

What Can We Learn From the Needs of Lay Audiences?

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HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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Call for Papers: Health Vis for Lay Audiences

<https://academic.oup.com/jamia/pages/cfp-visualization-health-data>



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Focus Issue Call for Papers:

Visualization of Health Data for Lay Audiences

Focus Issue Guest Associate Editors:

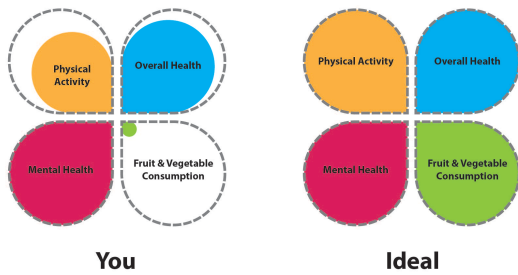
Adriana Arcia, PhD, RN (University of San Diego, San Diego, CA)
Natalie Benda, PhD (Weill Cornell Medical College, New York, NY)
Amanda Makulec, MPH (Data Visualization Society, Washington, DC)
Danny Wu, PhD, MS (University of Cincinnati, Cincinnati, OH)

Description of Focus Issue:

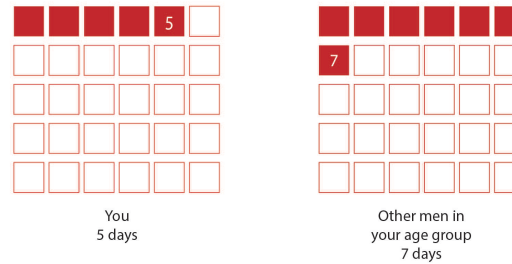
Since the Health Information Technology for Economic and Clinical Health (HITECH) Act incentivized the utilization of clinical informatics systems, the volume of health data that learning health systems are collecting and aggregating on patients has grown exponentially. Patients are also generating their own data through digital health tools that they and the health system want to leverage to improve health. In parallel with vast quantities of data, the 21st Century Cures Act requires that electronic health information be freely accessible and authorizes penalties for those who block data from patients. There are also non-clinical streams of data (e.g., environmental exposure, disease transmission) that are increasingly accessible to the public. Though barriers to accessing data are being lifted, the data are often available in a raw format that is rarely comprehensible without a significant amount of pre-

Tailored Information Visualizations for Lay Audiences

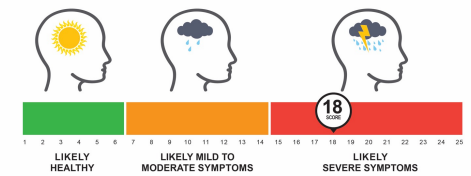
Health Compared to Ideal



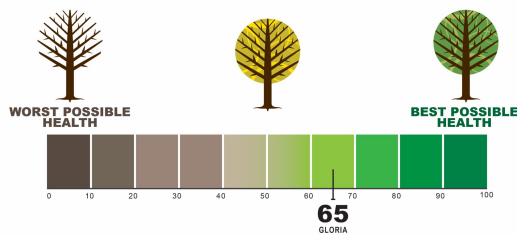
Days feeling worried, tense, or anxious in the last 30 days



Maria's Psychological Distress



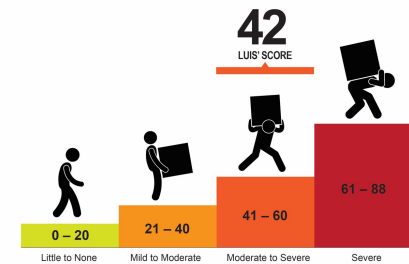
Overall Health



Ana's Depression Symptoms

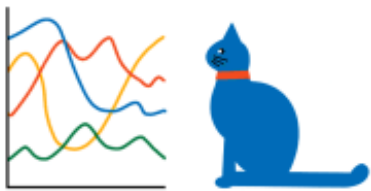


Caregiving Burden



Data Visualization vs. Information Visualization

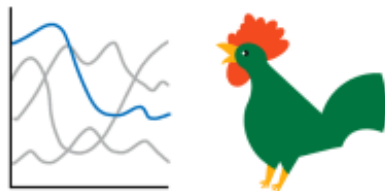
(aka Explore vs. Explain)



Discover

Example

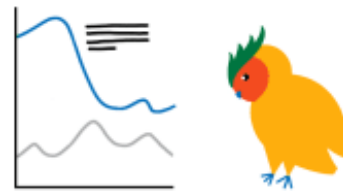
- Analysis charts



Inform

Examples

- Dashboard
- Report Appendix
- Exploratory infographics



Educate

Examples

- Data storytelling
- Report Executive Summary
- Explanatory infographics

EXPLORE

EXPLAIN



DIKW Pyramid

Image by Kat Greenbrook: <https://nightingaledvs.com/reasons-to-visualise-the-same-data-differently/>

Generic

Techniques to Reduce Stress

- 30 minutes of daily moderate exercise
- Mindfulness and meditation
- Progressive muscle relaxation
- Yoga
- Visualization
- Slow, deep breaths

verywell

<https://www.verywellhealth.com/how-to-reduce-stress-5207327>

Tailored

Prolonged Stress

(lasting at least 6 months)



You
Low



Other men in
your age group
Very High

Lay Audiences of Health Visualizations

People interacting with visualizations in a non-professional capacity.

- Patients
- Caregivers
- Community members
- Research participants
- Etc.

Differences: Lay vs. Professional Audiences

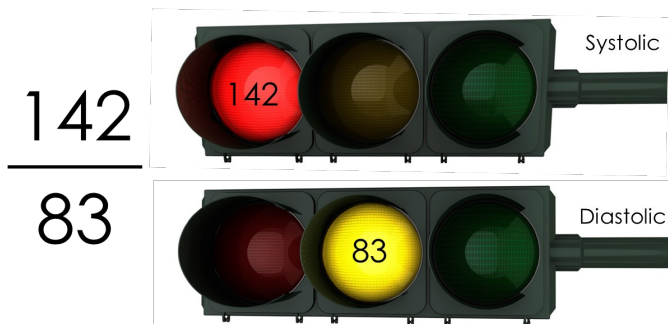
- Educational attainment
- Literacy, numeracy, graph literacy
- Domain expertise
- Persistence when usability is poor
- Quality requirements
- Room for error



Dr. Suzanne Bakken



Blood Pressure

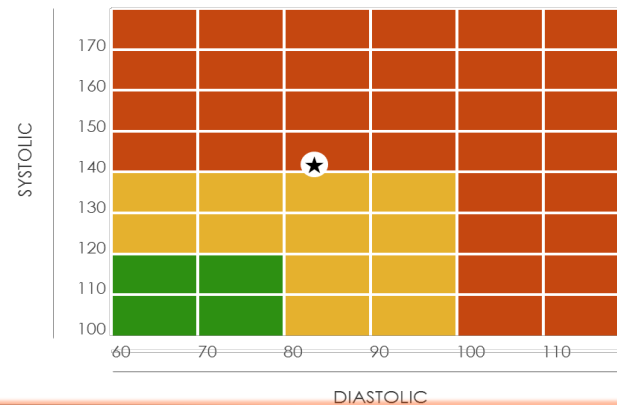


A

Blood Pressure

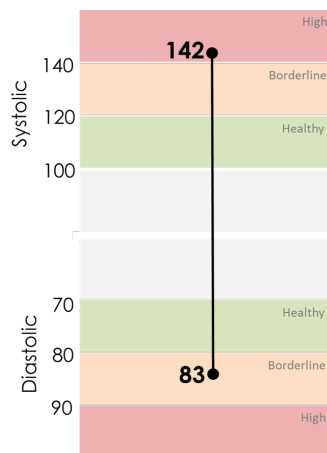
142/83mmHg

- NORMAL
- BORDERLINE
- HIGH



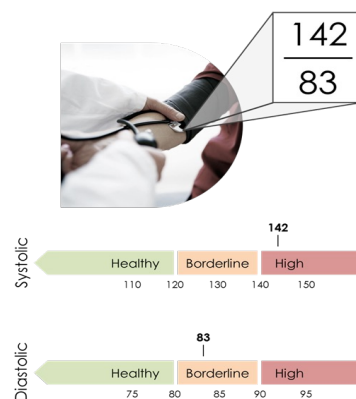
B

Blood Pressure

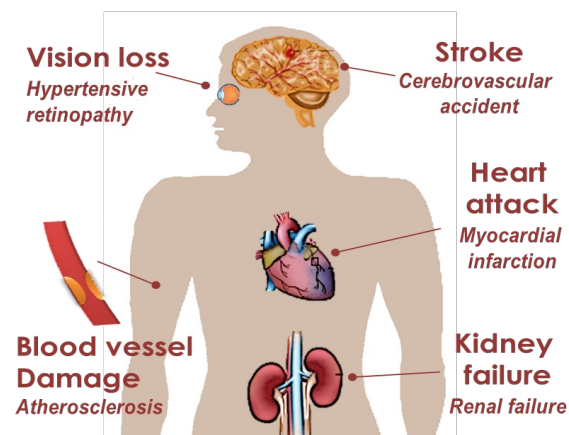


C

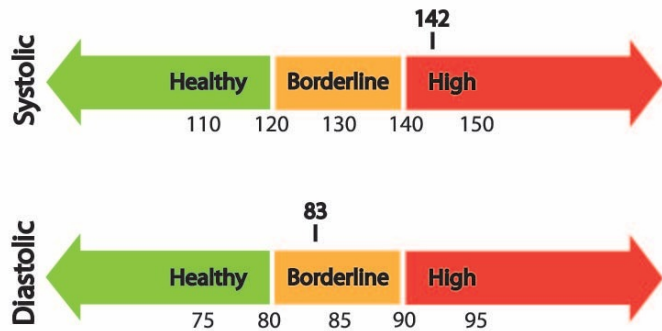
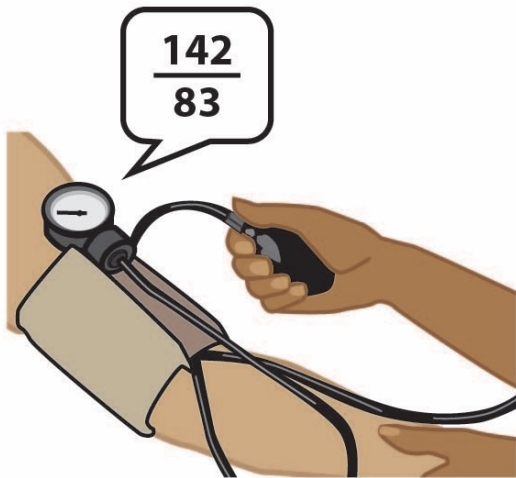
D Maria's Blood Pressure



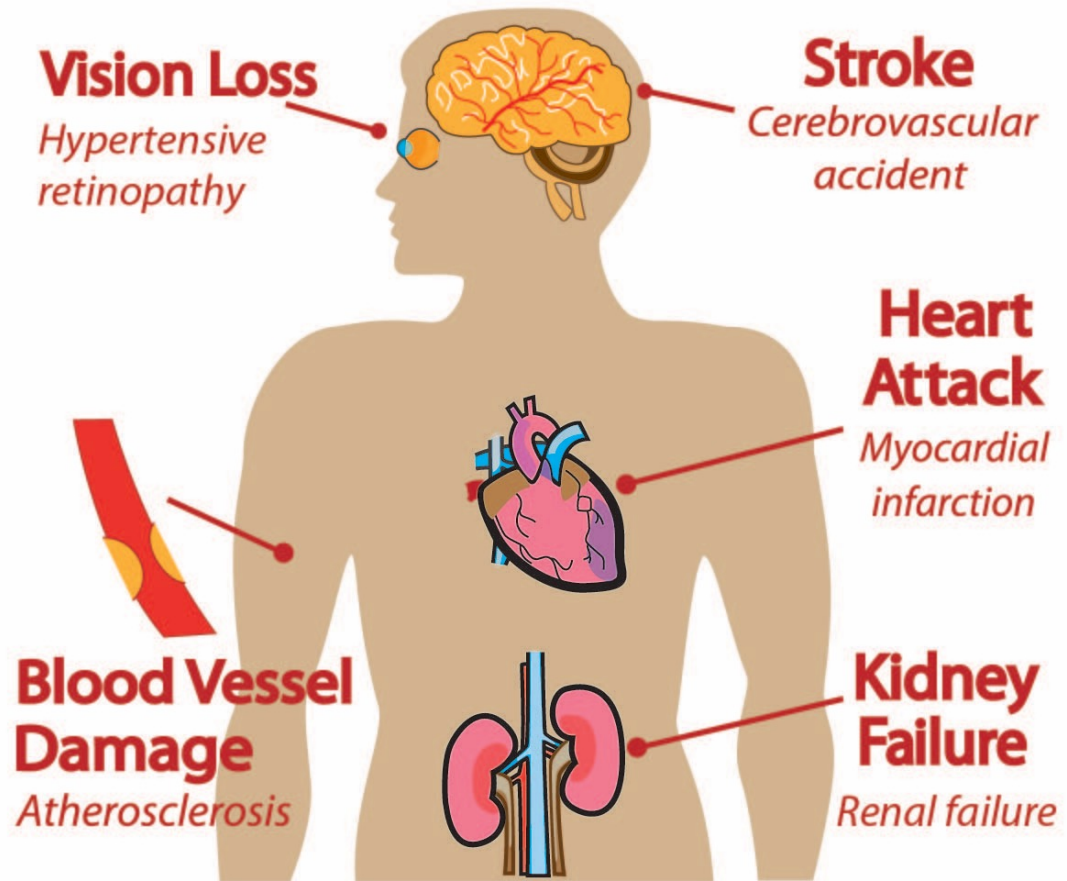
Risks of High Blood Pressure



Your Blood Pressure



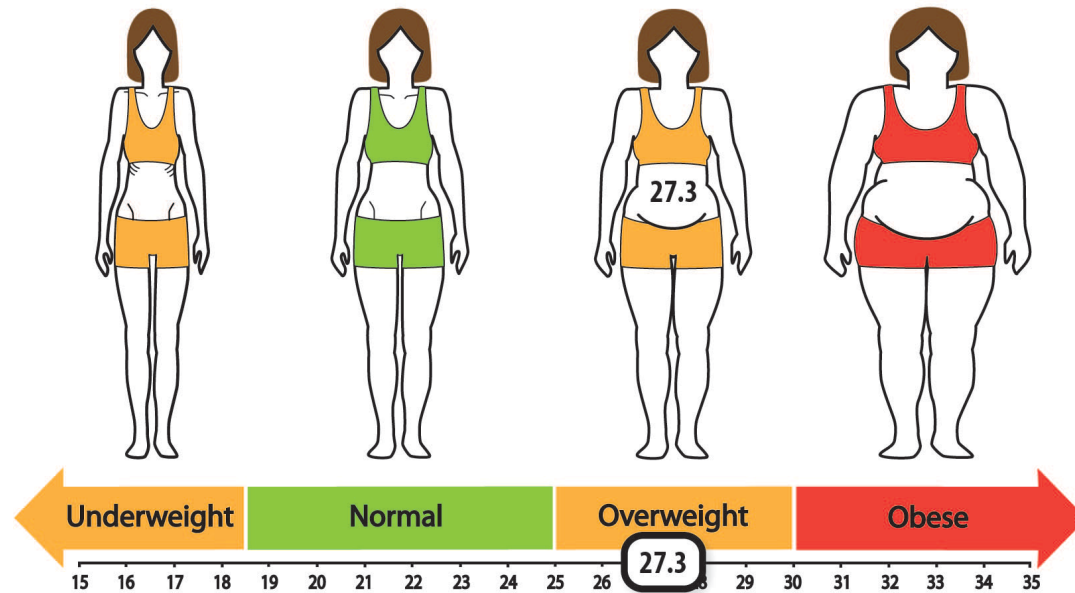
Risks of High Blood Pressure



Funding: Agency for Healthcare Research & Quality (1R01HS019853, 1R01HS022961); New York State Department of Economic Development NYSTAR (C090157); National Institute for Nursing Research (T32NR007969); National Library of Medicine (T15LMLM007079); National Center for Advancing Translational Sciences (UL1TR000040).

Reference Range Number Line

Body Mass Index (BMI)
kg/m²



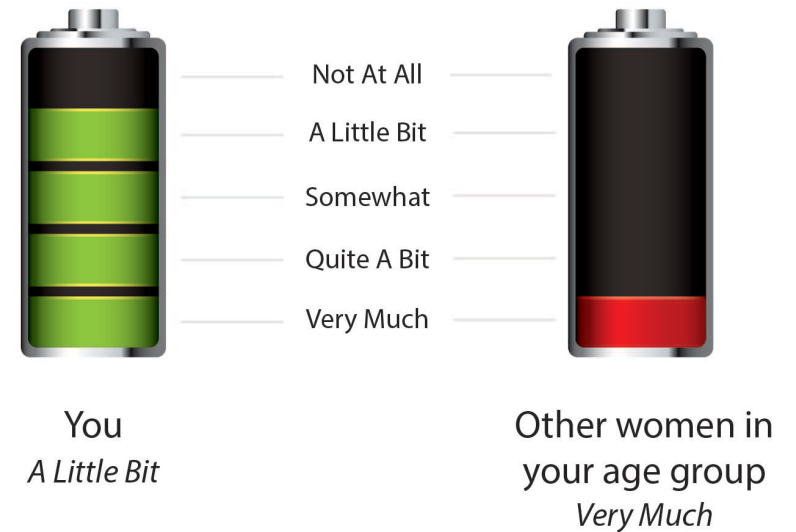
Body Mass Index (BMI) uses your height and weight to estimate how much body fat you have.

Visual Analogies

Overall Health

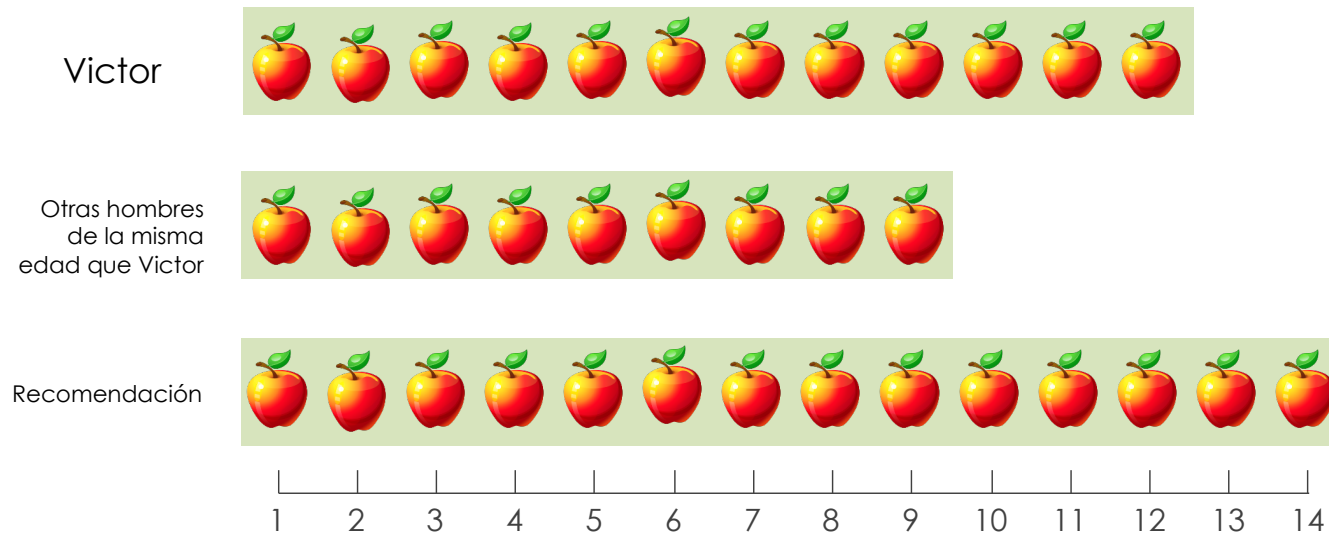


Feeling Run Down



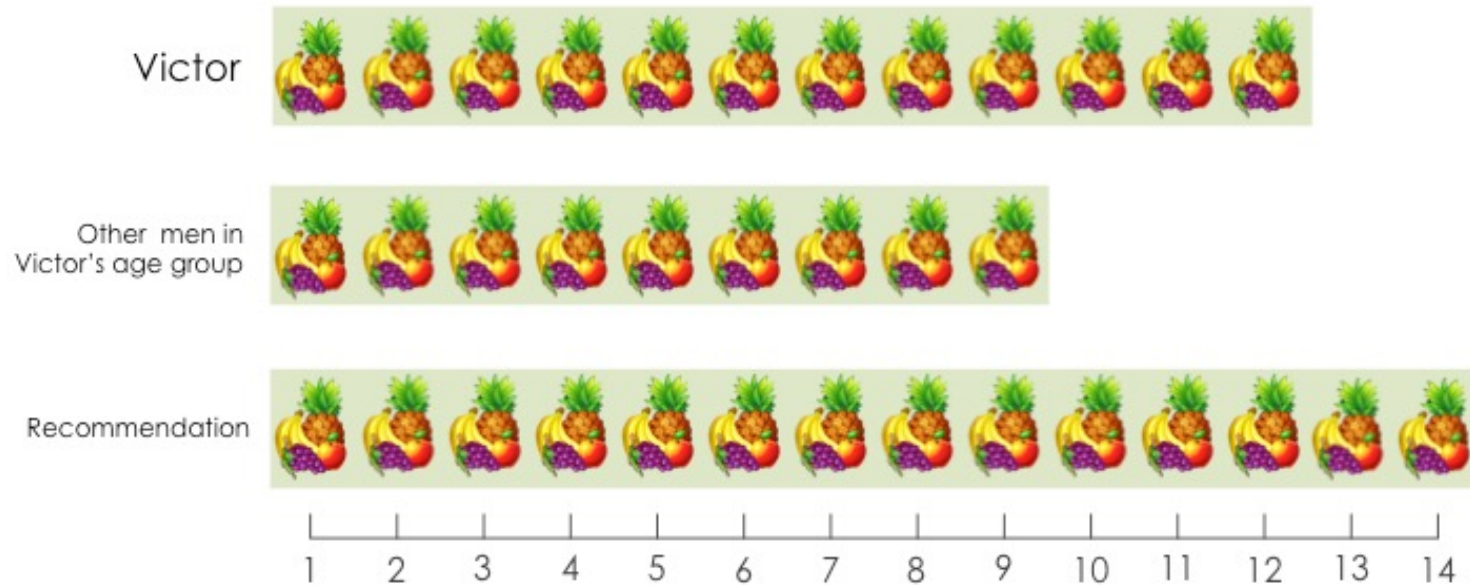
Literal Interpretation

Porciones de Frutas por Semana



Literal Interpretation

Fruit Servings per Week



Literal Interpretation and Difficulty Generalizing

Days of Exercise Per Week

Other men in Victor's age group



Victor



Days of Exercise Per Week

Maria



Other women in Maria's age group



What's the difference??

Overall Health

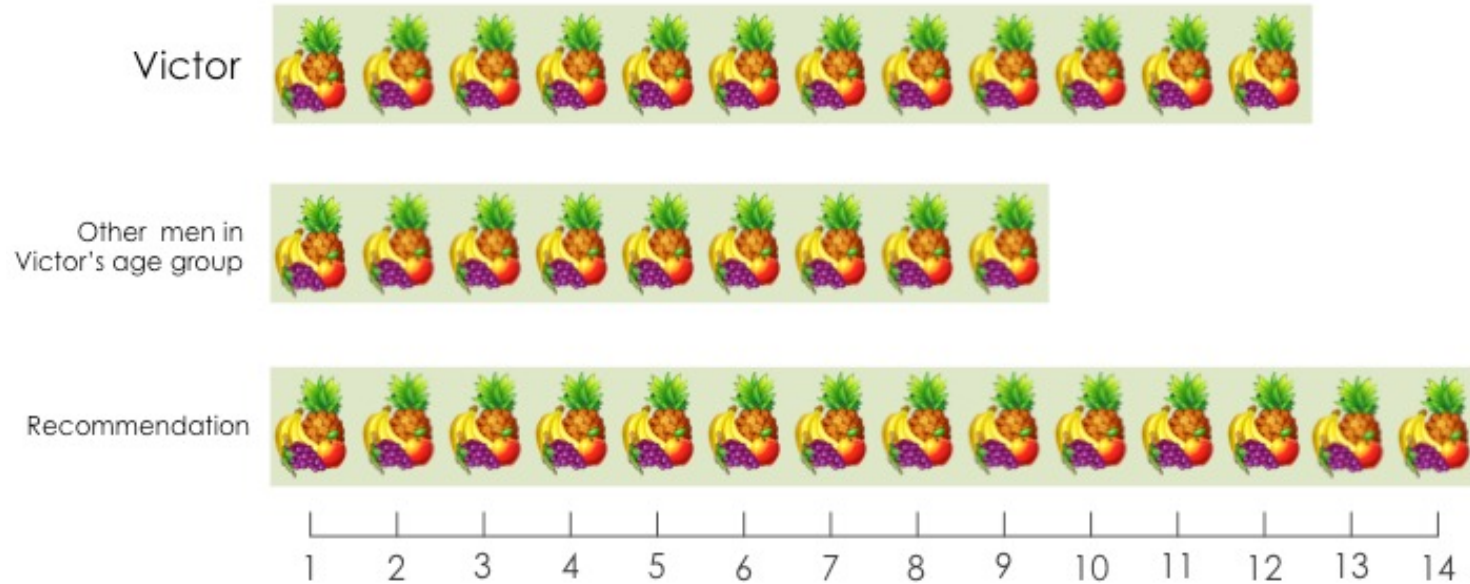


Days of Exercise Per Week



Title Neglect

Fruit Servings per Week



Title Neglect

Your BMI was 23.9

Body Mass Index (BMI) uses your height and weight to estimate how much body fat you have.

BMI categories:

Less than 18.5 is underweight 18.5 to 24.9 is normal

25.0 to 29.9 is overweight Over 30.0 is obese

Risks of excess weight include:

- Heart diseases (cardiovascular diseases)
- High Blood Pressure (Hypertension)
- Arthritis (osteoarthritis)
- Type 2 Diabetes (Type 2 Diabetes Mellitus)
- Cancers of the esophagus, pancreas, kidney, colon, & rectum

Interviewer: Okay, so you're looking at the categories?

Interviewee: I'm looking at the categories, yes.

Interviewer: What does it say at the very top?

Interviewee: Less than 18-

Interviewer: No, at the very top of the page.

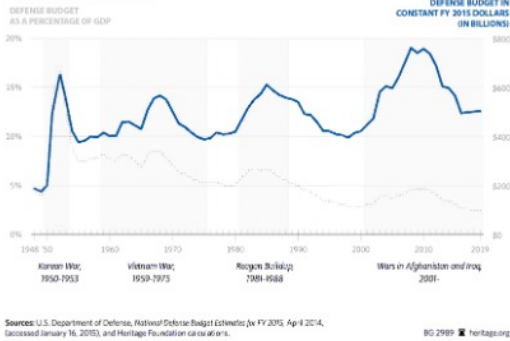
Interviewee: Body mass index. Use your height and-

Interviewer: At the very, very top of the page.

Interviewee: Your ... What's that mean. the BMI was 23.9?

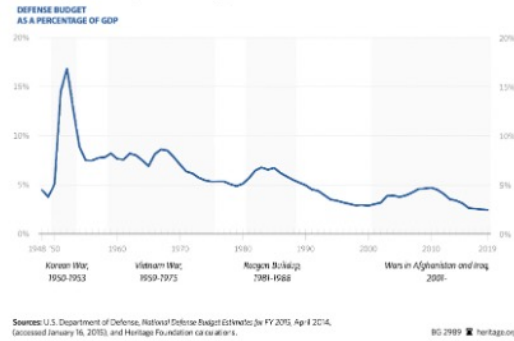
Do people read titles or not??

Defense budget on a steady decrease as a percentage of GDP over the past 50 years



(a) Military visualization with a supporting title (miscued)

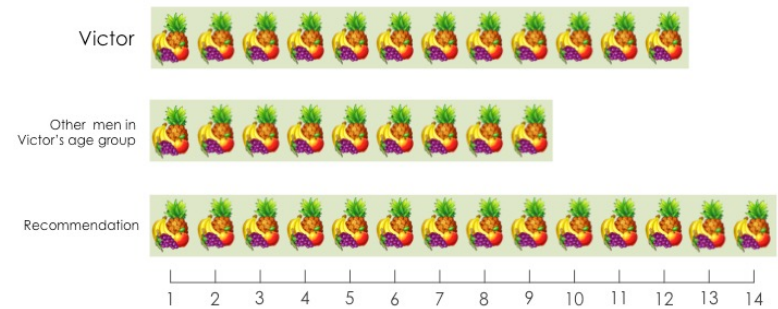
Defense budget on an increase in constant dollars heading towards \$500 billion by 2019



(b) Military visualization with a non-supporting title (contradictory)

Kong, H. K., Liu, Z., & Karahalios, K. (2019, May). Trust and recall of information across varying degrees of title-visualization misalignment. In Proceedings of the 2019 CHI conference on human factors in computing systems (pp. 1-13). <https://dl.acm.org/doi/10.1145/3290605.3300576>

Fruit Servings per Week



Just give people the punchline

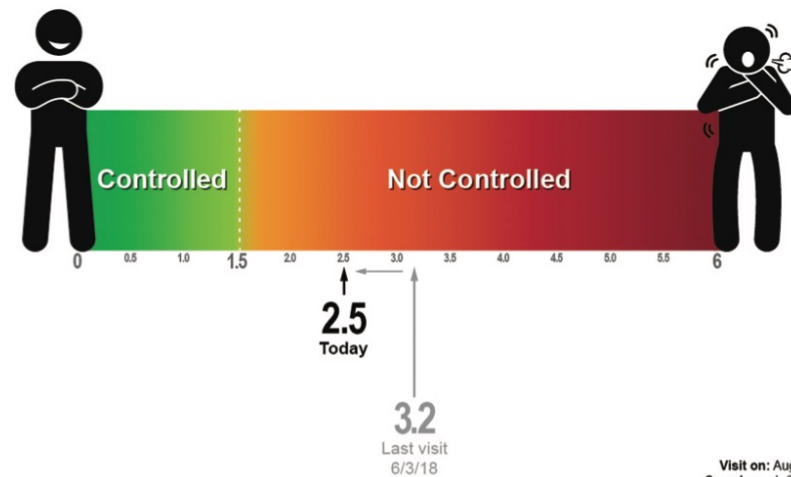
Today, you answered some questions about your asthma symptoms.

Here are your **results**.

JENNY'S LEVEL OF ASTHMA CONTROL

Your asthma is not in control

Your score is 2.5
You made good progress!



Visit on: August 21, 2018
Seen by: J. Cardozo, FNP

Give next steps

Plan for you:

- Take Symbicort daily
- Use albuterol before workouts
- Take roach control measures

- J. Cardoso, FNP

Spirometry output

Summary of All forced tests

	FEV1	FVC	PEF	FEV1/FVC	Quality	VAR	Time	Date
Base	2.14	2.80	6.66	76%	Good Blow	-1%	3:24 PM	06/09/2017
Base	2.16	2.84	6.84	76%	Good Blow	0%	3:25 PM	06/09/2017
Base+	2.16	2.84	6.84	76%	NLHEP QC Grade: A	-		

ATS/ERS Criteria [2005]: Criteria Not Met.

Insufficient number of good forced tests, 3 or more are required.

Key: ~ - Default best, ^ - Manual best, + - Individual best

Variation is based on FEV1 + FVC.

Selected indices of the best blows

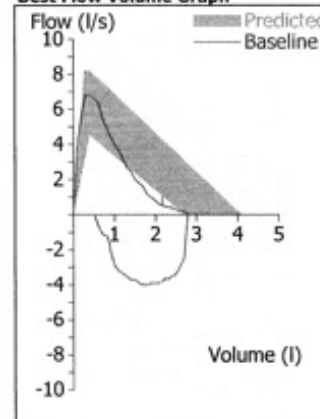
Index	Base	%Pred	Zscr	Post1	%Pred	%Chg	Zscr	[Min	Pred	Max]
FEV1	2.16 l	81%	-1.4					2.06 l	2.65 l	3.24 l
FVC	2.84 l	83%	-1.3					2.71 l	3.40 l	4.10 l
PEF	6.84 l/s	106%	0.3					4.75 l/s	6.47 l/s	8.19 l/s
FEV1/FVC	76%	97%	-0.4					69%	79%	88%

Measured values that are between brackets are abnormal values.

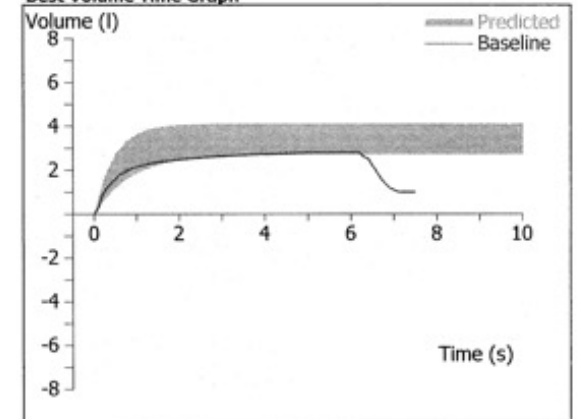
Relaxed: Variation is based on VC. Forced: Variation is based on FEV1 + FVC.

Predicted Source: USA - Xiaobin Wang (1993) 6-7 years, John L. Hankinson (1999) 8-80 years
Results at BTPS.

Best Flow Volume Graph



Best Volume Time Graph



What do the results of my lung function test mean?

Introduce terminology



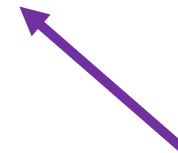
The amount of air you blew out in 1 second.
FEV₁ pre-bronchodilator

2.7 Liters

The amount of air that patients like you* are expected to be able to blow out in 1 second.
FEV₁ predicted

3.8 Liters

Give numerical results



You blew out **71%** of the amount of air expected for patients like you*.
FEV₁ % predicted

Show part-to-whole relationship



80% or more = normal



60-79% = moderate obstruction



59% or less = severe obstruction



Define categories & make value judgments



*Guidelines are based on sex, age, height, and race/ethnicity.

What do the results of my lung function test mean?

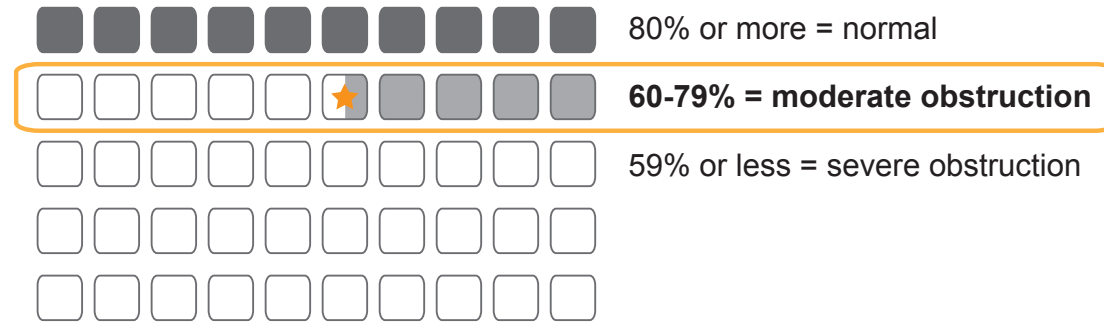
The amount of air you blew out in 1 second.
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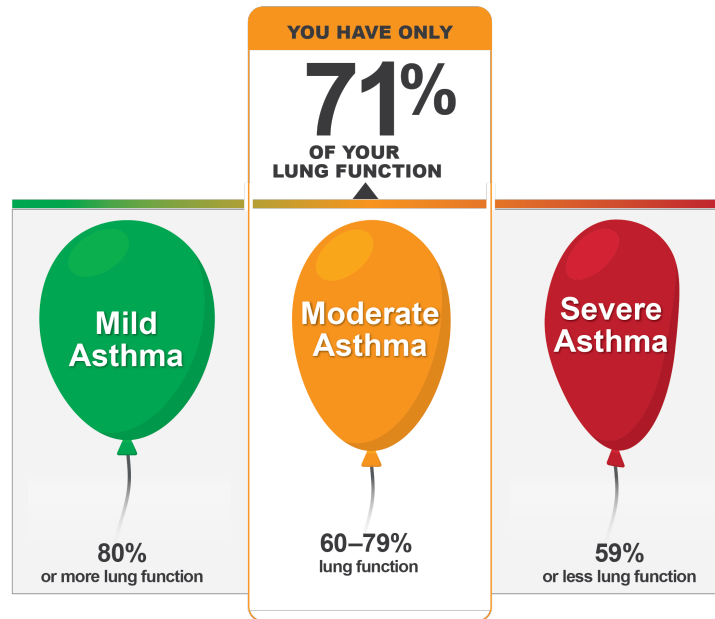
3.8 Liters

You blew out **71%** of the amount of air expected for patients like you*.
FEV₁ % predicted



*Guidelines are based on sex, age, height, and race/ethnicity.

What do the results of my lung function test mean?



Understanding Your Numbers

Guidelines are based on sex, age, height, and race/ethnicity.

FEV₁ PRE-BRONCHODILATOR <i>The amount of air you blew out in 1 second.</i>	2.7 LITERS	71% FEV₁ % PREDICTED <i>You blew out 71% of the amount of air expected for patients like you.</i>
FEV₁ PREDICTED <i>The amount of air patients like you are expected to be able to blow out in 1 sec.</i>	3.8 LITERS	

What do the results of my lung function test mean?

Today, you blew out **2.1** liters of air in one second.

This is called **FEV₁**
(Forced Expiratory Volume)

That's about as much air as would fit
in a **2-liter** bottle of soda.



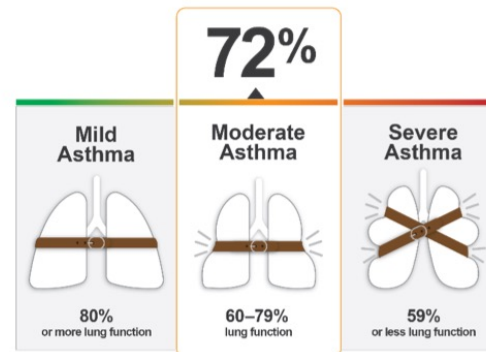
Women like you should be able to
blow out about **2.9** liters of air in one second.

Same age, height, & race/ethnicity

This is called **FEV₁ Predicted**

That means you have only
72% of your expected lung function
which is classified as **Moderate Asthma**.

This is called **FEV₁ % Predicted**



What do the results of my lung function test mean?



Today, you blew out **3.1 liters** of air in one second.

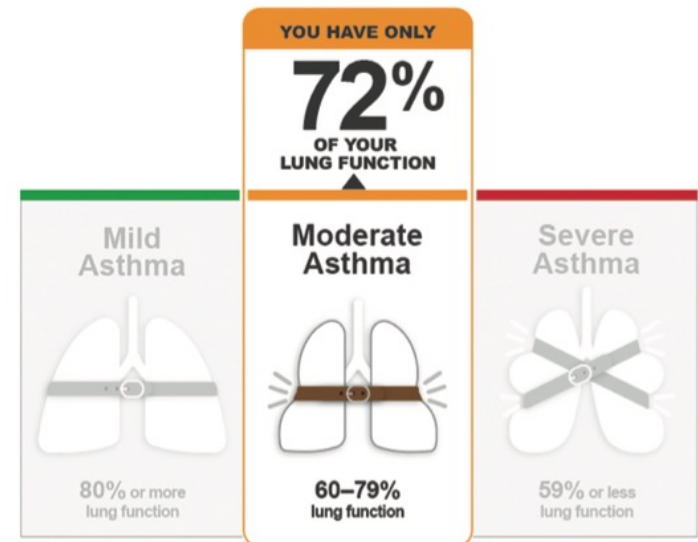
This is called FEV₁ (Forced Expiratory Volume)

That's about as much air as would fit in one-and-a-half 2-liter bottles of soda.



SAME age, height, & race/ethnicity
Men like you should be able to blow out about **4.3 liters** of air in one second.

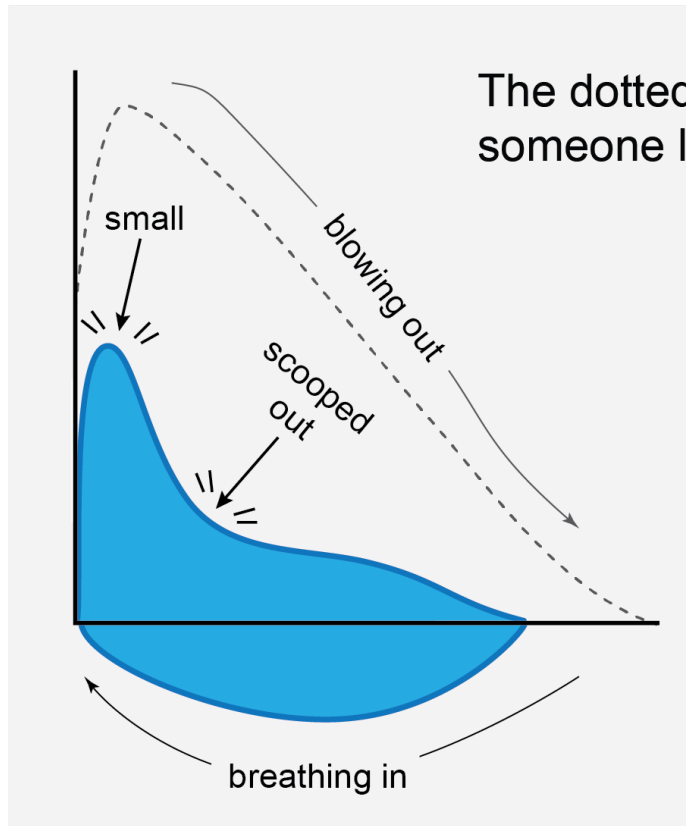
This is called FEV₁ PREDICTED



This means that you have only **72%** of your expected lung function, which is classified as **Moderate Asthma**.

This is called FEV₁ % PREDICTED

This type of graph is called a **Flow Volume Loop**.

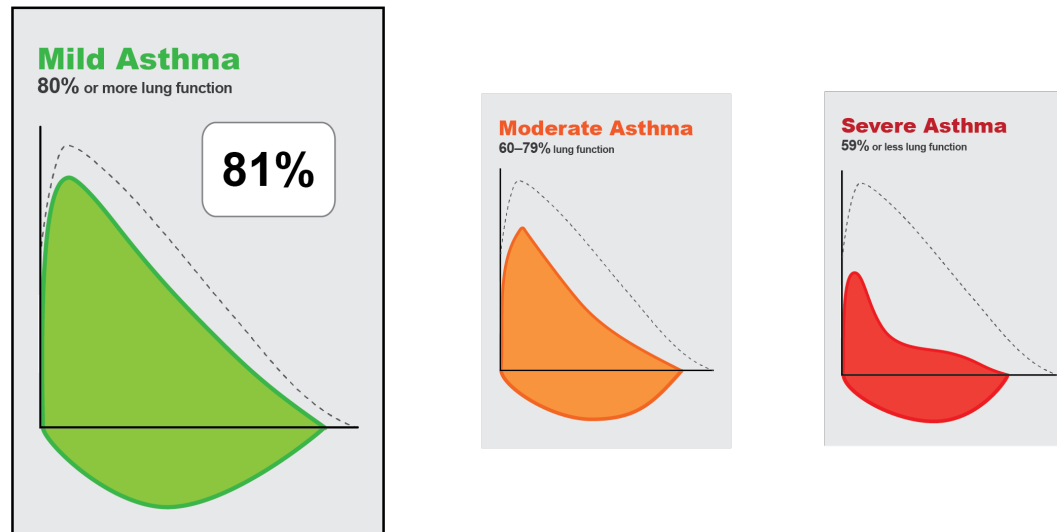


The dotted line shows how much air someone like you should be able to blow out.

The blue shape shows how well the air moved in and out of your lungs.

The smaller your loop, and the more scooped out it is, the more severe your asthma.

Your Flow Volume Loop from today's test shows that your asthma is **mild**.



Taking your controller medicine and avoiding triggers can help you stay close to the dotted line.

72%



**Mild
Asthma**



80%
or more lung function

**Moderate
Asthma**



60–79%
lung function

**Severe
Asthma**

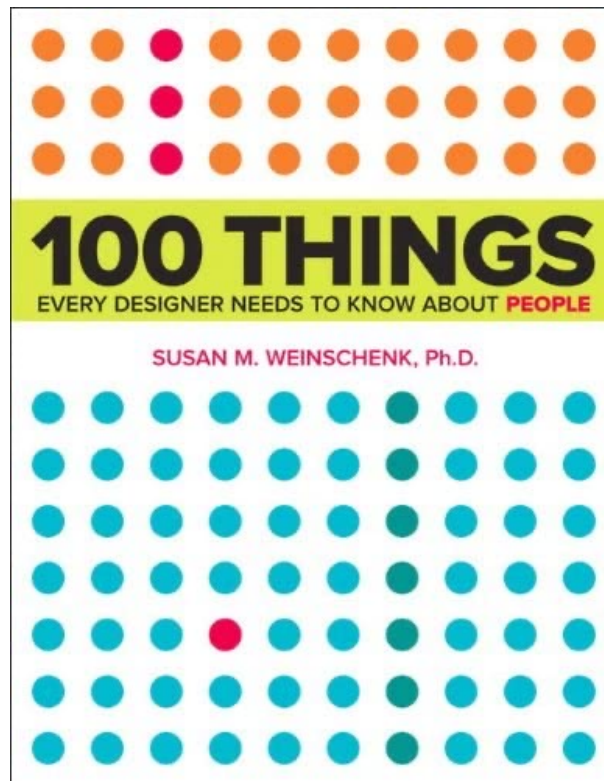


59%
or less lung function

Tips for Visualizing for Lay Audiences

- Clearly literal or clearly metaphorical
- Use what works in the wild
- Just give people the punchline... and give them next steps
- Put yourself in the shoes of the problem-based learner
- People care most about their own lived experience
- Scaffold the information to respect learning hierarchy
- Leverage existing competencies
- Use conceptual metaphors with robust entailments

But what about professional audiences?



BITSI – Browser-based Infographic Tailoring Self-Service Interface

Single image interface

The screenshot displays the BITSI interface with a dark sidebar on the left containing 'Single Image', 'Batch File', and 'Debug' options. The main content area includes several input fields: 'Language' (set to English), 'Name' (Simba), 'Today's date' (2022-01-13), 'Previous date' (2021-11-04), 'Today ACT' (18), and 'Previous ACT' (14). A 'Download PDF' button is located below the input fields. The 'Image preview' section shows a horizontal scale from 0 to 25, divided into three zones: 'Very Poorly Controlled' (red, 0-15), 'Not Well Controlled' (orange, 15-20), and 'Well Controlled' (green, 20-25). A person icon is positioned at 14 (labeled 'Last visit 11/04/21') and another at 18 (labeled 'Today'). The 'Text preview' section displays the following text: 'Name: Simba', 'Date text: Date: January 13, 2022', 'Score: Your score is 18', 'Interpretive: Your asthma is not well controlled', and 'Progress: You made good progress!'.

BITSI – Browser-based Infographic Tailoring Self-Service Interface

Batch file interface

BITSI

The 'id_file' column is used for the file name to account for duplicate 'display_name' values.

Batch file input

Browse... example_batch_for_screenshot.xlsx

Upload complete

Generate batch files

```
'data.frame': 1 obs. of 4 variables:
 $ name      : chr "example_batch_for_screenshot.xlsx"
 $ size      : int 10346
 $ type      : chr "application/vnd.openxmlformats-officedocument.spreadsheetml.sheet"
 $ datapath  : chr "/var/folders/l1/q22ct4sd3ll2cdj1jpnj__jwc6w09l/T//Rtmpo5WJJR/2b40a06e82663df287b28cf"
```

Data errors

Show 10 entries

Search:

	reason	display_name	language	today_date	today_act_score	previous_date	previous_act_score	id_file	today_year	today_month	today_day
1	Invalid today date	Kermit	english		11				2019	6	31

Showing 1 to 1 of 1 entries

Previous 1 Next

Good data

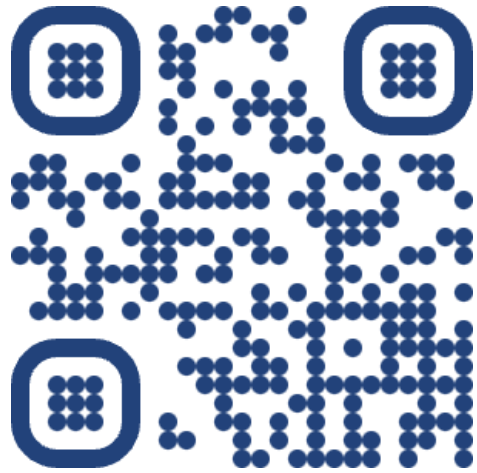
Show 10 entries

Search:

	reason	display_name	language	today_date	today_act_score	previous_date	previous_act_score	id_file	today_year	today_month	today_day
1		Simba	english	2022-01-13	18	2021-11-04	14		2022	1	13

Showing 1 to 1 of 1 entries

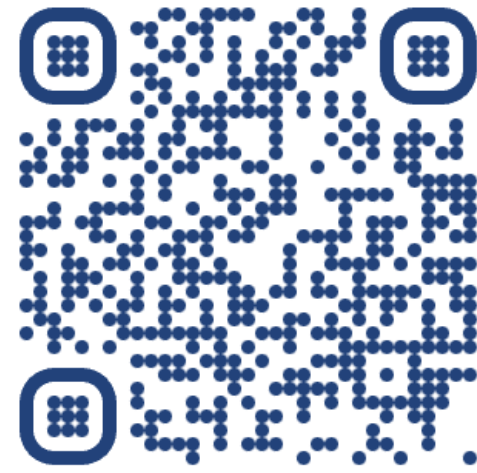
Previous 1 Next



BITSI Demo

<http://bitsi.pics>

NOT for use with patient data



BITSI on GitHub

<https://github.com/chendaniely/bitsi>

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<https://academic.oup.com/jamia/pages/cfp-visualization-health-data>



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