The Future of Patient Engagement: Partnerships with Patient Hackers and Patients as Designers

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Conflict of Interest

Dana Lewis
Has no real or apparent conflicts of interest to report.

Scott Leibrand
Has no real or apparent conflicts of interest to report.
Agenda

• Understanding real-life obstacles in health care
• The disconnect between the priorities in health care stakeholders
• Why people are driven to DIY
• The contrast between traditional innovation and user-driven innovation
• The need for partnerships with patients
Learning Objectives

• Articulate the importance of patient-centered innovation in population health

• Analyze how activated patients can have an impact on their own health outcomes

• Describe the characteristics of patient hackers
An Introduction of How Benefits Were Realized for the Value of Health IT

• Satisfaction
  – Patients have better outcomes & improved QOL
  – Doctors have more engaged patients, less time spent managing care
• Patient engagement
  – Patients are partnering with providers (& others) to determine best method of care
• Savings
  – Decreasing short term financial risk of hospital admissions from hypoglycemia
  – Decreasing long term cost by improved care and outcomes
Close your eyes, please.
The reality of diabetes: even if you do everything right, you can still die in your sleep.
“Can we have louder alarms?”

• Industry responses:
  – “They’re loud enough!”
  – “No one sleeps through their CGM alarms”
  – “It’s not that big of a deal”
  – “Maybe you shouldn’t live alone”

• “Why #WeAreNotWaiting? Because our lifesaving drugs are also lethal, and we need technology that adjusts in real-time.”
  - @DanaMLewis & @ScottLeibrand
“State of the art” medical technology:

- Device A doesn’t talk to Device B
- You can’t hear the alarms
- ...and patients can’t get their own data from the devices.
“As patients, we must secure access to our health data, have the opportunity to learn from it, and the freedom to share it with whomever we wish, including donating it to research for the public good.

Freeing the data will also enable patient activation and promote individual responsibility, and it will clear our path to precision medicine.”

- Hugo Campos
Diabetes is the original DIY

- People with diabetes make 300+ decisions a day that influence their blood glucose.

- Example calculation for a meal:

  Carbs (26 carbs*1:10) + correction for high BG (BG-100*1:40) + % for resistance – activity walking here + sitting still for next 3 hours + stress/excitement – current insulin on board = how much insulin needed?
Meet #DIYPS

122 Update BG?
3.3 U IOB + 30 g carbs
Est BG of 83-209 in 1-2h, 110 eventually
If your net IOB is 3.3, (adjusted for temp basals), then your BG should end up within range (90-110).

No action required.

Snooze for: Bolus or Temp Basal or for Carbs
Snooze Wizard or No Data alarms, or just shut up Everything

Alarms currently snoozed:
Tue, Feb 4
6:50
122 45 Up 6:46
IOB 3.3 U, 30 g
83-209 -> 110

@DanaMLewis @ScottLeibrand | #WeAreNotWaiting
What is #DIYPS?

1. Louder alarms
2. Remote monitoring
3. Data from all diabetes devices
4. Real-time predictive alerts
5. Personalized recommendations
..but we realized we could do even more.
We turned the “louder alarm system” into a closed loop artificial pancreas.
“Traditional innovation is not good enough. We need more, we need better, and we needed it years ago.”

- @DanaMLewis & @ScottLeibrand
(Can you spot the artificial pancreas?)
#WeAreNotWaiting, because 5 years:

• …is always the answer for when a cure for diabetes is coming…(I’ve been waiting 13 years)…

• …is how long it was predicted to take an artificial pancreas to come to market before we started #DIYPS in 2013…

• …and is too long to wait.
#OpenAPS: from (n=1) to (n=1)*31
How fast would health care change if patients could innovate alongside pharma & medical device companies?

@ScottLeibrand @DanaMLewis | #WeAreNotWaiting
Traditional innovation

User-driven innovation

@ScottLeibrand @DanaMLewis | #WeAreNotWaiting
Concerning trend:

Partnership is the new proprietary.

(That’s not good enough.)
Alternate reality:

- What if IBM had a monopoly on building PCs?
- What if AT&T controlled the information superhighway and the Internet never took off?
"Implants are the most personal of personal devices.

They should answer first to us, then to our doctor and finally, maybe, to a particular vendor in the cloud.

Right now, that sequence is reversed.”

- Adrian Gropper, MD
Permissionless innovation:

Yes, it does apply to health care.
FDA Draft Guidance on Medical Device Interoperability:

• Much note is made of “authorized users” – but patients not included?

• FDA should encourage manufacturers to design their products for *maximum* interoperability, including for use cases not intended by manufacturer.

• Manufacturers should not be liable for third party innovation, even beyond original intended use.
Imagine what else is possible with open-source, collaborative development from a patient community with on-the-market medical devices or hardware?

&

Imagine what else is possible if you partner with already-innovating patients?
Let patients innovate.

Give us access to our data, our devices – and you’ll be surprised what we can do.
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Questions?

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• **Hashtags:**
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