

What about me?

The data consumers want and why

Susan Biggar
Senior Manager, Consumer Partnerships
Friday, 27 May 2016

Errrr...What if we tracked data at home?



The Orchestra Project: A data partnership



- Drew

The Orchestra Project : Clinician view

“How are you feeling?” is a pretty standard conversation starter during a doctor’s visit.

The challenge is that we don’t capture [the response] in a way that we can use [like] we do for blood pressure.’

—Dr Danielle Lavallee
Univ of Washington

Lavallee D.C. et al (2016) Incorporating Patient-Reported Outcomes into health Care to Engage Patients and Enhance Care.

<http://patientsplaybook.com/news-insights/2016/4/5/dhnpvqrhkoa87qvgmtdoe8047ggl2j>

The Orchestra Project: Patient/family perspective

‘Now we both speak data. I feel more confident, and they feel like they have the information they need to make better decisions.’

—Erin Moore
Drew’s mother



<http://patientsplaybook.com/news-insights/2016/4/5/dhnpvqrhkoa87qvgmtdoe8047ggl2j>

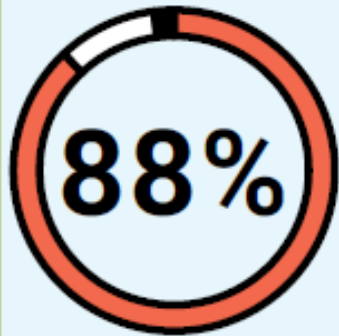
The data consumers want

- 1. Health is a partnership**
- 2. What about me?**
 - I want to stay well
 - I want to get well
- 3. What about you (the health service)?**
 - Performance
 - Experience

Health is a partnership: Consumers

‘The patient and their family are thought of as equal partners in their care, whose needs as well as their unique skills and insight are respected and valued.’

–Victorian consumer, HIC RACP consultations, 2016



88% believe that working with their health care professional AS A PARTNER will help them manage and improve their overall health.



Health care as collaboration = Participatory Medicine

<http://participatorymedicine.org/>

Health is a partnership: E-patient Dave



‘People perform better when they’re informed better.’

– Dave deBronkart

<http://www.epatientdave.com/2012/10/21/we-perform-better-when-we%E2%80%99re-informed-better/>

ANALYSIS

ESSAY

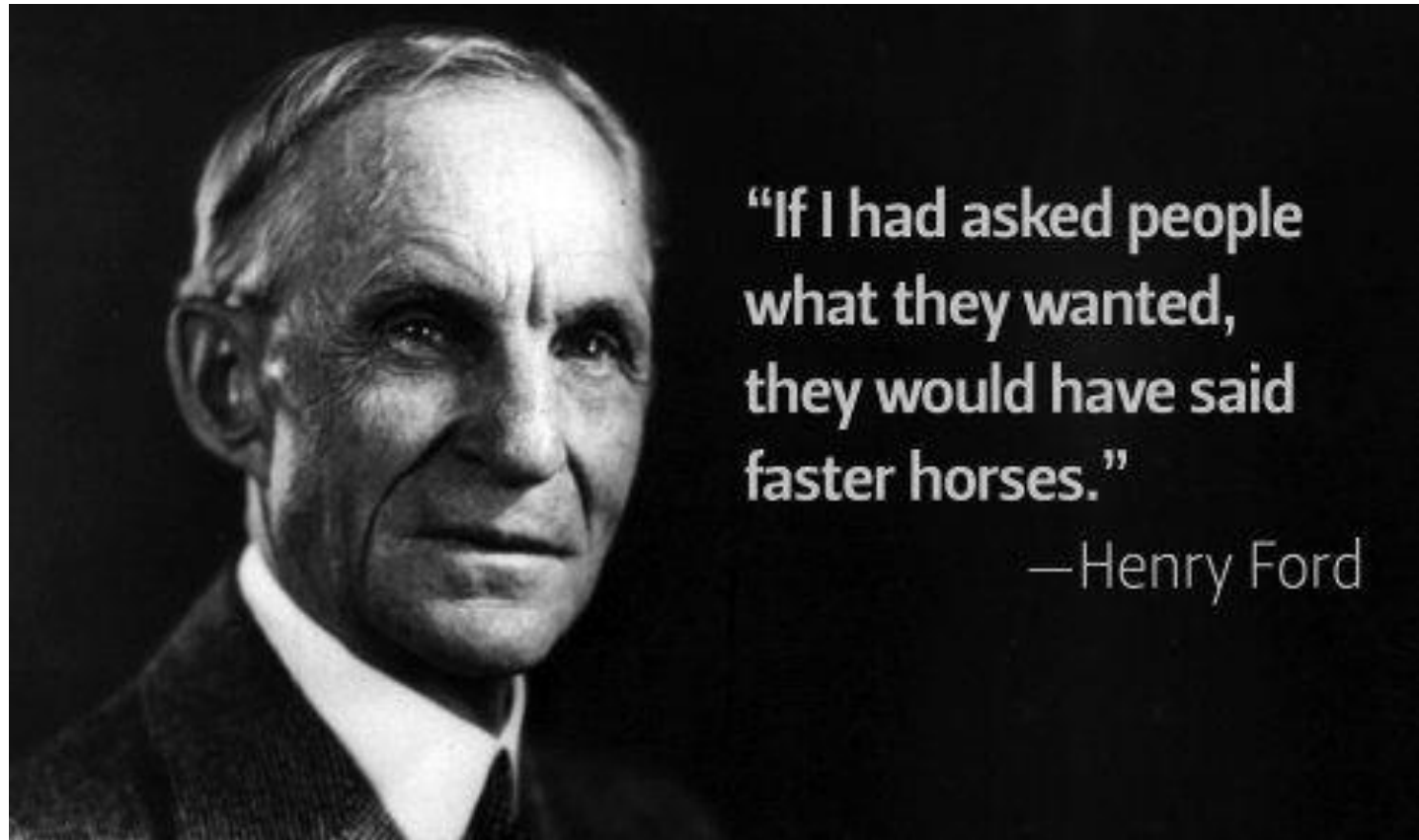
How the e-patient community helped save my life: an essay by Dave deBronkart

Dave deBronkart—otherwise known as e-Patient Dave—describes his four year odyssey from cancer diagnosis to international patient superstar. His journey shows the contribution that patients can make to the complexities of medicine

Dave deBronkart *policy adviser on patient engagement*

Nashua, New Hampshire, USA

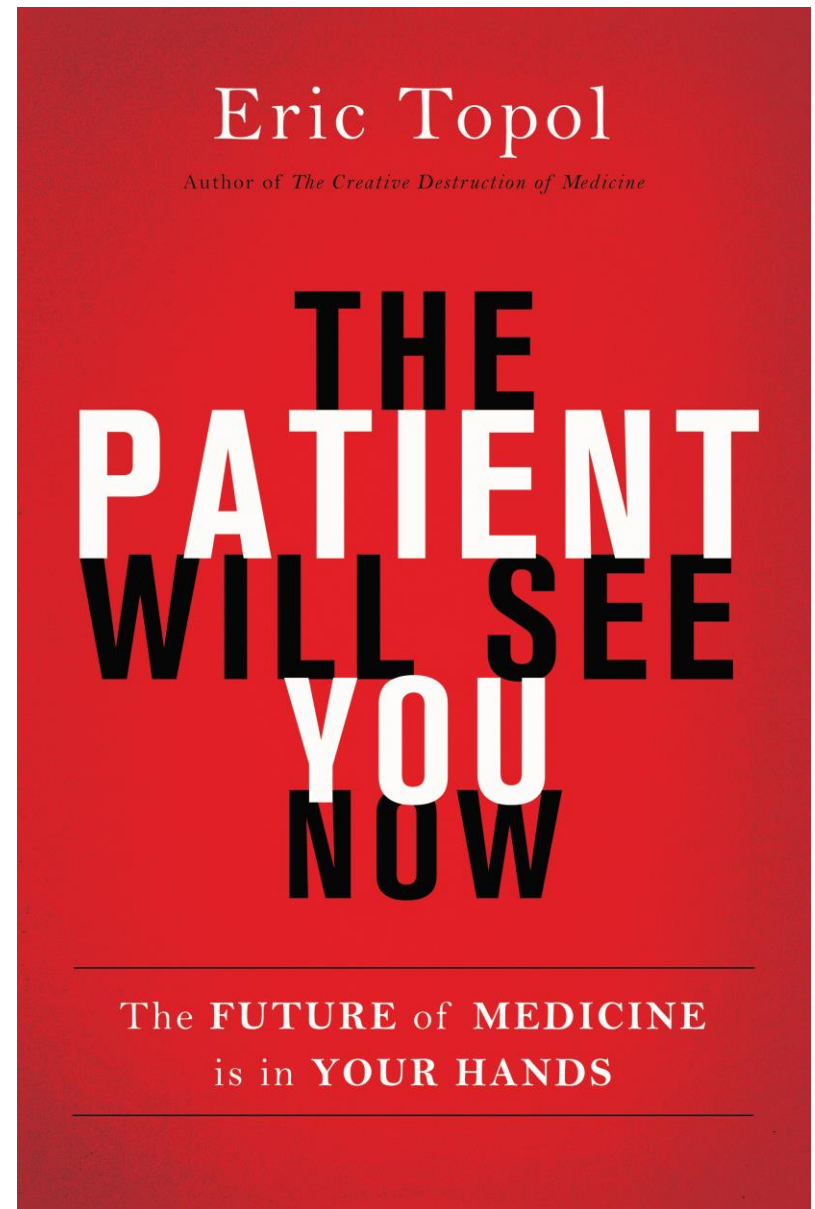
Health is a partnership: Embracing the e-patient



Health is a partnership

‘The first time I had an ECG emailed to me by a patient with the subject line “I’m in atrial fib, now what do I do?”, I knew the world had changed.’

— Eric Topol



Challenges to a data health partnership

- Few consumers know what data is available and how it might help them to stay/get well.
- Not all consumers want the same data.
- Not all consumers want the same data across their whole 'health journey'.
- But...few consumers complain of getting too much of **their own** data.



I DON'T KNOW
WHAT I WANT...
BUT I'M PRETTY
SURE I WON'T
BE HAPPY
'TIL I GET IT.

JimHunt.us and LoriWelbourne.com

**Sometimes
complex
challenges
require a
simple
solution:**

Ask

The data consumers want

1. Health is a partnership
2. What about me?
 - I want to stay well
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3. What about you?
 - Performance
 - Experience

I want to stay well



84% believe self-tracking their health data & sharing it with their health care professional (HCP) between visits would help them better manage their health.*

* Health data includes blood pressure, heart rate, respiratory rate, glucose, physical activity and other key assessments

<http://participatorymedicine.org/>

Wearable health technology



- 78% of consumers would be willing to wear technology for health-tracking
- 76% followed doctor's advice to wear health technology to track health
- 90% willing to share wearable or app data with doctor
- Consumers (77%) and doctors (85%) agree using wearables helps patient engagement

—Accenture 2016 Consumer Survey on Patient Engagement

Using patient generated data



Sarah Riggare

To manage her Parkinson's disease, Sara Riggare spends 1 hour in neurological healthcare and 8,765 hours in selfcare per year.

www.riggare.se

Sara Riggare, 2014

Other industries have done this



SAMPLE
ST.
E QLD 4214



2

5 Feb 16 – 2 May 16

Electricity bill

YOUR USAGE BREAKDOWN

Average cost per day **\$1.23**
Average daily usage **23.45 kWh**
Same time last year **12.34 kWh**



b

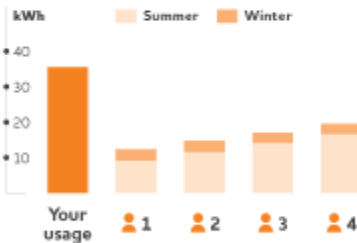
Your indicative greenhouse gas emissions

This bill **X.X tonnes**
Same time last year **X.X tonnes**
Saved with GreenPower **N/A**

Find out more about greenhouse gas emissions at originenergy.com.au or www.switchon.vic.gov.au

HOW YOU COMPARE

Using the table on the right, you can compare your average daily electricity consumption to other households in your area. Note the different usage bands for summer and winter, and be aware that these comparisons relate to households without a pool.



c

For more information on electricity usage and energy efficiency, visit energymadeeasy.gov.au

AVERAGE DAILY ELECTRICITY

Here is the average daily electricity usage costs (excluding GST) for your supply address - this doesn't include any discounts and supply charges.



d

ACCOUNT DETAILS

er
01

01

DUE DATE

23 May 16

AMOUNT DUE

\$123.45

3

Pay by due date to avoid a \$12 late fee

ENERGY PLAN

ending 18 Aug 16
available on this energy plan

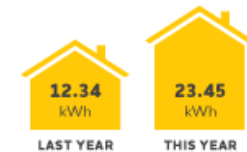
YOUR USAGE SUMMARY

Average cost per day **\$1.23**
Average daily usage **23.45 kWh**
Same time last year **12.34 kWh**

12% increase
in usage since last year

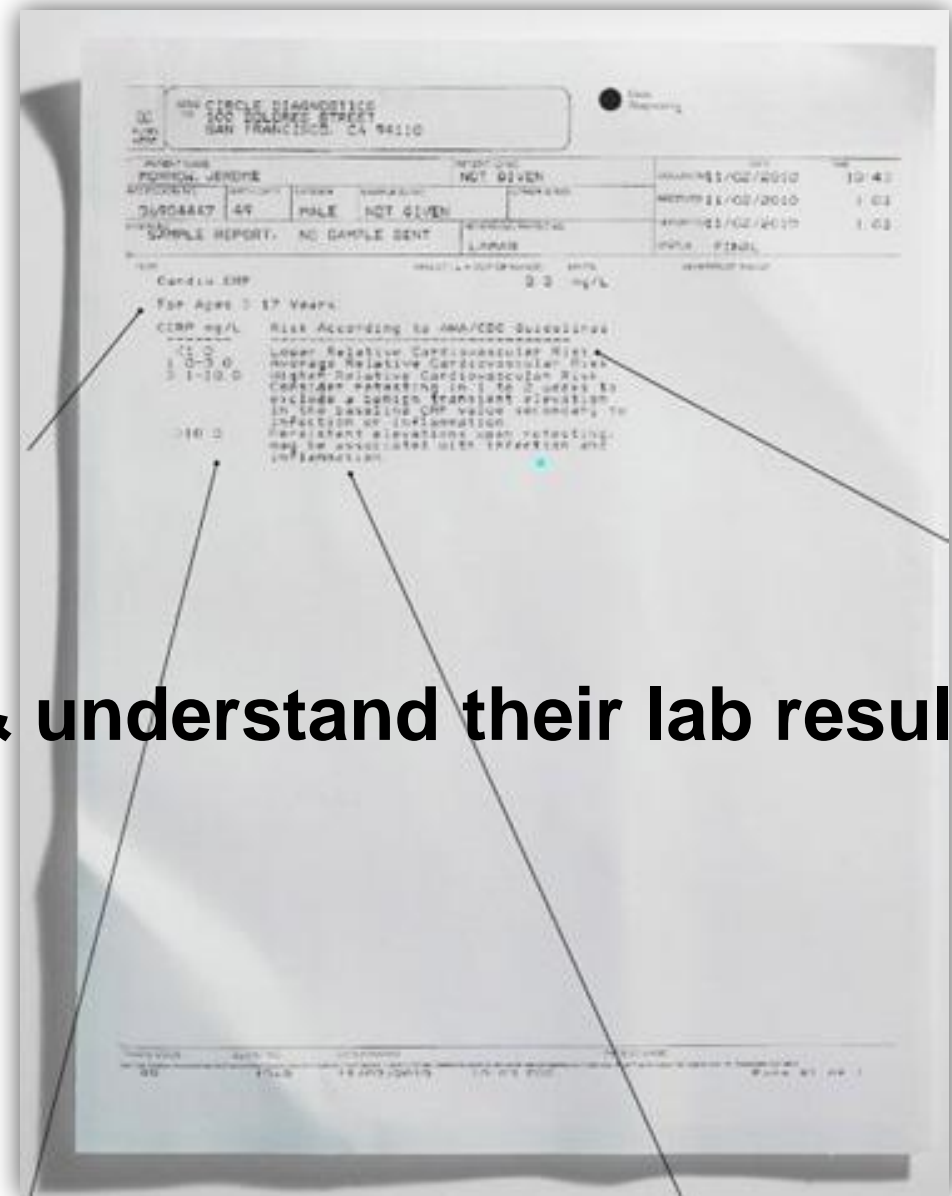


Your indicative greenhouse gas emissions
This bill **X.X tonnes**
Same time last year **X.X tonnes**
Saved with GreenPower **N/A**



5

I want to stay well



Can consumers see & understand their lab results?

I want to stay well: My own data can help

Steven Leckart,
Wired Magazine
29 November 2010.

Blood Work Cardiology Result

BACTA MEDICAL CENTRE

ORDERED BY: Dr. Francis Pulaski

Patient

NAME: Jerome Morrow

GENDER: M AGE: 49 DOB: 01/10/1961

Bacta Medical Centre
pulaski.f@bactamed.edu
(603) 555-9564 x1523

COLLECTED: 11/02/2010, 10:40 a.m.

RECEIVED: 11/02/2010, 1:03 p.m.

1 About this test

This report evaluates your potential risk of heart disease, heart attack, and stroke.

2 Your results

CRP level test



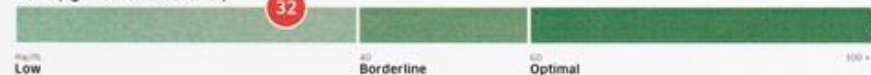
Total cholesterol level



LDL ("bad" cholesterol)



HDL ("good" cholesterol)



3 Your risk You show an elevated risk of cardiovascular disease.

If you're a smoker with blood pressure of 130 mm/Hg but a family history of heart attack before age 60 (in one or both parents), your risk over the next 10 years is:

15%

Your risk would be lowered to:

12% if your blood pressure were 120 mm/Hg.

10% if you quit smoking.

6% if you reduced your cholesterol to 160 mg/DL.

Use your CRP results and cholesterol level to calculate your 10-year risk of a cardiovascular event at www.reynoldsriskscore.org.

4 What now?



Diet and exercise can improve your cholesterol levels.



Avoid drinking alcohol, except in moderation: one to two drinks per day.



Ask your doctor about statins or other medications that can lower cholesterol.



Consider retesting in one to two weeks, in case your CRP level was caused by infection.



Health Issues Centre

I want to
get well...
Hospitals speak a
data language



“I joke, but I only half joke, that if you come to one of our hospitals, missing a limb, no one will believe you until they get a CAT scan, MRI, or orthopedic consult.”

- Abraham Verghese

Wachter, The Digital Doctor

I need data to be part of the conversation



Dave deBronkart, slide share, 'What epatients want and why they need to be empowered'

Patient portal: Benefits

- Respect – co-ownership of care
- Transparency about issues
- Increase individual consumer engagement
- Timeliness
- No more labelling – HVP
- Patient safety

‘From day one, I had patients emailing me about sexual issues that they never would talk to me about directly.’
-Ted Eytan, physician

Wachter, The Digital Doctor, p. 184.

Patient portal: Challenges

- Sensitive results
- Changed consumer expectations
- Changed work processes
- Interconnectivity between systems

‘Once you get used to checking your lab results on your phone the day they were drawn, you’re never going back to, “Come in next week and we’ll talk about it.”’

—Mark Smith, health policy guru

Wachter, The Digital Doctor, p. 184.

The data consumers want

1. **Health is a partnership**
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3. **What about you?**
 - Performance
 - Experience

Performance data is not a new concept



Ernest Codman

- In 1910, Codman advocated for 'End Results Hospital'
- Patients outcomes tracked and reported
- He believed it would allow patients to make informed choices about where to receive care
- And help doctors improve their care
- He was 'drummed off' the staff of his hospital in 1914...

Performance data: Cystic fibrosis



Clicks required:

- Research
- ACFRT
- Reports
- ACFDR 2010 – Australian CF centre comparisons
 - Lung function (FEV1)
 - BMI

Performance data: Non-health tools

www.choice.com.au:

‘Save time and money. Products and services rigorously tested, rated and reviewed. No spin.’

The screenshot shows the Choice website's navigation bar with the logo, social media icons, a search bar, and links for 'Join', 'Log in', and 'Menu'. Below the navigation bar are four key features: 'SAVE TIME AND MONEY', 'RIGOROUS LAB TESTING', '1000s OF RATINGS', and 'UNBIASED EXPERT ADVICE'. The breadcrumb trail indicates the path: 'HOME AND LIVING > LAUNDRY AND CLEANING > WASHING MACHINES > WASHING MACHINES'. The main heading is 'Washing machine reviews', with a 'Share:' link and a 'Last updated: 14 March 2016' timestamp. A 'Narrow your results' section shows filters for 'Brand' with options for 'AEG (1)' and 'Ariston (0)'. A 'Read more' link with a dropdown arrow is present, along with a purple 'Compare all products' button. A descriptive paragraph states: 'A washing machine is a big investment, so it pays to do your homework first. The good news is, we've done the hard work for you! Our test compares many top and front load washers to help you pick the perfect buy. Find out more about **how we test**. Not sure what you need? Use our **buying guide** first.'

Performance data: Health tools



Browse hospitals

Find hospitals within an Australian state or territory

Victoria

Select a town or city to see hospitals in that area.



Victoria

- Ballarat
- Bendigo
- Geelong
- Hamilton
- Horsham
- Maryborough
- » Melbourne**
- Mildura
- Orbost
- Ouyen
- Seymour
- Shepparton
- Swan Hill
- Traralgon
- Wangaratta
- Warrnambool
- Wodonga

Hospitals within Melbourne

Albert Road Clinic

31 Albert Road
Melbourne, Vic 3004



Angliss Hospital

Albert Street
Upper Ferntree Gully, Vic 3156



Austin Hospital [Heidelberg]

145 Studley Road
Heidelberg, Vic 3084



Avenue Plastic Surgery

20 The Avenue
Windsor, Vic 3181



Beleura Private Hospital

925 Nepean Highway
Mornington, Vic 3931



Bellbird Private Hospital

198 Canterbury Road
Bentley, Vic 3120



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Next »

Performance data: What do consumers want

- Hospital safety rates – infection, falls, staff ratio, hand hygiene, mortality
- Patient centredness – ability to be involved in decisions, listened to, care orders followed
- Procedural/specialty performance
- Coordinated care – transitions, consistent medical team, timeliness
- Cost

Customer
experience:
Non-health



Consumer experience: Health

The screenshot shows the Patient Opinion Australia website. At the top, there are utility links for social media, language selection, font size and contrast, and a login button. The main header features the 'PATIENT OPINION AUSTRALIA BE HEARD.' logo and a tagline: 'An independent site about your experiences of Australian health services, good or bad. We pass your stories to the right people to make a difference.' Below the header is a navigation bar with 'Home', 'Tell your story', and 'About us' buttons. A search bar is also present with a magnifying glass icon and the text 'Search for stories about...' and an example: 'eg Royal Brisbane Hospital, heart surgery, depression, 2250'. The main content area is divided into several sections: 1. A large text block stating 'We believe that patients' feedback - good or bad - is essential to improving Australian health services.' with a 'Tell your story - Make a difference' button. 2. A 'Patient Opinion in 2 minutes' section with a play button icon and a cartoon illustration of a patient and staff. 3. A 'Featured stories' section with a 'View latest stories' button and a featured quote: 'I can not speak highly enough of the consistent care and most experienced midwife.' with a 'STORY HAS A RESPONSE' indicator. 4. A 'Make yourself heard' section with the text 'Whether you're a patient, carer or service user, share your story and help make a difference.' and a 'What's your story?' button.

Follow us: Blog

Select Language ▼

Size: Contrast: Log in

PATIENT OPINION AUSTRALIA
BE HEARD.

An independent site about your experiences of Australian health services, *good* or *bad*.
We pass your stories to the right people to make a difference.

[Information for staff](#)

Home [Tell your story](#) [About us](#)

[Search](#) Search for stories about...
eg Royal Brisbane Hospital, heart surgery, depression, 2250

We believe that patients' feedback - *good* or *bad* - is essential to improving Australian health services.

Tell us what was good and what could be improved, say thanks or call for change - we'll pass your stories to the people in the health services who can make a difference.

[Tell your story - Make a difference](#)

Patient Opinion in 2 minutes

Make yourself heard

Whether you're a patient, carer or service user, share *your* story and help make a difference.

[What's your story?](#)

Featured stories [View latest stories](#)

"I can not speak highly enough of the *consistent care and most experienced midwife*"

STORY HAS A RESPONSE

Consumer experience: Beth Israel Deaconess

Inpatient 1,2

Survey Questions	BIDMC Performance Q2 FY 16	National Database Q2 FY 16	Custom Comparison Database Q2 FY 16
<u>Communication with Nurses</u>	80%	80%	81%
<u>Responsiveness of Hospital Staff</u>	57%	67%	66%
<u>Communication with Doctors</u>	81%	81%	82%
<u>Pain Management</u>	69%	72%	72%
<u>Communication about Medications</u>	65%	64%	64%
<u>Room and Bathroom Always Kept Clean</u>	68%	74%	69%
<u>Quiet Room at Night</u>	49%	60%	49%
<u>Overall Rating of the Hospital</u>	74%	72%	75%
<u>Likelihood to Recommend BIDMC</u>	79%	73%	81%

<http://www.bidmc.org/Quality-and-Safety/Patient-Experience-and-Satisfaction.aspx>

Addressing the challenges to a data partnership

- Ask what consumers want
- Understand (and respect) why they want it
- If data isn't clear, make it clear
- Think about tomorrow



Thank you

Susan Biggar

s.biggar@healthissuescentre.org.au

www.susanbiggar.com

Twitter: @susanbbiggar

