

Data visualisations for clinical and patients use

The Kleefstra Sydrome Scientific Conference 2023

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Shifting the focus









Icons by pch.vector, skyclick, uniconlabs



visualization today: to provide us with **new kinds of "glasses"** to see the world.



Joel de Rosnay described a fascinating, futuristic device in 1979: the **macroscope**. Just





Moritz Stefaner blog http://well-formed-data.net/archives/1027/worlds-not-stories

Data visualization

The science of visual representation of data







Data visualization

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https://venngage.com/blog/how-to-choose-the-best-charts-for-your-infographic/

Human centered design





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Design Theories Rund Al Dwaik

Asking the "right" questions

- What is the ultimate goal? => info that needs to go through; action; decision to be made
- Who do we want to communicate it to? => **AUDIENCE**
- How do we want to communicate the message? => **chart type**

You are the content expert and are responsible for all the design decisions!





Florence Nightingale







John Snow





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Choosing the "right" visualization to present data



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https://blog.wolfram.com/2021/08/03/john-snow-the-birth-of-epidemiology-data-analysis-visualization/



Edward Tufte Visual and Statistical Thinking





Zan @zanstrong · 13h Replying to @FILWD

Too often it seems that the data is assumed to be pure, & untouchable, rather than 1 perspective. Like a photo; but we know a photo is only 1 perspective on a scene at 1 moment in time. The photo is "true", but "interpretation" of the events it portrays are not necessarily true.



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Fast forward

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- Context of reserach papers: pdfs with static figures
- Databases on patient reported outcomes







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Ed Hawkings, Federica Fragapane

Patient-oriented approach

BIOCHEMISTRY Reference Range HAEMATOLOGY SODIUM 142 mmol/L (139 - 153) RBC 6.3 POTASSIUM 4.9 mmol/L (3.9 - 5.9) HAEMOGLOBIN 148 CHLORIDE 109 mmol/L (101 - 118) HAEMOCRIT 0.40 BICARBONATE 17 mmol/L (12 - 260) RETICULOCYTE % 1.0 NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (20.5 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0.5 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0.7 - 14) WBC 12.5 CALCIUM CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 F		
SODIUM 142 nmol/L (139 - 153) RBC 6.3 POTASSIUM 4.9 nmol/L (3.9 - 5.9) HAEMOGLOBIN 148 CHLORIDE 109 nmol/L (121 - 118) HAEMOGLOBIN 148 CHLORIDE 109 nmol/L (121 - 118) HAEMATOCRIT 0.40 BICARBONATE 17 nmol/L (12 - 26) RETICULOCYTE % 1.0 NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 L GLUCOSE, SERUM 3.2 L mmol/L (13.3 - 6.8) MCV 63 L GLUCOSE, SERUM 3.2 L mmol/L (2.5 - 10.0) MCHC 370 H CREATININE 0.08 mmol/L (0.05 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) <td< th=""><th></th><th>Reference Range</th></td<>		Reference Range
POTASSIUM 4.9 mmol/L (3.9 - 5.9) HAEMOGLOBIN 148 CHLORIDE 109 mmol/L (101 - 118) HAEMATOCRIT 0.40 BICARBONATE 17 mmol/L (12 - 26) RETICULOCYTE % 1.0 NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (2.5 - 10.0) MCC 370 H CREATININE 0.08 mmol/L (0.05 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (0.8 - 2.1) NEUTROPHILS% 67	x10^12/L	(4.9 - 8.2)
CHLORIDE 109 mmol/L (101 - 118) HAEMATOCRIT 0.40 BICARBONATE 17 mmol/L (12 - 26) RETICULOCYTE % 1.0 NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 ANION GAP 20.9 mmol/L (14.0 - 32.0) MCV 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (2.5 - 10.0) MCHC 370 H CREATININE 0.68 mmol/L (0.65 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	g/L	(100 - 206)
BICARBONATE 17 mmol/L (12 - 26) RETICULOCYTE % 1.0 NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 ANION GAP 20.9 mmol/L (14.0 - 32.0) MCV 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (26.5 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	L/L	(0.35 - 0.58
NA:K RATIO 29.0 (26.0 - 35.0) RETICULOCYTE ABS 63 ANION GAP 20.9 mmol/L (14.0 - 32.0) MCV 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (25.5 - 10.0) MCHC 370 H CREATININE 0.08 mmol/L (0.65 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	%	(0.0 - 1.5)
ANION GAP 20.9 mmol/L (14.0 - 32.0) MCV 63 L GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (2.5 - 10.0) MCHC 370 H CREATININE 0.08 mmol/L (0.65 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	x10^9/L	(10 - 110)
GLUCOSE, SERUM 3.2 L mmol/L (3.3 - 6.8) MCH 23 UREA 9.1 mmol/L (2.5 - 10.0) MCHC 370 H CREATININE 0.08 mmol/L (0.05 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	fL	(64 - 76)
UREA 9.1 mmol/L (2.5 - 10.0) MCHC 370 H CREATININE 0.08 mmol/L (0.05 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	pg	(21 - 26)
CREATININE 0.08 mmol/L (0.05 - 0.15) PLATELET COUNT 460 SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	g/L	(310 - 360)
SDMA 14 ug/dL (0 - 14) WBC 12.5 CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	x10^9/L	(200 - 500)
CALCIUM 2.6 mmol/L (1.9 - 2.9) NEUTROPHILS% 67 PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	x10^9/L	(4.5 - 17.0)
PHOSPHATE 1.4 mmol/L (0.8 - 2.1) NEUTROPHILS 8.4	%	
	x10^9/L	(3.5 - 12.0)
CA:P RATIO 1.9 (1.2 - 3.0) LYMPHOCYTES% 25	%	
PROTEIN, TOTAL 68 g/L (52 - 80) LYMPHOCYTES 3.1	x10^9/L	(0.9 - 3.5)
ALBUMIN 35 g/L (23 - 40) MONOCYTES% 5	%	
GLOBULIN 33 g/L (25 - 45) MONOCYTES 0.6	x10^9/L	(0.0 - 1.1)
A:G RATIO 1.1 (0.6 - 1.4) EOSINOPHILS% 3	%	
BILIRUBIN, TOTAL 0 umol/L (0 - 7) EOSINOPHILS 0.4	x10^9/L	(0.0 - 1.4)
ALP 112 IU/L (1 - 150) BASOPHILS% 0	%	
ALP STEROID ISOENZYME 31 IU/L BASOPHILS 0.0	x10^9/L	(0.0 - 0.1)
AST 48 IU/L (18 - 80) BLOOD SMEAR Automated (CBC.	
ALT 93 H IU/L (16 - 90) EXAMINATION		
CK 214 IU/L (73 - 510)		
CHOLESTEROL 6.4 mmol/L (3.5 - 9.0)		
AMYLASE 751 IU/L (333 - 1500)		
LIPASE 494 IU/L (77 - 750)		
GAMMA GT 6 IU/L (0 - 9)		
SAMPLE APPEARANCE Mild haemolysis		
Moderate lipaemia		

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Or Misgav, Nightingale, 2022. https://nightingaledvs.com/can-we-understand-blood-test-results-without-numbers-ask-participant-237

Renal

GenIDA exploration



Kleefstra sydrome patient reported outcomes

Source: GENIDA database



https://genida.unistra.fr/

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GENIDA

https://public.flourish.studio/visualisation/12906970/

- ► Pregnancy/ Early life/ Personal care
- ► Intellectual disability and Autism aspects
- Physical and neurological problems
- Sensory problems
- ► Other problems





Take away

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Shifting the focus from data => audience

- What is the ultimate goal of visualization?
- Who is the audience? What do they care about?

The purpose of the type of visualizations I make isn't visualization per se. The purpose fo those visualizations is to help people **make sense of the world** through a combination of visuals and words.

Thank you!

Alberto Cairo





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https://github.com/Financial-Times/chart-doctor/blob/main/visual-vocabularv/Visual-vocabularv.pdf

FT graphic: Alan Smith; Chris Campbell; Lan Dott; Lie Fauren; Graham Partish; Billy Dhreeberg: Sharener; Paul McCallan; Martin Stabe Impired by the Graphic Continuum by Jon Schwaltish and Severino Ribecca

🚟 ft.com/vocabulary

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