We built it but will they come?

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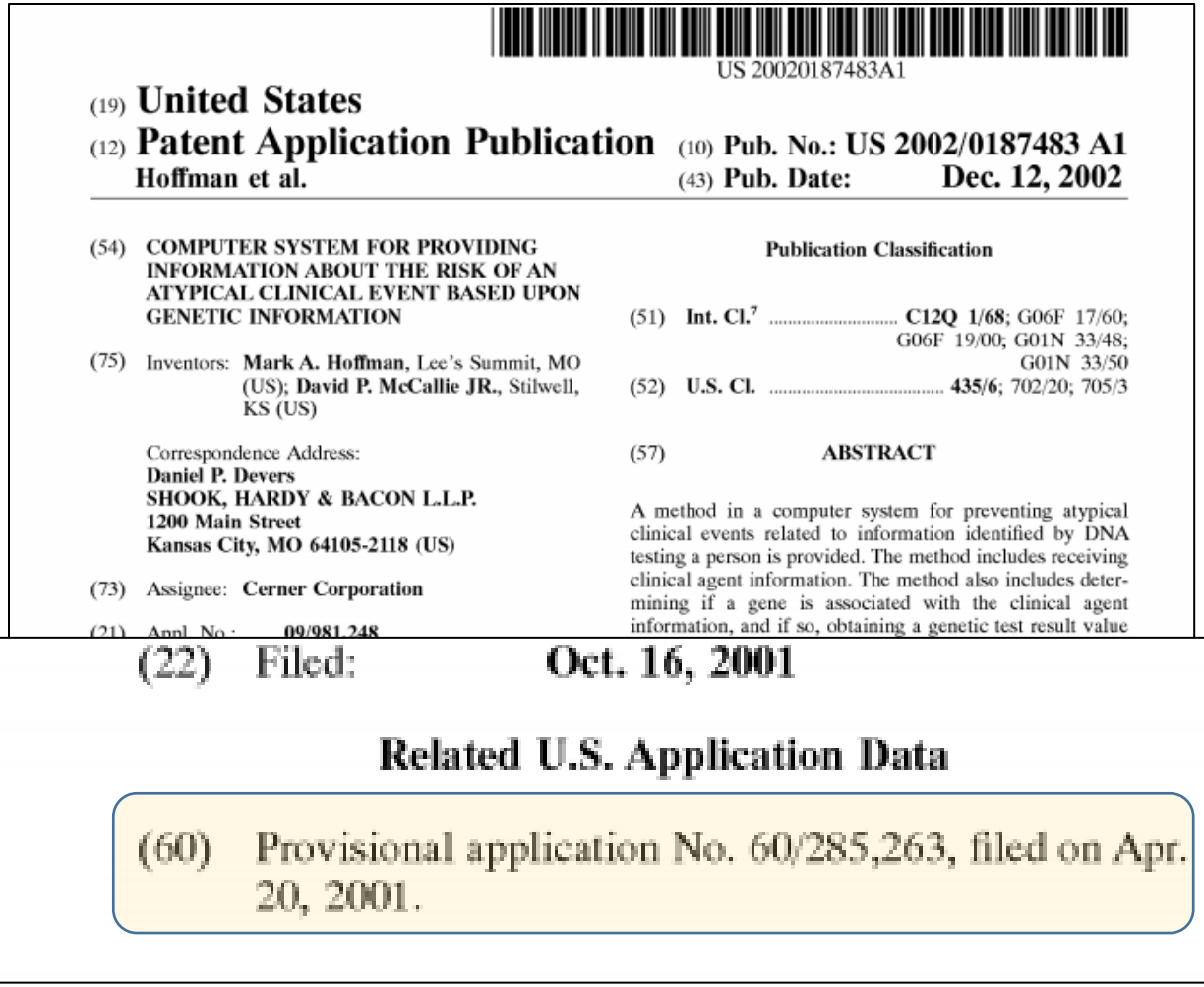
Nearly 20 years ago….

- Filed patent on Genomic CDS **April 20, 2001**
- Core concept: Alert user if clinical order is contraindicated by genetic information.



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Hoffman et al. (43) **Pub. Date: Dec. 12, 2002**

(54) **COMPUTER SYSTEM FOR PROVIDING INFORMATION ABOUT THE RISK OF AN ATYPICAL CLINICAL EVENT BASED UPON GENETIC INFORMATION**

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(52) **U.S. Cl.** **435/6**; 702/20; 705/3

(57) **ABSTRACT**

A method in a computer system for preventing atypical clinical events related to information identified by DNA testing a person is provided. The method includes receiving clinical agent information. The method also includes determining if a gene is associated with the clinical agent information, and if so, obtaining a genetic test result value

Related U.S. Application Data

(60) Provisional application No. 60/285,263, filed on Apr. 20, 2001.

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We built it …

- Lab information system (LIS)
- Standardized terminology (Clinical Bioinformatics Ontology)
- Genomics CDS strategy

… They came

- Molecular diagnostics and cytogenetics labs
- Some genetics specialists
- Oncology

… They didn't

- Most generalists
- Most specialties

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Periods of EHR / Genomics

2000-2008	Meaningful Use	2009 - 2015	Innovation Entrepreneurship	2016 - present
• What is genomics? • We don't even have an EMR...		• Hurray - now we have an EMR ! • But wait - we have to fulfill the MU requirements and can't deal with “this”.		• So many options • Will this startup survive? • Still seen as academic • Patient portal is real • How will this help with COVID-19?
Lab Systems – automation		Ground up build discrete data		Niche applications

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Children's Mercy Genomic Medicine Center

- **Goal:** 30,000 children + family members
- 100k genomes + health information

Genomic Answers for Kids project progress

We are working hard to make progress for patients with genetic disease!

2,149	4,987	5,624	897,614	213
families enrolled	individuals enrolled	genomic analyses	gigabases sequenced*	diagnoses from study

Most important stakeholders

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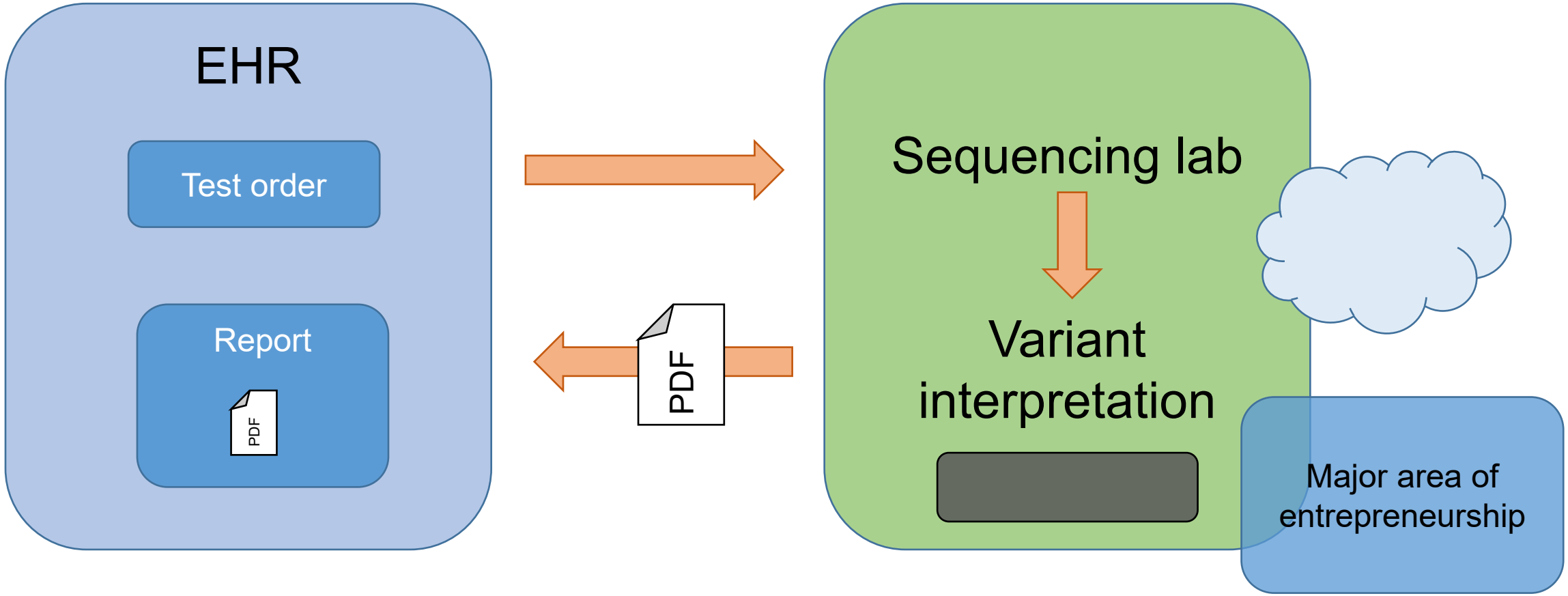
Common architecture: Current state of clinical genomics / informatics



A pdf is a **dead end** for decision support, re-analysis

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Optimizing resource allocation

Direction of funding:

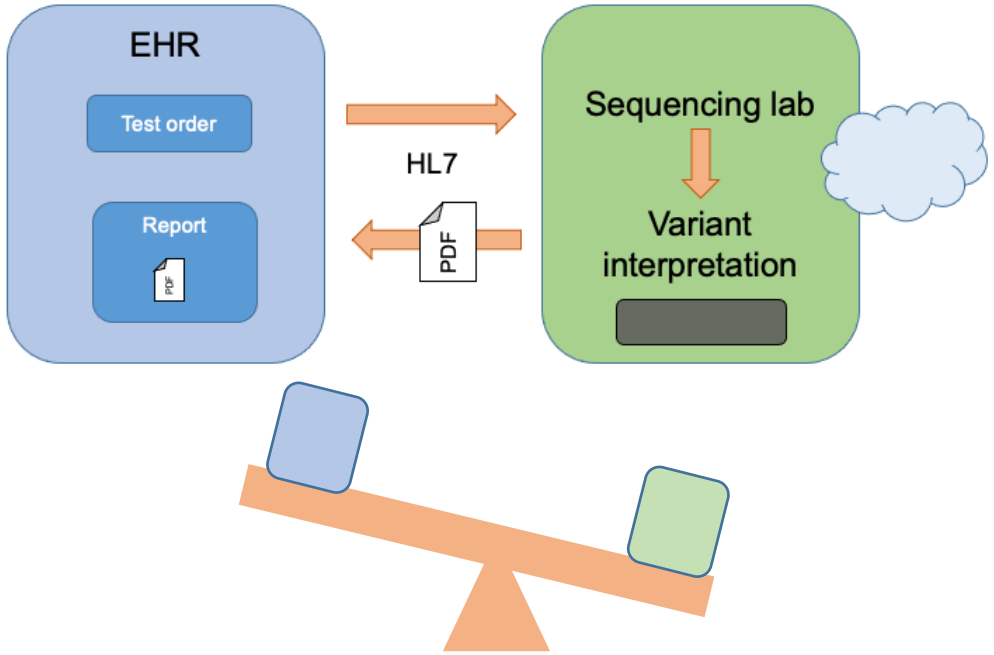
- FTE - manual EHR build for discrete storage

Direction of funding:

- Cloud storage, analytics
- Next next generation seq (long read etc…)
- 3rd party niche applications

Gaps:

- Increase utilization among providers (demand)
- Human factors (!!)
- Confidence in reimbursement
- FHIR in practice
- Consistent storage of clinically actionable variant data



Gaps:

- Standard clinical interpretations
- Policy clarity around automated re-interpretation of results – billable?

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Difficult observations from the field

- **FHIR** has a lot of promise and potential as a data standard but still early
- Content standards about variant interpretation still limited
- **Strong reluctance** in health systems to use OS in production systems.
- Labs willing to pay for 3rd party niche applications
- Providers much less willing to pay for EHR-adjacent genomics CDS

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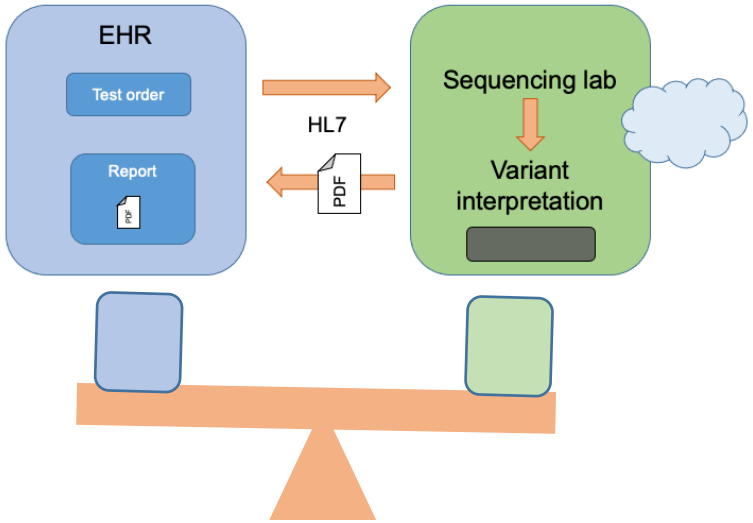
How do we rebalance?

- Train providers – they must see the **value** every day and be comfortable
- **HUMAN FACTORS:** Work on the "experience" side of the equation
- **Content: CPIC** like resource for clinical genetics
- **Economics:** Demonstrate **financial benefits** of using genomic info to improve care
- EHR vendors respond to their clients: Reward providers for using genomics standards in EHR



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I'm still cautiously optimistic!

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