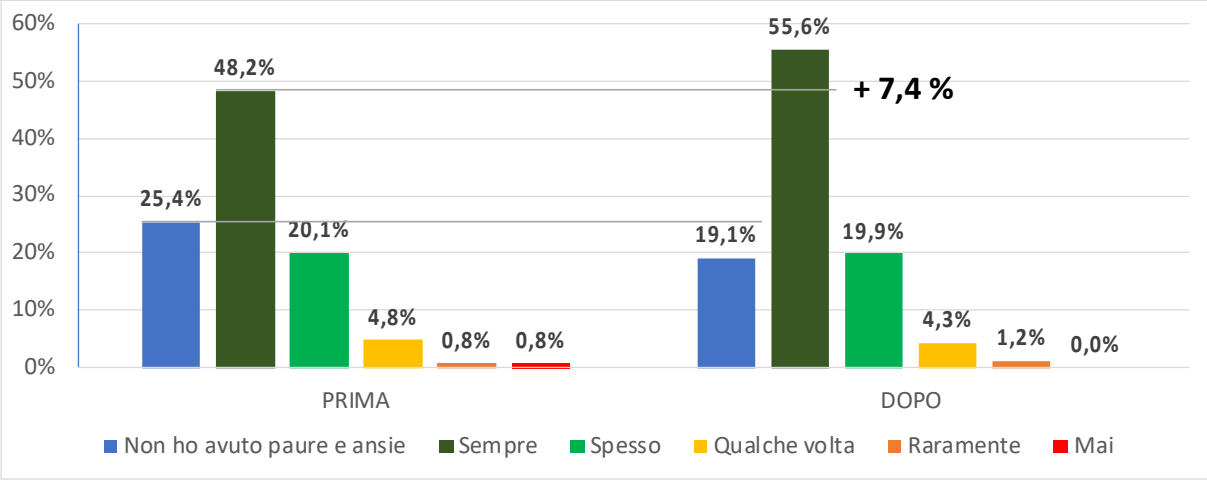
	Paure ed ansie	Parlare come se il paziente non fosse presente	Rispetto e dignità	Risposte chiare degli infermieri	Gestione del dolore	Coinvolgimento del paziente	Comunicazione con i	Collaborazione medici-infermieri	Informazioni alla dimissione	Informazioni sulla terapia	Consiglierebbe ospedale	Valutazioni complessive
Q1- Lavoro per compiti	1,09 +		1,11 +					0,9 −		0,91 −		
Q2 - Prendere le decisioni			1,14 +	1,1 +					1,14 +	1,19 +		
Q3 - Infermiere unico	1,09 +		1,11 +						0,92 −			1,04 +
Q4 - Continuità dopo l'evento acuto	0,86 −		0,78 −	0,84 −								0,86 −
Q5- Coinvolgimento del caregiver					1,08 +	1,12 +						
Q6 - Team ben definito			0,91 −									
Q7 - Supervisore			1,1 +	1,08 +								
Q9 - Sinergia con OSS												

M.Vainieri, C.Barchielli,N. Bellé. "Modelli organizzativi e performance dell'assistenza infermieristica". Il Mulino, 2020

IMPACT OF THE INTRODUCTION OF PSICOLOGICAL SUPPORT ON PATIENT EXPERIENCE

Durante il ricovero, i medici l'hanno aiutata ad affrontare paure ed ansie che aveva riguardo al suo stato di salute?

PRIMA vs DOPO
introduzione psicologo in corsia



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Grazie per l'attenzione!

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