

# ACNM Data Collection Technical Development Plan

SEPTEMBER 2013





Prepared by:



Private Practice is a technology platform with a mission to improve maternity care by changing the way providers and patients experience health care delivery. We believe activating mothers to engage with providers during pregnancy and birth can be the tipping point for a lifetime of engagement in their own health and the health of their families.

# Maternity Neighborhood



The **Maternity Neighborhood** is a family of connected tools for client engagement, patient-centered outcomes research, and clinical quality improvement that securely exchange data on Private Practice's innovative technology platform. Each tool is designed to improve the experience

and outcomes of care and enhance the relationship between the woman and her care team. These tools provide a compelling alternative to incompatible and disconnected systems that drive costs up, contribute to low patient and provider satisfaction, and reduce safety and efficiency.

## Task Force Committee Members:

- |                       |                 |
|-----------------------|-----------------|
| Leslie Cragin, Chair  | Linda Nanni     |
| Lorrie K. Kaplan, CEO | Mary Barger     |
| Karen King            | Tanya Tanner    |
| Diana Jolles          | Fausto Miranda  |
| Cathy Collins-Fulea   | Kerri Schuiling |

# Introduction

**The American College of Nurse-Midwives (ACNM) has a long history of supporting data collection among members, but has not established a midwifery data registry. Many factors converge to create new opportunities to leverage data to benefit women, babies, midwives, and our health care system.**

## **These factors include:**

- Increased use of performance measures in maternity care, including mandatory reporting of core measures to the Joint Commission for most hospitals beginning in 2014
- Emerging payment models that reward high quality, high value care
- Policy makers' interest in new models of care delivery
- A maturing data driven quality improvement movement
- Rapid adoption of electronic health records, resulting from federal "Meaningful Use" incentives
- ACNM participation in the Women's Health Registry Alliance, an ACOG sponsored initiative that aims to provide a central, collaborative home for registries that seek to improve women's health outcomes
- Increasing midwife participation in DNP programs, leading to increased need for midwifery research data

# Approach

**In April 2013, ACNM contracted with Private Practice, Inc. to develop a Technical Development Strategy for ongoing patient level data collection, storage, and analysis of outcomes by Certified Nurse-Midwives and Certified Midwives. Private Practice took a four pronged approach to developing our recommendations and strategy.**

- 1.** We conducted key informant interviews with internal (9) and external (2) stakeholders representing various perspectives including education, research, clinical practice (solo, independent group practice, MD-owned group practice, integrated health system), health information technology, hospital administration, quality improvement, and policy. (See Appendix A: List of Key Informant Interview Participants.)
- 2.** In collaboration with ACNM staff and the HIT Section of the Division of Standards and Practice, we conducted a survey of the membership on their attitudes about and use of health IT and participation in data collection. A total of 883 members responded to the HIT Survey. Almost two thirds (63%) were in collaborative practices with physicians. Three quarters (76%) attend births in hospitals, 5% attend births in birth centers, and 6% attend home births. Nearly all were using or preparing to use electronic health record systems. (See Appendix B: Key Findings from HIT Survey.)
- 3.** We reviewed and analyzed relevant research, reports, legislation, and commentaries to identify trends and factors in the broader landscape. (See Appendix C: Selected Articles and Reports)
- 4.** We planned and conducted a day long workshop with the ACNM Data Collection Taskforce to present preliminary findings and gather additional perspectives and insights. (See Appendix 4: Workshop Agenda and Slides.)

# Insights & Analysis

## **Recent rapid growth in ACNM Benchmarking Project participation has strained the organization's ability to manage data and analytics and exposed limitations related to data quality.**

- Participation has more than doubled since 2010.
- The increased participation has brought new data quality and validation challenges, because participating practices are increasingly heterogeneous (different staffing and collaboration models, more high risk pregnancies, etc.)
- Data collection started with Excel spreadsheets and evolved to include a web service with Excel remaining as the primary tool for collecting and analyzing data.
- An Excel-based infrastructure does not scale with the collection, hosting, and analysis needs as the quantity and complexity of data increases. Each spreadsheet requires human validation. Spreadsheet cells are loosely structured and not validated at time of input. Changes to the spreadsheet structure complicate aggregate calculations.
- Thus, there is increasing need for staff, volunteers and other resources to manage the Benchmarking Project, even as the opportunities to use and leverage the data are increasing.

## **Directly exporting data out of enterprise electronic medical records (EHRs) into a data registry is not a reasonable short- or medium-term goal for ACNM.**

- If we focused on the most common EHR (Epic), we would still have to deal individually with hospitals/health systems because each Epic installation is customized to the institution (and sometimes further customized at the practice level).
- All specialties with national data registries, with the exception of the American College of Cardiology, require direct data entry outside of the EHR. ACC's registry is outpatient only and has required a massive infrastructure and investment to support data mapping with each EHR. Despite this investment, physician participation is still low.
- Only 2% of midwives report the ability to export patient-level data out of their EHRs.
- There are no data standards. Consensus definitions from the reVITALize project have not been implemented in EHRs and it is not ACOG's expectation that they will be adopted rapidly.
- Midwives and OBs express lack of trust in EHR data. There are pockets where people are working on structuring data entry to get better data out of Epic but this is a multi-year goal. During the

installation phase, Epic is mostly concerned with pleasing clinicians, which means flexible data entry and minimal use of standard reportable fields.

- However, there are some companies that specialize in becoming an enterprise “layer” getting data for performance measurement out of EHRs. ACNM may choose to partner with such companies (e.g. Crimson) to assist with measure development and gain access to midwifery data. This strategy should be pursued while simultaneously creating the infrastructure to accept and analyze that data. By doing so, ACNM can combine this data with data from other input sources for maximal benefit.

### **Collaborative practice models and intrapartum transfer/referral pose major challenges both for data collection and midwives’ ability to use data for advocacy/policy.**

- National provider performance reporting initiatives are hampered by lack of ability to map outcomes to midwifery care. CMQCC’s planned public reporting initiative will report at the coverage group level for this reason.
- In the HIT Survey, the most common reason for non-participation in benchmarking was “The midwives and MDs in my practice share a caseload and I am not sure which births to count.”

### **Diverse data collection needs among members contribute to low participation in cooperative data collection. Flexibility on the data entry side is key to adoption by midwives.**

- Clinical researchers collect many variables in common, such as mode of birth, interventions in labor, and key outcomes. However, individual research teams may need to collect unique or less common data variables for research purposes. Considerable time and money is wasted building and maintaining siloed databases because available data registries (MANA Stats and the AABC PDR) do not meet these specific needs of CNM/CM researchers.
- Private practice or community midwives do not desire this level of data collection but want basic stats and tend to keep birth logs. They want the minimal amount of data that is useful to them. Data are more useful if they help with day-to-day needs, such as care coordination, quality assurance, and tracking productivity. Midwives also want to keep birth logs for curiosity and personal satisfaction (e.g. reaching a milestone number of births).
- Student midwives need to collect data about all clinical experiences, not just births, and report that to preceptors and program directors. They also need a mechanism to track their competency in core midwifery skills and procedures.
- Midwives in low and middle income countries have diverse data collection needs that mirror the needs of US midwives, however infrastructure and capacity barriers exist and vary by setting (lack

of electricity/connectivity, limited literacy and computer/data entry skills etc.) and the specific data collection needs depend on the location (regional hospital, rural health post, community-based care). Vast opportunities to strengthen the global midwifery workforce and impact maternal and newborn mortality exist with development of effective electronic and mobile tools for data collection, decision support and education/training.

### **Usability matters.**

- Poorly designed systems and poor usability of Health IT tools drains productivity and professional satisfaction. This is a serious threat in the midst of our workforce crisis.
- Midwives want to collect data, and most already are. But they don't want "another thing" on their plate, especially if time-consuming.

### **Data registries have a potential role in reporting for payment incentives, Joint Commission accreditation, and other programs, but for the foreseeable future, these reportable measures rely on ICD9 and vital statistics data. It should be ACNM's long term goal to tie Medicaid and possibly private payer payment incentives to participation in any data registry ACNM develops.**

- CMQCC's Maternity Data Center facilitates reporting to Joint Commission, but their data comes from the Office of Statewide Health Planning, which gets ICD9 codes from all hospitals, and Office of Vital Records. This is not a model ACNM or ACOG can reasonably emulate across 50 states.
- Hospitals can use data from registries that participate in the CMS "Physician Quality Reporting System" for Medicare Part B payment incentives. This requires a threshold number of Medicare beneficiaries so it is not an option for maternity care at this time. However, this may be a model Medicaid adopts in the future. CNMs are eligible for the incentives tied to PQRS reporting.
- The EHR Improvement Act, which is stalled in Congress, would create a mechanism by which participation in a "qualified data registry" would be sufficient for specialty providers to qualify for Meaningful Use Incentives (or avoid penalties). It is not clear if non-physician professional associations would be eligible.

### **Hospitals have security and liability concerns that are barriers to data collection and entry into external data collection tools or via personal devices. However, these attitudes are likely to shift.**

- "BYOD (bring your own device) Strategies" are emerging, with the more progressive hospitals adopting policies that embrace personal devices and actively manage security threats.
- Hospitals are increasingly supporting participation in registries that are certified/recognized because this certification is tied to Medicare reimbursement. The Physicians Quality Reporting

System is the vendor certification program for Medicare incentives.

- Current information/data management workflows pose threats to security, especially related to continued reliance on paper and technology work-arounds. Even midwives with electronic data collection first collect the data onto paper forms, which are then transcribed into data collection tools. Paper data forms are often hand carried from location to location, creating opportunities for compromised security. Midwives describe a variety of informal means of communicating about patient care, including texting, personal email accounts, and Facebook messaging.

**ACOG is not actively planning a maternity data registry, however the long term vision for clinical data registries is an “ecosystem” design.**

- ACNM is currently engaged in the Women’s Health Registry Alliance, which is an initiative of ACOG to get all women’s health related data registries under one umbrella, with a long-term goal of linking these registries.
- The Agency for Healthcare Research and Quality recently launched a Registry of Patient Registries with the aim of reducing redundancy and eventually enabling linkage of registries into an “ecosystem” where patient data can exist in all relevant registries and researchers or clinical decision support systems can query data across registries.
- There is considerable overlap between ACNM’s membership and membership in AABC and MANA, our two sister organizations with data registries. It should be a priority to enable relevant data to flow into all three midwifery registries without duplication of data entry effort.

## General Conclusions

1. The current Benchmarking Project is not sustainable. The existing technological infrastructure cannot keep up with increasing data complexity and human resources are needed to bridge the widening gap between system demands and capabilities. At the same time, access to high quality data is increasingly imperative for ACNM to leverage new opportunities in our transforming health care system.
2. ACNM should approach a midwifery data registry by giving priority to data portability. Data portability is the ability to move data easily into or out of different databases, analytic tools, and registries. Portable data allows for multiple uses of the same data, depending on user needs and system capabilities. Data portability requires common data definitions and technical specifications to optimize security, scalability, and data flow.
3. ACNM should engage in a multistakeholder effort to create and disseminate data definitions for “midwifery care in labor,” “midwife-attended birth” and possibly other related concepts. Although it is not necessary to work with AABC and MANA to establish a core data set, data variables that are common among the three organizations could be defined and reported in a standard manner.
4. To maximize participation, ACNM should introduce data collection tools that are flexible and user-friendly and glean useful data for care coordination and practice management.
5. ACNM should strive for an open process that invites collaboration and extends the data ecosystem.

# Proposed Development Plan

## Summary

1. Benchmarking 2.0: build a new infrastructure that will grow with ACNM's Benchmarking Project and set the stage for patient-level data collection.
2. Establish processes for integration and migration of existing data sets and formats.
3. Offer a customized tool for tracking maternity patients and outcomes - an electronic alternative to the typical "birth log".
4. Expand these tools to be a data registry platform which enables modular extension, as a revenue potential for ACNM.

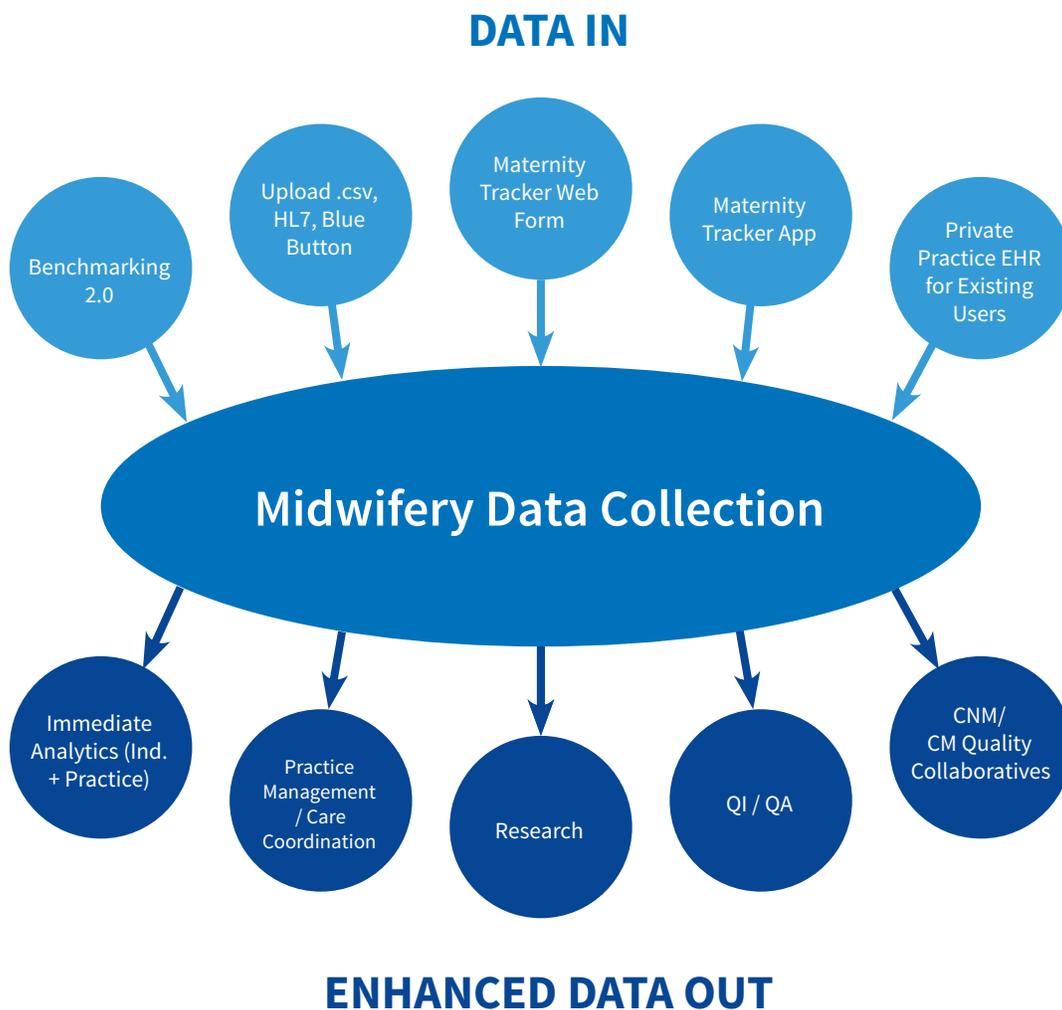
## Detailed

1. Benchmarking 2.0: build a new infrastructure that will grow with ACNM's Benchmarking Project and set the stage for patient-level data collection.
  - Replace the current benchmarking application with one that reduces or eliminates the amount of staff time allocated for cleaning and analyzing data. This includes consideration of a platform architecture that can host, analyze, and exchange aggregate and patient-level data.
  - Establish core measure definitions for patient-level data collection and map these definitions to current Benchmarking variables.
  - Establish a new data collection user interface for manual entry of practice-level data to replace the current Benchmarking interface (required for architectural overhaul).
  - Implement a data definition interface which allows external practice-level and patient-level data to be mapped to ACNM's data registry.
2. Establish processes for integration and migration of existing data sets and formats.
  - Establish process for mapping variables to existing data definitions
  - Enable import of external structured data. This will allow practices currently collecting patient-level data in another system to upload data (without the double data-entry problem) into ACNM's data registry, rather than providing only aggregate data. Accept .csv, blue button, and HL7. Supports patient-level data collected in Excel, a vendor application, a custom database, or a similar tool that a practice may be using.
3. Offer a customized tool for tracking maternity patients and outcomes - an electronic alternative to the typical "birth log".
  - Develop a custom application (web-based, mobile, or both) that lets midwives track maternity care patients and births one-by-one.
  - Key Features:
    - user-friendly interface
    - list patients sorted by name or EDD
    - customize collected variables within a standard variable set, and add up to 3 custom fields (data in custom fields will not be delivered to the registry)
    - real-time analytics of basic measures such as number of vaginal births, cesarean rate, episiotomy rate, ...
    - securely share the maternity log with other users in the practice

4. Expand these tools to be a data registry platform which enables modular extension, as a revenue potential for ACNM.

■ Modular features might include:

- Real time benchmarking
- Reporting NQF Measures (or proxy measures using clinical data) at provider/practice level
- Measure development
- Expanded features for researchers (e.g. integration of research instruments)
- Patient Surveys (Experience and Clinical based outcomes, PROs)
- Tools for Students/Educators



# Value & Revenue Opportunities

**Each phase offers potential value to various stakeholders, with related revenue opportunities for ACNM:**

Phase	Value	Revenue Opportunities
1. Benchmarking 2.0	<ul style="list-style-type: none"> <li>■ Improved workflow/time savings for ACNM staff and volunteers</li> <li>■ Quality improvement, preservation/spread of midwifery hallmarks</li> <li>■ Promotion/advocacy for midwifery and high-quality, high-value care</li> </ul>	<ul style="list-style-type: none"> <li>■ Sponsorship of the project by appropriate commercial “quality partner,” with branding and other exposure opportunities</li> <li>■ Advertising on data entry interface</li> <li>■ Grant funding (e.g. RWJF, Kellogg, Merck for Mothers)</li> </ul>
2. Integration/migration of existing data sets	<p>All of above, plus:</p> <ul style="list-style-type: none"> <li>■ Practice management/business development</li> <li>■ Job satisfaction/workforce growth</li> <li>■ Clinical decision support</li> <li>■ Transparency, patient education, shared decision making</li> <li>■ Global applications</li> <li>■ Research data</li> </ul>	<ul style="list-style-type: none"> <li>■ Fees to midwives/health systems for data mapping and analytics</li> <li>■ Fees for other registries, ACOs, etc. to pull data out of ACNM’s registry</li> <li>■ Fees for research support</li> <li>■ Grant funding for up-front costs and/or for research projects using data</li> </ul>
3. Maternity Tracker	<p>All of above, plus:</p> <ul style="list-style-type: none"> <li>■ Professional self-maintenance</li> <li>■ Global applications</li> </ul>	<ul style="list-style-type: none"> <li>■ Additional opportunities for advertising sponsorship revenue</li> <li>■ fee for use of the app (perhaps reduced or waived for members)</li> <li>■ basic version of app free or very low cost with additional fees for “premium” features that enhance usefulness for practice management</li> </ul>
4. Modular extensions	<ul style="list-style-type: none"> <li>■ Additional value for any of the above.</li> </ul>	<ul style="list-style-type: none"> <li>■ Fees from users</li> <li>■ Fees for other registries, ACOs, etc. to pull data out of ACNM’s registry</li> <li>■ Additional advertising and sponsorship opportunities</li> </ul>

# Appendix A: Key Informant Interview Participants

## ACNM members/leaders

- **Tonia Moore-Davis:** Benchmarking Liaison to the ACNM Division of Standards and Practice.
- **Cathy Emeis and Maggie Shaw:** Midwives in clinical faculty practice at Oregon Health Sciences University. They have developed their own database and data collection process for research and benchmarking.
- **Debbie Cibelli:** practice owner of midwife-led hospital practice with MFM back-up. She participates in benchmarking and has not adopted an electronic health record system because of data quality and patient care concerns.
- **Melinda Hoskins:** Member of Health Information Technology Section and midwife in solo private practice. She is about to begin attending births again. Uses Practice Fusion.
- **Tanya Bailey:** chair of AMCB Exam Committee; works in a busy Ob-Gyn owned private, practice in Brown Summit, North Carolina.
- **Lisa Kane Low:** Midwife in clinical faculty practice at University of Michigan. Her group has developed a custom database and data collection tool for research and benchmarking. Chair of Physiologic Birth Toolkit Subcommittee, Optimality Index Working Group of DOR, and documents section of DOSP.
- **Cindy Urbanc:** Practicing midwife at Kaiser Hawaii, member of national leadership team at Kaiser, very active in global health.
- **Cara Krulewitch:** President of AMCB. Works in Department of Defense.
- **Joan Slager:** ACNM incoming treasurer, Quality Management and Business Section, billing and coding expert.

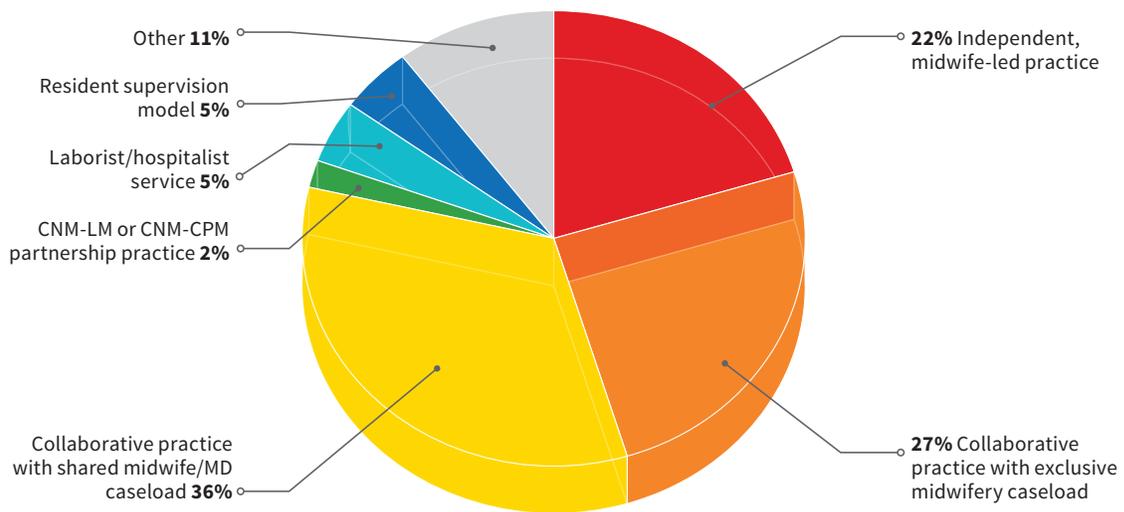
## External Stakeholders

- **Elliott Main:** Medical director of California Maternal Quality Care Collaborative, head of reVITALize project, measure developer, maternity data expert.
- **Amanda Skinner:** CNM who now directs the office of Performance Improvement and Clinical Integration for the Yale-New Haven Hospital ambulatory care system. YNHH just completed an Epic installation.

# Appendix B: Key Findings from HIT Survey

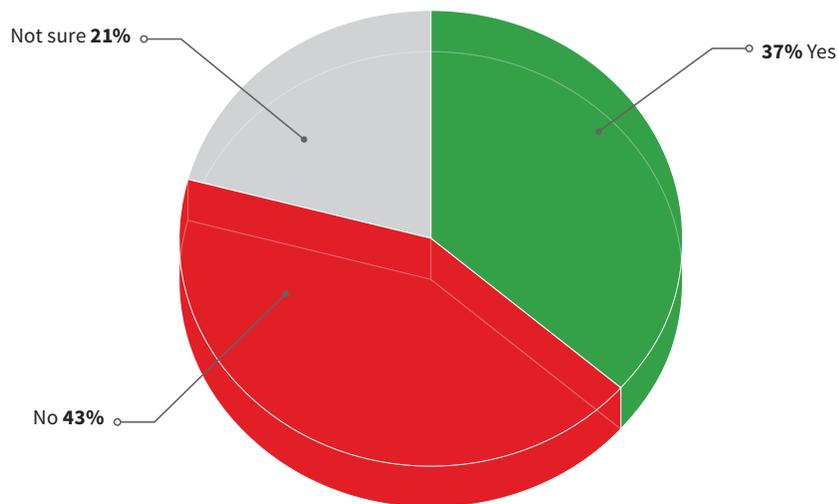
What type of practice do you work in?

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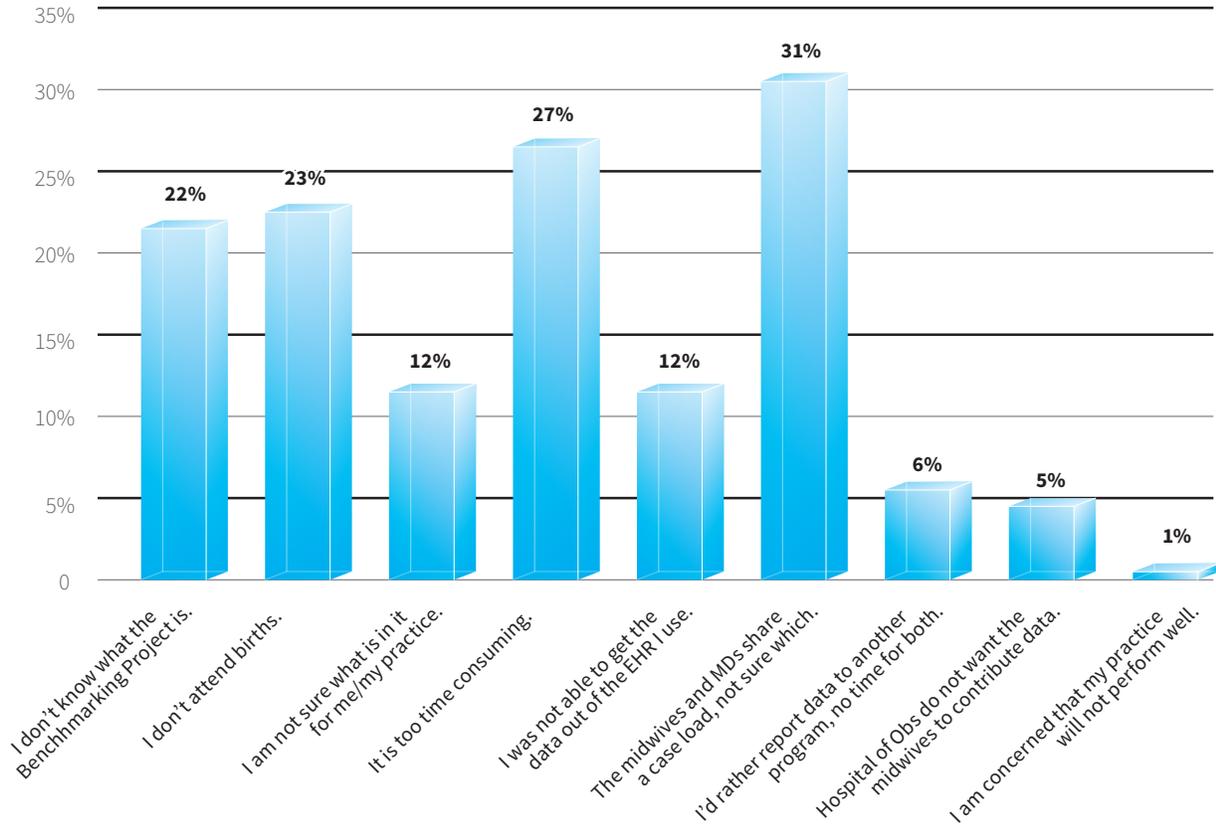


Did you participate in Benchmarking within the last 3 years?

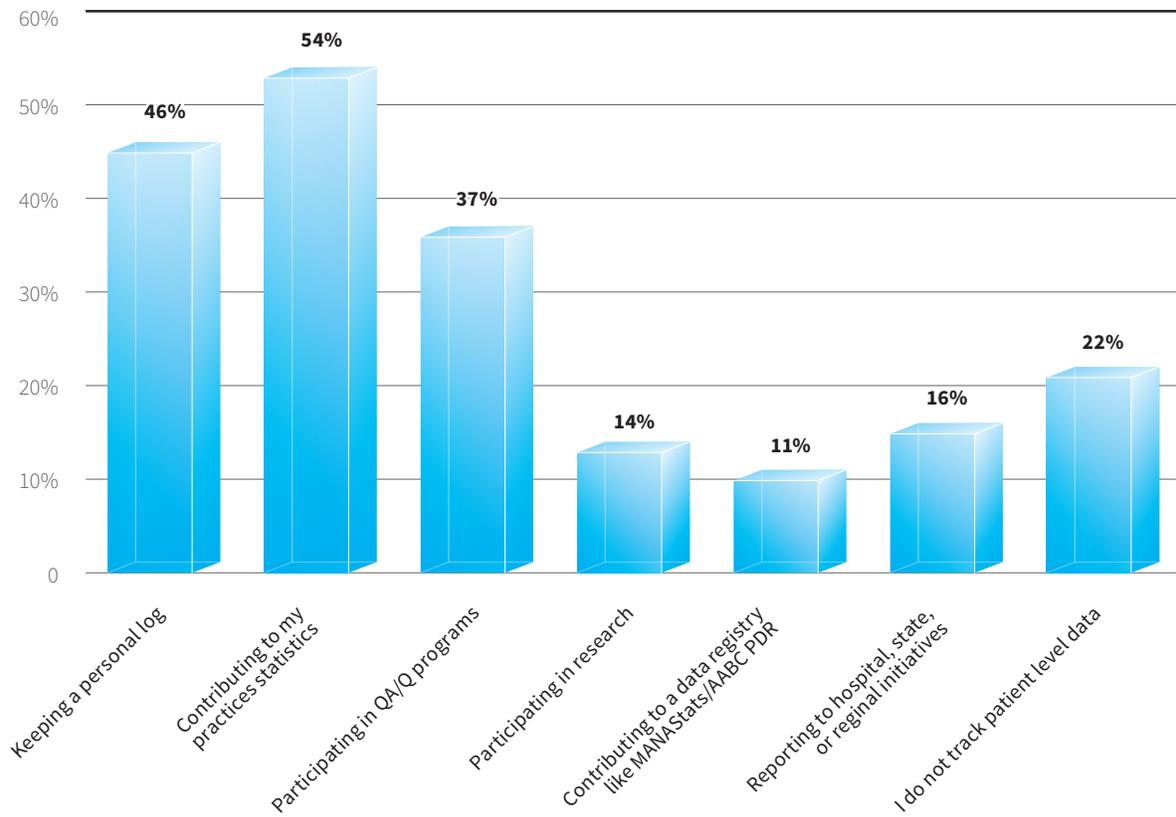
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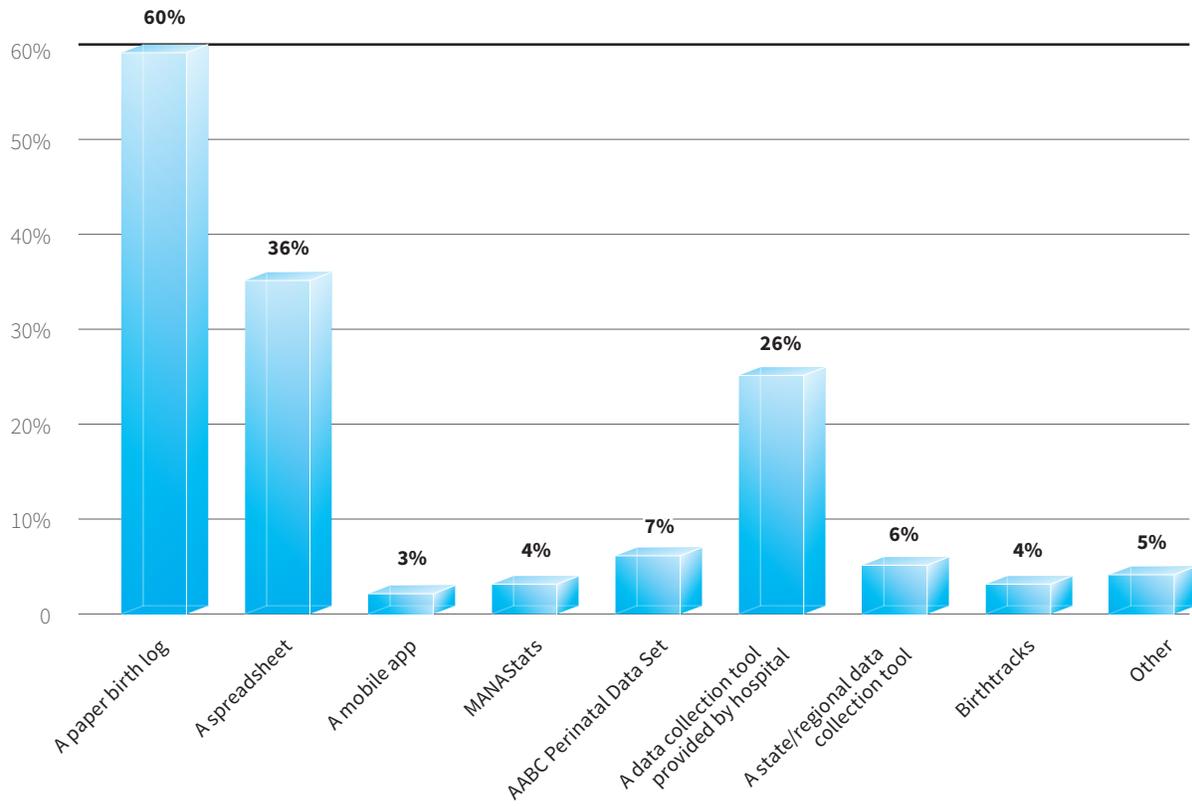
## Why didn't you participate in Benchmarking?



## Why do you collect patient-level data?

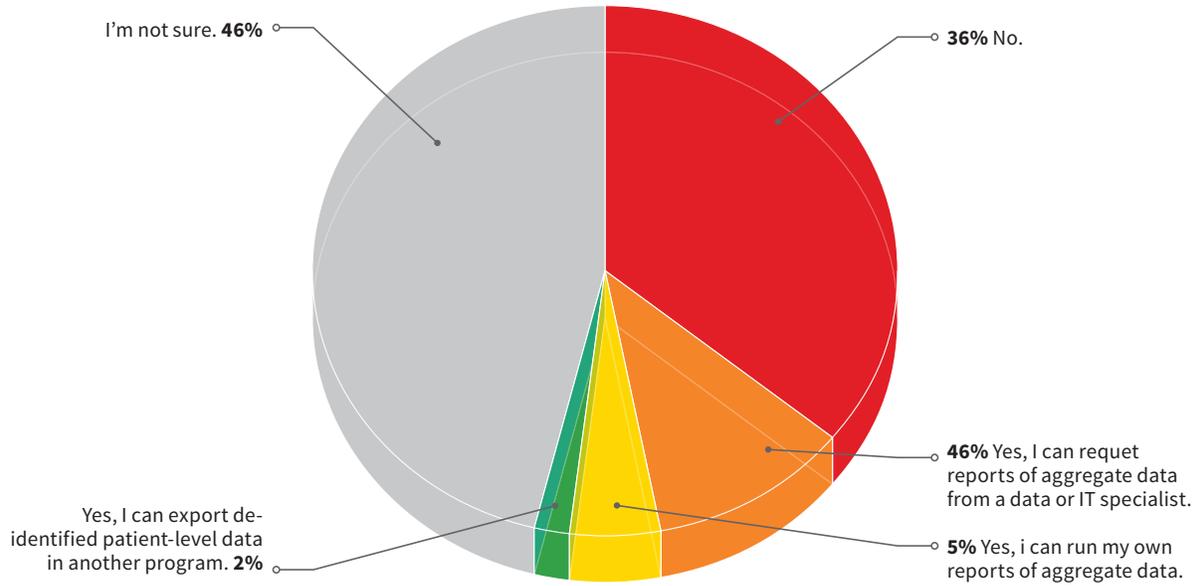


## What do you use to collect patient-level data?



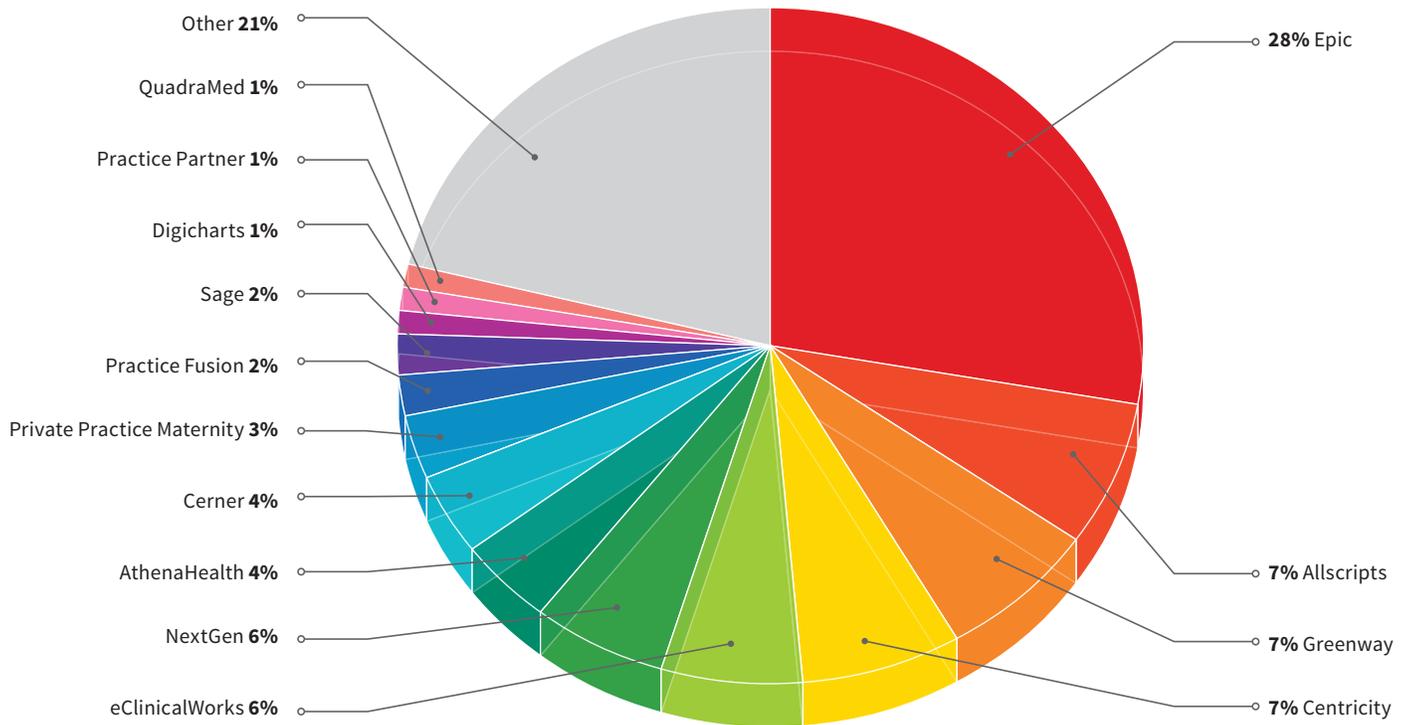
## Can you get data out of your EHR?

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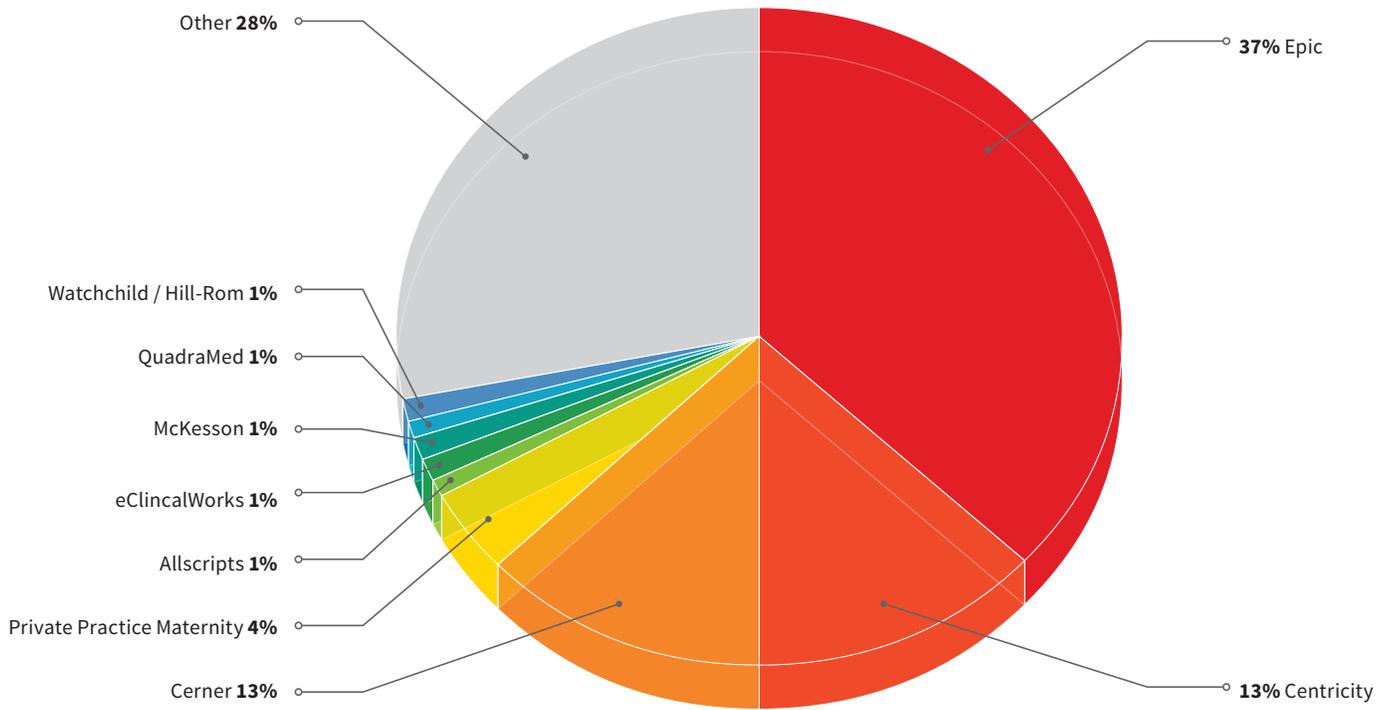
## What Ambulatory EHR system do you use?

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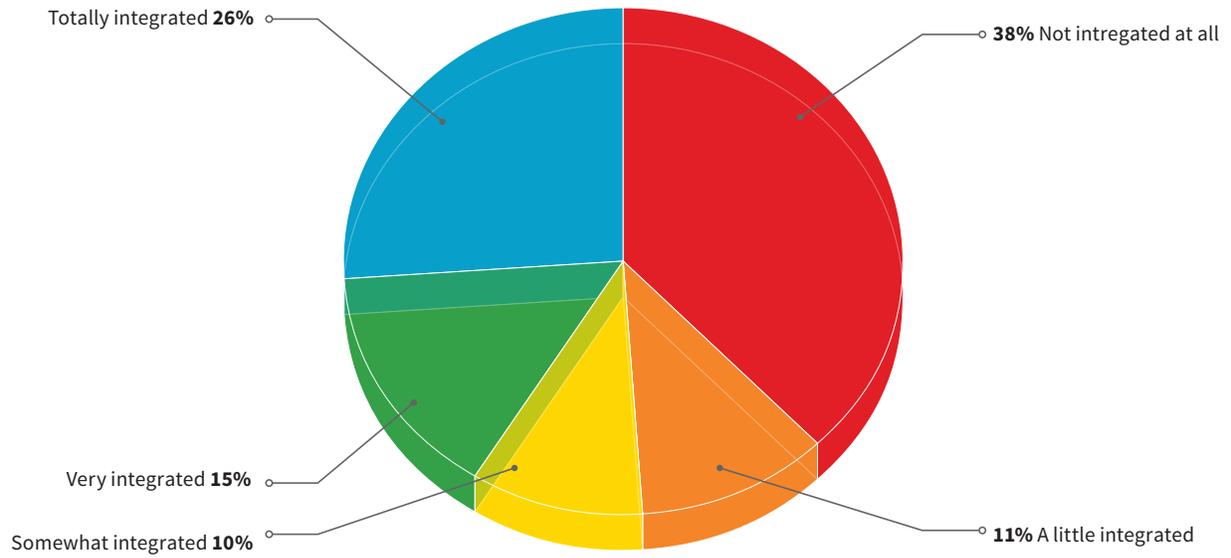
## What IP EHR system do you use?

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## How integrated are your ambulatory and IP EHRs?

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# Appendix C: Selected Articles & Reports

- Agency for Healthcare Research and Quality. (2013). Registry of Patient Registries - Frequently Asked Questions. <https://patientregistry.ahrq.gov/faq>
- Agency for Healthcare Research and Quality. (2013). Regional Health eDecisions: A Guide to Connecting Health Information Exchange in Primary Care. Rockville, MD; AHRQ. <http://www.healthit.ahrq.gov/sites/default/files/docs/citation/eDecisionsReport.pdf>
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- Oetgen, W. J. (2012). Current status of PINNACLE registry: Eleven myths and eleven facts. New Orleans, LA: American College of Cardiology Board of Governors. <http://chapteraffairs.acc.org/quality/tools/Documents/BOG%20PINNACLE.pdf>
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- Agency for Healthcare Research and Quality. (2013). Registry of Patient Registries - Frequently Asked Questions. <https://patientregistry.ahrq.gov/faq>
- Agency for Healthcare Research and Quality. (2013). Regional Health eDecisions: A Guide to Connecting Health Information Exchange in Primary Care. Rockville, MD; AHRQ. <http://www.healthit.ahrq.gov/sites/default/files/docs/citation/eDecisionsReport.pdf>
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- Centers for Medicare and Medicaid Services (2013). Physician Quality Reporting System. <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/index.html?redirect=/PQRI>
- GovTrack. (2013). Text of H.R. 1331: Electronic Health Records Improvement Act. <http://www.govtrack.us/congress/bills/113/hr1331/text>
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