In the many US National Grand Challenges, e.g. in 2012 T. Kalil, Deputy Director for Policy for the White House Office of Science and Technology Policy posited GC #2 of 8: “Personal Health Monitoring System ("OnStar for the Body Prize") - Develop and demonstrate a system which continuously monitors an individual's personal health-related data leading to early detection of disease or illness.”
Collecting Every Heart Beat (because we get a limited number):
Quantifying Self helps everyone become a hypochondriac

Introduction

In August, 2010 I spoke at the Bay Area Quantified Self (QS) MeetUp about the many new devices that were being introduced to measure and record health data (Bell, 2010). The QS community that Gary Wolf and Kevin Kelly started in 2007 is about collecting and understanding quantifiable metrics that can be used to understand one’s on health, wellness and physical condition. Q-Selfies collect data and draw conclusions by conducting experiments on themselves and family members. QS is the qualitative facet of lifelogging.

Our lifelogging book, Total Recall (Bell & Gemmell, 2009) outlines how and why a person would store everything in their life. It is based on our Microsoft MyLifeBits research project conducted from 1998 to 2007. We defined lifelogging to be mostly about storing the qualitative facets of life including professional communications, personal records and family activities e.g. correspondence, documents, and photos to aid memory and personal recollection. In 2002, I began collecting health data as an early BodyMedia user with emphasis on exercise and diet. Figure 1 shows several lifelogging devices that I’ve worn for capturing health data and everything I see. We speculated that storing and analyzing personal health information would provide a great benefit for health and wellness especially for persons with chronic diseases e.g. asthma, diabetes, heart. For example in the last decade, since my heart rate has increased by over 1.5 bpm, my life expectancy may be shortened by about three \( \frac{70.8}{68.5} \times 3 \) percent.

Ideally, if enough were known about all the variables affecting heart rate, the time of the next beat could be known. Of course this means knowing: the environment e.g. temperature, air density, wind, air quality; activity level e.g. sleeping, sitting, standing, walking, running, biking, rowing; diet and digestive loads including stimulants; physical health including allergies, sicknesses, and chronic ailments e.g. asthma, bronchitis; and all the kinds and levels of stress. I’ve observed all of these conditions as qualitatively affecting my own heart’s behavior, angina pain, and lung function e.g. shortness of breath, but none have been isolated and quantified sufficiently to be useful in predicting the quantitative changes. I understand a few obvious situations well enough to change behavior e.g. the importance of sleep, starting off rapidly in cold weather insures high heart rate resulting in shortness of breath, drinking more wine requires a longer absorption time, and contentious or stressful situations elevate HR degree and duration. A lung infection or a heavy cold requires an additional 2-5 bpm.

Based on the use and understanding of current wrist HR monitors and their evolution, an uncanny amount is known or can be deduced about the exact state of person, 24x7 including their overall state of health, stress and the specific activity they are engaged in. However to get to this state will require a good model of the heart-lung system that is validated my thousands of users who wear the devices and record their own status along with exogenous conditions to a data collection and analytics platform.
What I Did

A timeline of the last decade of my own heart and related health events to be described herein is given in Fig 2 and covers an 11 year period as I near expected EOL—hence register a high number of health related events. The figure shows: three pacemaker implants and various average HR counts coming from semi-annual readouts; a second bypass in 2007 to repair damage from a 1996 heart attack; a two month multiple variable tracking experiment using BodyTrack aimed at trying to understand the causes of onsets of angina and shortness of breath as a function of HR and environment; a year of daily average HR counts from a Basis wrist monitor; and finally how illness or major surgery (bladder cancer and a nephroureterectomy) further affect HR and add to the complexity of understanding. During the period weight and physical performance metrics e.g. swimming, rowing and walking rates have been recorded to measure overall well-being.

Tracking and Recording Health Data: In 2002, with the BodyMedia arm band introduction, my “gold standard” monitor, I started to incorporate health data, especially HR and energy expended for weight control and general health into my lifelog. The BodyMedia has a control panel for the arm band measures (Fig. 3a) and the food intake (Fig 3b) that one laboriously accounts for measured food intake. In 2015 numerous devices have been introduced to monitor personal health. A few of these wearables are shown on my body, Fig. 1. Unlike the BodyMedia that determines a person’s energy output by measuring heat flux and activity, simpler devices either ask about or measure steps and movement.

In October 2012, after attending the annual September QS meeting, I was motivated to collect a data stream in an experiment to understand the conditions leading to angina pain and shortness of breath when I walked or exercised. After meeting Dr. Paul Abramson, a self-tracking advocate and practitioner and Anne Wright of CMU, I became an Abramson “trackee”, using the CMU BodyTrack aka Fluxstream.org stream data cloud collecting system (see Fig 4.) BodyTrack uploads data from the BodyMedia (steps, energy expended (mets), and sleep) and Mymee-iPhone app for manually logging heart rate, heart rate variability observations (SweetBeat with a Polar strap, a $5 app for a $400 iPod touch), diet (calories), the degree of angina pain, and shortness of breath, plus swimming and rowing performance.

Figure 5 shows the output from the BodyTrack data streams. By recording enough situations I hoped to understand the levels of stress and other contributing factors affecting the onset of angina or shortness of breath and also whether the two occurred together. I took data for two months until a bladder cancer was discovered and I abandoned logging. However, my conclusion from use, is that a tool like BodyTrack is essential as the basis for person understanding and any clinical study!

1 “What I did, What did I learn” is the format and spirit of the Quantified Self, or QS “show & tell” MeetUp presentations when individuals are given 10 minutes to report the their quantified self (n=1) experiments.

2 The cancer was deemed to be more important to address than understanding my heart-lung behavior. The cancer moved to the ureter. A nephroureterectomy was performed in April 2014 and in the process we found my heart had deteriorated requiring a biventricular ICD that was installed in September 2014. This pacemaker raised the Ejection Fraction from .27 to an almost normal .45. Right after the operation, my personal physician had observed lung abnormality on the CT that after finding a lower capacity,, partially accounts for shortness of breath. The upside of all these maladies is more data e.g. anesthetic, hospital stays about heart rate.

16 June 2015
Understanding Heart Rate from Pacemakers and HR Wrist Bands. In 2006 I started reviewing pacemaker heart rate histograms from the St. Jude pacemaker that had been installed in 2004. The semi-annual checkup reports gave me the exact number of heart beats and a histogram in 10 bpm buckets. I felt strongly that pacemaker counts and distributions were potentially useful for giving a good indication of health and well-being over the six month period and the distributions showed activity or sedentariness measured by higher or lower heart rates. My belief in the value of this measure does not seem to be shared-- especially by the pacemaker manufacturers who could provide quite a lot of automatic analysis based on the periodic readings. Worse yet, pacemaker count and distributions are not available from my latest Medtronic ICD!

In March 2013, I started wearing the BASIS monitor that records steps and minute by minute average heart rate, skin temperature, perspiration and calories. It also estimates sleeping, awake, and active times. Figure 6a shows the average daily heart rates since the ICD installation September 8, 2014 to June 15, 2015.

What I learned: Pacemakers, BodyTrack Logging and Wrist Monitors
Although I have collected lots of data, I learned very little about what is going on with my heart including its ability to work with an abnormal lung—however with my latest and third biventricular pacemaker, by stimulating more of the heart to increase flow, the angina has gone away and I’m able to regulate (i.e. reduce) exertion level to avoid or not having to stop because of shortness of breath or pain.

Pacemaker data: beautiful and potentially informative, sitting alone because no one cares
My first two pacemakers tallied every heart beat and put the tally into a histogram of heart beat frequencies. In my case the data was readout every six months. From Figure 2, there are a few interesting observations. Heart rate from the first pacemaker was about 75 bpm, and didn’t come down until the bypass to solve the problem of a clogged artery that occurred with the 1996 heart attack. The first pacemaker was removed earlier than expected when a software bug in the pacemaker controller-readout console had over-estimated battery end-of-life.

With the second pacemaker and recovery from the bypass and an infection, HR stabilized at about 68.5 for about three years. One six month interval, 69.8 occurred when I was unable to spend almost half time in Australia as I had since 2006. This pacemaker was used 5 years until it was found that biventricular pacing was required due to heart deterioration resulting in an EF of 28%.

The third Medtronic biventricular ICD has given my heart a major boost and restored it to almost its pre-infarction past (1996). However, from my needing to record everything in my life, it is a decade step back in time, because it doesn’t provide a readout of the number of beats. Thus, I have no exact measurement of HR and am unable to calibrate any external wrist heart monitors e.g. Basis, iWatch. Based on the last year of using the Basis monitor, see Fig 6a daily average HR varies between 66 and 78 with an average of 70.7 since the pacemaker was installed. On May 12, I have started using a nebulizer in the evening to administer budesonide that has resulted in reducing heart rate to 66-69.
16 June 2015

**BodyTrack, BodyMedia, etc. Components of HTAP, a Health Tracking and Analysis Platform**

My first use of BodyMedia in 2002 had resulted in the 10 pound weight loss I had been seeking. Wearing the band, and putting other data in manually proved a very accurate measure of my energy expenditure. For energy input, I put in the food I consumed—the painful part of fitness measurement. Weather data, especially extremes and humidity data was not taken. In a few cases, the day to day, I believe could have counted for the two to four beat differences. Today, smartphone apps such as MyFitnessPal do essential the same thing, but in addition require a person to manually describe energy consumed e.g. amount and type of exercise if this information can’t be deduced from the smartphone’s activity.

With the BodyTrack that recorded data from my BodyMedia and Mymee inputs, I gained minimal insight even though I had lots of data from observations of having angina pain or not, and degrees of shortness of breath. However, I feel that this kind of monitor is needed in order to understand the fluctuations and especially cause and effect. The system Fig. 4 also illustrates the fact that each monitoring system is a separate data silo: BodyMedia for activity and diet; Mymee for manual input: SweetBeat for HRV; and BodyTrack for collecting data from the other three silos.

In retrospect, trying to understand the onset of angina and shortness of breath was really just a seeking a palliative for a deteriorating heart that ultimately required additional stimulation. While the biventricular pacemaker is doing well, I am not looking forward to the next life-changing event.

**Basis Wrist Monitoring of HR**

Since the Basis monitor provided minute by minute samples of HR and other data it raises the most questions. The Basis HR data are plotted in Figs 61a-e. With each daily download of data, I am unable to guess whether HR will be up or down from the previous day. The Basis data Fig 6a. shows the HR has periodic swings that may come from diet or stress and is reduced by more calm and exercise—especially swimming in a Sydney salt water pool helps the most because of the ambience and salt water buoyancy. Cold, windy and damp San Francisco seemed to raise the average HR. Unfortunately, my HR in Sydney for a 6 week and 9 week stay were above the average HR for the total time worn— that contradicts the several pacemaker observations of a lower HR in Sydney and general feeling of having lower stress and HR. Figure 6e shows the weak correlation between HR and number of steps take, I took over 4200\(^3\) steps per day over a 240 day measurement period and 10,000 steps/day raises HR about 3.4 beats from a nominal HR of 69.3.

In May after observing the cyclic fluctuation in heart rate since September, in response to a chronic cough, using the nebulizer to administer budesonide in the evening, I was able to reduce my heart rate to 68 for a week. Medicating in the morning has a minimal effect on HR, partially because of the additional 8 hours of medication.

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\(^3\) The monitor readings are lower than actual that include charging time, forgetting to put it on after a shower or swim, ignoring some of the steps taken on a treadmill and registering lower than what other monitors recorded. Swimming times were sometimes accounted for in step-time equivalence.
Conclusions

On mentioning these experiments to my doctor in Sydney who queried me about what I’ve learned e.g. wine increases heart rate and more wine takes longer to be absorbed. Unimpressed, she said: “But, you knew that already. These devices will create a lot of hypochondriacs”. (My 10 year record of visits to her practice is held on a 5x7 handwritten card. My Stanford health record is at least 100 GBytes that includes the nooks and crannies of various arteries.) Her comment raised to question: what good is all this data other than personal entertainment or actionable change? Or early warning signs of stroke or heart attack?

Stream data coming from widespread use of devices and with manual annotation of other factors e.g. weather, activity, diet is required in order to have enough data for “big data” analytics.

In order to get beyond this stage of isolated self-observations to understand the instantaneous state of health, will require a tracking system that 1000s of us use that can cover the various dimensions described in the introduction. Several of the dimensions are qualitative e.g. stress, digestive load and are not easily codified. Nevertheless, I have hopes that with a few more status descriptors we can get a better accounting. As such, a person will have a pretty good idea of the consequence of every action. Furthermore, future monitoring devices will be able to understand exactly where a person is, what they are doing, and details of their health and wellness.

References


Bell & Gemmell, Total Recall: HOW THE E-MEMORY REVOLUTION WILL CHANGE EVERYTHING, 2009

Appendix Timeline of Personal Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mar-83</td>
<td>Cardiac arrest, followed by first double bypass</td>
</tr>
<tr>
<td>Apr-96</td>
<td>Heart attack while cycling that was unattended to ...</td>
</tr>
<tr>
<td>Nov-02</td>
<td>BodyMedia first use to understand energy expended and to help reduce weight</td>
</tr>
<tr>
<td>Jun-04</td>
<td>Pacemaker (St. Jude) installation to deal with earlier heart attack</td>
</tr>
<tr>
<td>Mar-06</td>
<td>HR: 72.9 first observation of pacemaker histogram to track HR.</td>
</tr>
<tr>
<td>Jul-07</td>
<td>Second, double bypass (and sternal infection)</td>
</tr>
<tr>
<td>Jun-09</td>
<td>HR: 61.9. Pacemaker EOL detected. Software bug in EOL prediction. EF: .45</td>
</tr>
<tr>
<td>Sep-09</td>
<td>Pacemaker #2 installed. Decided against a biventricular device.</td>
</tr>
<tr>
<td>Aug-10</td>
<td>QS Meetup talk on Lifelogging with focus on potential for health.</td>
</tr>
<tr>
<td>Aug-11</td>
<td>HR: 67</td>
</tr>
<tr>
<td>Aug-12</td>
<td>HR: 68.3.</td>
</tr>
<tr>
<td>Sep-12</td>
<td>QS 3rd Annual MeetUp. Met Dr. A. Started tracking with Fluxnet platform. EF: .37</td>
</tr>
<tr>
<td>Jan-13</td>
<td>Bladder cancer detection and surgery. Abandon tracking to focus on bladder cancer.</td>
</tr>
<tr>
<td>Aug-13</td>
<td>HR: 69.8. 1.2 bpm higher than previous and subsequent. No time in Oz.</td>
</tr>
<tr>
<td>Feb-14</td>
<td>Basis Fitness monitor first used</td>
</tr>
</tbody>
</table>

16 June 2015
Apr-14  Nephroureterectomy, EF: 0.28
Sep-14  *Pacemaker #3 Biventricular ICD.* No ability to read HR count or histograms. EF: 0.45.
Feb-15  QS Talk. Can we understand and account for every heart beat?
Jun-15  HR: 70.7 (Basis). Count since ICD installation. 4250+ steps/day
Figures

Figure 1. Lifelogging me c2013 with image capture (SenseCam-type) and health lifelogging devices. The iThing was used for manual input to Mymee and calculating Heart Rate Variability (HRV) from the chest strap. Mymee data is uploaded to its cloud. These data streams are moved to the BodyTrack aka Fluxnet database. The Autographer and Narrative cameras take pictures every 20-30 seconds and record location and temperature data.

Figure 2. Timeline of pacemakers, procedures, and heart rate measures. Note the high HR pre-bypass and first pacemaker versus a number of years of stability with second pacemaker until hear required biventricular pacing. HR fluctuation due to operations was not detected by pacemaker samples.
Figure 3a. BodyMeda arm band one day track from 22 November 2002 showing energy expended (calories), lying down, sleep, steps counter, galvanic skin resistivity, heart rate (from Polar strap). The main console for weight control includes a listing of food consumed during the day.

Figure 3b. BodyMedia panel for adding food and tallying net calories (food – exercise)
Figure 4. BodyTrack platform for capturing data streams for helping determine onset of angina pain and shortness of breath (SOB). BodyMedia databases and Myeee databases are fed to the BodyTrack database. Mymee collects and holds manual input data as shown in the figure.

Figure 5. BodyTrack aka Fluxnet created by CMU where data about an individual is stored as cloud data. Data comes from two sources: BodyMedia daily logs and Mymee an iPhone app that collects data that a user manually enters. Mymee input includes Heart Rate Variability (HRV), photos e.g. food, exercise from swimming, walking, and rowing and shortness of breath (SOB) and Angina pain level. BodyMedia determines the energy expenditure (mets) and sleep.
Figure 6a Daily average heart rate and 5-day moving averages since installation of current ICD. The blue areas are times in Australia. The two yellow bands show the reduction of HR after I started evening lung treatment. The interval in between was a 5 day trip to the Denver area (mile elevation) that

Figure 6b One hour meeting with a lawyer showing HR rise with two contentious issues.
Figure 6c. Basis heart rate for 3 days showing the effect of high (15 oz.) wine consumption and a full day to be absorbed.

Figure 6d. HR for 1 February that included a QS talk. Average HR was 74 vs 70.5 for long terms, that included waking up to create slides, a glass of wine at lunch, and more energy expended (8,000 steps) than usual. Higher exercise i.e. walking helped absorb the wine and reduce HR.
Figure 6e. HR versus steps/100.

**Resting HR versus Daily HR (avg.) 5 week data**

\[ y = 0.7708x + 10.312 \]

\[ R^2 = 0.5511 \]

**Daily HR (avg.) versus steps taken/100 ICD only**

\[ y = 0.0328x + 69.277 \]

\[ R^2 = 0.0502 \]