

# Integrating Patient-reported Measures and Predictive Data in a Shared Decision Report for Knee and Hip Arthritis Treatment Decisions

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- PCORI

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*The views in this work are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.*

- AHRQ

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# PROs for shared decision making

*Shared decision making* is a key component of patient-centered health care. Patients and clinicians working together to select treatments and care plans can improve patient outcomes.

The use of patient-reported outcomes (PROs), in addition to EHR data, to facilitate patient-clinician shared decisions is new and poses new informatics challenges.



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**FORCE** The logo for FORCE (For Outcomes Research in Care) features the word 'FORCE' in a bold, blue, sans-serif font. To the right of 'FORCE' is the TJR logo, which consists of a stylized 'TJR' in blue with a black circle above the 'J'.

# EHR: strengths and limitations in shared decision tools

The electronic health record (EHR) digitally aggregates patient's health data at each episode. EHR systems:

- Capture and store clinical data per episode for medical, legal, and administrative purposes.

## EHR Limitations

- EHRs collect data *locally*. If the patient visits different hospitals or clinicians, today's EHR does not integrate patients' health data across clinical settings and time.
- EHRs collect data *when the patient visits* a hospital or MD, and may miss data if the patient does not visit; thus, data are potentially incomplete and biased.
- Decision tools *within* EHRs are based on local data, not national data.



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# A.S.K. Study:

## Arthritis care through Shared Knowledge

- Develop and test a novel shared decision tool (with patient-centered predictive analytics) for surgeons and patients with knee/hip osteoarthritis (OA) who are considering total joint replacement (TJR) surgery.
- Evaluate if this tailored shared decision tool will
  - (a) enhance OA patient's decision quality,
  - (b) influence OA outcomes after medical or surgical treatment.



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# A.S.K. Study based on FORCE-TJR Registry

## **FORCE-TJR: *Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement***

National TJR research cohort/registry

*Primary outcome = Patient-reported pain and functional (plus clinical data)*

VIEWPOINT

JAMA 2012; 308(12): 1217-18

1567

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## **Beyond Joint Implant Registries**

A Patient-Centered Research Consortium  
for Comparative Effectiveness in Total Joint Replacement

Patricia D. Franklin, MD, MPH, MBA

Jeroan J. Allison, MD, MS

David C. Ayers, MD

**D**ESPITE THE PROVEN EFFECTIVENESS OF TOTAL joint replacement (TJR) surgery in relieving advanced knee and hip arthritis pain, TJR outcomes have come under intense public scrutiny in recent years. The 2010 recall of ASR metal-on-metal hip implants<sup>1</sup> heightened awareness of the importance for implant safety surveillance for this high-cost and high-use procedure and exposed the need for a national systematic patient-centered outcomes monitoring system. These safety concerns and the exponential growth in TJR use—

To address this need, the Agency for Healthcare Research and Quality funded a 4-year \$12 million research program, Function and Outcomes Research for Comparative Effectiveness in TJR (FORCE-TJR).<sup>4</sup> Led by a team of researchers at the University of Massachusetts Medical School in cooperation with a national network of surgeons, FORCE-TJR assembled a consortium of orthopedic practices to serve as a research laboratory to generate CER to guide surgeon and patient decisions. The FORCE-TJR has a national scope, is representative of US practices, includes longitudinal patient-reported outcomes, and has the ability to measure implant failure as well as important clinical outcomes and complications.

**The FORCE-TJR Approach**

## JOINT REGISTRY UPDATE

Joint Replacement Registries in the United States:  
A New Paradigm

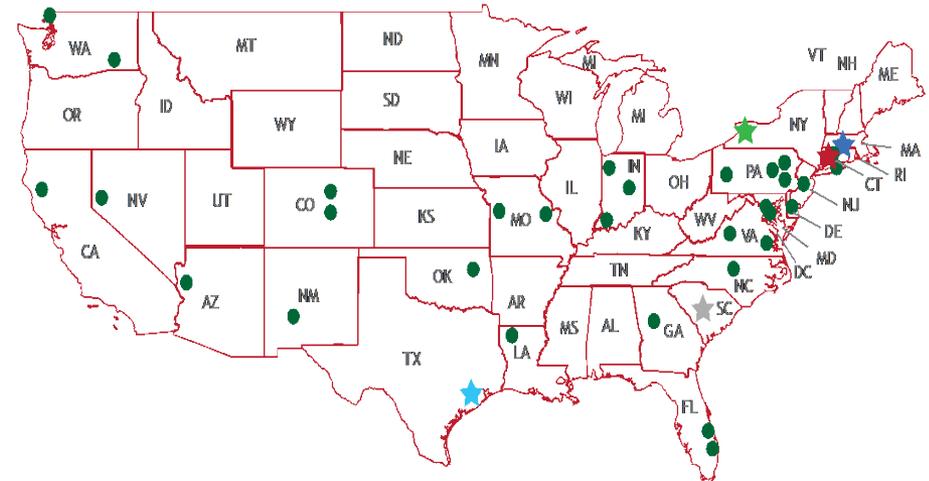
David C. Ayers, MD, and Patricia D. Franklin, MD, MBA, MPH

# FORCE-TJR: US representative sample of 200 surgeons; 30,000 patients in 28 States

- Stratified random sample of US surgeons
- 75% are community-based
- Fellowship-trained and general orthopedic surgeons
- High and low volume surgeons/hospitals; urban and rural
- Teaching hospitals, non-teaching
- Private, public and HMO insurance
- All major implant manufacturers

*National norms from 2011-2016  
Medicare and Private Insurers*

Map of Participating Core Centers and Community Sites



#### Core Clinical Centers

- ★ UMass Medical School, Worcester, MA
- ★ Connecticut Joint Replacement Institute, Hartford, CT
- ★ The University of Rochester Medical Center, Rochester, NY
- ★ Medical University of South Carolina, Charleston SC
- ★ Baylor College of Medicine, Houston, TX

#### Community Sites

- Community Sites currently enrolled



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# FORCE-TJR: key capabilities to build shared decision tools

- Collect data from patients directly (not limited to one EHR), but can return data to patient or EHR for storage
- Data capture process is pre-determined and scheduled, so does not miss follow-up time points
- Complete, pre-defined risk and outcome data as well as PRO data
- Capture data from representative patients across country, so can provide national norms and support access to national databases



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# Patient-reported symptoms and risks compared with national norms

- Collect PRO and symptom data from patients directly

- Data capture process is pre-determined and scheduled, so will not miss follow-up time points

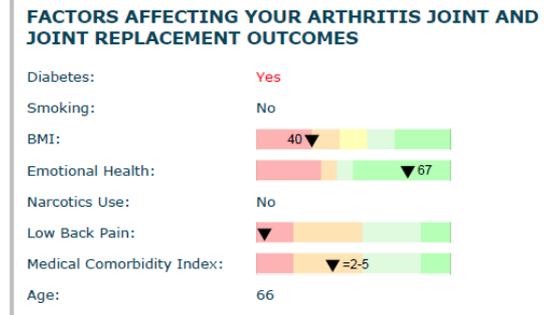
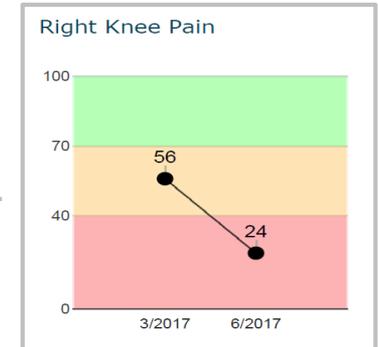
- Obtain needed risk and outcome data from patient survey

- Capture data from OA patients across country, so can provide national norms and support access to national databases

Trended Symptoms over Time

Patient Risk Profile

Color-coded Norms



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# Predictive Analytics: What outcomes are patients like me likely to achieve?

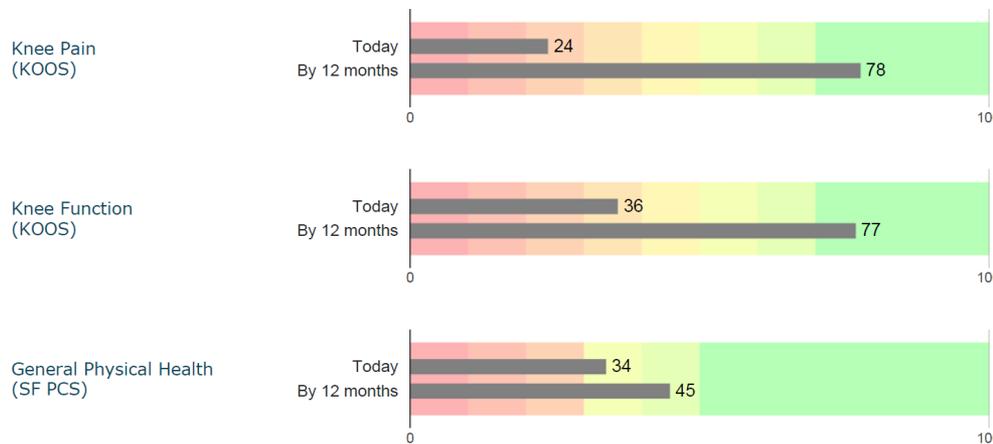
- Collect data from patients directly
- Data capture process is pre-determined and scheduled, so will not miss follow-up time points
- Obtain needed risk and outcome data from patient survey
- Capture data from patients across country, so can provide national norms and support access to national databases

Multi-variable risk models for key outcomes

Individualized predictive outcomes based on similar patients

| TKR ADL 12 Prediction |        |         |        |       |
|-----------------------|--------|---------|--------|-------|
| Predictors            | Coef.  | Lower   | Upper  | Pst   |
| male                  | -1.272 | -2.065  | -0.479 | 0.002 |
| age0to_ctr            | -0.745 | -1.303  | -0.187 | 0.009 |
| race_black            | -4.302 | -8.097  | -2.508 | 0.000 |
| race_aaan             | -4.690 | -9.027  | -0.352 | 0.034 |
| race_asian            | -4.345 | -8.862  | 0.172  | 0.059 |
| race_other            | 2.199  | 1.852   | 6.248  | 0.297 |
| hispanic              | 0.612  | -1.536  | 3.160  | 0.637 |
| edu_lshigh            | 0.581  | -0.569  | 1.730  | 0.322 |
| edu_emcoll            | 0.207  | -0.897  | 1.311  | 0.714 |
| edu_coll              | 0.039  | -1.161  | 1.238  | 0.950 |
| edu_other             | 0.022  | -2.143  | 2.098  | 0.984 |
| inc_45to70            | -0.091 | -1.125  | 0.944  | 0.864 |
| inc_70to100           | 1.202  | 0.040   | 2.363  | 0.043 |
| inc_gt100             | 1.673  | 0.573   | 2.774  | 0.003 |
| job_yes               | -0.003 | -0.828  | 0.801  | 0.979 |
| job_unk               | -0.194 | -1.972  | 1.604  | 0.840 |
| medicare              | 0.216  | -0.710  | 1.142  | 0.648 |
| medicaid              | -2.148 | -4.025  | -0.262 | 0.026 |
| ins_mlt               | 0.396  | -0.708  | 2.679  | 0.254 |
| ins_other             | -0.801 | -1.863  | 0.260  | 0.139 |
| adl0ctr               | -0.783 | -0.819  | -0.748 | 0.000 |
| bilateral             | 1.172  | -0.638  | 2.980  | 0.204 |
| pain0ctr              | -0.053 | -0.059  | -0.046 | 0.005 |
| mcs0ctr               | 0.231  | 0.196   | 0.266  | 0.000 |
| underwt               | 3.973  | -1.617  | 9.562  | 0.164 |
| overwt                | 0.746  | -0.464  | 1.956  | 0.227 |
| obese                 | -0.197 | -1.422  | 1.047  | 0.766 |
| obese_severe          | -0.785 | -2.221  | 0.651  | 0.284 |
| obese_morbidly        | -0.099 | -1.779  | 1.582  | 0.908 |
| mccom_eq1             | -1.908 | -2.425  | -0.391 | 0.001 |
| mccom_2to5            | -1.540 | -3.067  | -0.014 | 0.048 |
| mccom_6to8            | -3.244 | -5.602  | -0.886 | 0.007 |
| mccom_unk             | 1.236  | -5.808  | 8.281  | 0.731 |
| smoker_yes            | -0.483 | -1.233  | 0.268  | 0.207 |
| smoker_unk            | -1.327 | -4.447  | 1.793  | 0.405 |
| osupain_mild          | -1.099 | -2.002  | -0.197 | 0.017 |
| osupain_moderate      | -2.293 | -3.317  | -1.270 | 0.000 |
| osupain_severe        | -4.730 | -6.330  | -3.130 | 0.000 |
| osupain_unk           | -0.213 | -4.059  | 3.633  | 0.934 |
| ltpain_1              | -2.023 | -2.894  | -1.163 | 0.000 |
| ltpain_2              | -2.162 | -3.657  | -0.668 | 0.005 |
| ltpain_3              | -9.220 | -11.285 | -7.155 | 0.000 |
| ltpain_unk            | -16.25 | -4.504  | 1.245  | 0.234 |
| _const                | 35.059 | 33.350  | 36.769 | 0.000 |

Patient's Likely Change in Pain, Function, and Physical Health After Surgery



at 100 if > 100  
at 100 if > 100  
at 100 if > 100



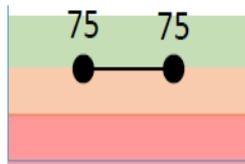
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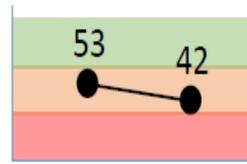
# Patient Feedback on Report Design

Right Hip Pain



11/2016 3/2017

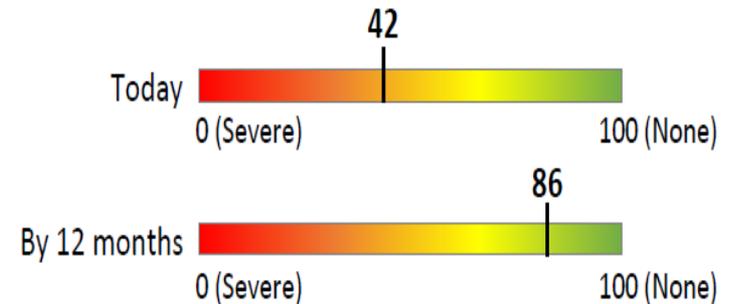
Right Knee Pain



11/2016 3/2017

“In my mind [the report] is part of the treatment plan. A lot of times they leave the patient out. They give the diagnosis and tell them to take that pill or whatever. By giving the answers to the questions, it helps you be involved in the actual decision making and to understand why.”

“A graph might work. I’m a visual person... to see the little stacks (bar graphs), like you came in here a year ago and you were at 20 and one year later you are at 70 and you’re working towards a goal of 80.”

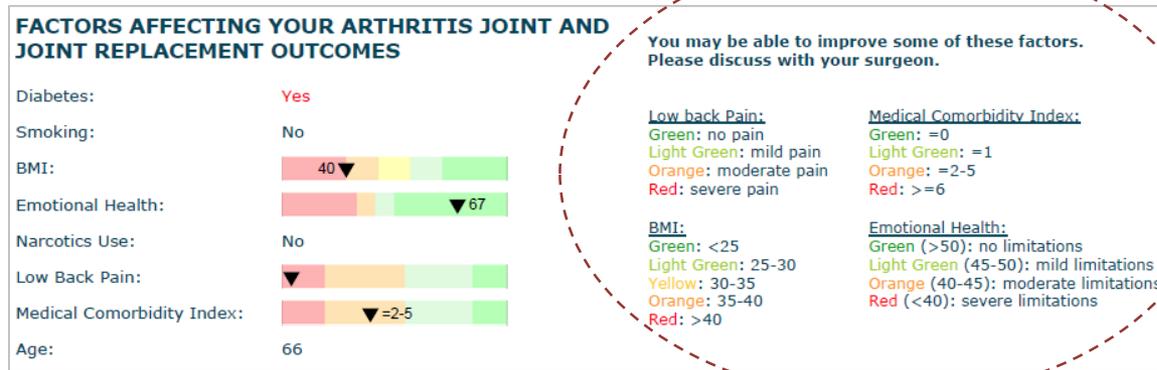


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# Clinician Feedback on Report Design



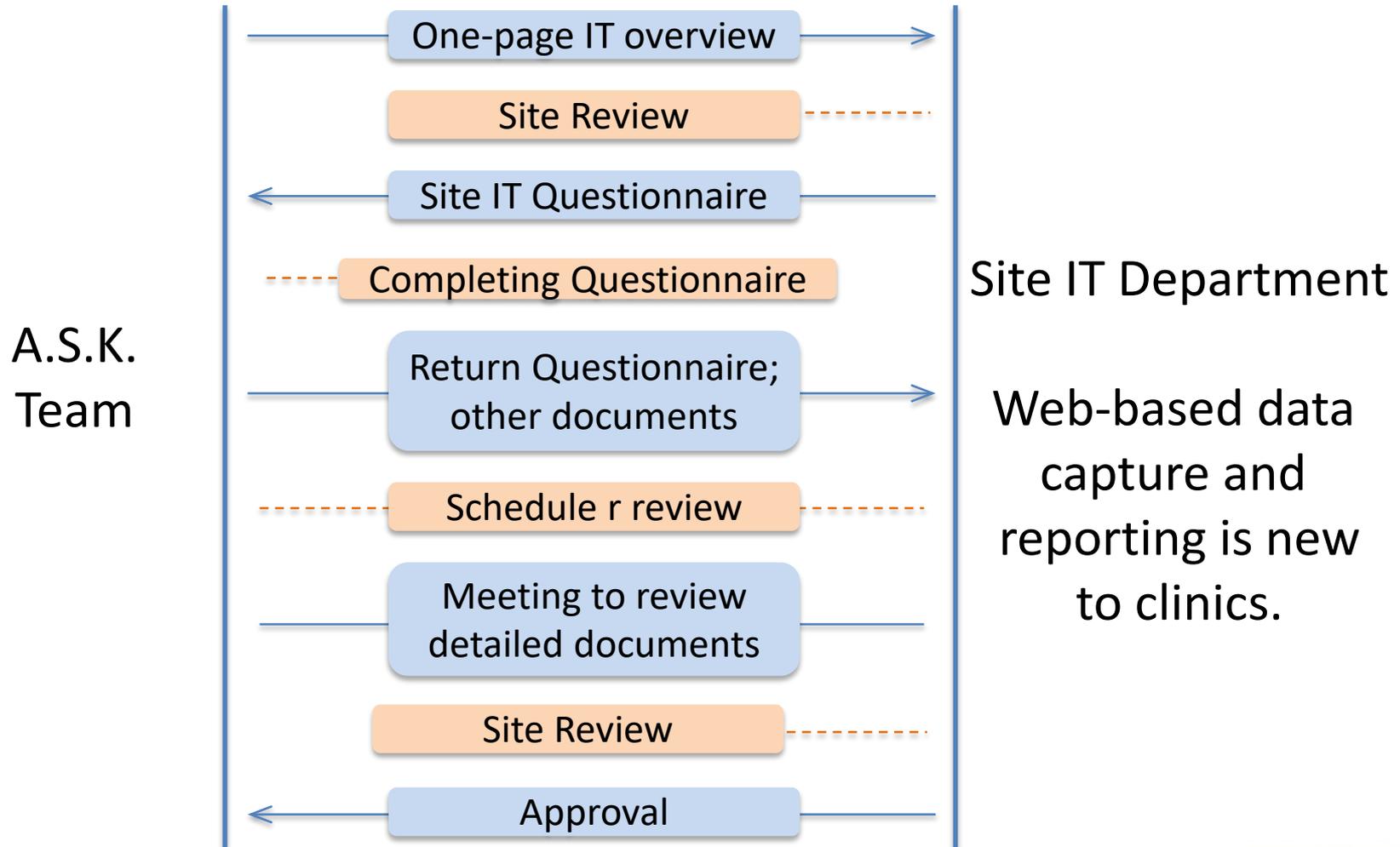
Color-coding definitions and norms



Wording and content modifications

MD (CT): “The report is great for highlighting the risks to patients, and managing expectations.”

# Hospital IT Review/Approvals Require Time; All Approved A.S.K.



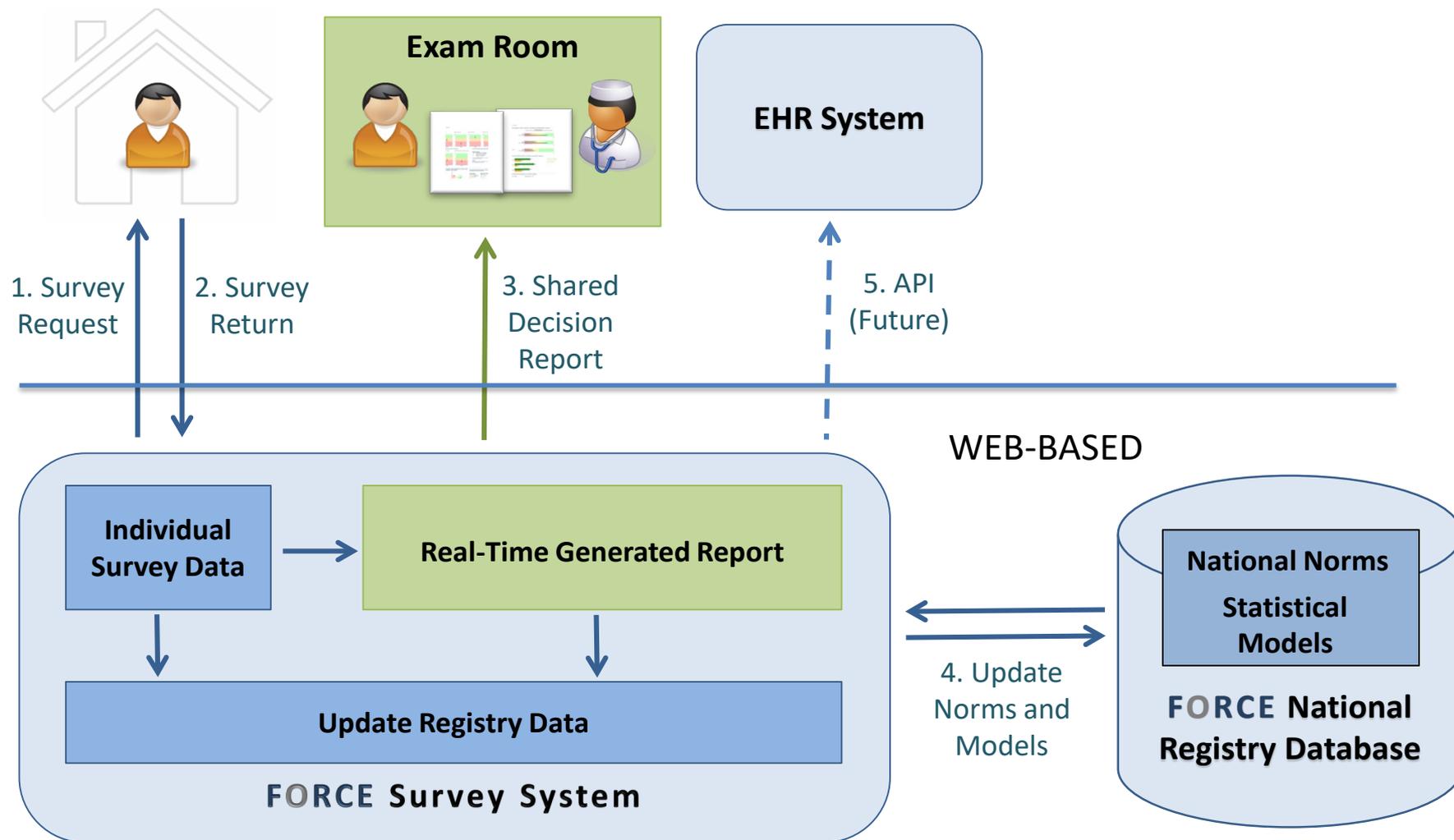
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\*Process in Orange takes time.



# A.S.K.: Integrate Patient, National, EHR Data



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# A.S.K. Shared decision report based on patient-reported data

1. Trended patient-reported symptoms/PROs
  - Pain, activities of daily living, physical function
2. Risk factors for post-TJR complications
3. Predicted TJR outcomes for similar patients
  - Pain relief, functional gains
4. Predicted TJR impact on pain with patients' priority activities
5. Complication risks
6. Summary evidence for non-surgical treatments



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# Technical Lessons Learned

- **Returning data to EHRs**
  - Longitudinal registry data collected in parallel can supplement EHR data.
  - Returning data to EHRs may involve processes like identifier matching, new field creation, automated and secure data transfer, etc.
- **Security and privacy review by hospitals/practices**
  - To protect patients' data, security and privacy checks are required by all sites. The review and approval process varies and ranges from 1-2 months to 4-5 months.
  - Research IT implementation is a new concept.



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# Dissemination and EHR Inter-operability

- FORCE-TJR web system can collect patient-reported data as a third-party platform, and readily interface with EHRs (e.g., API) for storage of the PRO data and decision reports.
- Discrete data and/or reports can be emailed to patients and additional clinicians (e.g., primary care doctors)- even if not using same EHR.
- Longitudinal direct-to-patient data capture is automated and can support EHRs to store complete “picture” of treatment impact, disease progression.



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# Thank You!

A.S.K. Team

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