Communicating risks and evidence to patients in a clear and balanced way

Alex Freeman
Winton Centre for Risk and Evidence Communication
Whatever you communicate must be...

USEFUL
Whatever you communicate must be...

USEFUL

TRUSTWORTHY
Whatever you communicate must be...

**USEFUL**

- The right information

**TRUSTWORTHY**

- Communicated in the right way
Whatever you communicate must be...

**USEFUL**
- The right information
- Communicated in the right way

**TRUSTWORTHY**
- Balanced
- Accurate
1. The right information...

What is:
• Relevant to this person?
• Useful to this person?

Do they have all the information they need to make an informed decision?
Roast potatoes and toast that's a bit too brown may cause cancer, say authorities

Other starchy foods such as crisps can contain acrylamide, a harmful chemical formed at high temperatures, says British food watchdog.
Bacon, ham and sausages have the same cancer risk as cigarettes warn experts

12:02, 23 OCT 2015 | UPDATED 20:27, 23 OCT 2015 | BY JANE KIRBY

Processed meats are now on World Health Organisation list of substances as carcinogenic as tobacco

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This website uses 'cookies' to give you the best experience. Using this website means you agree to our use of cookies. You can change which cookies are set at any time by following this link.
Statins ARE safe and we should give them to six million more people because benefits outweigh any harm, says biggest study ever

- Statins prevent at least 80,000 heart attacks and strokes in UK every year
- Tens of thousands more could be avoided if greater number took them
- Number taking statins could be doubled to 12million, researcher said
Statins ARE safe and we should give them to six million more people because benefits outweigh any harm, says biggest study ever

- Statins prevent at least 80,000 heart attacks and strokes in UK every year
- Tens of thousands more could be avoided if greater number took them
- Number taking statins could be doubled to 12million, researcher said

Now MORE experts claim statins are a waste of time: They say studies show cutting bad cholesterol fails to slash heart risk

- Millions being misled about the controversial drugs says group of doctors
- They said side-effects may be far more common than studies suggest
- A London cardiologist says millions of patients have been 'overmedicated'
Sources of reliable, trustworthy evidence

- NICE ‘evidence search’
  https://www.evidence.nhs.uk

- Cochrane library
  http://www.cochranelibrary.com

- EvidenceAlerts from BMJ/McMaster
  https://plus.mcmaster.ca/EvidenceAlerts/

- PubMedHealth What Works?

- InformedHealth
  https://www.informedhealth.org

- Science Media Centre
  http://www.sciencemediacentre.org
Individual risk...
What do individuals need to be told?

“The doctor is under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments.

The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.”
You’re in the hot seat...

Your patient has had the results of a cancer test come back positive. She asks ‘what are the chances that this means I really have cancer?’

You know the test is 90% accurate, but she is also in a low risk group for cancer – only 1% of her demographic are likely to have it. What do you tell her?
You’re in the hot seat...

Your patient has had the results of a cancer test come back positive. She asks ‘what are the chances that this means I really have cancer?’

You know the test is 90% accurate, but she is also in a low risk group for cancer – only 1% of her demographic are likely to have it. What do you tell her?

90%  81%  8%  1%
Results from 160 doctors posed a very similar question about the chances that a patient has cancer.

Results from 160 doctors posed a very similar question about the chances that a patient has cancer.

Correct answer is 8%.

A positive test result is either wrong (very unlikely), or it’s correct and she has a rare disease (also very unlikely).

It’s the balance if which is MORE unlikely...

Thinking in frequencies is easier...

1000 women

10 cancer

9 positive

9 negative

990 no cancer

99 positive

891 negative

\[
\frac{9}{9 + 99}
\]
2. Communicated in the right way...

Calls for ibuprofen sale restrictions after study finds cardiac arrest risk

Over-the-counter drug linked to 31% increased cardiac arrest risk, with the figure rising to 50% for diclofenac, says research

There have been fresh calls for restrictions on the sale of the painkiller ibuprofen after another study found it heightens the risk of cardiac arrest.

Taking the over-the-counter drug was associated with a 31% increased risk, researchers in Denmark found.

Other medicines from the same group of painkillers, known as non-steroidal anti-inflammatory drugs (NSAIDs), presented an even higher risk, according to the findings published on Wednesday in the European Heart Journal.

Diclofenac, available over the counter in the UK until 2015 and still taken on prescription, raised the risk by 50%.

Prof Gunnar Gislason of the University of Copenhagen, who led the study, called for tighter controls on the sale of ibuprofen and other NSAIDs. He said: “Allowing these drugs to be purchased without a prescription, and without any advice or restrictions, sends a message to the public that they must be safe.”
What is ‘risk’?
What is ‘risk’?

Probability
What is ‘risk’?

Probability

+ Perception
What is ‘risk’?

Probability

+ Perception (Feelings about probability/nature of threat)
Calls for ibuprofen sale restrictions after study finds cardiac arrest risk

Over-the-counter drug linked to 31% increased cardiac arrest risk, with the figure rising to 50% for diclofenac, says research
Probabilities: Absolute versus relative risks

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What are the chances of having a cardiac arrest in the first place?
Probabilities: Absolute versus relative risks

What are the chances of having a cardiac arrest in the first place?

1 in 10,000 (approx) (in the 30 day period considered by the paper)

Winton Centre blog: https://medium.com/wintoncentre/here-we-go-again-2d44693611ac
Probabilities: Absolute versus relative risks

What are the chances of having a cardiac arrest in the first place?

1 in 10,000 (approx) (in the 30 day period considered by the paper)

So, after a ‘30% increase’ your risk increases to:

1.3 in 10,000 (approx)

Winton Centre blog: https://medium.com/wintoncentre/here-we-go-again-2d44693611ac
The 3rd generation oral contraceptive pill ‘doubles’ the rate of potentially fatal venous thrombosis

UK Committee on Safety of Medicines 1995
The 3\textsuperscript{rd} generation oral contraceptive pill ‘doubles’ the rate of potentially fatal venous thrombosis

UK Committee on Safety of Medicines 1995

10,000 extra abortions
30,000 extra conceptions
The 3rd generation oral contraceptive pill ‘doubles’ the rate of potentially fatal venous thrombosis

UK Committee on Safety of Medicines 1995

10,000 extra abortions
30,000 extra conceptions

Absolute risks:
1 in 7000 for 2nd generation pill
2 in 7000 for 3rd generation pill

(Barnett & Breakwell, 2003)
How to express the absolute risk?

Cancer kills 2,414 people out of 10,000  
Cancer kills 24.14 people out of 100

Cancer kills 24.14% of people  
Cancer kills nearly a quarter of people
Some research on perception...

• Which cancer death rate is higher?

1286 out of 10,000  or  24.14 out of 100  

Yamagishi, 1997
Some research on perception...

• Which cancer death rate is higher?
  1286 out of 10,000  or  24.14 out of 100

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• Which bowl would you like to choose from?
  10 balls, 1 is a winner  or  100 balls, 7 are winners

  Denes-Raj & Epstein, 1994
Some research on perception...

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• Which of the following represents the biggest risk?
  1 in 100 or 1 in 1000 or 1 in 10
  Galesic & Garcia-Retamero, 2010
Some research on perception...

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% with incorrect answer: USA 25% Germany 28%
Some research on perception...

• Which cancer death rate is higher?
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  Yamagishi, 1997

• Which bowl would you like to choose from?
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• Which of the following represents the biggest risk?
  1 in 100 or 1 in 1000 or 1 in 10  
  Galesic & Garcia-Retamero, 2010

Keep the denominator the same!
Some more research...

- Is this prisoner high or low risk of reoffending?

If they are classified as:

20% chance of reoffending or

20 out of 100 prisoners like this would likely reoffend

Slovic et al, 2000
Some more research...

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If they are classified as:

20% chance of reoffending or

20 out of 100 prisoners like this would likely reoffend

Expressed as a frequency => much higher rating of ‘risk’

Slovic et al, 2000
Framing also affects feelings...

• Surgery: Of 100 people having surgery 90 live through the postoperative period, 68 are alive at the end of the first year and 34 are alive at the end of five years.

• Radiation Therapy: Of 100 people having radiation therapy all live through the treatment, 77 are alive at the end of one year and 22 are alive at the end of five years.

Which would you choose?
Framing also affects feelings...

• Surgery: Of 100 people having surgery 90 live through the post-operative period, 68 are alive at the end of the first year and 34 are alive at the end of five years.

• Radiation Therapy: Of 100 people having radiation therapy all live through the treatment, 77 are alive at the end of one year and 22 are alive at the end of five years.

18% chose radiation therapy
Framing also affects feelings...

• Surgery: Of 100 people having surgery 10 die during surgery or the post-operative period, 32 die by the end of the first year and 66 die by the end of five years.

• Radiation Therapy: Of 100 people having radiation therapy, none die during treatment, 23 die by the end of one year and 78 die by the end of five years.

Which would you choose?
Framing also affects feelings...

• Surgery: Of 100 people having surgery 10 die during surgery or the post-operative period, 32 die by the end of the first year and 66 die by the end of five years.

• Radiation Therapy: Of 100 people having radiation therapy, none die during treatment, 23 die by the end of one year and 78 die by the end of five years.

44% chose radiation therapy

(McNeil et al. 1982)
And so does the nature of the threat...
These all make it seem worse:

• Uncontrollable/involuntary
• Affects children
• Man-made
• Fatal
• Unfamiliar
• Exposed without knowledge
• Any benefits not visible
• Not scientifically well understood
• Catastrophic
• Experienced (by self or through someone else)
• Not equitable
Using graphics to help understanding...
Gun deaths in Florida

Number of murders committed using firearms

2005: Florida enacted its ‘Stand Your Ground’ law

Source: Florida Department of Law Enforcement

C. Chan 16/02/2014
CANCER DANGER IN BACON

Eating processed meat is as bad as smoking

REGULARLY eating bacon, burgers, sausages or ham causes bowel cancer, health chiefs revealed yesterday.

The stark warning was issued by the World Health Organization, after scientists officially linked cancer with eating processed meats for the first time.

Foods like hot dogs and bacon will now be placed in the same category as plutonium and smoking as things that definitely cause cancer.

And media are now urging us to ditch our BLTs, replacing them with the likes of a bean salad. After...
According to the World Health Organization...

Eating **50g** of processed meat a day - less than two slices of bacon - increased the chance of developing colorectal cancer by **18%**.

Source: IARC/WHO
© Global News
Firstly, what are the actual absolute figures?

<table>
<thead>
<tr>
<th>NUMBERS</th>
<th>GRAPHS</th>
<th>PICTURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>background risk: 6% (baseline risk: 0.06)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>increase: 18% (relative risk: 1.18)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The risk of developing bowel cancer for people is 6%. The risk for those eating a bacon sandwich every day is increased to 7%.

On average, for one extra person to develop bowel cancer, we would need a group of 93 more people eating a bacon sandwich every day. Of these, 6 would develop bowel cancer anyway.
background risk: 6% (baseline risk: 0.06)

increase: 18% (relative risk: 1.18)

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OBAMACARE ENROLLMENT

AS OF MARCH 27
6,000,000

MARCH 31 GOAL
7,066,000

SOURCE: HHS
background risk: 6% (baseline risk: 0.06)

increase: 18% (relative risk: 1.18)

The risk of developing bowel cancer for people is 6%. The risk for those eating a bacon sandwich every day is increased to 7%.

On average, for one extra person to develop bowel cancer, we would need a group of 93 more people eating a bacon sandwich every day. Of these, 6 would develop bowel cancer anyway.
For every person they do help (blue), the ten highest-grossing drugs in the United States fail to improve the conditions of between 3 and 24 people (red).

1. **ABILIFY** (aripiprazole)  
   Schizophrenia

2. **NEXIUM** (esomeprazole)  
   Heartburn

3. **HUMIRA** (adalimumab)  
   Arthritis

4. **CRESTOR** (rosuvastatin)  
   High cholesterol

5. **CYMBALTA** (duloxetine)  
   Depression

6. **ADVAIL DISKUS** (fluticasone propionate)  
   Asthma

7. **ENBREL** (etanercept)  
   Psoriasis

8. **REMICADE** (infliximab)  
   Crohn’s disease

9. **COPAXONE** (glatiramer acetate)  
   Multiple sclerosis

10. **NEULASTA** (pegfilgrastim)  
    Neutropenia

From *Nature*, April 2015, Nicholas J. Schork, director of human biology at the J. Craig Venter Institute
Whatever you communicate must be...

**USEFUL**
- The right information
- Communicated in the right way

**TRUSTWORTHY**
- Balanced
- Accurate
3. Balanced...?

Case study: Cancer screening information

Women in which of these countries were best informed about the benefits of mammography?

• UK
• Germany
• Netherlands
• Spain
• Russia
• Poland
• France
• Italy
• Austria
<table>
<thead>
<tr>
<th>Country</th>
<th>Realistic</th>
<th>Overestimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Russia</td>
<td>18%</td>
<td>82%</td>
</tr>
<tr>
<td>Spain</td>
<td>7%</td>
<td>93%</td>
</tr>
<tr>
<td>Italy</td>
<td>7%</td>
<td>93%</td>
</tr>
<tr>
<td>Austria</td>
<td>5%</td>
<td>95%</td>
</tr>
<tr>
<td>Poland</td>
<td>5%</td>
<td>95%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>4%</td>
<td>96%</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>2%</td>
<td>98%</td>
</tr>
<tr>
<td>France</td>
<td>2%</td>
<td>98%</td>
</tr>
<tr>
<td>Germany</td>
<td>2%</td>
<td>98%</td>
</tr>
</tbody>
</table>

Gigerenzer, Mata & Frank Journal of the National Cancer Institute 2009
“Breast screening has been shown to reduce the risk of dying from breast cancer by around 35%.”

The Welsh NHS leaflet Breast Screening

“Screening mammograms . . . reduce the chance of dying from breast cancer by approximately 33%.”

New Zealand Breast Cancer Foundation
What ARE the benefits of mammography?

<table>
<thead>
<tr>
<th>Benefits?</th>
<th>No Screening</th>
<th>Screening over 10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer mortality</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Total cancer mortality</td>
<td>21</td>
<td>21</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Harms?</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>False positives with biopsies</td>
<td>–</td>
<td>50 – 200</td>
</tr>
<tr>
<td>Unnecessary treatments (e.g. lumpectomy)</td>
<td>–</td>
<td>2 - 10</td>
</tr>
</tbody>
</table>

Gøtzsche PC & Jørgensen KJ 2013. Cochrane Database of Systematic Reviews
BREAST SCREENING

The Facts

Why do I need breast screening?

- Breast screening saves an estimated 1,400 lives each year in this country.
- We will call back some women for more investigations if we are not sure about their mammogram. After more tests, we will find that many of these women will not have cancer. If you are called back it can cause worry.
New NHS leaflets, 2013

“Consider the offer”

• Presents pros and cons
• Does not make recommendation
• ‘Uniform reporting of harms and benefits’
• No use of relative risks
Fact Box:

• Clear, relevant question

• Summary of data in frequencies, not percentages

• Absolute risks, not relative

• Constant denominator (out of 1000)

• Infographic to illustrate the numbers:
  • Frequency tree
  • Icon array to show break down of harms/benefits
    (although this one is quite complicated...)

• Links for references!
4. Accurate

UK unemployment rises to 1.7m

UK unemployment rose by 21,000 to 1.7 million between December and February, the Office for National Statistics (ONS) says.
The number of people unemployed for the same period was estimated at 1,696,000, with a stated 95% confidence interval of +/- 72,000. This means that we can be 95% sure that the true number of unemployed people was between 1,624,000 and 1,768,000. Again, the best estimate from the survey was that the number of unemployed people was 1,696,000.

UK unemployment rose by 21,000 to 1.7 million between December and February, the Office for National Statistics (ONS) says.
# How to be honest about your degree of certainty

**Dabigatran versus warfarin for atrial fibrillation**

- **Participants:** Patients with atrial fibrillation and a risk of stroke (CHADS2 score = 1 or higher)
- **Interventions:** Dabigatran (150 mg twice daily)
- **Comparison:** Warfarin

## Outcomes

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Plain language statements</th>
<th>Absolute Effect Without Dabigatran</th>
<th>Absolute Effect With Dabigatran</th>
<th>Relative effect</th>
<th>Certainty of the evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Death</strong></td>
<td>Dabigatran probably reduces the risk of dying.</td>
<td>76 per 1000</td>
<td>68 per 1000</td>
<td>RR 0.89 (0.79 to 0.91)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Follow-up: 2 years</td>
<td></td>
<td>Difference: 8 patients less per 1000 (95% CI: 17 less to 1 more per 1000 patients)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Nonfatal stroke</strong></td>
<td>Dabigatran reduces the risk of a nonfatal stroke.</td>
<td>34 per 1000</td>
<td>23 per 1000</td>
<td>RR 0.64 (0.51 to 0.81)</td>
<td>High</td>
</tr>
<tr>
<td>Follow-up: 2 years</td>
<td></td>
<td>Difference: 11 patients less per 1000 (95% CI: 15 to 6 less per 1000 patients)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
How to be honest about your degree of certainty
Whatever you communicate must be...

**USEFUL**

- The right information
  (What does this particular patient need to know? Are you giving them everything they need to know?)

- Communicated in the right way
  (Beware how you present the numbers, your language, and try to use graphics - carefully)

**TRUSTWORTHY**

- Balanced
  (Present both potential harms and potential benefits in an even-handed way)

- Accurate
  (Give links and references to deeper information And be upfront about your level of uncertainty)