The Pregnancy & Health Profile: A Screening and Risk Assessment Tool

Family History for Prenatal Providers

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Objectives

1. Describe the Pregnancy & Health Profile tool
2. Describe implementation in four clinical settings
3. Present data on patient and provider response and clinic outcomes
4. Discuss next steps

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Historical Perspective

- Need identified through:
    - HRSA, SACHNC, ACOG Genetics Committee
- 2008 HRSA Funding Announcement: "Family History for Prenatal Providers"
    - Integrate genetics and NBS information into a health history
    - Assist genetic clinical decision-making
    - Educate the patient and the provider
    - Address the life-course of the female patient

Pregnancy & Health Profile: A Screening and Risk Assessment Tool

- Helps the busy primary care provider
  - →Translates family history data for clinical care
- Engages the patient as an active participant
- Provides a personalized clinical encounter
  - → Clinical decision support
  - → Provider and patient materials
- Freeware

Conditions with Decision Support

Mendelian Congenital

- Ashkenazi Jewish-associated diseases
- Cystic fibrosis
- Fragile X
- Sickle cell disease
- Spinal Muscular Atrophy
- Tay-Sachs
- Thalassemia

Mendelian Pregnancy & Lifespan

- Thrombophilia
- Hemophilia
- von Willebrand
- HBOC
- Lynch

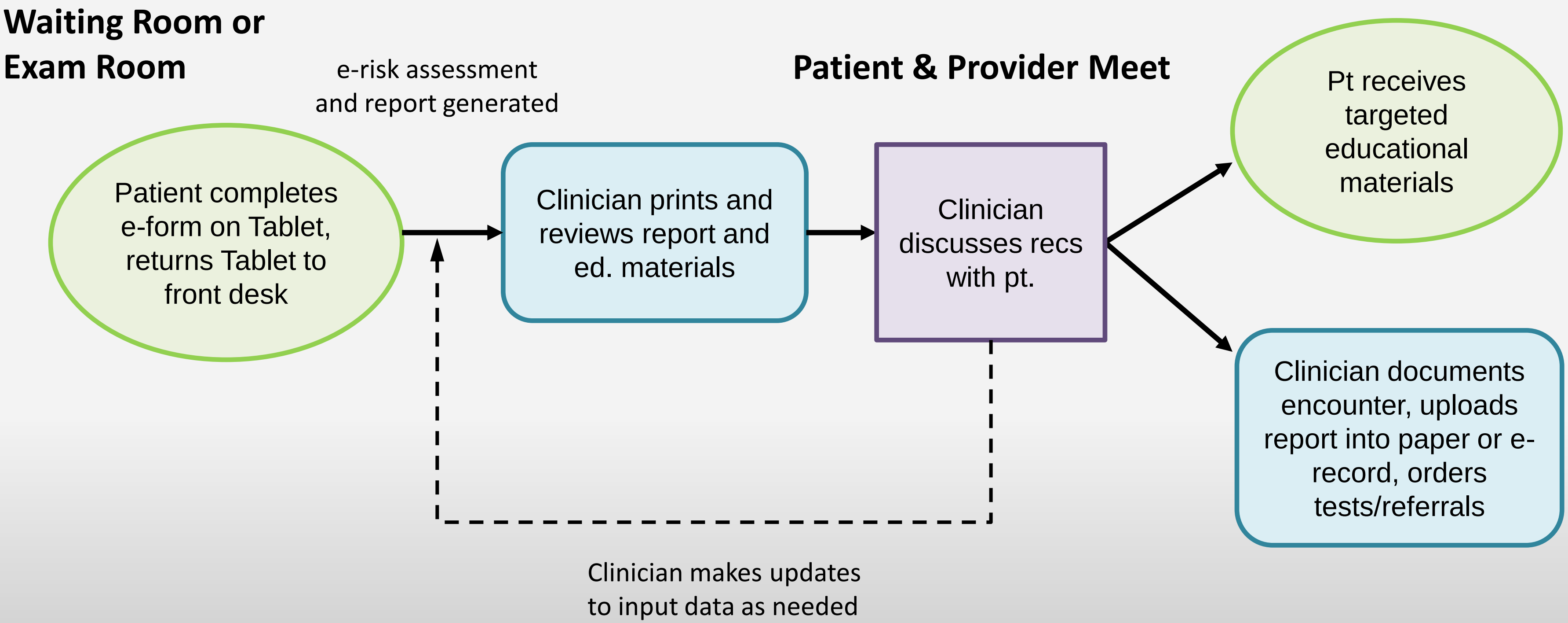
Complex Congenital

- Consanguinity
- Hearing loss, congenital and early-onset (<40 y)
- Vision loss, congenital and early-onset (<40 y)
- Congenital heart defect
- Neural tube defect

Complex Pregnancy & Lifespan

- Cardiovascular Disease
- Diabetes
- Epilepsy
- Hypertension
- Mental Illness
- Osteoporosis
- Pre-term birth
- Recurrent pregnancy loss (2+)
- Sudden death

How it Works



Waiting Room or Exam Room

e-risk assessment and report generated

Patient & Provider Meet

Patient completes e-form on Tablet, returns Tablet to front desk

Clinician prints and reviews report and ed. materials

Clinician discusses recs with pt.

Pt receives targeted educational materials

Clinician documents encounter, uploads report into paper or e-record, orders tests/referrals

Clinician makes updates to input data as needed

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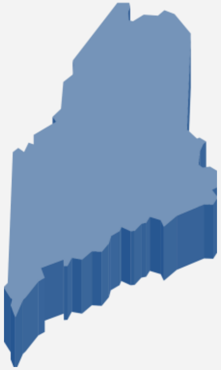
Implementation & Evaluation

Clinical Implementation

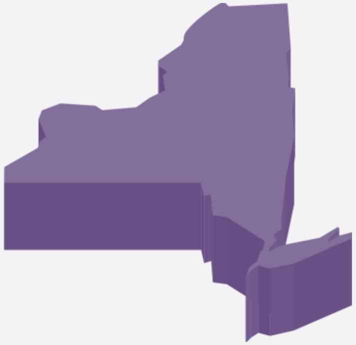
Augusta & Fairfield, ME



Maine-Dartmouth Family Medicine Residency

Family Medicine Practice, Academic

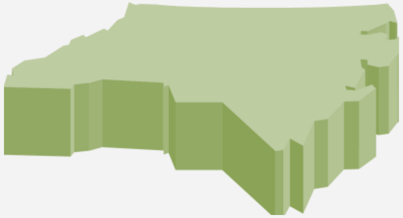
Bronx, NY



Montefiore Medical Center Comprehensive Family Care Center

Community Health Center, Academic

Asheville, NC



Mountain Area Health Education Center

State Area Health Education Center, Academic

Indianapolis, IN

Clearvista practice, Community Health Network

OB Practice, Community Hospital System

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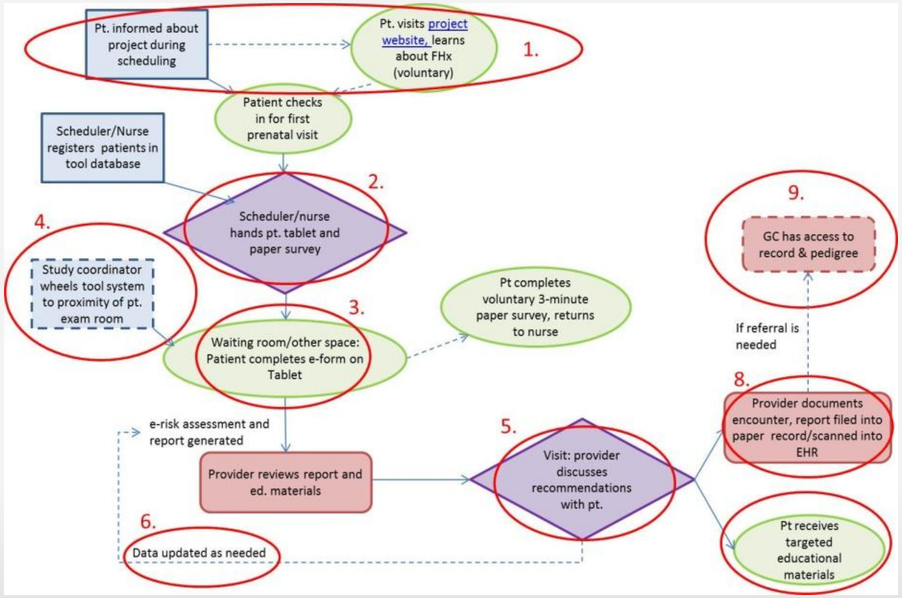
Overview of Summative Evaluation Design

Source of Data	Outcome	Method
Administrators	✓Approach to integrating tool ✓Challenges with implementation ✓Level of effort and resources needed for integration	Interview
Patients	✓Time required for patients to use tool ✓Patient satisfaction with tool	Post-tool survey
Providers	✓Knowledge ✓Confidence using family history ✓Satisfaction using tool, including efficiency ✓Perceived usefulness of tool	Pre-tool survey Post-tool survey
Provider behavior	✓Provider practices regarding guidelines for: • discussion, counseling, education; • referrals to specialists; and • screening tests offered and ordered	Chart audits

Process & Implementation Evaluation

- Key steps, resources, and staff support needed
- Impact on clinic and provider work flow
- Barriers and successes in implementation and integration
- Changes needed to support future use



Pt. informed about project during scheduling

Pt. visits project website, learns about FHx (voluntary)

1.

Patient checks in for first prenatal visit

Scheduler/Nurse registers patients in tool database

2.

Scheduler/nurse hands pt. tablet and paper survey

4.

Study coordinator wheels tool system to proximity of pt. exam room

3.

Waiting room/other space: Patient completes e-form on Tablet

Pt completes voluntary 3-minute paper survey, returns to nurse

9.

GC has access to record & pedigree

If referral is needed

8.

Provider documents encounter, report filed into paper record/scanned into EHR

e-risk assessment and report generated

5.

Provider reviews report and ed. materials

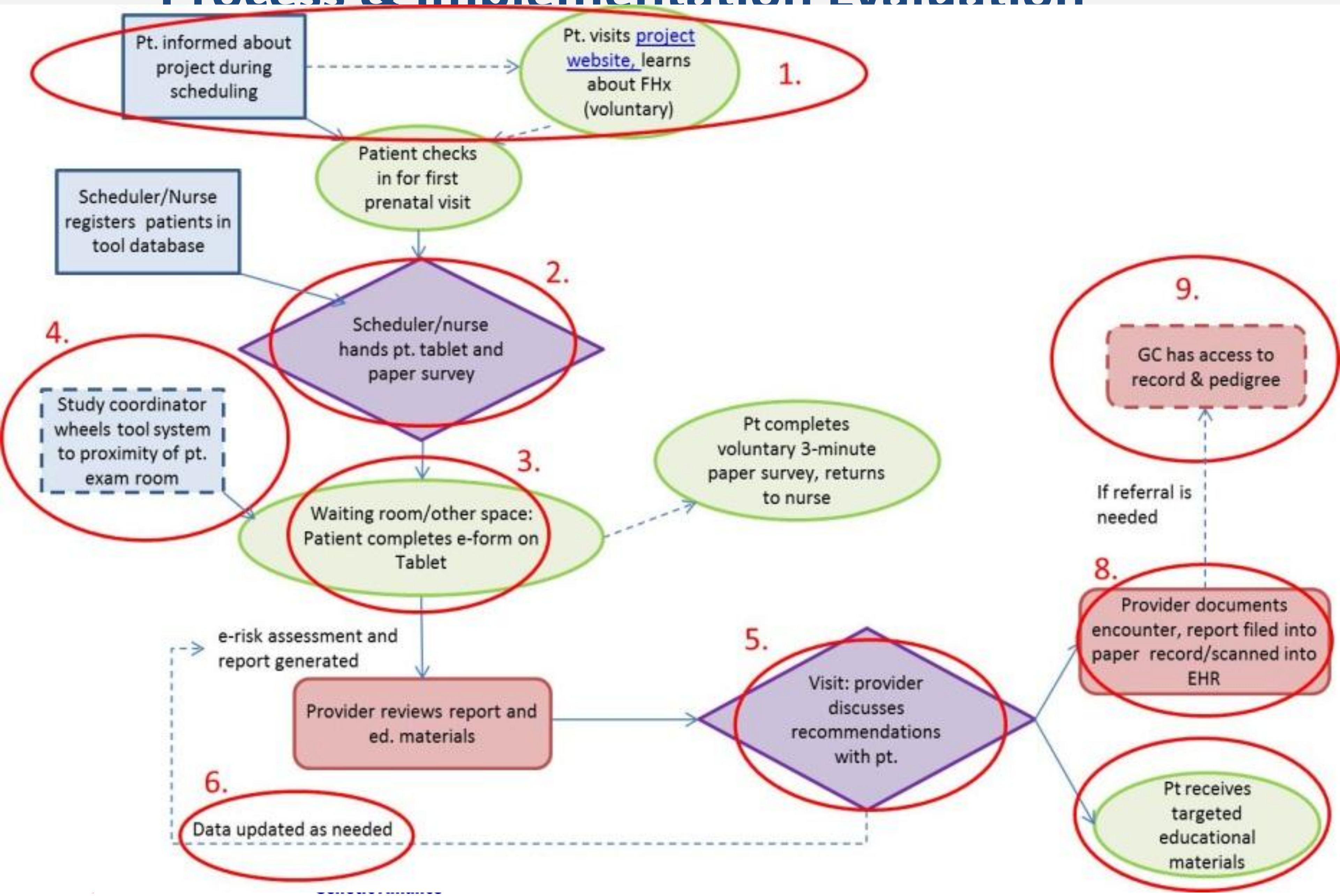
Visit: provider discusses recommendations with pt.

6.

Data updated as needed

Pt receives targeted educational materials

Process & Implementation Evaluation



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Conclusions from Implementation Data

1. Customization is critical
    - Clinic flow, implementation, and installation plans
    - Continuous assessment and modification of clinic and work flow
    - Providers desire customizable tool
2. Clinical champion and IT support critical

Patients

Findings from
Patient Feedback Survey
n=513/618 (83%) total across 4 sites

Unpublished Data: Confidential

Patient Demographic Characteristics

		NC n=225	ME n=42	NY n=37	IN n=209	Total n = 513	p-value
Age :	15-17 yrs	6%	11%	3%	0%	4%	***
	18-24	37	36	31	16	29	
	25-34	45	48	51	68	54	
	35-46	12	5	11	15	13	
Highest grade completed							***
	Less than high school	23	33	20	2	16	
	High school grad	22	31	14	7	15	
	Some college	27	21	43	22	26	
	College graduate	21	11	11	49	31	
	Graduate school	7	3	9	19	12	
First pregnancy		29	31	22	42	34	*
English 1st language		97	97	72	94	94	***
Very comfortable with computers		83	76	92	94	88	**

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Patient Ethnicity/Race

	NC n=225	ME n=42	NY n=37	IN n=209	Total n = 513	p-value
Hispanic or Latina	6%	6%	65%	3%	9%	***
Race:						
Caucasian or White	85	92	25	83	81	***
African-American / Black	10	0	42	11	11	
Asian or Pacific Islander	1	0	0	5	3	
Native American	0.5	3	4	0	1	
Caribbean or West Indian	0.5	0	25	0	2	
Multi-racial	4	6	4	1	3	

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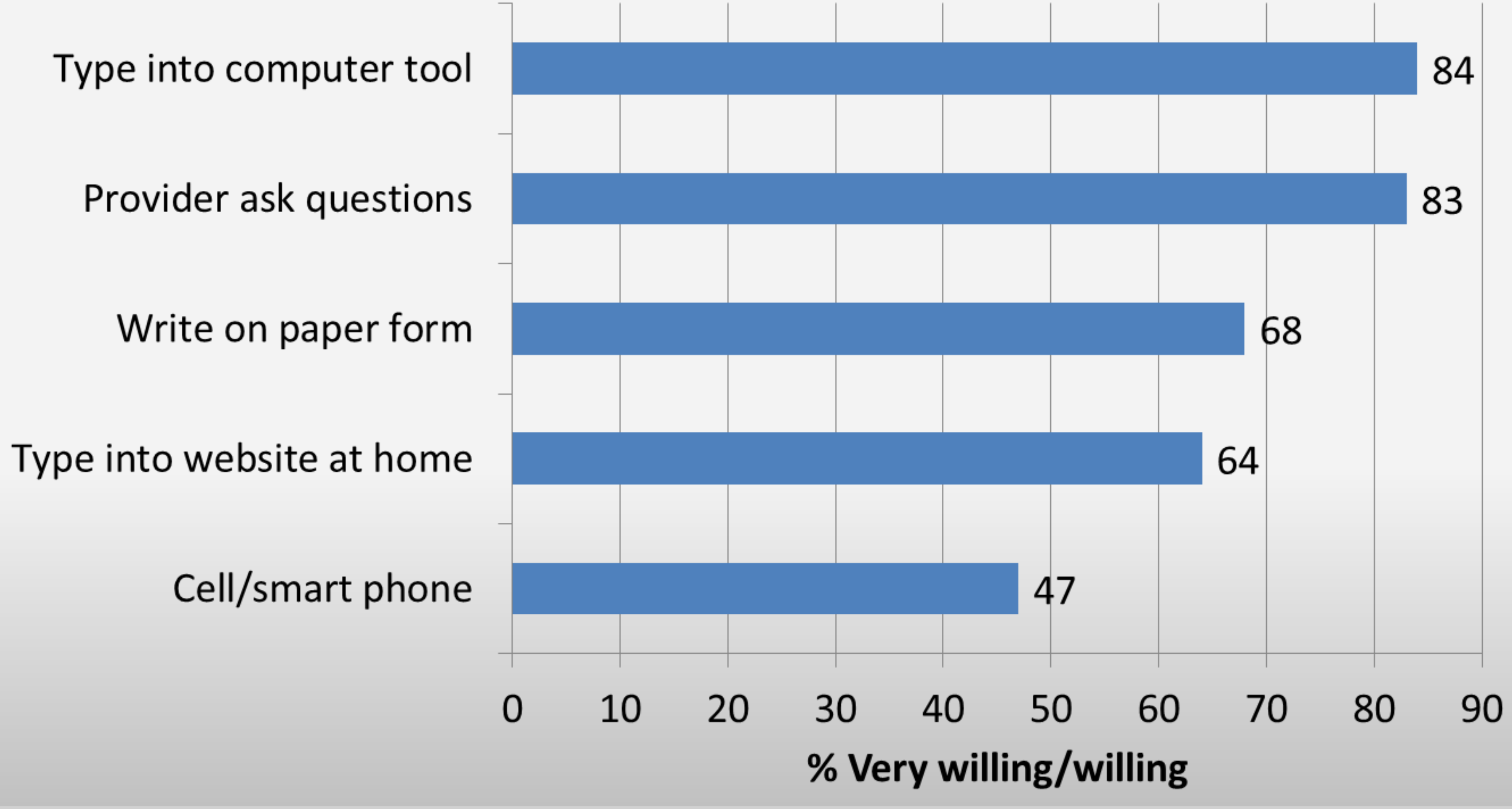
Patient Feedback

Tool was easy to use	96%
Questions were easy to understand	98%
Not worried about confidentiality of information entered into the tool	96%

How willing would you be to provide your personal & family hx info to your provider via…(n=513 across 4 sites)



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Conclusions from Patient Data

1. Tool tested in diverse patient population
2. Acceptability and usability high across populations
3. Patients comfortable entering personal and family history info into computer
4. Equally willing to provide info in computer tool as compared to verbally to provider
5. Computer tool more desirable than paper tool

Providers

Findings from
Provider Feedback Survey
n = 20 / 65 (30% response)

Unpublished Data: Confidential

Provider Characteristics (n = 20)

- Provider type
  - 10 Obstetricians (8 NC, 1 NY, 1 IN)
  - 6 Family Medicine Physicians (ME)
  - 2 Nurse Midwives (NC)
  - 2 Other (RD/OB Educator and Nurse at IN)
- Patient Volume
  - 47% saw 2 – 5 pts total
  - 41% saw 12 – 60 pts
  - 12% saw 200 – 275 pts

Knowledge & Confidence

Knowledge

- OB: No pre-post change (89.0% to 89.1% average scores)
- FM: 67.9% pre to 85.7% post average scores (p = 0.018)

Confidence

- Knowing when to refer and conduct follow-up for at-risk patients increased

Satisfaction & Usefulness: Impact on Clinic Flow

Positive	Negative
• Made process of seeing new pt. faster, smoother • Reduces time spent on taking high quality pt. family history • Pre-formed questionnaire with all appropriate questions and info…allows me to focus on details that make every pregnancy different	• Hindered productivity of visits • Difficulty documenting more immediate pregnancy-related issues (e.g., physical abuse, blood type) • More time spent clarifying responses & follow up with pt.

% who reported useful or very useful	**FMs (n=8)** % (n)	**OBs (n=13)** % (n)
Patient data pre-populated into form	57.1 (4/7)	53.9 (7/13)
Family history collection & pedigree	37.5 (3/8)	61.5 (8/13)
Structure/organization of report	25 (2/8)	38.5 (5/13)

Satisfaction & Usefulness: Patient Engagement

Positive	Negative
- Made conversation of history easier for pt. - Engaged pt. to ask good questions about risk of passing conditions to newborn - Allows pts. to open up about many different genetic issues - Helped me give more educational info to pts.	- Missed one-on-one interaction where I could clarify issues & build rapport

% who reported useful or very useful	FMs (n=8) % (n)	OBs (n=13) % (n)
Patient questionnaire	60 (3/5)	61.5 (8/13)
Patient fact sheets	60 (3/5)	44.4 (4/9)

Satisfaction & Usefulness: Clinical Decision Support

Positive	Negative
• Offering right screening tools • Liked recommendations, referrals, teaching list and genogram	• Too lengthy, too much paper • Unfamiliar report • Hard to decide what to do with it all • List made too many referrals not needed • Many more ultrasound were ordered

% who reported helpful or very helpful	FMs (n=8) % (n)	OBs (n=13) % (n)
Ethnicity-based risks (*Example: Hemoglobinopathy)*	57.1 (4/7)	57.1 (5/13)
Complex birth outcomes (*Example: neural tube defect)*	57.1 (4/7)	57.1 (5/13)
Non-genetic health conditions *(Example: blood clots)*	42.9 (3/7)	42.9 (3/13)
Conditions unrelated to pregnancy *(Example: hereditary cancer)*	28.6 (3/7)	28.6 (4/13)

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Conclusions from Provider Data

1. Confidence in identifying & managing pts at-risk increased
2. Value in questionnaire and fact sheets for patient engagement, education
3. Mixed perceptions of impact on work flow and practice
4. Mixed perceptions of value of clinical decision support
5. Report needs to be shorter & tailored to meet providers' needs

Performance Measures

Findings From
Patient Medical Records & Tool
n = 522 total across 3 sites

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Genetic Performance Measures

	Assessed through pre- and post-chart audits
1	% of patients that have a documented 3-generation family history. 3-Generation Definition: At least one member of three generations documented. For example: the patient, her children, and her parents. (ACOG. *Obstet Gynecol.* 2011;117:747-750)
2	% of patients and FOBs that have documented ethnicity and ancestry data. (ACOG. *Obstet Gynecol.* 2011;117:747-750)
3	% of patients for whom there is documented discussion, counseling, or education about cystic fibrosis carrier screening. (ACOG. *Obstet Gynecol.* 2011; 117:1028-31)
4	% of African-American patients for who there is documented discussion, counseling, or education about SCA carrier screening. (ACOG. *Obstet Gynecol.* 2007; 109:229-37)
5	% of Asian-American patients for who there is documented discussion, counseling, or education about thalassemia carrier screening. (ACOG. *Obstet Gynecol.* 2007; 109:229-37)

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Conclusions from Performance Measures

1. Tool collects greater detail and higher quality family history information
   - Especially FOB and ancestry info
2. Cystic fibrosis screening rates similar pre and post or improved with tool
3. Additional analyses planned to further study outcomes

Summary

1. Clinical implementation
    - Identified process and recommendations for clinical implementation
2. Patient feedback
    - High patient satisfaction
3. Provider outcomes
    - Mixed provider feedback about decision support
    - Value patient engagement and education
    - Improvements in confidence

Next Steps

1. Disseminate prenatal tool for free download

   http://www.hughesriskapps.net

2. Continue to study the impact of the tool in a prenatal population

3. Develop adaptations for additional clinical settings (e.g., pediatric, adult)

4. Develop web-based and non-English language versions

Thank You

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