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Harvesting Wearable Device Data

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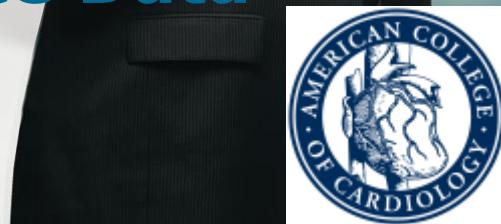
COMMITMENT

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Conflict of Interest

Ajay K. Mittal, MS, B. Tech.

Has no real or apparent conflicts of interest to report.

Agenda

- Learning Objectives
- Background
- Problem Statement
- Approach
- Challenges
- Summary/Conclusion
- Q&A

Learning Objectives

1. **Explain** why it is important to capture 'non-episodic' health data from wearable devices and integrate it with registry data for a comprehensive clinical picture
2. **Define** typical devices, apps and the data to be collected and the rationale for identifying the data elements
3. **Illustrate** how non-episodic data can be collected from various devices and mobile applications using one-time user login and consent
4. **Identify** and analyze challenges related to data and privacy concerns related to wearable devices

Background – ACC

- Founded in 1949, the American College of Cardiology is a **non-profit** organization located in Washington DC
- Over 52,000 members worldwide
- The mission of the American College of Cardiology (ACC) is to **transform cardiovascular care** and improve heart health
- The ACC's vision is a world where **innovation** and **knowledge** optimize cardiovascular **care** and **outcomes**
- In 1997, the National Cardiovascular Data Registry (NCDR) was created as an exploration into strategies for improving cardiovascular care through the use and application of **clinical data**

ACC

NCDR

Outpatient

Non-Episodic

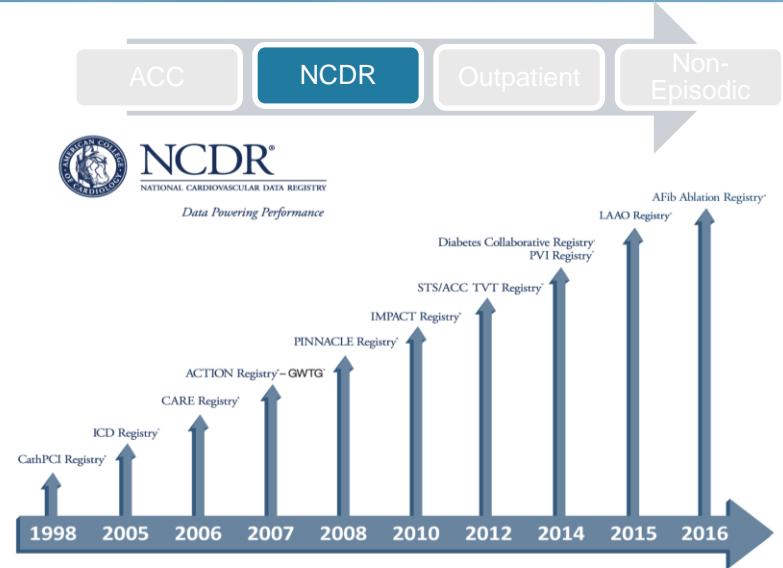
“Science tells us what we can do;
Guidelines what we should do;
Registries what we’re actually doing.”

~Lukas Kappenberger, MD

Source: ACC/NCDR

Background – NCDR

- The National Cardiovascular Data Registry (NCDR®) is the ACC's suite of cardiovascular data registries helping hospitals and private practices **measure** and **improve** the quality of care they provide
- the NCDR, cardiology's comprehensive registry offering, consists of eight hospital-based registries and two outpatient registries
- The NCDR offers the relevant data elements and **metrics**, **actionable reports**, voluntary **public reporting** and other **quality improvement** programs



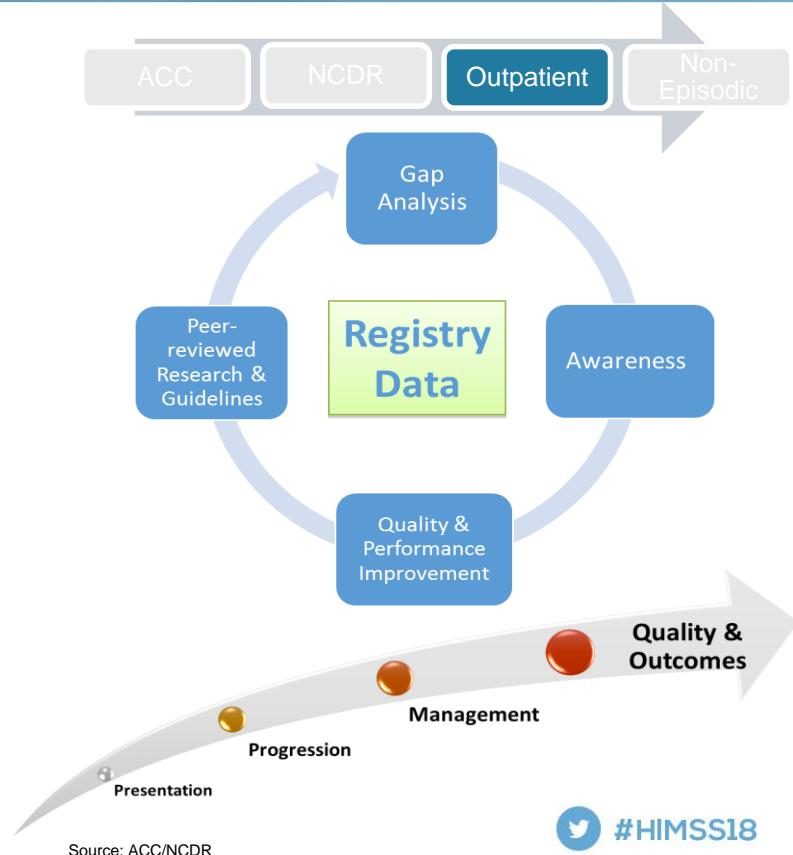
- 10 national programs
- ~ 2200 hospitals, 500 practices
- ~ 10,000 cardiologists
- ~ 60M clinical records

Source: ACC/NCDR

Outpatient Registries

The ACC/NCDR outpatient registries offer a large scale, multispecialty, real-world **data collaboration** that allows for:

- National benchmarking and reporting mechanisms to continuously inform practices and providers of their performance against **evidence-based measures and metrics**
- **Longitudinal** study of diabetes presentation, progression, management and outcomes, even as patients receive treatment from **multidisciplinary** care teams, including primary care physicians, endocrinologists, cardiologists, and other diabetes care providers



ACC

NCDR

Outpatient

Non-Episodic

Outpatient Registries

- Outpatient registries collect data from service providers based on visit to a service provider and are referred to as an '**episodic encounter**'
- With the prevalence of mobile devices, social media, and health awareness, individuals are capturing data that are not related to an encounter or a doctors' visit and is referred to as '**non-episodic**' encounter
- The general hypothesis is to collect both kinds (episodic and non-episodic) of data over a period of time (**longitudinality**) to improve overall outcomes and patient care



Problem Statement

- There is an immense amount of non-clinical data points being recorded by remote wearable health devices and smartphone applications available to consumers
- The challenge is how that data can be **collected** and **leveraged** to improve population health management
- This presentation provides an overview of **how**, **what** and **why** such data from wearable devices can be collected to formulate a more comprehensive profile of patient health data
- This non-clinical data can provide additional **insights** to the **longitudinal perspective** of a patient's health that might otherwise be missing and can help guide physicians to effective heath care decisions

Approach

The pilot project focused on the three aspects for the planning and execution:

1. Technology
2. Business
3. Governance



Approach - Technology

- The focus related to technology was to identify popular **wearable devices** and the **relevant interface** to collect the data. The project focused on a seamless and easy **user interface** for the end-user to opt-in.
- The ACC partnered with a vendor to leverage a proprietary application program interface (**API**) technical solution to collect **de-identified data** recorded from four different remote health products* commonly in use :
 - Runkeeper
 - FatSecret's (Calorie Counter app)
 - Fitbit
 - Google Fit
- To manage overall scope for the pilot, certain broadly used trackers, e.g. Garmin wearables, MyFitnessPal were excluded

*Apps and devices are the registered trademarks of respective firms

Approach – Technology workflow

Participant	Invite	Status
Subject 1	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Not Signed Up
Subject 2	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (2 Devices)
Subject 3	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (1 Device)
Subject 4	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (1 Device)
Subject 5	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (1 Device)
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Subject 8	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (1 Device)
Subject 9	<input type="button" value="SEND EMAIL INVITE"/> <input type="button" value="GENERATE INVITE LINK"/>	Enrolled (1 Device)

What is FITDAAP?
FITDAAP is an observational research project to determine the feasibility of gathering remote monitoring and wearable health device data. The entire project will be conducted virtually by requiring participants to download a mobile phone application (Runkeeper, Fit Secret, or Google Fit, "App") or to obtain remote health monitoring device (Fitbit, "Device"). The App or Device will gather the data selected data points and pass it through the proprietary GetHealthMAP™, a complex application used to get the data, and will then be de-identified, aggregated, and analyzed.

Download Apps

- Runkeeper
- Calorie Counter
- Google Fit
- Fitbit

Principal Investigator: Angelo Poirakis

Please click on connect to provide access to data as part of this study. You will be redirected to the device manufacturer's login screen to enter the credentials and provide access to the study.

Fitbit

Calorie Counter

Runkeeper

GoogleFit

Log in

Allow

Deny

Data shared with Your App will be governed by Your Organization's privacy policy and terms of service. You can revoke this consent at any time in your Fitbit account settings. More information about these permissions can be found here.

- HIPAA Compliant Data storage on the cloud
- De-identified aggregated data is pulled on a nightly basis by ACC team
- Once registered, users don't need to take any action (except to disconnect)

Approach - Technology

- The vendor provided a portal and necessary credentials while maintaining the confidentiality of the individuals to sign-up for the portal and agreeing to collect the data on their behalf
- The team also developed a nightly data feed (**de-identified and aggregated**) to be available to ACC for data integration and analysis

Approach - Business

- Identify the devices (e.g. Fitbit, Google Fit)
- Identify the data elements (blood pressure, daily steps, etc.)
- While this may seem simple or trivial, in reality, there were lot of deliberations to get a consensus among various stakeholders. Once a decision was made, the ACC technology team worked with the vendor and stakeholders to identify a viable solution which was feasible to implement



Approach - Governance

- HIPAA compliance and privacy
- For the pilot, the first the project team obtained approvals from the Internal Review Board (IRB) and Human Resources to use the employees as the participants
- Legal team was consulted to draft joint communication from HR, Legal and the project team to solicit employee participation
- Once employees agreed to opt-in for the pilot, they were sent a link with credentials to sign up via the device they would like to use and register and track the data for the duration of the study

Challenges - Recruitment

- The team did not anticipate that it would be a challenge to recruit participants for the pilot
- The team underestimated the reservation about signing up for the study and the willingness to participate
- The team considered ideas to provide incentives for participation, however, it would have skewed the motivation and intended purpose of the pilot



Challenges - Active Participation

- The team selected several different health tools to assess data collection and inclusion from multiple sources
- It was immediately evident that the more active participation that was required of participants, the lower the level of contribution to that selection of the data
- As a result, the calorie counter that required daily logging of information, had minimal contributions

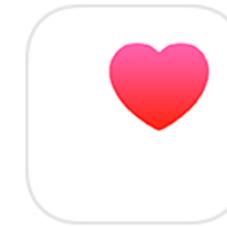


Challenges - Legal/HR

- Given the scope of the pilot and the contribution towards the overall population health management, the team thought it should not be difficult to pursue the pilot study within ACC
- However, the team soon realized the HIPAA, privacy and other issues are not trivial to overcome and over simplify
- The team went through a lot of learning to reach the desired outcome to solicit participation

Challenges - Technology

- It was not obvious that an API would be readily available for one of the popular device, e.g., Apple Health. The API is not available due to technology architecture
- The team also had to ensure that all personally identifiable information (PII) is masked at all times due to privacy concerns
- The team conducted thorough testing in lower environments before releasing the portal to the end-users to mitigate security and privacy concerns



Summary/Conclusion

- Based on monthly data aggregation efforts, some data points reflected better passive data capture or active logging by participants than others.
- Fitbit looks to be the strongest data source, followed by Runkeeper, and then FatSecret Calorie Counter app
- Approximately 75% of the total valid data records captured during this pilot were from Fitbit devices, and based on its capture methodology, it provides the most longitudinal data capture, recording a data value almost daily for each user for step count and their associated calories burnt. Fitbit's next strength rested in its recorded sleep data



Summary/Conclusion - continued

- Runkeeper had the next highest rate of data capture. Runkeeper's data strength was for the logged activities, though clinical significance of collected data points is to be determined
- The FatSecret Calorie Counter application was used by less than 20% of total users, but its calories consumed and nutrition facts data provides insight into eating habits. Fitbit records weight and Body Mass Index (BMI) data, but Runkeeper does not. For Runkeeper, no information was able to be collected on blood glucose or body fat data

Summary/Conclusion - continued

- Remote health device and monitor data could be included in the NCDR registries data if the remote health data points were extant already, otherwise, the registry could include these data points as part of a registry version upgrade, subject to scientific approval

Summary/Conclusion - continued

- Based on the results of this pilot, it is feasible to consider the long term longitudinal data strategy to include non-episodic health data, if clinically-overseen data elements can be included in the registry. Considerations must be made regarding the specific non-episodic data elements considered for inclusion
- Additional data-sources and data elements can be considered for future data collection and integration efforts
- ACC will need partnership with the service providers and will need necessary education for the participants to educate them on the potential benefits and participation for longitudinal data

Learning Objectives – Recap.

- ✓ **Explain** why it is important to capture 'non-episodic' health data from wearable devices and integrate it with registry data for a comprehensive clinical picture
- ✓ **Define** typical devices, apps and the data to be collected and the rationale for identifying the data elements
- ✓ **Illustrate** how non-episodic data can be collected from various devices and mobile applications using one-time user login and consent
- ✓ **Identify** and analyze challenges related to data and privacy concerns related to wearable devices

Questions

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NCDR®
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