Artificial Intelligence & Predictive Analytics

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FH Foundation

The FH Foundation is a patient-centered nonprofit organization, dedicated to research, advocacy, and education for Familial Hypercholesterolemia (FH).

Our mission is to raise awareness of FH and save lives by increasing the rate of early diagnosis and encouraging proactive treatment.
Artificial Intelligence and Predictive Analytics to FIND FH®

- What is Familial Hypercholesterolemia and why is predictive analytics needed?
- Validation of FIND FH model
- Implementation of FIND FH model
- Barriers to address
How do we find 90% undiagnosed FH?

FH Foundation National Database up to 12/31/2016
Precision screening for familial hypercholesterolaemia: a machine learning study applied to electronic health encounter data

Summary
Background Cardiovascular outcomes for people with familial hypercholesterolaemia can be improved with diagnosis and medical management. However, 90% of individuals with familial hypercholesterolaemia remain undiagnosed in the USA. We aimed to accelerate early diagnosis and timely intervention for more than 1.3 million undiagnosed individuals with familial hypercholesterolaemia at high risk for early heart attacks and strokes by applying machine learning to large health-care encounter datasets.

Methods We trained the FIND FH machine learning model using deidentified health-care encounter data, including procedure and diagnostic codes, prescriptions, and laboratory findings, from 939 clinically diagnosed individuals with familial hypercholesterolaemia (99 of whom had a molecular diagnosis) and 83,136 individuals presumed free of familial hypercholesterolaemia, sampled from four US institutions. The model was then tested to a national

Positive Predictive Value
85%
FIND FH (Flag, Identify, Network, Deliver) validation process

**Step 1**
Secure longitudinal encounter data to train the model

- The Ohio State University
- Stanford Medicine
- Duke Medicine
- Johns Hopkins Medicine
- 939 clinically diagnosed FH individuals
- 66,666 presumed FH negative individuals

**Step 2**
Apply the model to national and health system datasets

- Validation on national healthcare encounter data
  - FIND FH applied to database
  - N=100,000,000 individuals
  - 132 M Probable FH individuals nationally
- Validation on healthcare system encounter data
  - FIND FH applied to integrated healthcare delivery system database
  - N=764,000 individuals
  - 866 probable FH individuals identified

**Step 3**
Charts reviewed by FH Expert

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- DLCN, MEDPEDI, Simon Broome and expert clinical judgment

**Results**

- National dataset 87% confirmed FH
- OHSU dataset 77% confirmed FH

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Implementing FIND FH in health systems

1. Health system encounter data (diagnosis, procedure, prescription claims and lab results) identified & secured
   - Health system encounter data (Dx, Px, Rx, Lx)

2. Data set de-identified per HIPAA rule
   - Application of the FIND FH® Algorithm to identify probable individuals* with FH

3. De-identified patient centric data
   - Apply FIND FH algorithm data set to health system
   - Probable FH individuals* aggregated to the HCP Level

4. Probable FH individuals* aggregated to the HCP Level

*Patient that has a profile consistent with other individuals with FH
Quality Improvement Workflow at Penn Medicine

**FHF → Penn Medicine Data Transfer**
- Return “Probable FH” Patients with brief history from FIND FH® to study team

**HCP Outreach**
- Contact HCP to engage Patient
- HCP responds yes/no and/or provide details of previous clinical strategies

**Patient Outreach**
- If permission granted, patient contacted and invited to clinic
- Patient visits Center for Preventive Cardiology

**Medical Consultation**
- Evaluation for FH, advanced cardiac risk assessment, interventions to reduce risk, genetic testing

**Patient Education Consultation**
- Diagnosed FH patient encouraged to join CASCADE FH® Registry and patient portal
- Patient provided print/digital FHF resources

FIND FH: Penn Medicine progress through May 2019

- 442 providers treating ~3,000 patients contacted
- 233 providers responded (53% response rate), who managed a total of 2,174 patients
- Received permission to contact 1,755 patients (81%)
- 300 patients reached as of May 2019
  - 47 patients seen in clinic
  - 22/47 received a positive FH clinical diagnosis during visit
  - 40/47 had a change in clinical management (85%)
Implementing FIND FH: Barriers to Address

- FH awareness and education among PCPs is low
- Evidence-based guidelines (ACC/AHA) to consider FH & LDL-C > 190 mg/dL high risk conditions are not institutionalized
- Policy or quality metrics to incentivize guideline recommended treatments are lacking
- Cascade screening currently not easily performed in the US

Precision screening is now a reality

Screen 10 to find 8, instead of screening 1,760
We gratefully acknowledge the generous support of our FIND FH Sponsor.

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