Making patient outcome data *accessible, useable and assessable*

Professor Sir David Spiegelhalter

Chairman of the Winton Centre for Risk & Evidence Communication, University of Cambridge

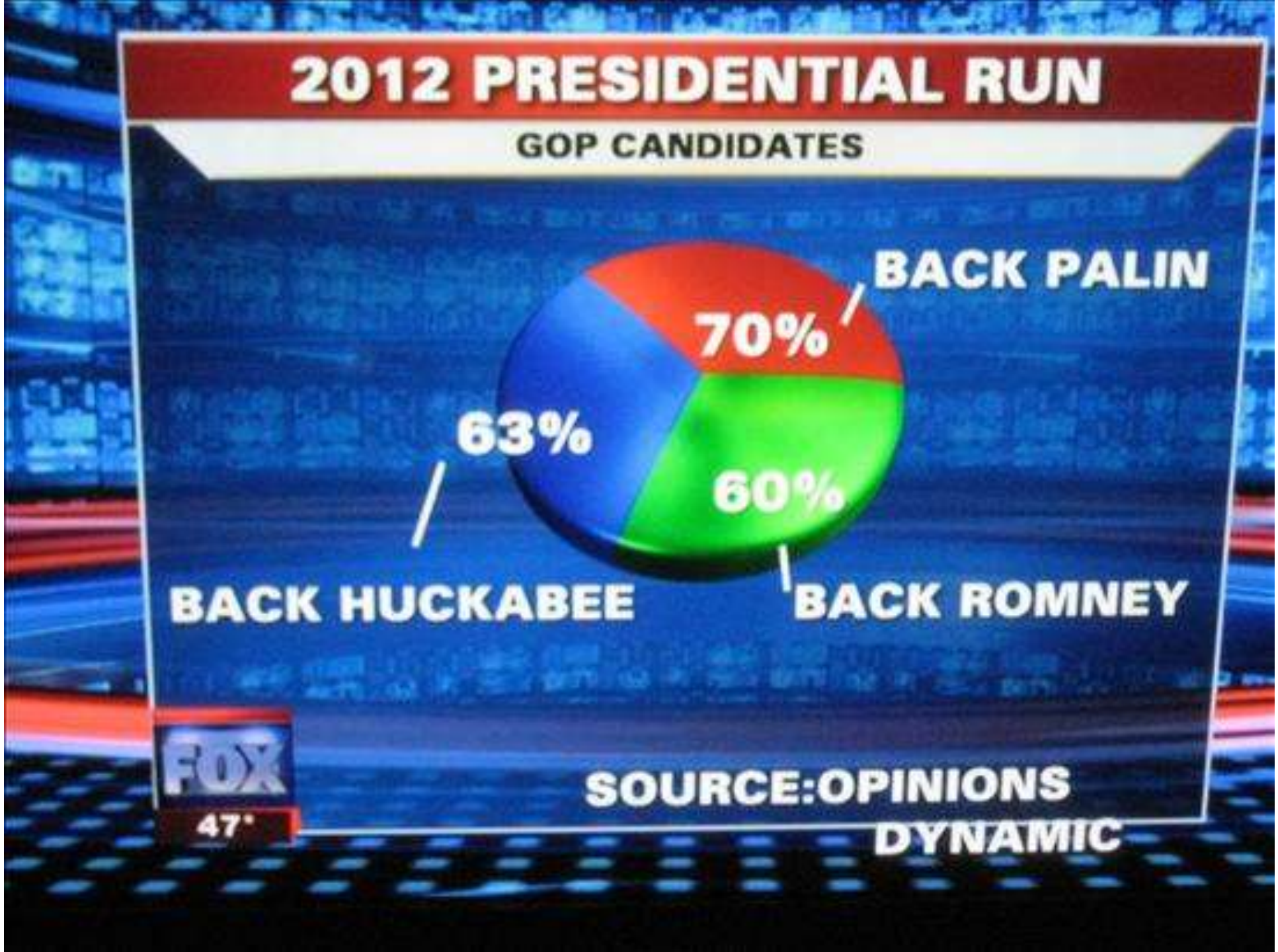
President, Royal Statistical Society

NCAPOP Seminar, 2017

Trust in numbers…

Onora O’Neill: trust should be based on…

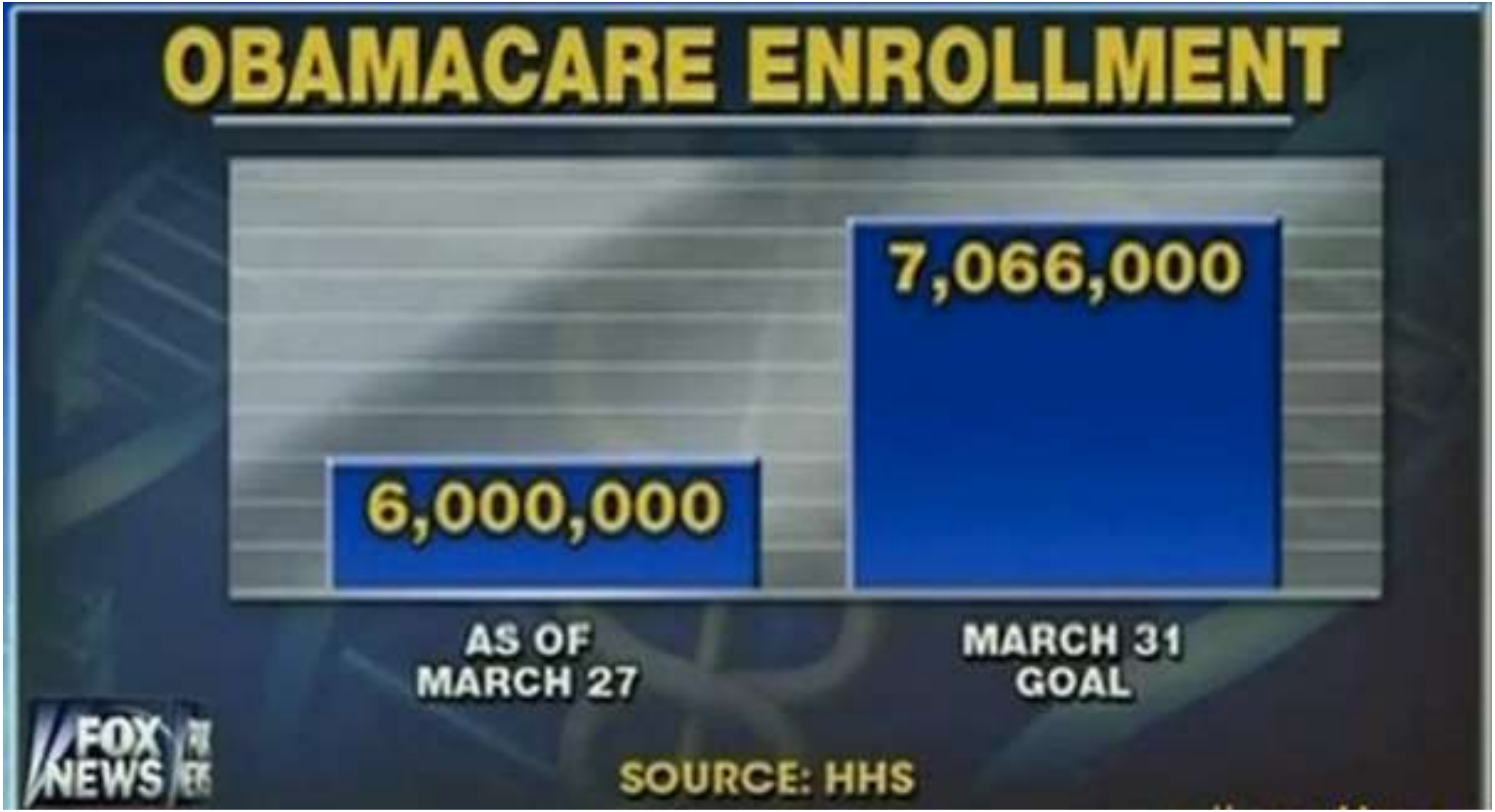
- Competence


2012 PRESIDENTIAL RUN
GOP CANDIDATES
BACK PALIN
70%
63%
60%
BACK HUCKABEE
BACK ROMNEY
FOX
47°
SOURCE:OPINIONS DYNAMIC

trust in numbers…

Onora O’Neill: trust should be based on…

- Competence
- Honesty

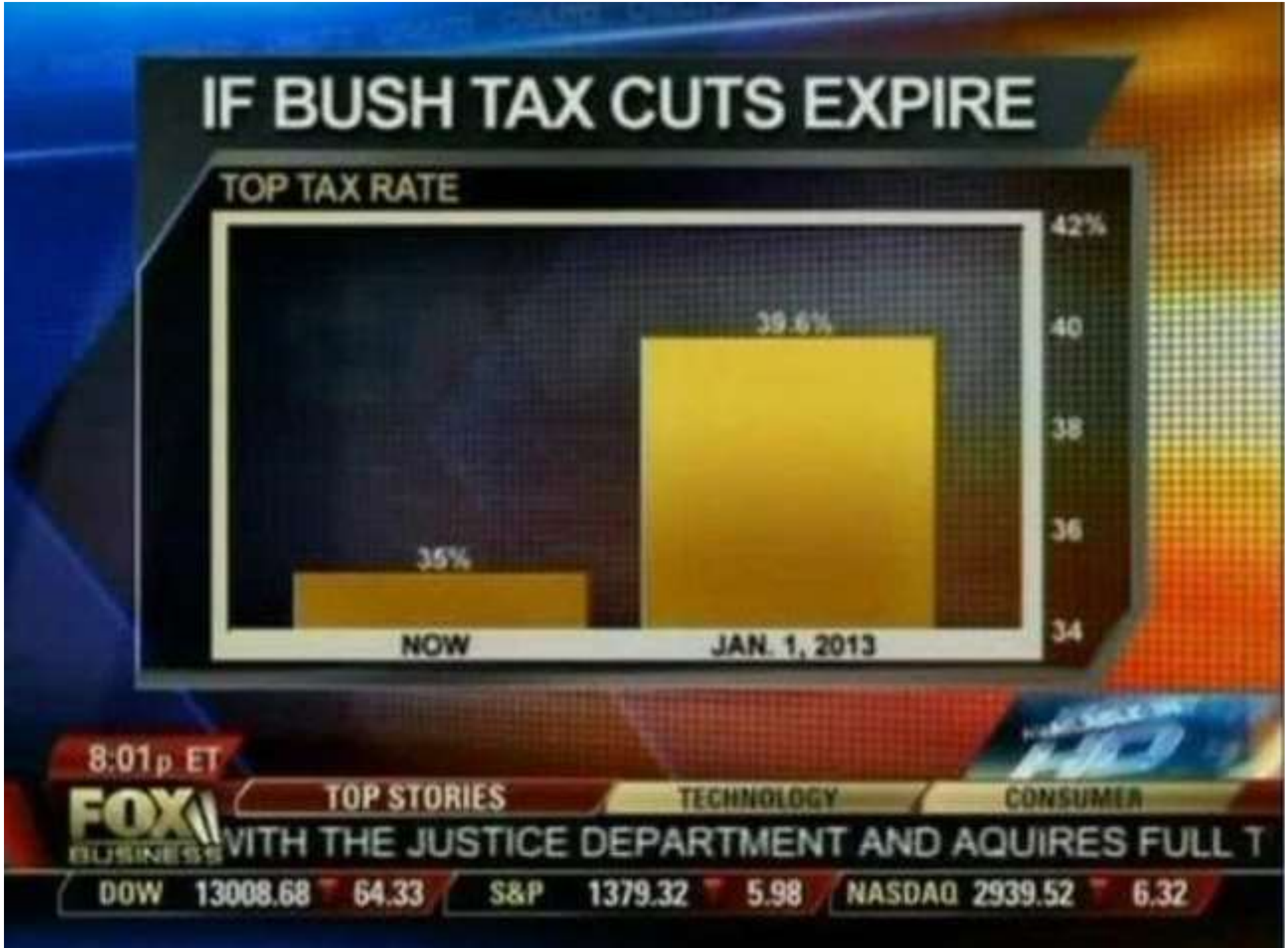

OBAMACARE ENROLLMENT
6,000,000
7,066,000
AS OF MARCH 27
MARCH 31 GOAL
FOX NEWS
SOURCE: HHS

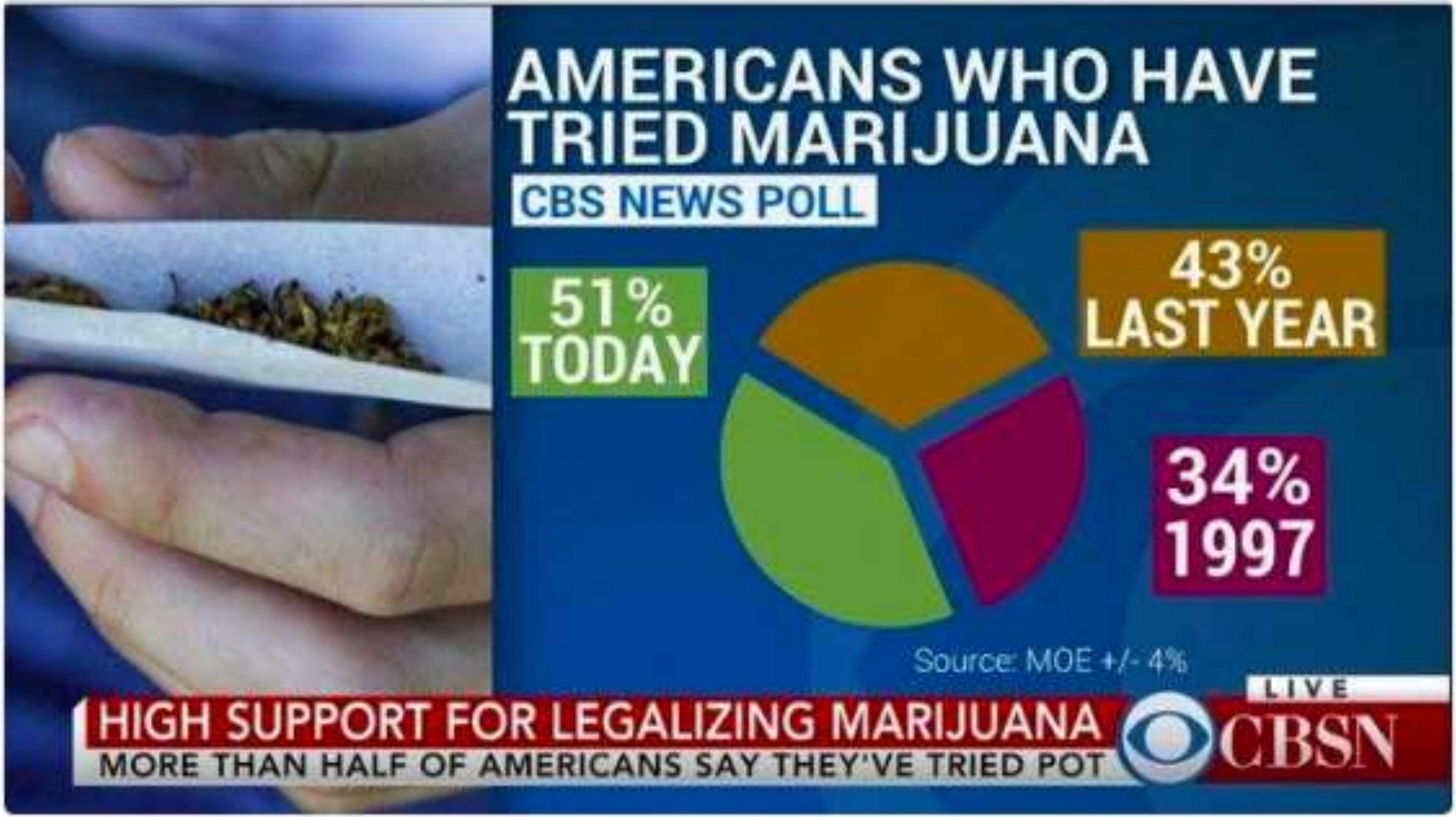

Fox news
OBAMACARE ENROLLMENT
8M
6M
4M
2M
0
6,000,000
7,066,000
AS OF MARCH 27
MARCH 31 GOAL
SOURCE: CBO
FOX NEWS
AMERICA'S newsroom
HUFFPOST

trust in numbers…

Onora O’Neill: trust should be based on…

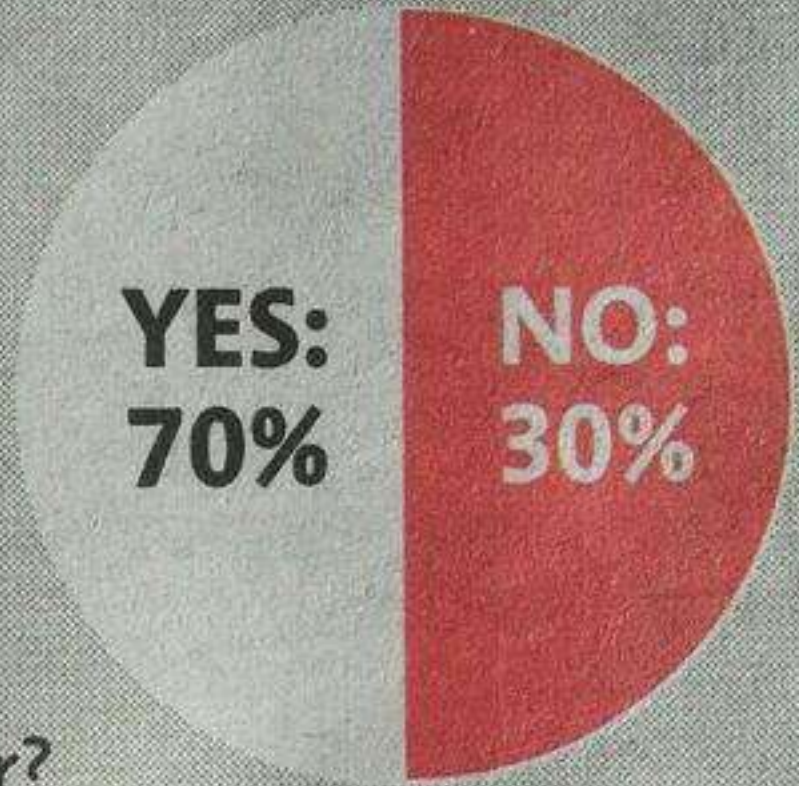
- Competence
- Honesty
- Reliability


IF BUSH TAX CUTS EXPIRE
TOP TAX RATE
42%
40
38
36
34
39.6%
35%
NOW
JAN. 1, 2013
8:01p ET
FOX BUSINESS
TOP STORIES
TECHNOLOGY
CONSUMER
VITH THE JUSTICE DEPARTMENT AND AQUIRES FULL T
DOW 13008.68 64.33
S&P 1379.32 5.98
NASDAQ 2939.52 6.32


AMERICANS WHO HAVE TRIED MARIJUANA
CBS NEWS POLL
51% TODAY
43% LAST YEAR
34% 1997
Source: MOE +/- 4%
HIGH SUPPORT FOR LEGALIZING MARIJUANA
MORE THAN HALF OF AMERICANS SAY THEY'VE TRIED POT
LIVE
CBSN

DAILY POLL

WE ASKED:
There's been a reduction in the number of top grades awarded in this year's GCSEs. Should they be made even harder?



Onora-O'Neill..

- Don't aim to 'increase trust'
- Aim to demonstrate *trustworthiness*
- People must be able to assess that trustworthiness
- Information should be *accessible, useable,* and *assessable*

HQIP
Healthcare Quality
Improvement Partnership

Patient and public involvement in quality improvement

April 2016

New UK Cancer Screening leaflets, 2013

- *“Consider the offer”*
- Presents pros and cons
- Does not make recommendation
- ‘Uniform reporting of harms and benefits’

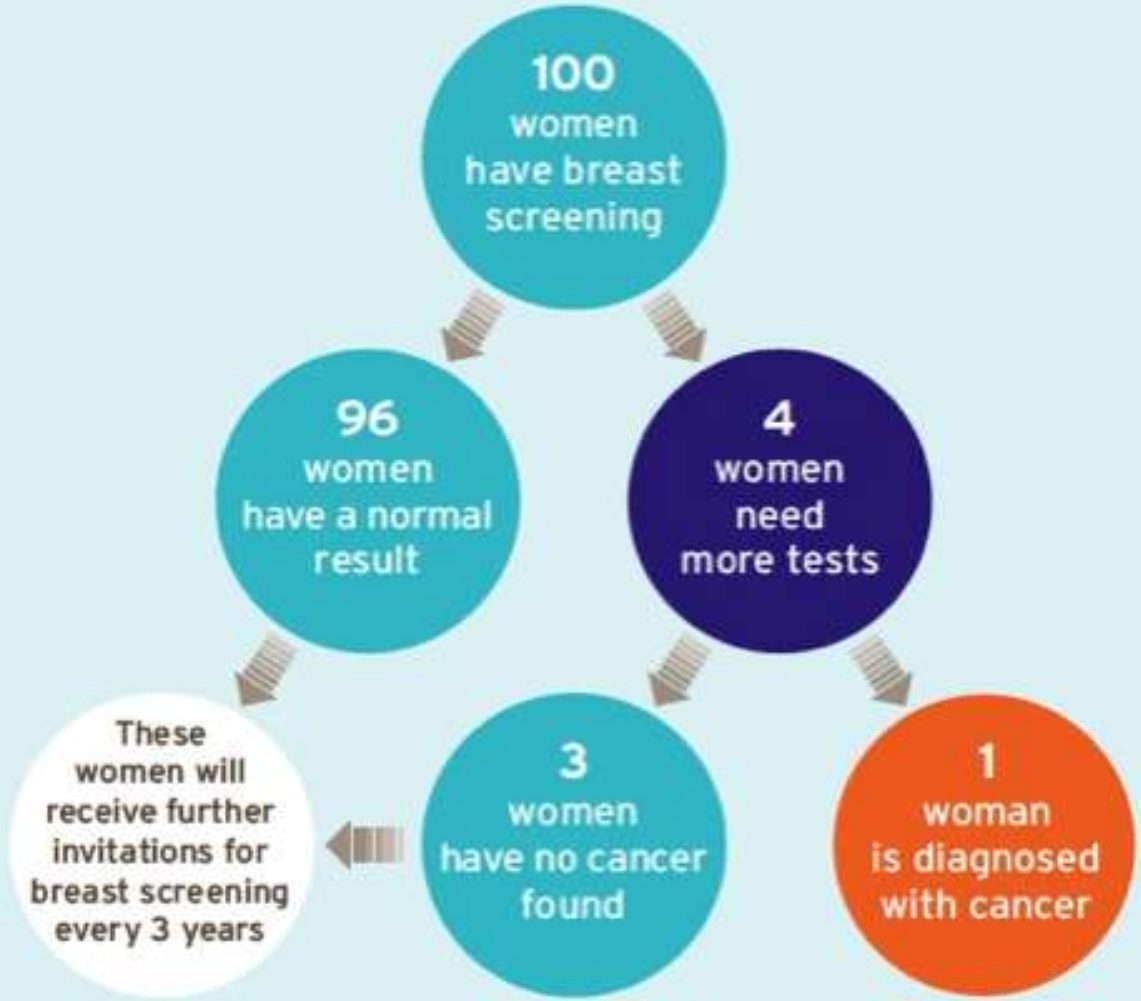
OPM® Office for Public Management

Citizens' Jury on information for women about breast screening

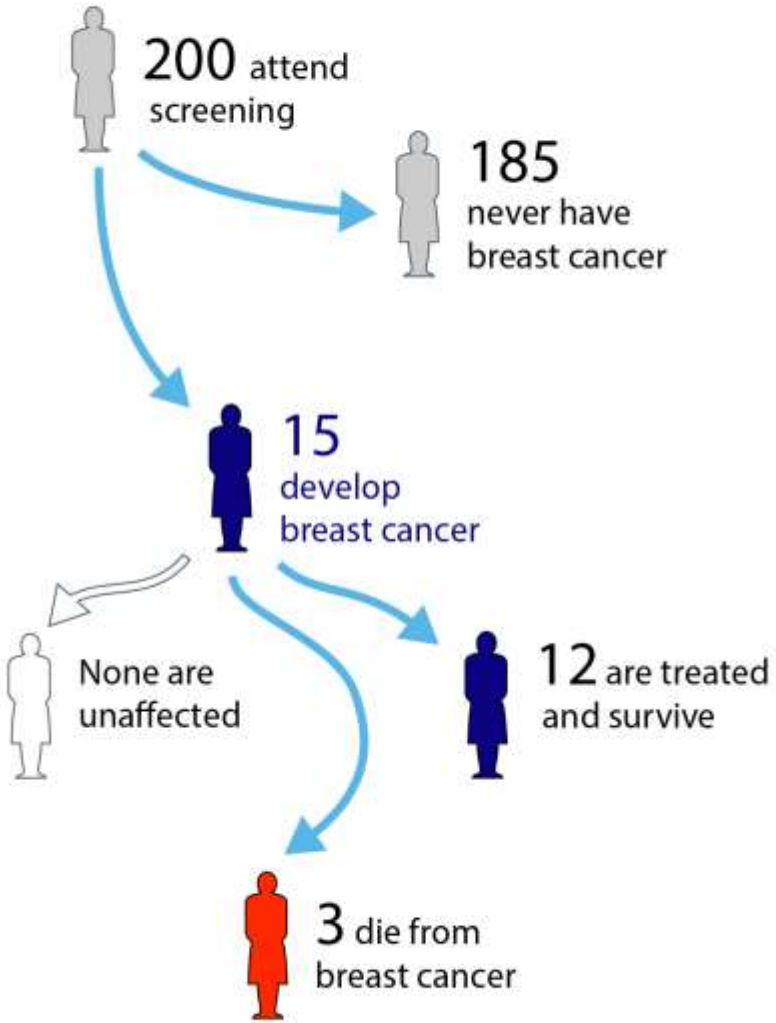
Report to Informed Choice about Cancer Screening

Public engagement through *Citizens' Jury*

What happens to 100 women **each time** they have breast screening



200 women between 50 and 70 who attend screening



A numeracy paradox?

- Leaflets optimised for people with low numeracy
- Those people tend to be less interested in shared-care / informed-choice

Health Psychology
2011, Vol. 30, No. 3, 336–341

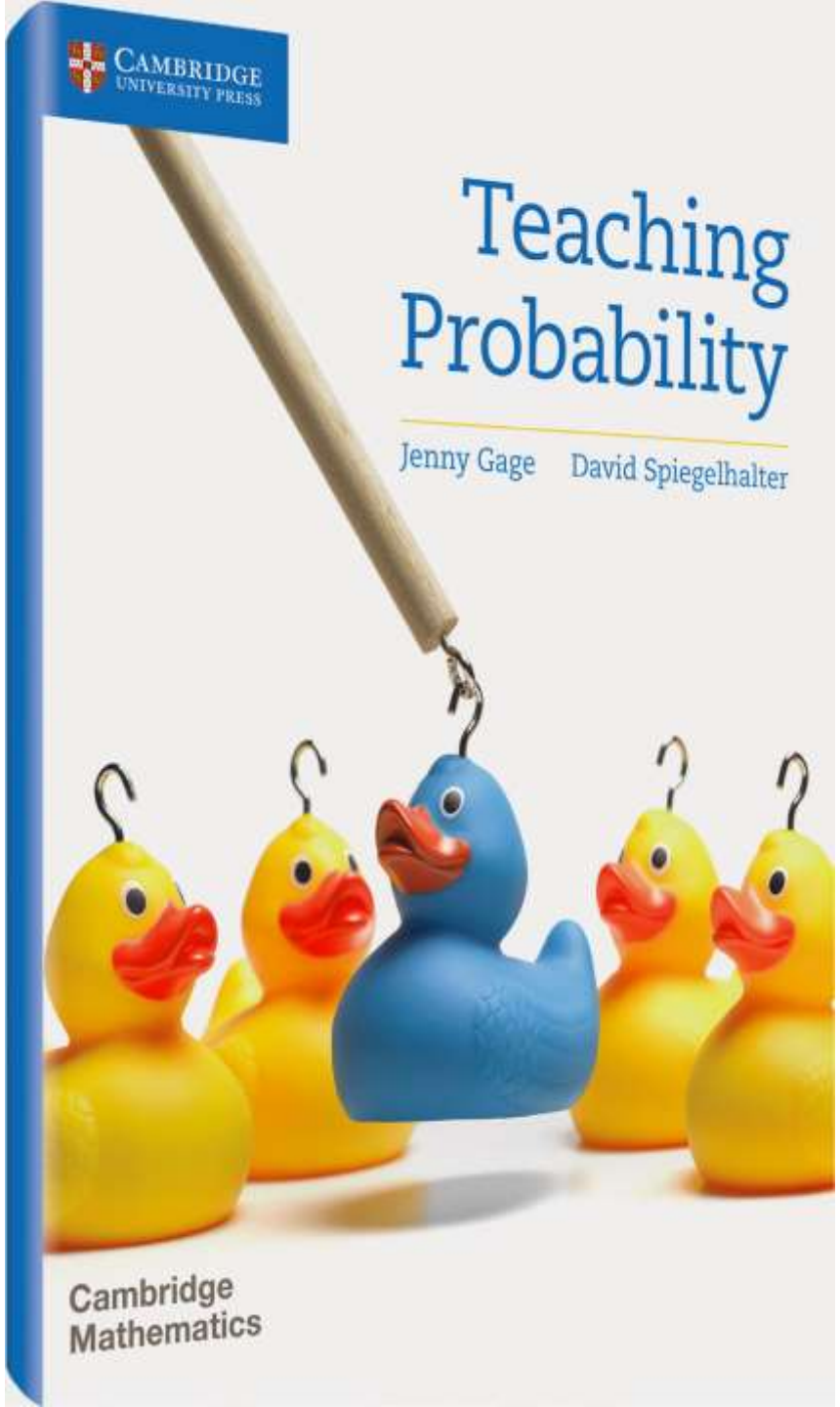
0278-6133/11/$12.00 DOI: 10.1037/a0022723

Do Low-Numeracy People Avoid Shared Decision Making?

Mirta Galesic
Max Planck Institute, Berlin, Germany

Rocio Garcia-Retamero
University of Granada

expected frequency trees
now part of GCSE Maths
1-9 syllabus



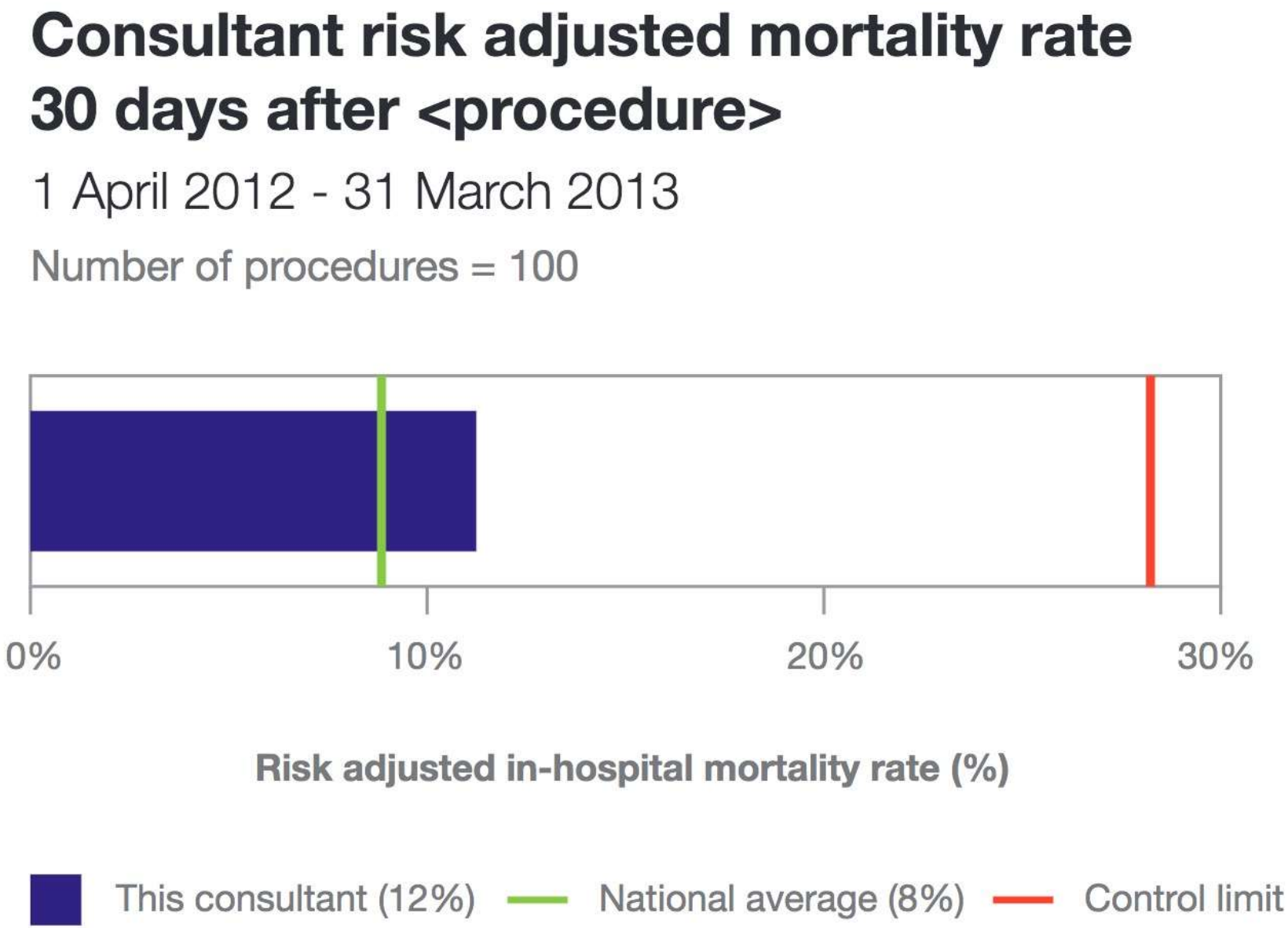
HQIP service user network

HQIP
Healthcare Quality Improvement Partnership

Clinical Outcomes Publication

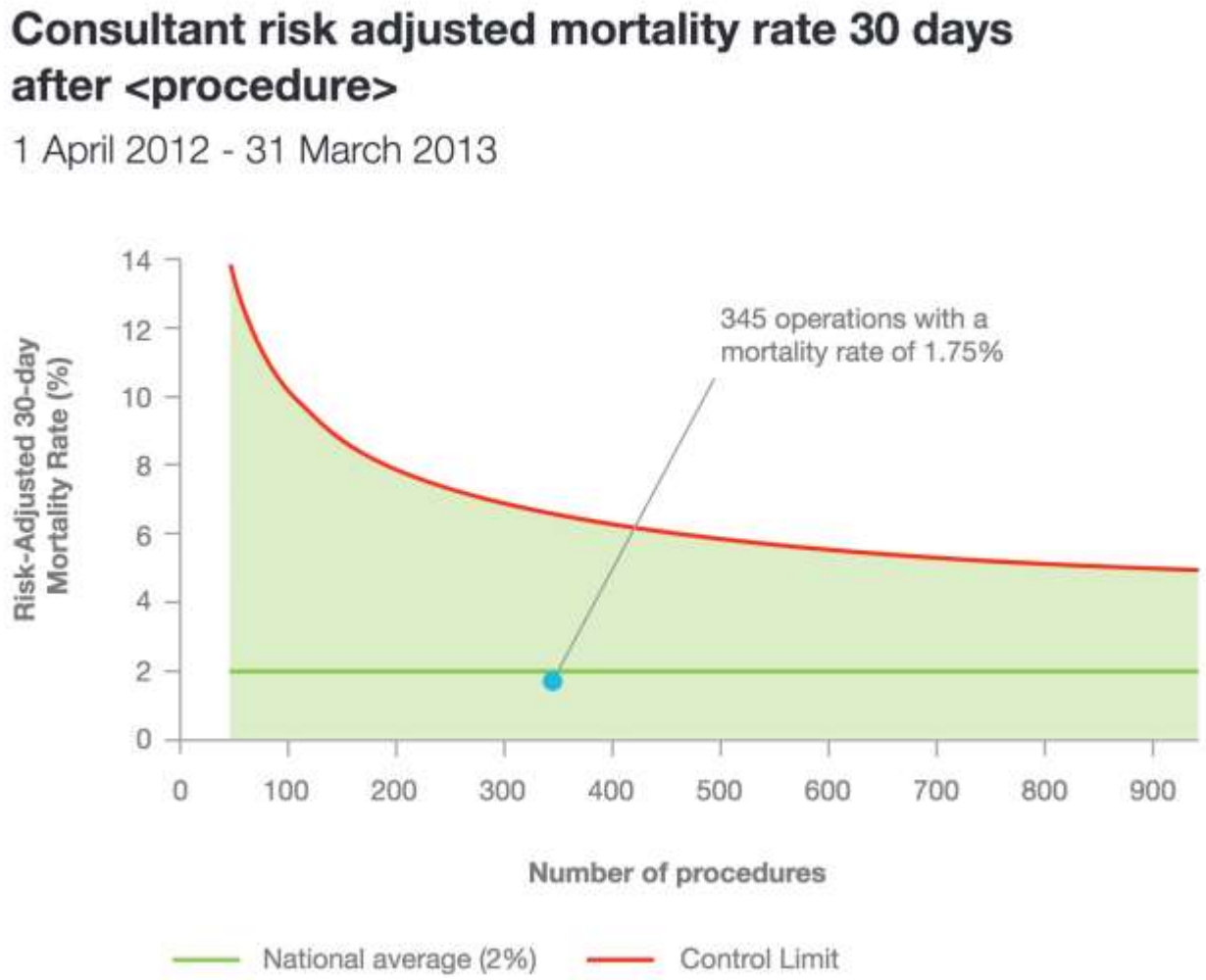
Style Guide for National Clinical Audits

This type of chart is recommended when showing mortality outcomes with control limits.



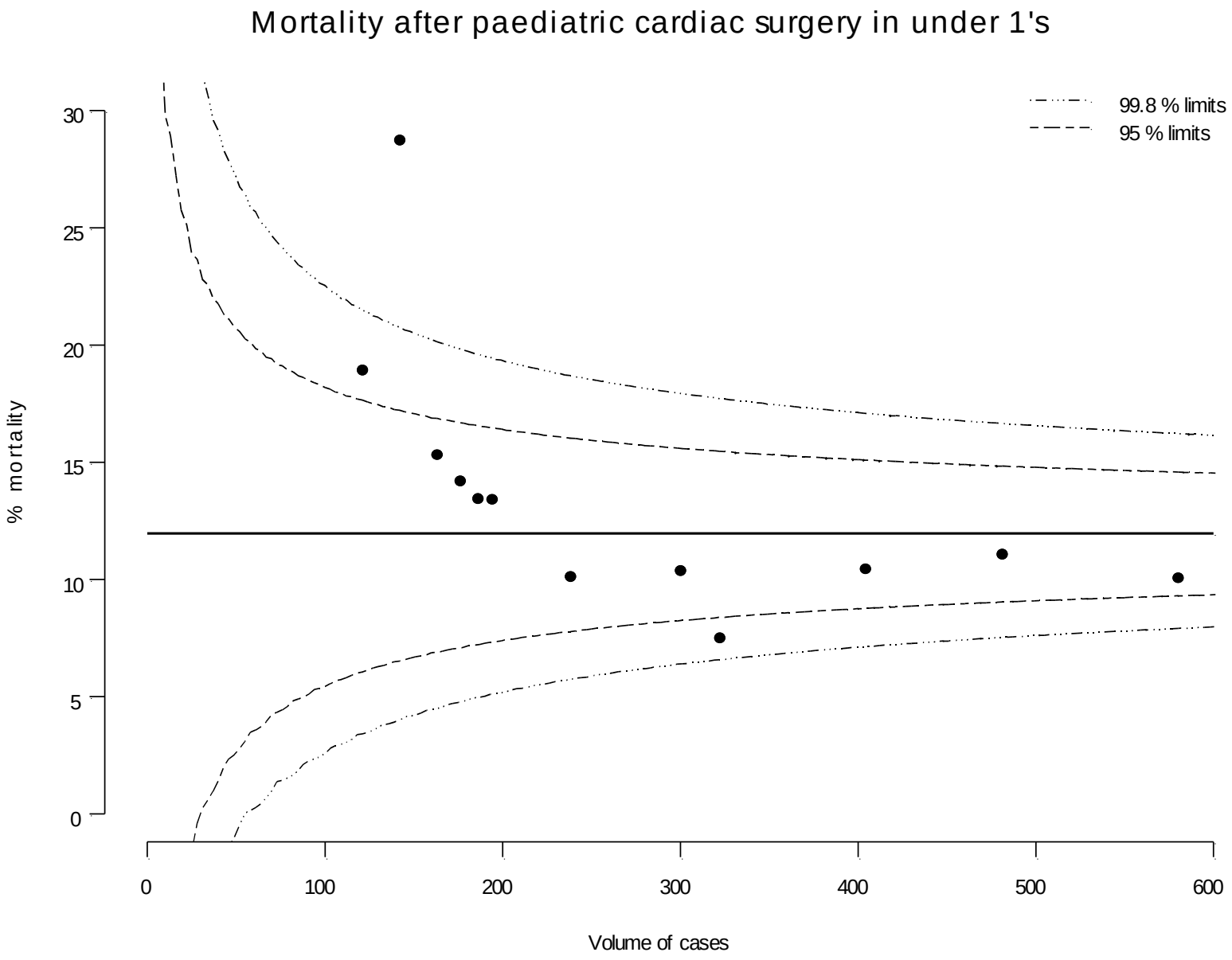
Funnel Plot

The HQIP Service User Network indicated that the Control Limit Chart, shown on page 12, is easier to understand than a funnel plot. However, we acknowledge that some specialties may find it difficult to move away from using funnel plots. Therefore we include a 'best practice' example of a funnel plot here.



Little point in having a funnel unless centres are going to be compared

The Bristol Inquiry into excess mortality



NHS Digital

- NHS Digital indicators
  - Indicator Portal news
    - Site updates
    - Known issues
  - CCG Outcomes Indicator Set
    - Domain 1 - Preventing people from dying prematurely (CCG)
    - Domain 2 - Enhancing quality of life for people with long-term conditions (CCG)

Welcome to the NHS Digital Indicator Portal

This website gathers together a number of health and social care indicators. Currently these include:

- **Clinical Commissioning Group Outcomes Indicator Set**
  The CCG Outcomes Indicator Set (CCG OIS) is an integral part of NHS England's systematic appr

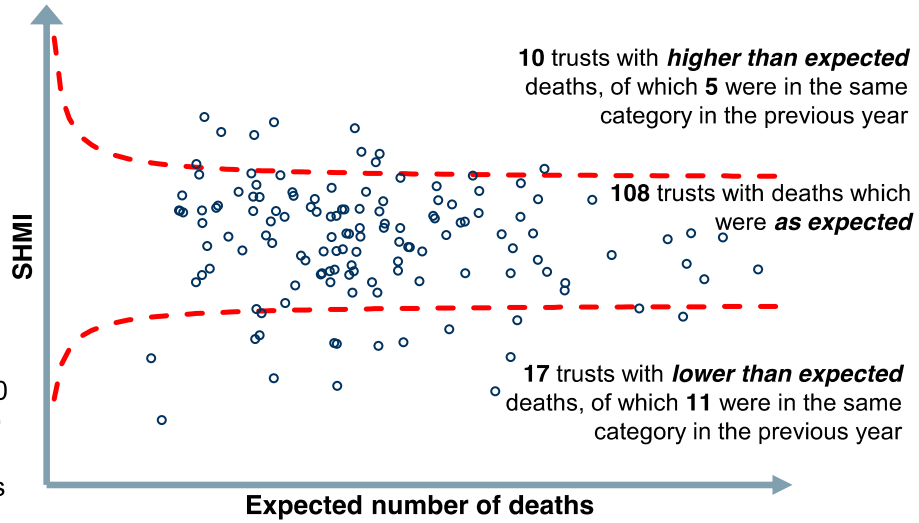
Deaths following time in hospital, England, April 2016 – March 2017

Quarterly statistics: Published 21st September 2017

This publication compares the actual number of deaths following time in hospital with the expected number of deaths, using the Summary Hospital-level Mortality Indicator (SHMI).

The expected number of deaths is estimated using the characteristics of the patients treated; age, sex, method of admission, current and underlying medical condition(s). It covers patients admitted to hospitals in England who died either while in hospital or within 30 days of being discharged.

Between April 2016 and March 2017, there were approximately 8.9 million discharges, from which 294,000 deaths were recorded either while in hospital or within 30 days of discharge for the 135 hospital trusts covered. This includes deaths from other causes as well as deaths related to the reason for the hospital admission.



The SHMI was developed in response to the public inquiry into the Mid Staffordshire NHS Foundation Trust.

It is used along with other information to inform the decision making of trusts, regulators and commissioning organisations.

The SHMI is not a measure of quality of care. A *higher/lower than expected* number of deaths should not immediately be interpreted as indicating poor/good performance and instead should be viewed as a '**smoke alarm**' which requires further investigation.

The SHMI cannot be used to directly compare mortality outcomes between trusts and it is inappropriate to rank trusts by their SHMI.

The 10 trusts with a ***higher than expected*** number of deaths were:

- **Blackpool Teaching Hospitals NHS FT**
- James Paget University Hospitals NHS FT
- Northern Lincolnshire and Goole NHS FT
- **South Tyneside NHS FT**
- **Southend University Hospital NHS FT**
- Southport and Ormskirk Hospital NHS Trust
- The Royal Wolverhampton NHS Trust
- **United Lincolnshire Hospitals NHS Trust**
- Wrightington, Wigan and Leigh NHS FT
- **Wye Valley NHS Trust**

The 17 trusts with a ***lower than expected*** number of deaths were:

- **Barts Health NHS Trust**
- **Cambridge University Hospitals NHS FT**
- **Chelsea and Westminster Hospital NHS FT**
- Croydon Health Services NHS Trust
- Frimley Health NHS FT
- **Guy's and St Thomas' NHS FT**
- Homerton University Hospital NHS FT
- **Imperial College Healthcare NHS Trust**
- Kingston Hospital NHS FT
- **London North West Healthcare NHS Trust**
- North Middlesex University Hospital NHS Trust
- **Poole Hospital NHS FT**
- Royal Free London NHS FT
- **St George's University Hospitals NHS FT**
- **The Whittington Hospital NHS Trust**
- **Torbay and South Devon NHS FT**
- **University College London Hospitals NHS FT**

Trusts in **bold** were also in the same category in the same period in the previous year. 'FT' means 'Foundation Trust'.

See the full release at http://digital.nhs.uk/pubs/shmiapr16mar17 **0300 303 5678** **ISBN 978-1-78734-124-1**
Responsible Statistician: Sally Harrison **enquiries@nhsdigital.nhs.uk**

But you can’t control the media..

NHS buries 19,000 'suspect' deaths: Expert demands urgent probe into 'avoidable' fatalities amid shock claims dozens of hospitals across Britain are 'potentially unsafe'

- **Sir Brian Jarman - man who helped expose Mid-Staffs scandal - made discovery**
- **Lib Dem health spokesman Norman Lamb demanded Jeremy Hunt investigate**
- **Sir Brian calculated 32,810 ‘unexpected’ deaths in English hospitals in five years**
- **But using the preferred NHS method, 13,627 were classed as such - 19,183 fewer**

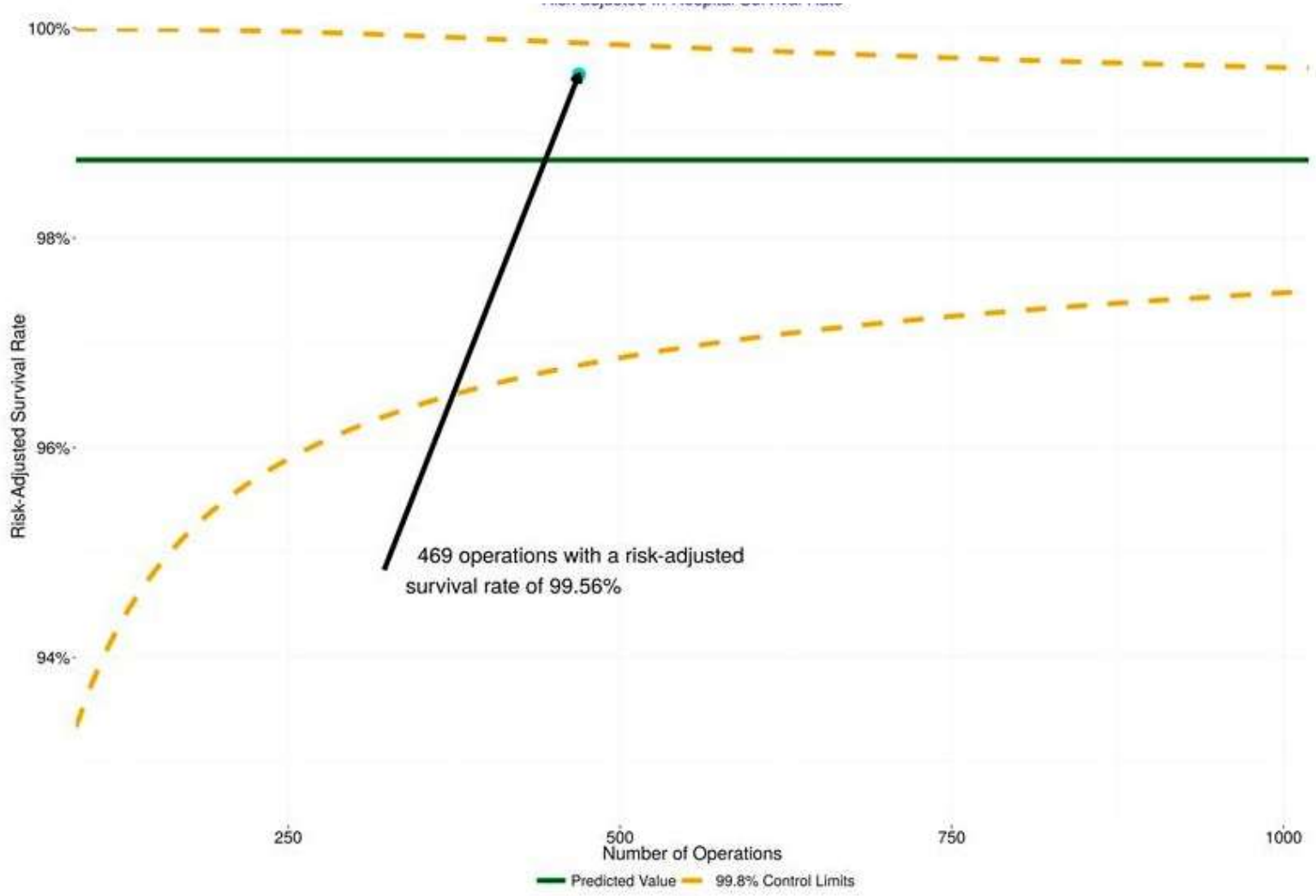
By STEPHEN ADAMS and MARTYN HALLE FOR THE MAIL ON SUNDAY
PUBLISHED: 22:28, 2 September 2017 | **UPDATED:** 23:44, 2 September 2017

Francis Charles Wells

GMC Number: **2269597**

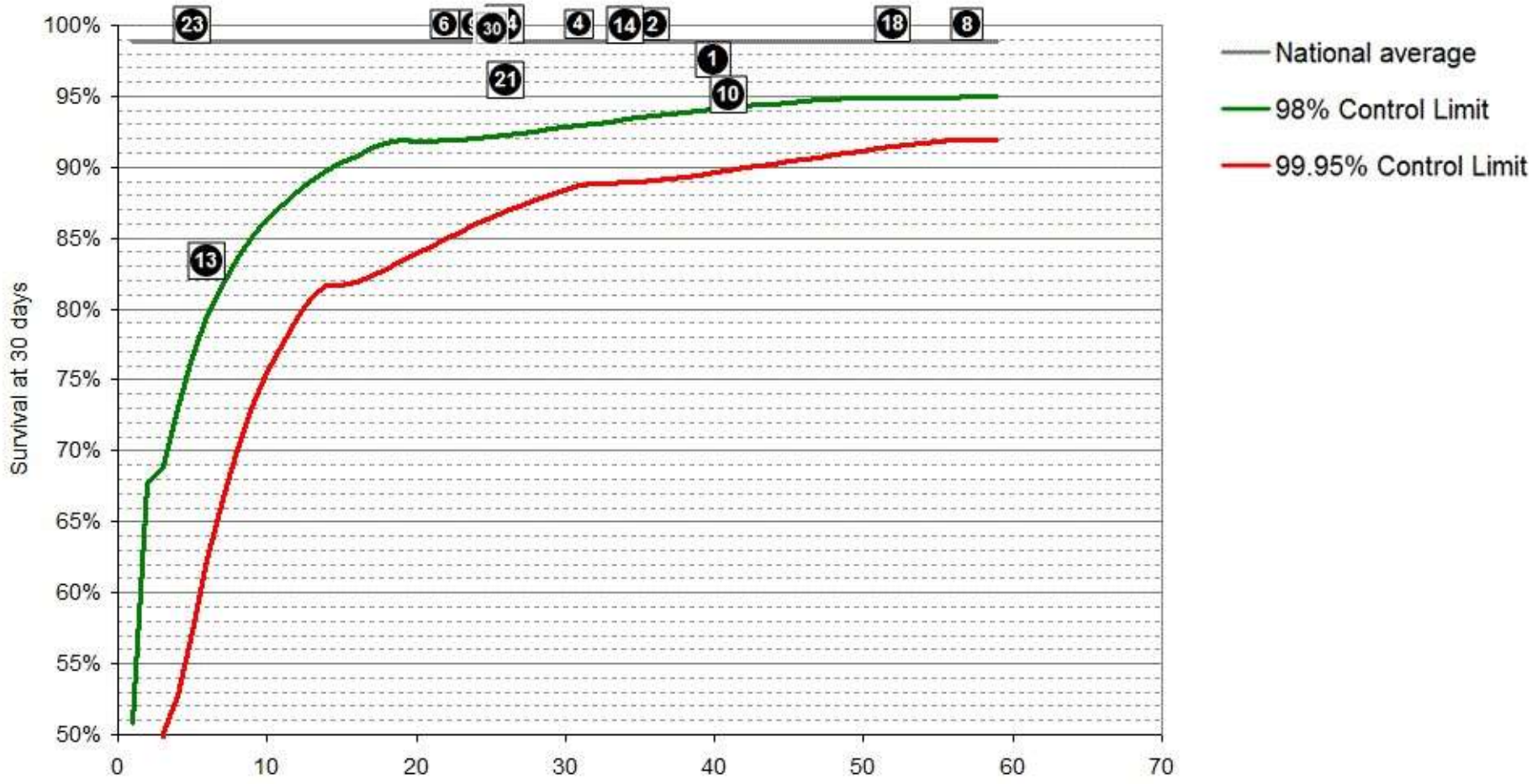
Hospital(s): **Papworth Hospital Foundation Trust**

Special Interests: **Adult Cardiac Surgery**



NICOR: NATIONAL INSTITUTE FOR CARDIOVASCULAR OUTCOMES RESEARCH
CONGENITAL HEART DISEASE WEBSITE

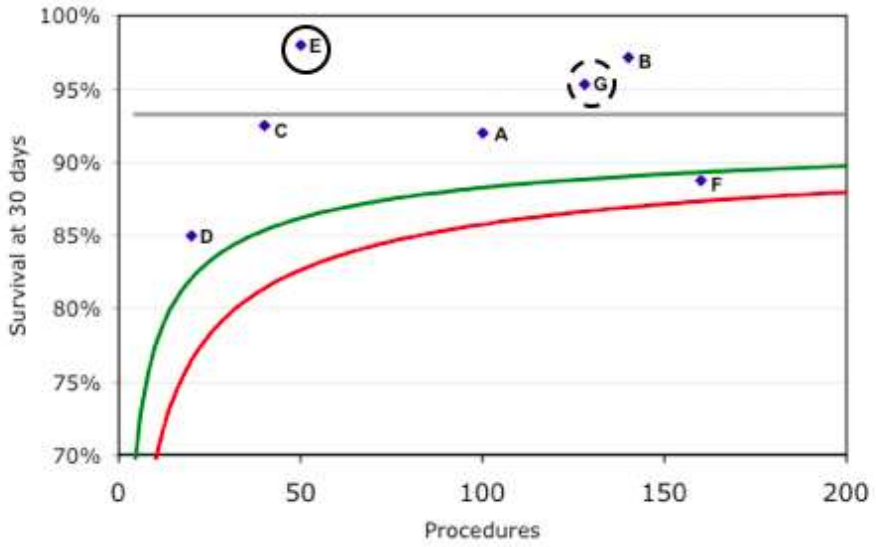
Surgery : Arterial switch (for isolated transposition) 2009-2012 - Paediatric

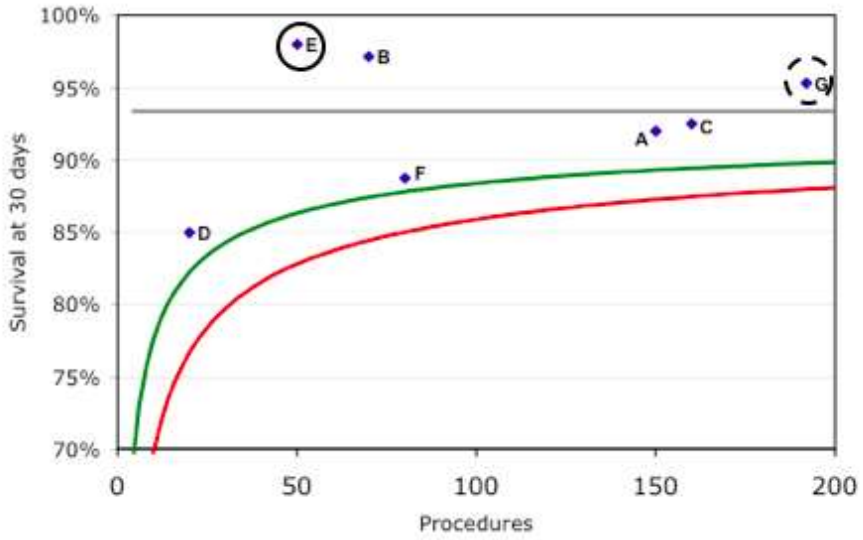


		Cases	Alive 30d	Dead 30d	Survival 30d
8	Great Ormond Street Hospital for Children	57	57	0	100.0%
18	Royal Brompton Hospital	52	52	0	100.0%

Is there a survival / volume tradeoff in patient preferences? (Rakow *et al*, 2014)

Figure 3. Plots shown for forced-choice preference data. Options enveloped in solid circles are identical for the left and right option sets.
(a) Comparison examining participants' sensitivity to institutional volume (displayed for survival frame only).

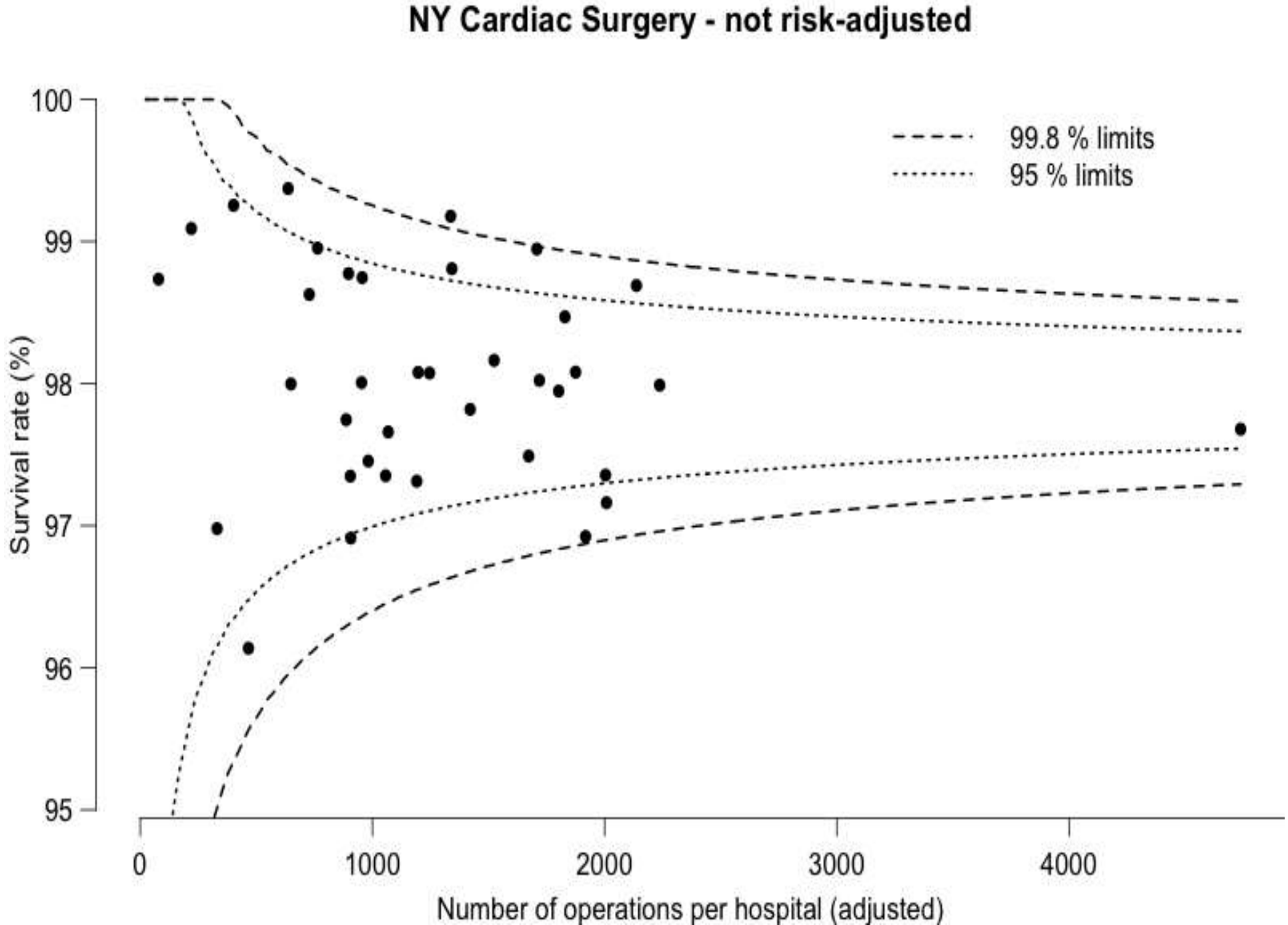


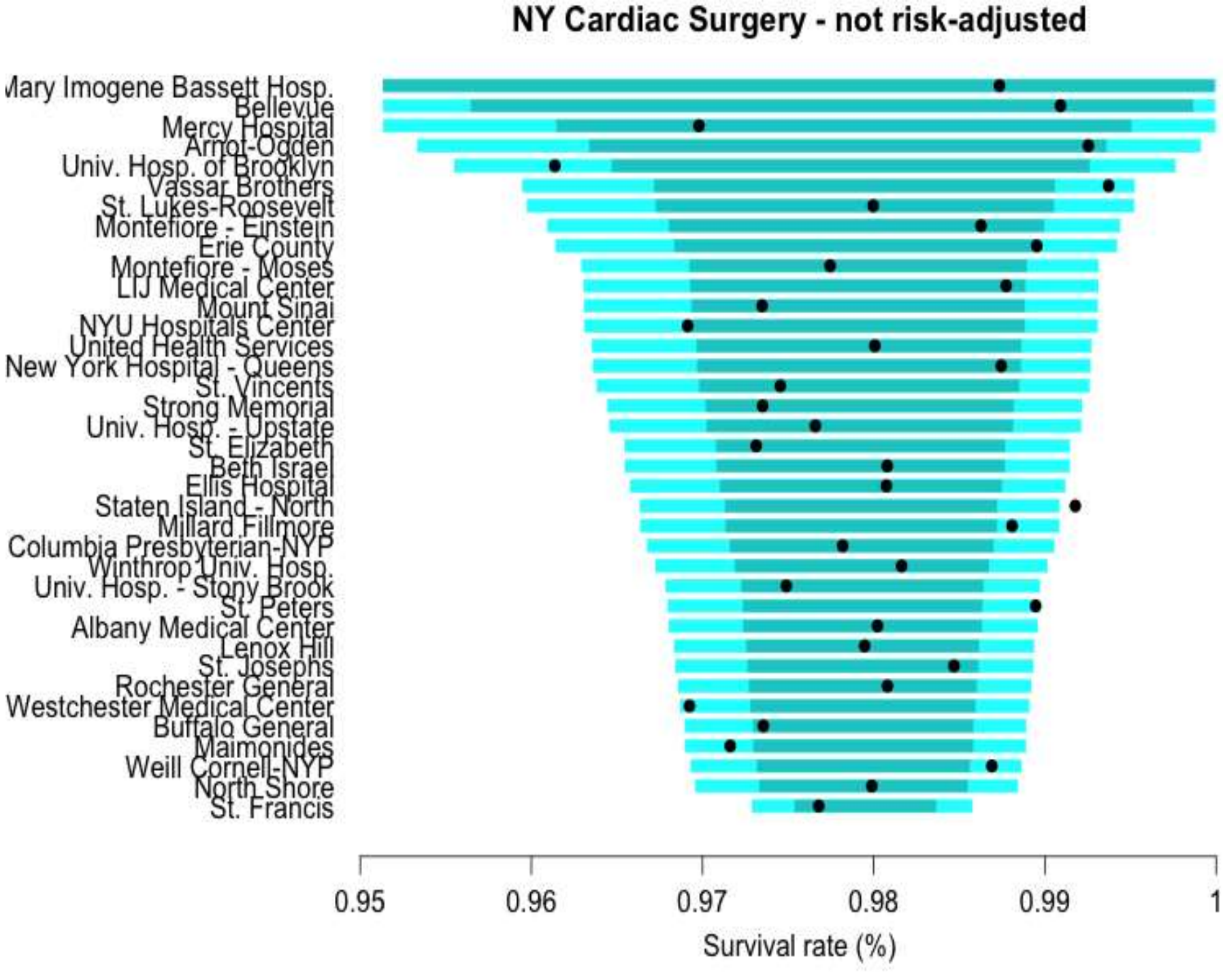


% who preferred G

53%

72%

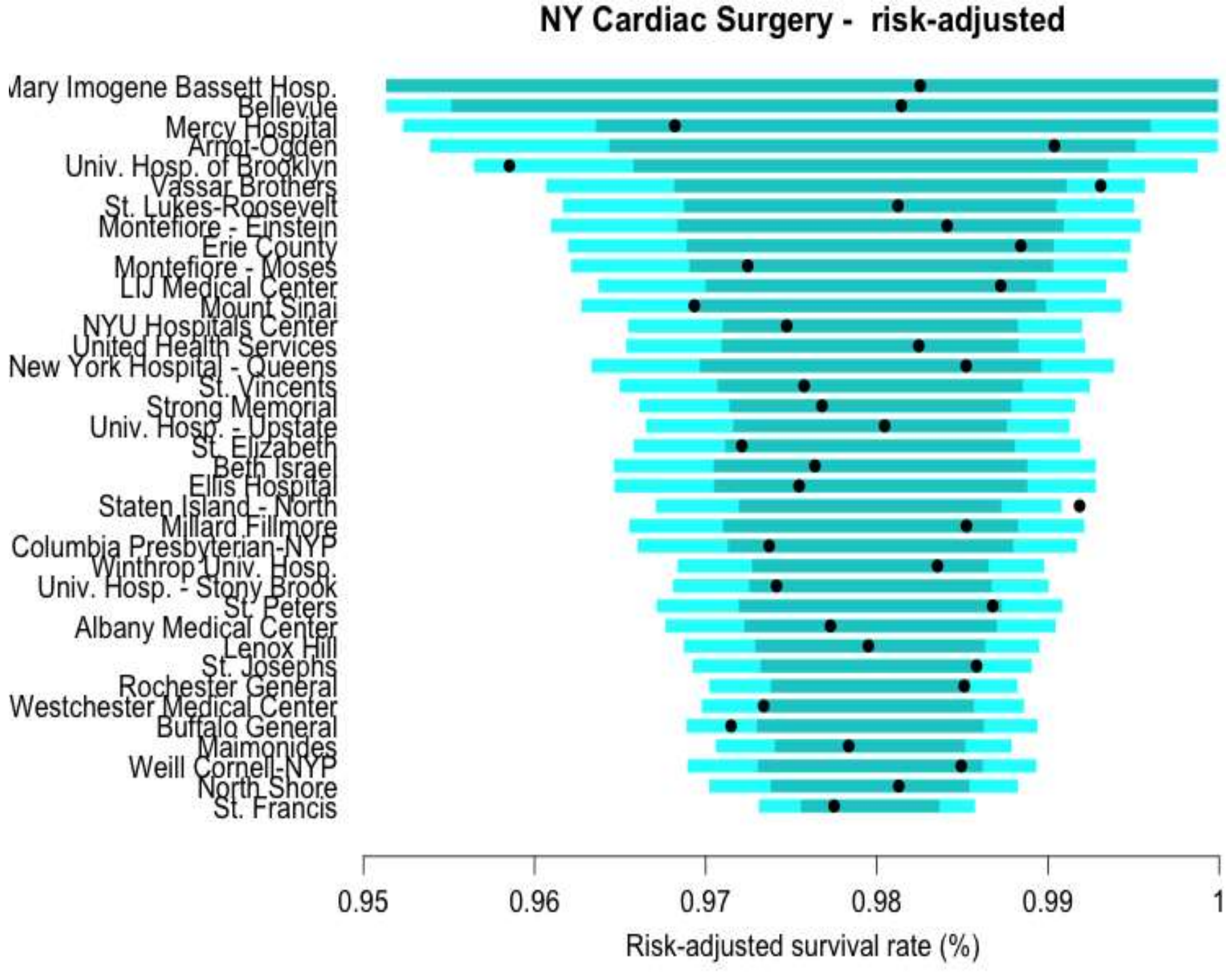

NY Cardiac Surgery - not risk-adjusted
99.8 % limits
95 % limits
Survival rate (%)
100
99
98
97
96
95
0
1000
2000
3000
4000
Number of operations per hospital (adjusted)


NY Cardiac Surgery - not risk-adjusted
Mary Imogene Bassett Hosp.
Bellevue
Mercy Hospital
Arnot-Ogden
Univ. Hosp. of Brooklyn
Vassar Brothers
St. Lukes-Roosevelt
Montefiore - Einstein
Erie County
Montefiore - Moses
LIJ Medical Center
Mount Sinai
NYU Hospitals Center
United Health Services
New York Hospital - Queens
St. Vincents
Strong Memorial
Univ. Hosp. - Upstate
St. Elizabeth
Beth Israel
Ellis Hospital
Staten Island - North
Millard Fillmore
Columbia Presbyterian-NYP
Winthrop Univ. Hosp.
Univ. Hosp. - Stony Brook
St. Peters
Albany Medical Center
Lenox Hill
St. Josephs
Rochester General
Westchester Medical Center
Buffalo General
Maimonides
Weill Cornell-NYP
North Shore
St. Francis
0.95
0.96
0.97
0.98
0.99
1
Survival rate (%)

Risk-adjusted survival rate (RASR)

- s_i = observed survival rate in centre i
- e_i = expected survival rate in centre i (average of predictive probabilities)
- e = overall expected survival rate
- logit $e = \log \frac{e}{1-e}$

$$\text{logit RASR}_i = \text{logit } s_i - \text{logit } e_i + \text{logit } e$$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Maimonides
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North Shore
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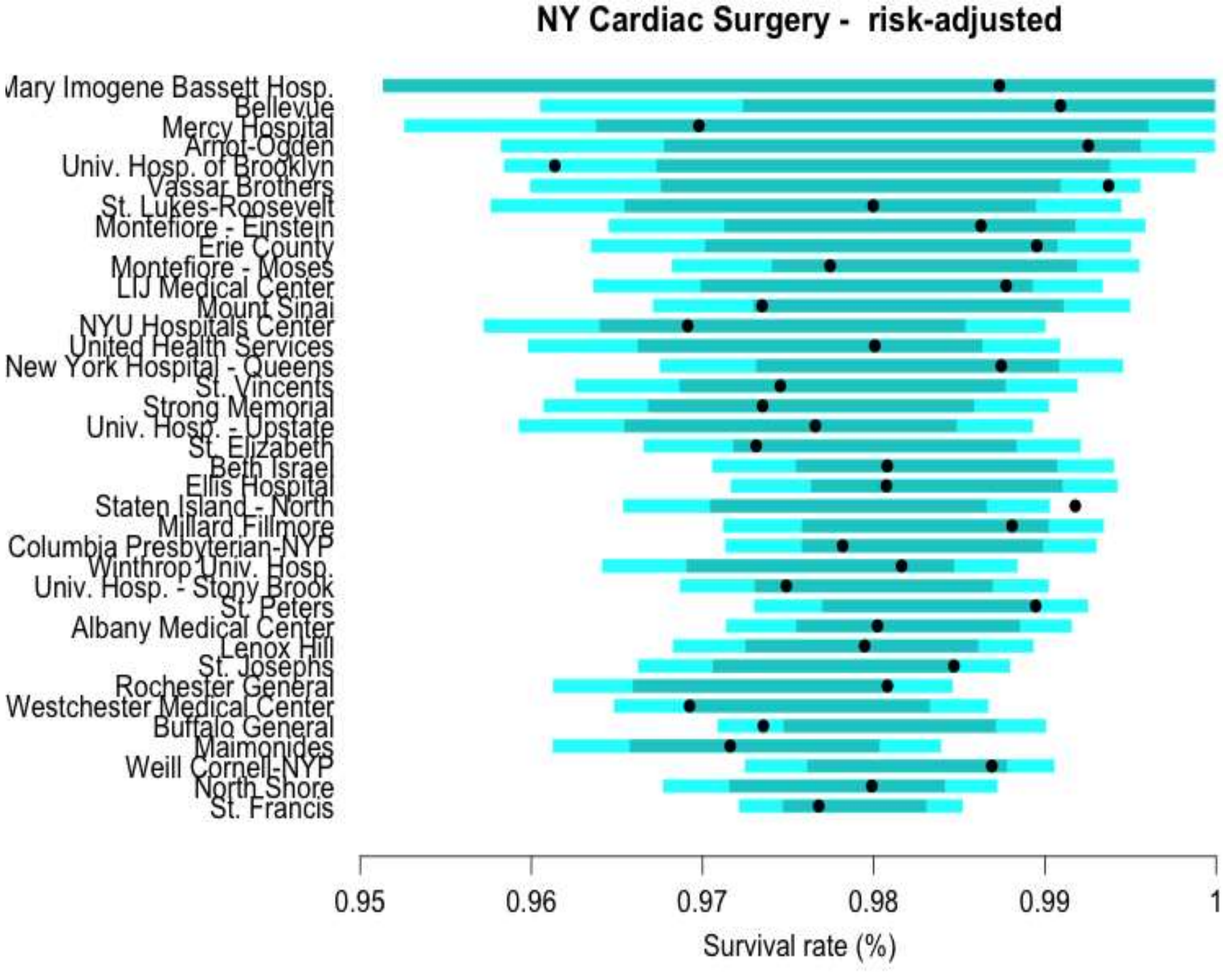
0.96
0.97
0.98
0.99
1
Risk-adjusted survival rate (%)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0.96
0.97
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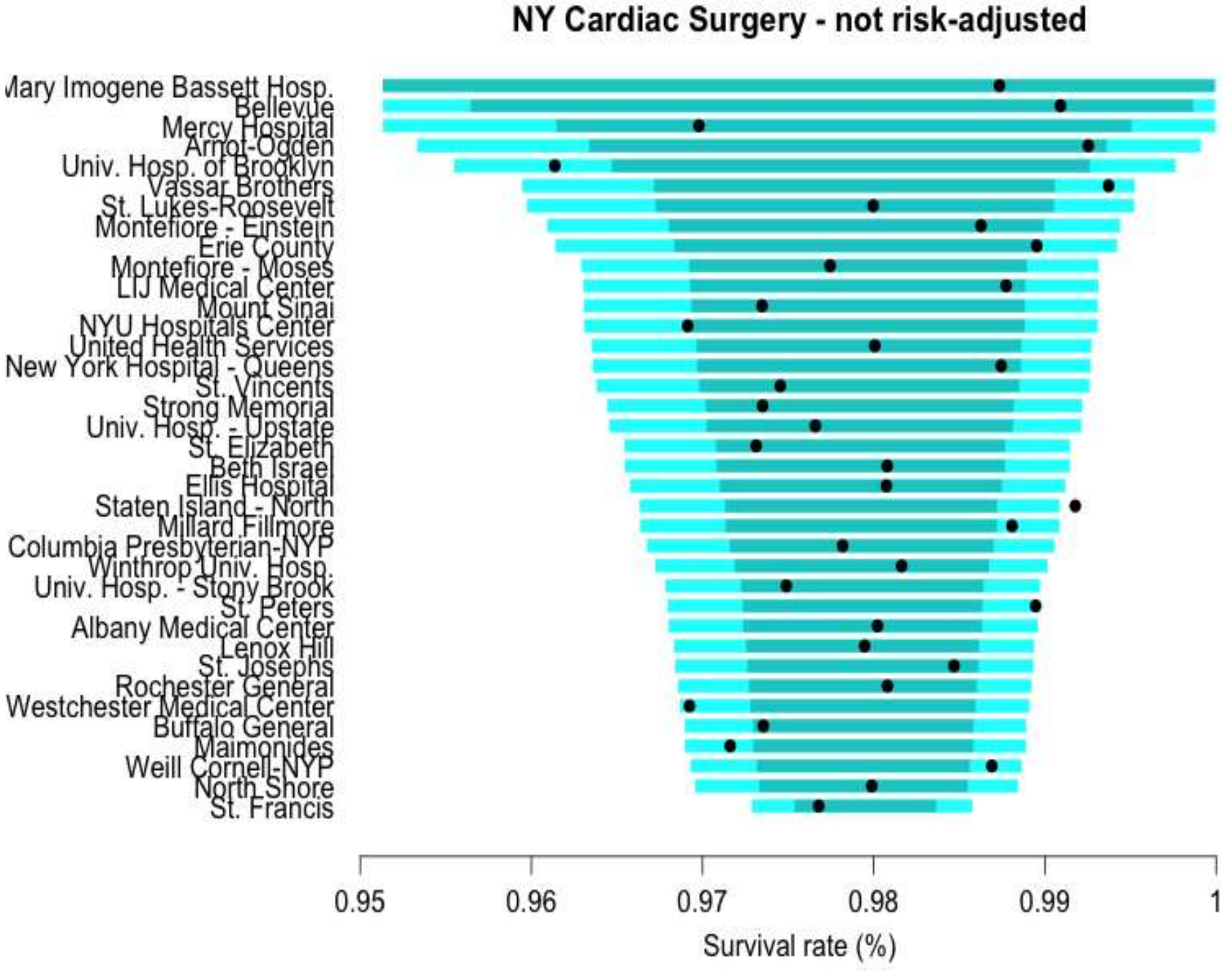
Survival rate (%)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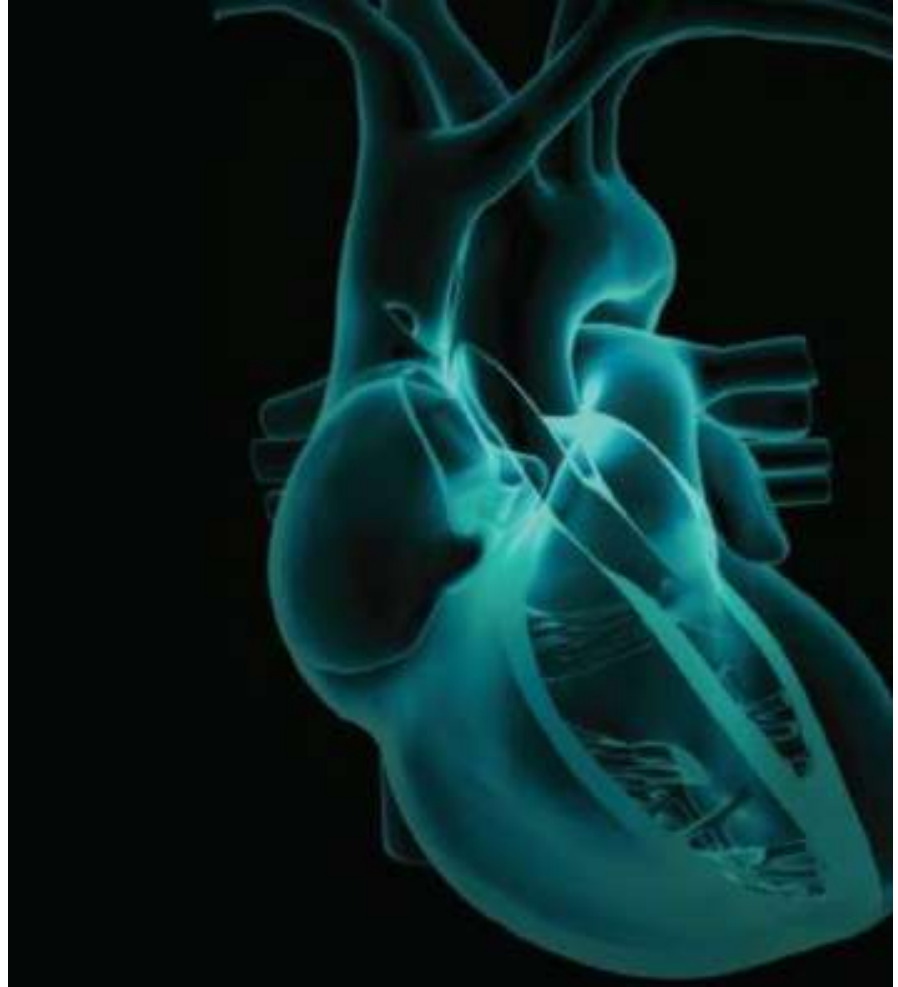
Buffalo General
Maimonides
Weill Cornell-NYP
North Shore
St. Francis
0.95
0.96
0.97
0.98
0.99
1
Survival rate (%)

Problems with funnels

- Technical issues with risk-adjustment
- “Multiple comparisons”
- Too much focus on single outcome 30-day mortality
- ‘Over-dispersion’
- Too much focus on (arbitrary) thresholds

It’s only an indicator

User Centred Design



National Congenital Heart Disease Audit Report 2012-15

Home | What, why, how? | Explore the data | Everything else

UNDERSTANDING CHILDREN'S HEART SURGERY OUTCOMES

This site is to help people make sense of the published survival data about children's heart surgery.

Our website will help you:

- explore what survival rates can and can't tell you
- understand how the NHS monitors children's heart surgery
- explore published data for UK hospitals

What, why, how?

What do we mean by survival rates?

Data

Explore published survival statistics

Browse hospitals on a UK map

Everything else

How are survival statistics monitored

What happens if the data raises

UCL | UNIVERSITY OF CAMBRIDGE | KING'S College LONDON | sense about science | Children's Heart Federation

Hospital		Number of Operations	Number of Deaths	Number of Survivors	Survival Rate %	Survival with predicted range ← full view full detail → 94% 96% 98% 100%
Belfast, Royal Victoria Hospital	RVB	204	2	202	99	
London, Harley Street Clinic	HSC	482	7	475	98.5	
Leicester, Glenfield Hospital	GRL	582	11	571	98.1	
Newcastle, Freeman Hospital	FRE	678	15	663	97.8	
Glasgow, Royal Hospital for Children	RHS	787	28	759	96.4	
Bristol Royal Hospital for Children	BRC	835	19	816	97.7	
Southampton, Wessex Cardiothoracic Centre	SGH	890	17	873	98.1	
Leeds General Infirmary	LGI	976	23	953	97.6	
Dublin, Our Lady's Children's Hospital	OLS	1056	23	1033	97.8	
London, Royal Brompton Hospital	NHB	1107	12	1095	98.9	
Liverpool, Alder Hey Hospital	ACH	1146	27	1119	97.6	
London, Evelina London Children's Hospital	GUY	1204	39	1165	96.8	
Birmingham Children's Hospital	BCH	1481	30	1451	98	
London, Great Ormond Street Hospital for Children	GOS	1881	30	1851	98.4	

predict




Google™ Custom Search Search

Home

What's New

Information for Patients and Public

Information for Professionals

PREDICT V1.2

PREDICT V2.0

FAQs

Disclaimer

Acknowledgements

Press

Publications

Contact

Privacy Policy

Usage Statistics

PREDICT Tool Version 2.0: Breast Cancer Survival; Input

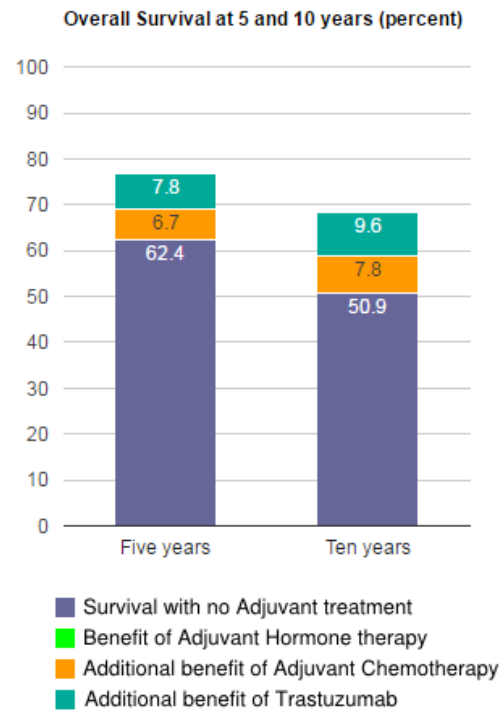
Age at diagnosis:	45		
Mode of detection:	○ Screen-detected	◉ Symptomatic	○ Unknown
Tumour size in mm:	20		
Tumour Grade:	○ 1	◉ 2	○ 3
Number of positive nodes:	2		☐ Micromet
ER status:	○ Positive	◉ Negative	
HER2 status:	◉ Positive	○ Negative	○ Unknown
KI67 status:	◉ Positive	○ Negative	○ Unknown
Gen chemo regimen:	○ No chemo	◉ Second	○ Third

Predict Survival | Clear All Fields | Print Results

PREDICT Tool Version 2.0: Breast Cancer Survival; Results

Five year survival
62 out of 100 women are alive at 5 years with no adjuvant therapy after surgery
An extra 7 out of 100 women treated are alive because of chemotherapy
An extra 15 out of 100 women treated are alive because of chemotherapy & Trastuzumab
Ten year survival
51 out of 100 women are alive at 10 years with no adjuvant therapy after surgery
An extra 8 out of 100 women treated are alive because of chemotherapy
An extra 17 out of 100 women treated are alive because of chemotherapy & Trastuzumab

To view the numbers in bars hover pointer over each bar-segment
(Or tap segment if using a mobile device)



*Disclaimer: **PREDICT** can only provide a general guide to possible outcomes in any individual case. As we are all different, for the more complete picture in your case, you should speak to your own specialist. You may wish to print this page out and share it with your specialist.*

Contact: info@predict.nhs.uk

Some issues with Predict

- Originally designed for clinical use in MDTs
- Then increasingly used in consultations
- Now being accessed on patient forums etc

Forum threads

Stats:

“for me it's a yes or no, will it come back or won't it, has it come back or hasn't it, percentages are sometimes hard to grasp”

Fear:

“Oh my goodness, I hate these things. I see them as a tool to inform your oncologist make treatment decisions. Use them for that but please don't frighten yourself.”

Evaluation:

“Very shocked to see how little extra protection the tamoxifen is giving me.”

Out of date:

“All statistics are, inevitably, out of date - the 10 year survival stats, say, have to be people who were treated ten years or more before”

Conflicting advice:

“Don't like my chances on the nhs one much prefer the Cancermath one!”

Results

Table | Curves | Charts | Texts | Icons

This table shows the survival percentages based on the information you have provided.

5 | 10 years after surgery

Treatment	Additional Benefit	Survival %
Surgery only	-	64%
+ Hormone therapy	8%	72%
+ Chemotherapy	6%	78%
+ Trastuzumab	4%	82%
Overall Survival		**82%**

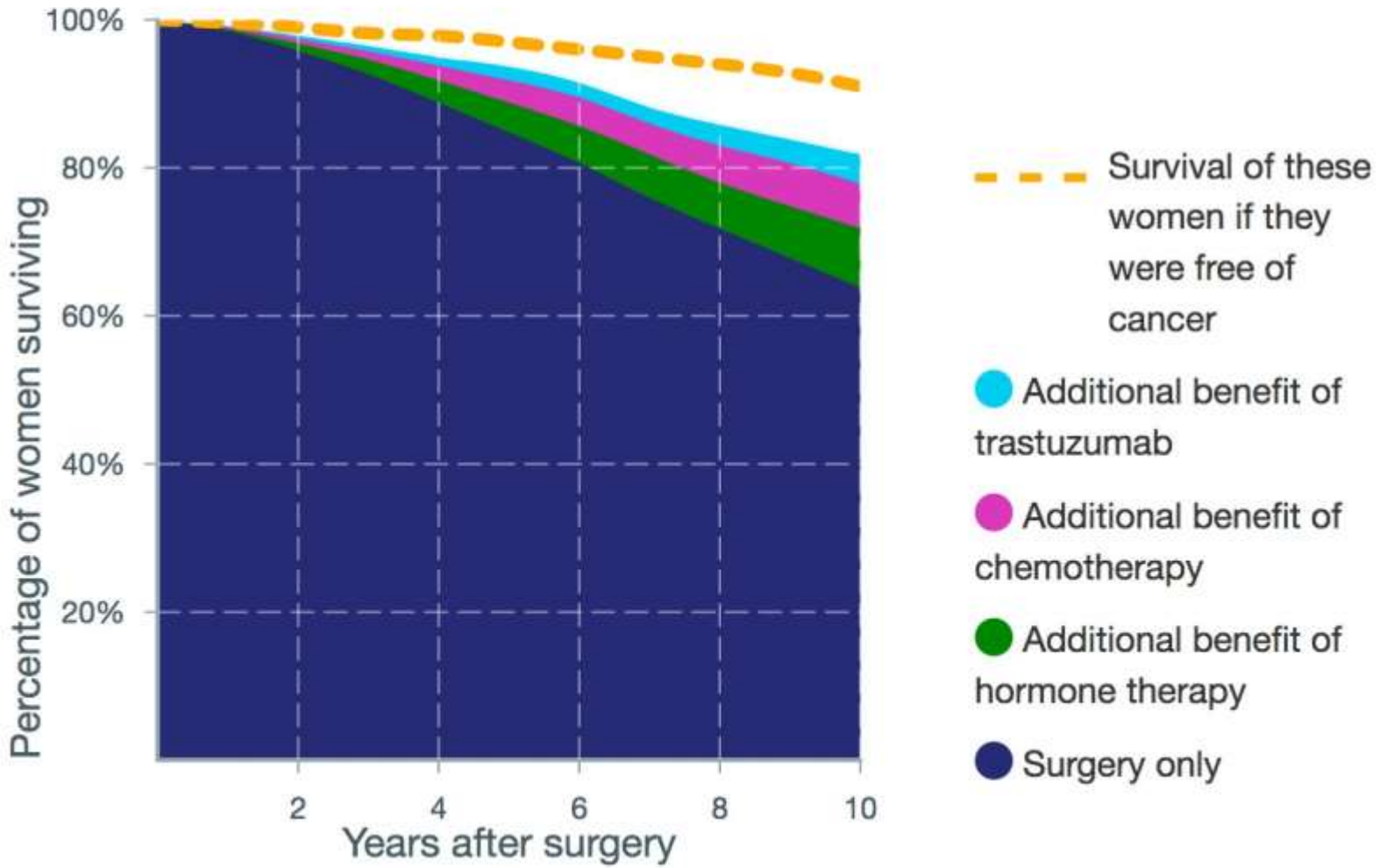
If these women were cancer free, 91% would survive 10 years.

Show ranges? i Yes | No

Results

Table | Curves | Charts | Texts | Icons

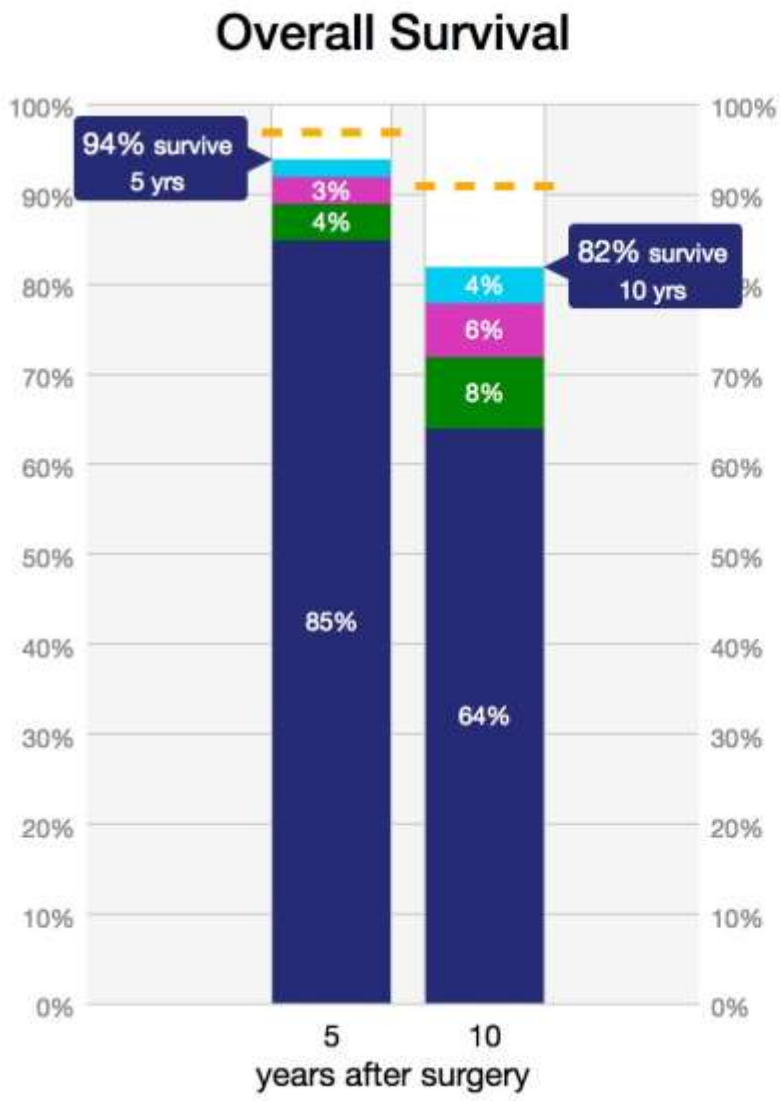
This graph shows the percentage of women surviving up to 10 years. These results are based on the inputs and treatments you selected



Results

Table | Curves | Charts | Texts | Icons

This graph shows the percentage of women surviving at 5 and 10 years. These results are based on the inputs and treatments you selected



Survival of these women if they were free of cancer

Additional benefit of trastuzumab is 2% at 5 years and 4% at 10 years

Additional benefit of chemotherapy is 3% at 5 years and 6% at 10 years

Additional benefit of hormone therapy is 4% at 5 years and 8% at 10 years

Surgery only survival is 85% at 5 years and 64% at 10 years

Results

Table | Curves | Charts | Texts | Icons

Based on the information you have entered:

5 | 10 years after surgery

64 out of **100** women are alive at 10 years with **surgery only**.

- **72** out of **100** women treated (an extra **8**) are alive because of **hormone therapy**.
- **78** out of **100** women treated (an extra **14**) are alive because of **hormone therapy** and **chemotherapy**.
- **82** out of **100** women treated (an extra **18**) are alive because of **hormone therapy**, **chemotherapy**, and **trastuzumab**.

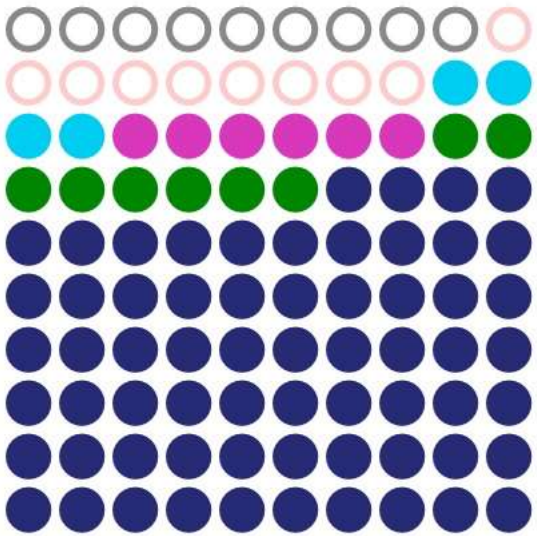
Of the women who would not survive, **9** would die due to causes not related to breast cancer.

Results

Table | Curves | Charts | Texts | Icons

This display shows the outcomes for 100 women. These results are based on the inputs and treatments you selected.

5 | 10 years after surgery



- 9 deaths due to other causes
- 9 breast cancer related deaths
- 4 extra survivors due to trastuzumab
- 6 extra survivors due to chemotherapy
- 8 extra survivors due to hormone therapy
- 64 survivors with surgery alone

Accessible and *useable*, OK. But *assessable*?

- How to prominently acknowledge limitations, caveats and uncertainties?

- Would this lose trust and credibility?

UK unemployment rises to 1.7m

20 April 2016 | Business

UK unemployment rose by 21,000 to 1.7 million between December and February, the Office for National Statistics (ONS) says.

Statistical bulletin:

UK Labour Market: April 2016

Estimates of employment, unemployment, economic inactivity and other employment-related statistics for the UK.

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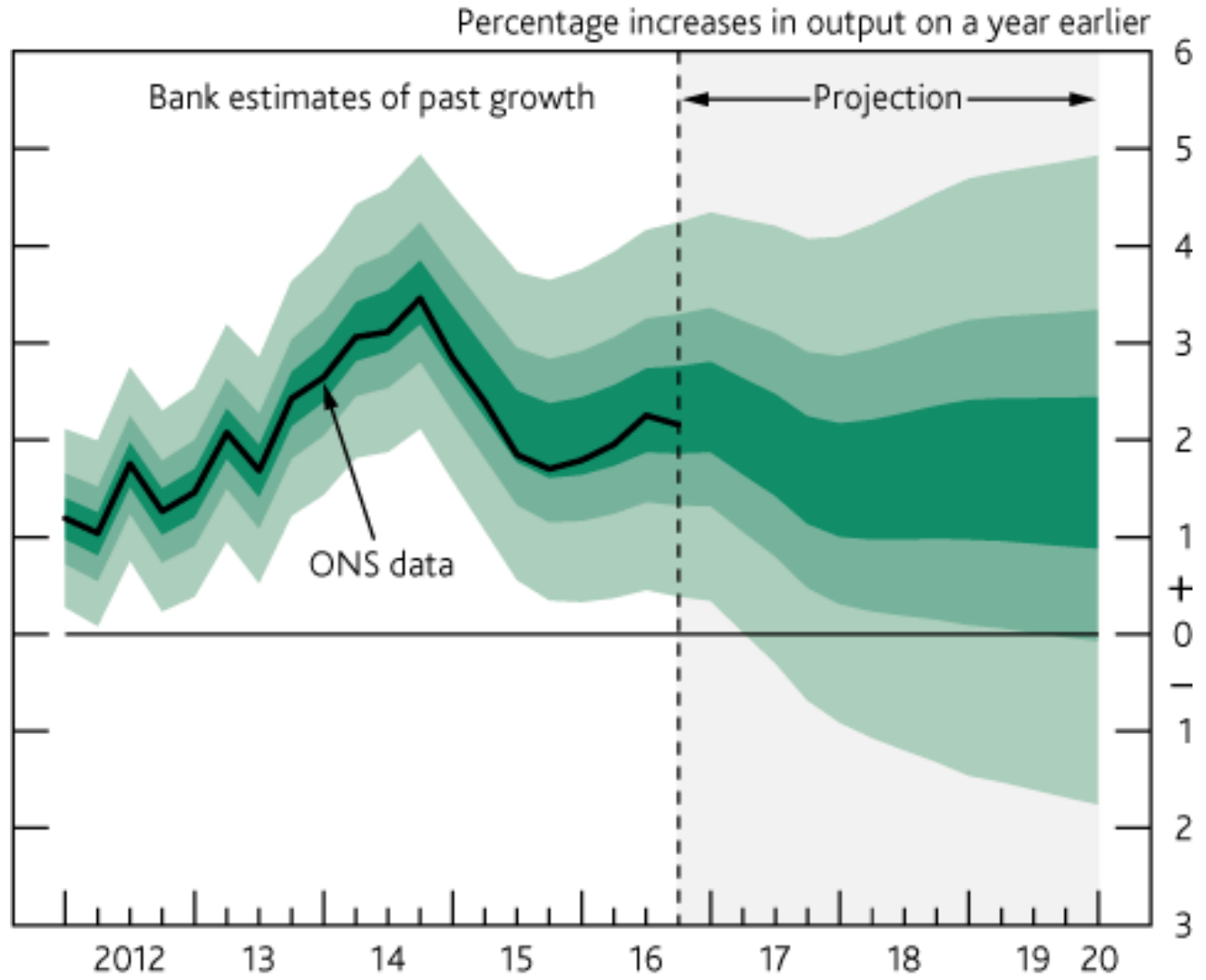
numbers. For example, for the 3 months to February 2016, the estimated change in the number of unemployed people since September to November 2015 was an increase of 21,000, with a 95% confidence interval of +/- 78,000. This means that we can be 95% certain the actual change in unemployment was somewhere between an increase of 99,000 and a fall of 57,000, with the best estimate being an increase of 21,000. As the estimated increase in unemployment of 21,000 is smaller than the confidence interval of 78,000, the estimated increase in unemployment is said to be "not statistically significant".

Bank of England Fan Chart – Feb 2017



Conclusions

- Aim for evidence that is
  - *accessible*
  - *useable*
  - *assessable*
- This means knowing and trusting the multiple audiences
- Consider multiple formats – one size does not fit all