



Working to end
evidence distortion
in medicine

The problem

Around half of all clinical trial results are never made public.

Patients are harmed because we do not know how safe and effective treatments really are.

A patient's story: Emma Yasinski

- “It’s more than a little unsettling to think that I’ll live for another 70 years or so with this device in my heart, but may never know what the research said about how it works.”



Received a novel mesh umbrella to cover a hole in her heart at age 7

A doctor's story: Dr Aus Alzaid

- “Doctors like myself would have continued prescribing the drug for all the years the trial was left unpublished, potentially and unknowingly exposing millions of patients to the risk of mental decline...”



Worried about dementia risk to his patients with diabetes

Presentation structure

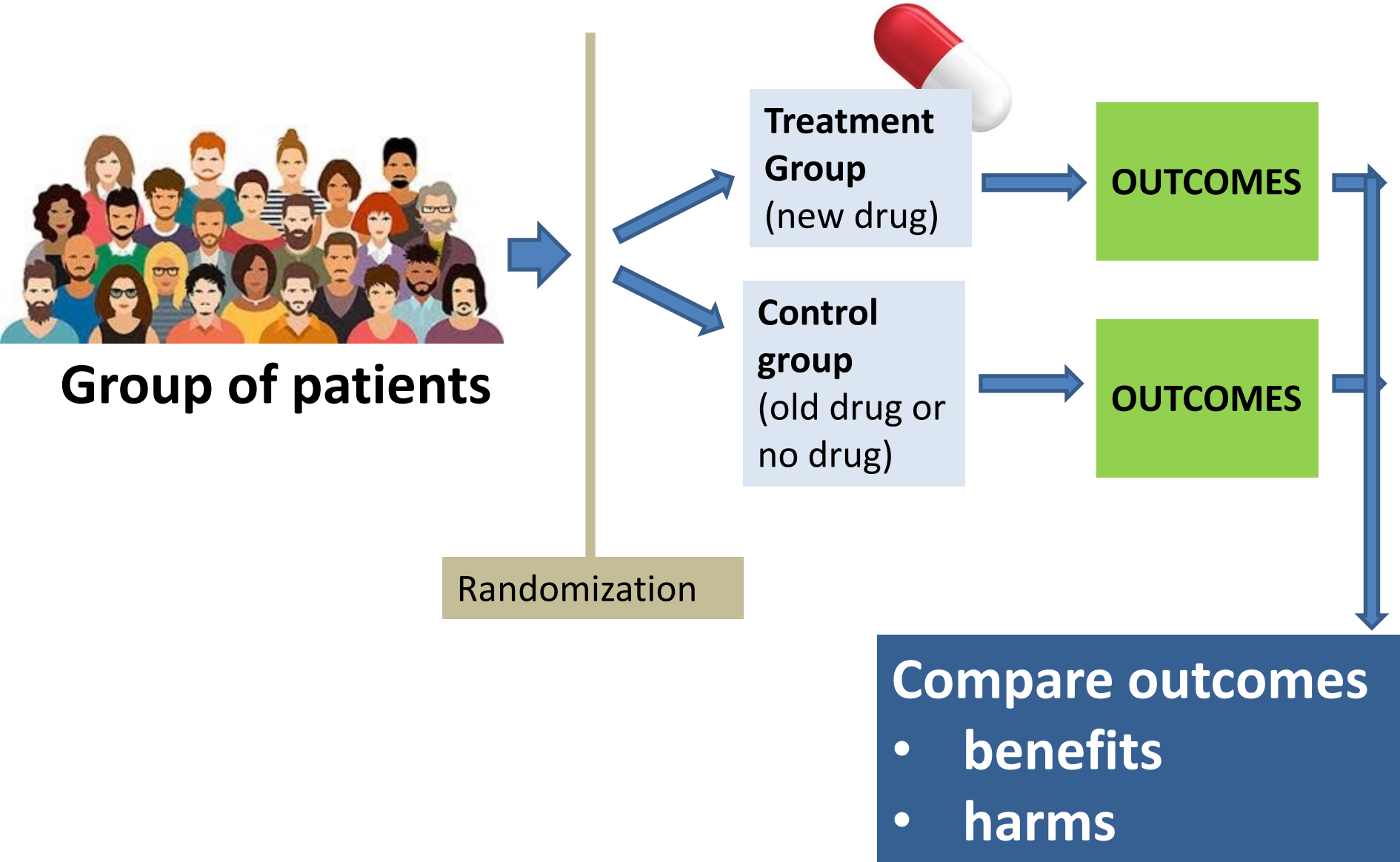
1 We have a problem

2 Why it matters

3 TranspariMED approach

4 TranspariMED impact

What are clinical trials?



Hidden evidence

What the FDA saw:

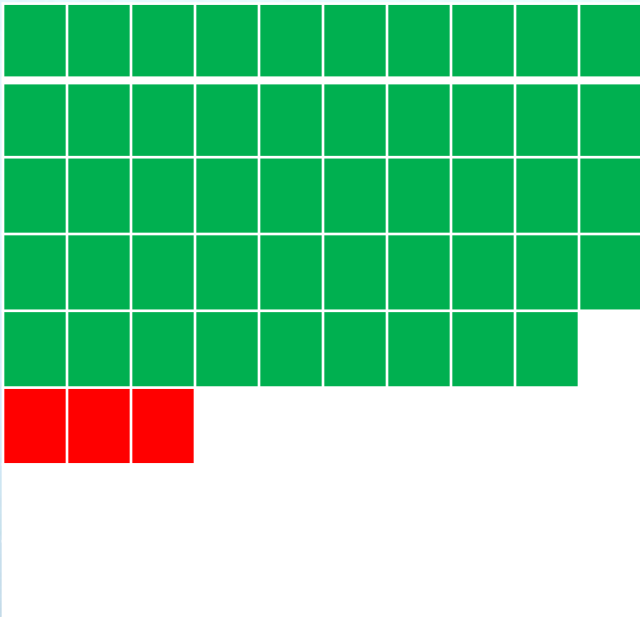
- **74 trials total**
- 38 trials had positive results
- 36 trials had negative results



Hidden evidence

What independent scientists and doctors saw:

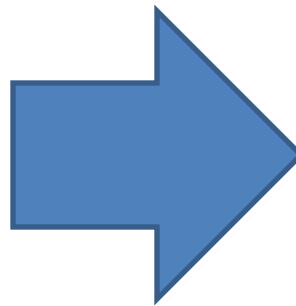
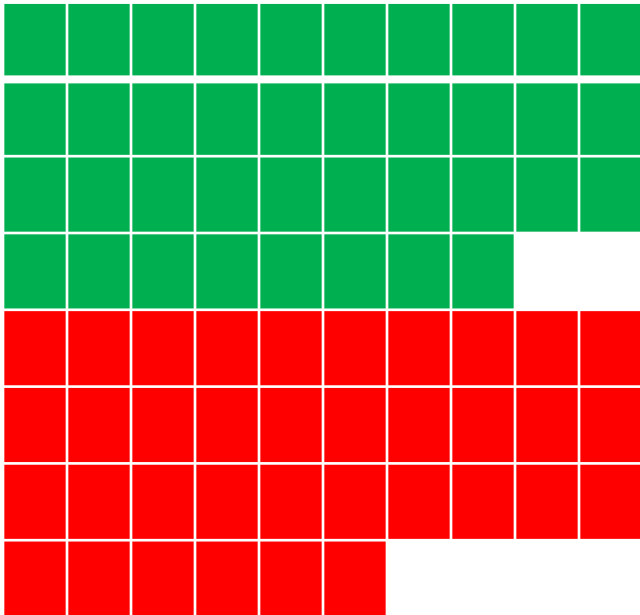
- **52 trials total**
- 49 trials had positive results
- only 3 trials had negative results



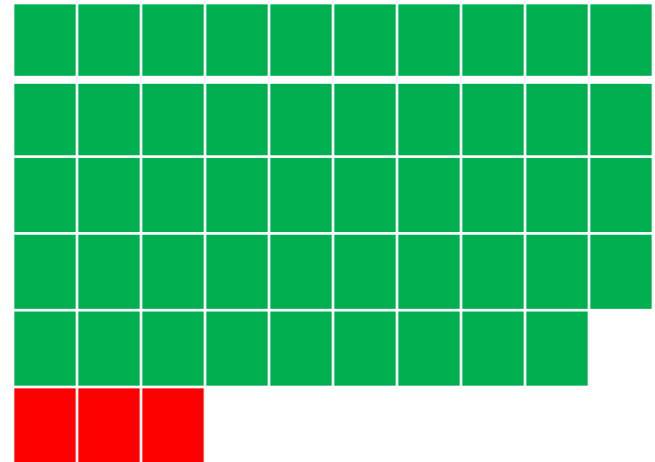
What happened here



Trials done: 74



Trials visible: 52

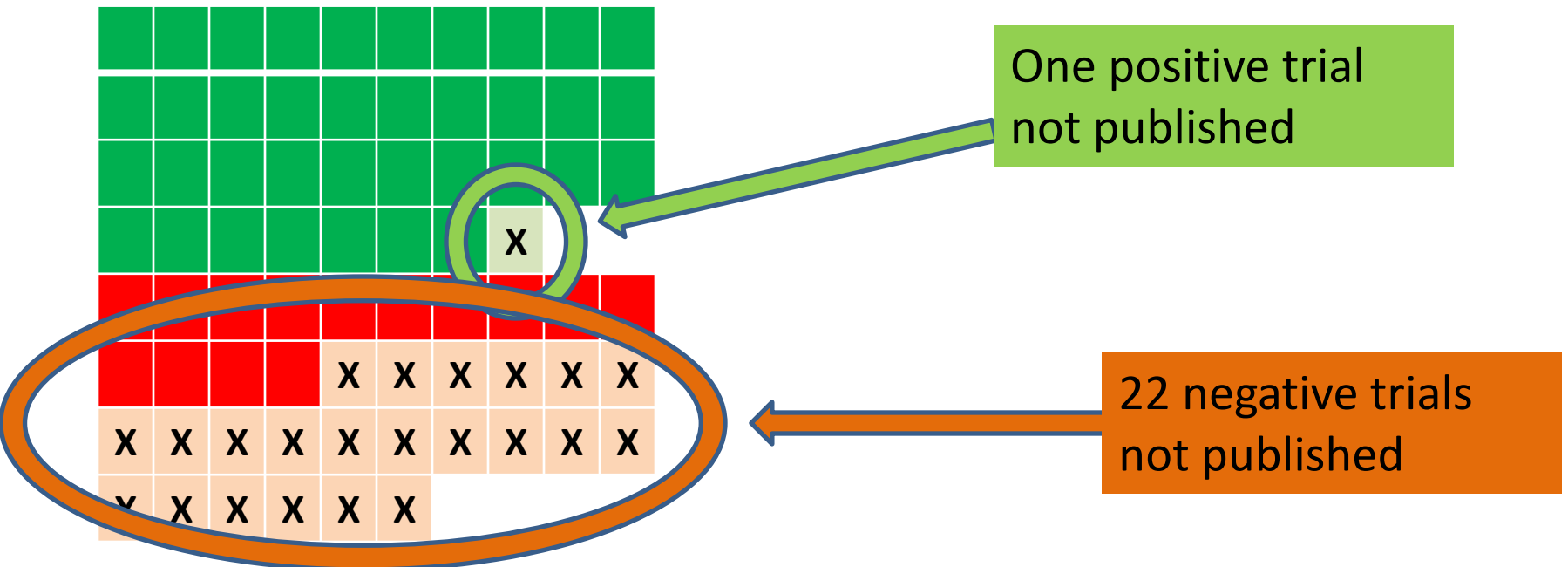


Source: Turner at al. "Selective Publication of Antidepressant Trials and Its Influence on Apparent Efficacy" *NEJM*, 2008

1. Publication bias

- The results of around half of all trials never get published
- Trials with negative results are far less likely to get published

Trials done: 74



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Case study 1: Heart disease

- Drug: Lorcainide (and other anti-arrhythmic drugs)
- Use: Patients who had suffered heart attacks



- 1980 academic trial with unusual deaths unpublished
- Dangers only recognized in 1988
- **“20,000 to 75,000 lives were lost each year in the 1980s in the United States alone” (JAMA)**

Case study 2: Depression

- Drug: Paroxetine
- Claim: safer than alternatives and just as effective
- **Cost: 4x as high as other antidepressant drugs**

- Data on 74% of trial participants had remained invisible
- Long battle for full data from Pfizer
- Harms understated & effectiveness still contested



Case study 3: Global pandemic

- Drug: Tamiflu
- Sales: \$18 billion
- **Cost: 96 countries stockpiled Tamiflu** patients

Tamiflu®

anti-viral drug

known

FOY29.COM
FDA WARNS ABOUT SERIOUS
SIDE EFFECTS OF TAMIFLU
KUTZTOWN AREA SC
INSTRUCTIONS: OPEN 2 HRS. LATE

flu (H1N1)



- Results from 8 trials not published
- Full data show drug is largely useless
- **WHO removed from essential medicines list in 2017**

10 capsules

No transparency means...

- **Positive effects hyped**
- **Public health funds misspent**
- **Research funds wasted (\$85 billion per year!)**
- **Scientific progress slowed down**

Important: It's not just Big Bad Pharma



Universities perform **worse** than industry

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How we are fixing it



1. Build broad coalitions



How we are fixing it



2. Develop solutions



How we are fixing it



3. Ramp up public pressure



Today 28
call f

an 1
ities

Trans and files ethics complaint
over the reported cancer trial result

Slechts een op de vier medicijnstudies
openbaar in België

Süddeutsche Zeitung

The Washington Post

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Day to day impact



European medicines regulators set to tackle missing clinical trial results

MISSED DATA



FDA to issue fines over hidden clinical trial results



German universities report record number of clinical trial results

**ASSISTANCE
PUBLIQUE**

France: Key institutions pledge to make clinical trial results public



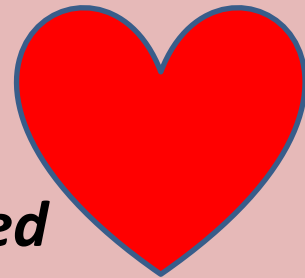
New Zealand cracks down on unreported clinical trials

Three big victories for patients



TranspariMED convinces UK government to set up national monitoring system
→ *in future all UK trial results will be reported*

TranspariMED convinces 23 top universities in Europe to make all drug trial results public
→ *thousands of missing results now being reported*



TranspariMED campaigning leads U.S. companies and universities to publish missing results
→ *national reporting rate soars from 50% to 75%*

The logo for TranspariMED is a large black oval with a white vertical bar on the right side. The word "Transpari" is written in white on the black background, and "MED" is written in black on the white background.

Transpari **MED**

Working to end evidence distortion in medicine

Thank you.

TranspariMED.org

[@TranspariMED](https://twitter.com/TranspariMED)

Never forget:

Every clinical trial directly affects **hundreds of real people.**



BY