Open Access to my Heart’s Data

MedCOMM, Helsinki
Hugo Campos

August 13, 2012
Hypertrophic Cardiomyopathy

Normal Heart

HCM Heart
1:500
Sudden Cardiac Arrest kills 325,000 people each year in the U.S.
35 Joules Delivered
Remote Monitoring
Remote Monitoring
Patients are the ones left in the dark.
I had been feeling weird... but didn’t think much of it

so... just went to the cardiologist yesterday because they were getting some funky readings on my home monitor and wanted to check my out. I have been feeling a little weird too, but didn't really think much of it... Well, come to find out one of my leads come out of place and they have to go back in to re-place it. Ughh!
"I had been feeling weird...
...but didn't think much of it"

so... just went to the cardiologist
my home monitor and wanted to
really think much of it... Well, I
have to go back in to re-place

ICD Warning
LEAD INTEGRITY ALERT
Contact your clinic.
Open
ignore

slide to view

Like · Comment

ICD Warning
LEAD INTEGRITY ALERT
Contact your clinic.
Open
ignore

slide to view

Like · Comment
Doctors’ experience
Patient’s experience
Industry:

“It does not fit our business model.”
Data is too complex and would generate anxiety.
Clinics will be overwhelmed with phone calls.

Fearful of being cut out of the care circle.
“There is so much value in the data. Our strategy is to exploit the data.”

Elizabeth Hoff,
GM / Cardiac Connected Care, Medtronic
Wall Street Journal, Health Blog, 6/26/2012
From: [email]
To: ers.crm-ps@medtronic.com <ers.crm-ps@medtronic.com>
Subject: Medtronic Form Submission

Product: Defibrillators (Implanted)
Category: Patient, Friend or Family Member

Question/Comment: Dear Medtronic,

Dear Medtronic,

I have a Medtronic Secura DR Cardioverter Defibrillator implanted for primary prevention of SCA.

I have a CareLink monitor, which continues to send transmissions. However, I am not currently under the care of a cardiologist because I am uninsured, and so I cannot ask my provider for my CareLink transmissions.

I am aware that HIPAA guarantees my right to access my health information, and would like to request copies of all the device interrogation data collected by Medtronic over CareLink since November 17, 2010.

Thank you for your attention,

Amanda [redacted]
Dear Amanda,

When you transmit via CareLink, the results of the transmission go directly to your doctor’s office and are not sent to Medtronic. For this reason, you will need to contact your physician’s office that you were previously at for the results.

If you are not sure which office to contact, please email again or contact Medtronic CareLink Patient Services at (800) 929-4043 and press option 2 for assistance. Our staff is available to take your call Monday through Friday from 8:00 a.m. to 5:00 p.m. Central Time.

Regards,

Michael-CareLink Patient Services
Medtronic, Inc.
Remote Monitoring Systems

- Medtronic
- Carelink
- Boston Scientific
- LATITUDE
- St. Jude Medical
- Merlin.net
- BIOTRONIK
- Home Monitoring

1MM+ patients on these remote monitoring networks.
Activity

You burned about the same as 1175 Cal/day from activity this week.

Your activity level is rated Lightly active.

You are in the 55 percentile of all men 45 to 54 yrs who are overweight.

This week you walked 5227 steps.

31% less than the median for men 45 to 54 yrs who are overweight.

You are in the 23 percentile of all men 45 to 54 yrs who are overweight.

$99
# Sleep

<table>
<thead>
<tr>
<th>Day</th>
<th>Times to Bed</th>
<th>Time to Rise</th>
<th>Time to fall asleep (min)</th>
<th>Times awakened</th>
<th>Actual sleep time (hr:min)</th>
<th>Sleep efficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sun</td>
<td>22:55</td>
<td>06:49</td>
<td>11min</td>
<td>8</td>
<td>7hrs 33min</td>
<td>98%</td>
</tr>
<tr>
<td>Mon</td>
<td>22:52</td>
<td>07:01</td>
<td>11min</td>
<td>5</td>
<td>7hrs 26min</td>
<td>95%</td>
</tr>
<tr>
<td>Tue</td>
<td>23:07</td>
<td>06:48</td>
<td>31min</td>
<td>10</td>
<td>6hrs 30min</td>
<td>95%</td>
</tr>
<tr>
<td>Wed</td>
<td>05:30</td>
<td>07:18</td>
<td>21min</td>
<td>4</td>
<td>1hr 15min</td>
<td>86%</td>
</tr>
<tr>
<td>Thu</td>
<td>22:30</td>
<td>07:15</td>
<td>34min</td>
<td>14</td>
<td>7hrs 16min</td>
<td>69%</td>
</tr>
<tr>
<td>Fri</td>
<td>00:03</td>
<td>10:30</td>
<td>11min</td>
<td>14</td>
<td>9hrs 6min</td>
<td>69%</td>
</tr>
<tr>
<td>Sat</td>
<td>23:57</td>
<td>15:58</td>
<td>2min</td>
<td>44</td>
<td>13hrs 10min</td>
<td>82%</td>
</tr>
</tbody>
</table>

**Average**

- Times to Bed: 00:08
- Time to Rise: 06:48
- Time to fall asleep: 17min
- Times awakened: 14
- Actual sleep time: 7hrs 28min
- Sleep efficiency: 91%
Sleep Quality

Total Z: 7 hr 5 min
Time to Z: 0 hr 7 min

Detailed Data

<table>
<thead>
<tr>
<th>Measurement</th>
<th>This Week 6/24-6/30/2012</th>
<th>Last Week 6/17-6/23/2012</th>
<th>Typical Men 40-49</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avg</td>
<td>Min</td>
<td>Max</td>
<td>Avg</td>
</tr>
<tr>
<td>ZQ</td>
<td>71</td>
<td>62</td>
<td>88</td>
</tr>
<tr>
<td>Total Sleep</td>
<td>7h 3m</td>
<td>6h 20m</td>
<td>8h 37m</td>
</tr>
<tr>
<td>Light Sleep</td>
<td>3h 55m</td>
<td>3h 23m</td>
<td>5h 8m</td>
</tr>
<tr>
<td>Deep Sleep</td>
<td>0h 48m</td>
<td>0h 30m</td>
<td>1h 3m</td>
</tr>
<tr>
<td>REM Sleep</td>
<td>2h 21m</td>
<td>1h 38m</td>
<td>2h 56m</td>
</tr>
<tr>
<td>Wake Time</td>
<td>0h 44m</td>
<td>0h 15m</td>
<td>1h 1m</td>
</tr>
<tr>
<td>Times Woken</td>
<td>10</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Rise Time</td>
<td>6:55 AM</td>
<td>5:35 AM</td>
<td>8:10 AM</td>
</tr>
<tr>
<td>Time to Z</td>
<td>0h 6m</td>
<td>0h 1m</td>
<td>0h 25m</td>
</tr>
</tbody>
</table>

Why are these numbers different from the sleep graph above?
Weight

$159
Blood Pressure

$129

[Graph showing blood pressure readings over time]

Fri 20 Jul 2012 10:48 AM

SYS 116 mmHg
DIA 74 mmHg
BPM 70
Hugo Campos

46 years old, 6 ft 0 in, 204 lbs

Allergies
There are no allergies listed for you.

Current conditions
- Hypertrophic Cardiomyopathy
- Hypertrophic obstructive cardiomyopathy

Current medications
- METOPROLOL SUCCINATE 100 TABLET, SUSTAINED RELEASE ...
- ATENOLOL 25MG TABLETS
- METOPROLOL SUCC ER 100 MG TAB
- METOPROLOL SUCC ER 100 MG TAB
- METOPROLOL SUCC ER 25 MG TAB

Emergency contacts
- Mr. Paul Lee Cannon 415-842-1234

Weight
LAST 90 DAYS

Blood pressure
LAST 6 MONTHS

See all of your health information

UPDATES
SATURDAY, JULY 28, 2012
Body Composition
Updated by Withings.

Weight Measurement
Updated by Withings.

FRIDAY, JULY 20, 2012
Blood Pressure Measurement
Updated by Withings.
$30,000

No data.
“I want the ability to independently verify the safety and efficacy of my medical device.”
What will it take for us to have *freedom* in our own bodies?
A device in every human
Thank you