BAD PHARMA

Ben Goldacre

Waterstone's Book Club
Reading Guide

ABOUT THE AUTHOR:

Ben Goldacre is a doctor, writer, broadcaster and academic who specialises in unpicking dodgy scientific claims from drug companies, newspapers, government reports, PR people and quacks. His first book, *Bad Science*, reached Number One in the non-fiction charts, sold over half a million copies, and has been translated into twenty-five languages. He lives in London.

ABOUT THE BOOK:

Doctors and patients need good scientific evidence to make informed decisions. But instead, companies run trials on their own drugs, which distort and exaggerate the benefits by design. When these trials produce unflattering results, the data is simply buried. All of this is perfectly legal. In fact, even government regulators withhold vitally important data from the people who need it most. Doctors and patient groups have stood by too, and failed to protect us. Instead, they take money and favours, in a world so fractured that medics and nurses are now educated by the drugs industry.

These are not abstract problems: patients are harmed, in huge numbers.

Bad Pharma is a clear and witty attack on this deplorable, fascinating, terrifying, brilliant mess. It shows exactly how the science has been distorted, how our systems have been broken, and how easy it would be to fix them.

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REVIEWS:

'Goldacre has managed to achieve something marvellous here … He has humanised the numbers so they become relevant. More than that, this is a book to make you enraged – properly, bone-shakingly furious – because it's about how big business puts profits over patient welfare, allows people to die because they don't want to disclose damning research evidence, and the tricks they play to make sure doctors do not have all the evidence when it comes to appraising whether a drug really works or not. A work of brilliance' *Daily Telegraph*

'This is an important book. Ben Goldacre is angry, and by the time you put *Bad Pharma* down, you should be too' *New Statesman*

'What keeps you turning its pages is the accessibility of Goldacre's writing … his genuine, indignant passion, his careful gathering of evidence and his use of stories, some of them personal, which bring the book to life' *Guardian*

'This is a book that deserves to be widely read, because anyone who does read it cannot help feeling both uncomfortable and angry' *The Economist*

'*Bad Pharma* will confirm his status as a thorn in the side of the medical Establishment – Goldacre's detailed research would be hard for any drug-company executive to contradict' *Sunday Times*

LINKS:

Email: ben@badscience.net
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Twitter: @bengoldacre
Ted talk: 'What Doctors Don't Know About the Drugs They Prescribe' at bit.ly/PIjL9Q

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READING GROUP QUESTIONS:

- Having read *Bad Pharma*, what surprised you most? The behaviour of pharmaceutical companies, of regulators, of academic journals and their editors, of the professional medical bodies, of doctors?
- Was there one incident related in *Bad Pharma* that shocked you more than any other?
- Whose fault do you think these problems are? Do you think anyone or any specific profession can be blamed?
- Do you think the author is too kind to anyone? Too harsh?
- Looking at Ben Goldacre's recommendations for fixing the system (perhaps focussing on a small number of them, or those from one section alone), how likely do you think they are to be implemented? Do you think they can work? What obstacles, if any, do you see?
- Would you consider volunteering for a medical trial on a treatment you were taking for an illness you had? What would make you more or less likely to do so?
- Clinical trials to get a new drug on the market generally involve 300–2000 people. Did this number surprise you? If you hadn't been told this, how extensive would you have imagined the trials to be?
- While you were reading, or since you have read, *Bad Pharma*, has there been a news story – about a drug, or the pharmaceutical industry perhaps – that you've seen in a different light, whether the story was positive or negative, given what you now know?
- Are you aware of any other industries whose research can be opaque, and whose marketing and advertising might be subjected to greater scrutiny? Consider, for example, the cosmetics industry, which is often accused of making unfounded 'pseudoscientific' claims.
- Is it wrong to hold medicine to higher standards than other sectors?
- Do you think there are any similarities between Big Pharma and Big Oil, Big Tobacco and Big Business generally? Are there strategies they can all employ to ensure their continuing success?

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THE INSPIRATION FOR *BAD PHARMA*:

I wrote *Bad Pharma* because we need to fix a set of problems that have been allowed to persist in my own profession – medicine – for far too long. Trial results can be withheld from doctors and patients, quite legally; trials are often poorly designed, or biased towards the sponsor's product; doctors are misled about which treatments work best; and so on. These problems have a real impact on patient care, because we don't have the information we need to choose the most effective treatments for patients. Often, we tolerate actively misleading information.

I've spent a long time, as a doctor, wondering why these problems have been able to persist for so long, especially since they're all routinely documented in the academic literature, and they're all perfectly fixable. Drug companies could easily turn a profit, without misleading doctors, or hiding unflattering data.

Complacency is clearly part of the explanation. Although we work with life and death, doctors, academics, pharmacists, patient groups, regulators and the rest of us in medicine are the same as any other set of workers. We can all easily fall into a rhythm of 'getting by', responding by reflex to proximate incentives: getting the next grant, getting the next academic publication, getting through the next clinic, processing the paperwork, and keeping our heads above the waterline.

Once you get into the detail, it's easy to see how the problems described in *Bad Pharma* have persisted, because they exploit the small incentives in peoples' everyday lives.

Doctors don't want to pay their own money out, for example, to stay up to date with the new evidence on new treatments: not in their fifties, not when they feel like qualified doctors, and not if they don't have to, with mortgages and their kids' university fees to think about. A few education sessions from a drug company seem harmless enough, especially when all your friends do it, and you think you're clever enough to spot a ruse.

And regulators have plenty to worry about with their own decisions, and the petty legal squabbles they fight every week with drug companies: they don't want to open up a new front, and try to force companies to share their results with doctors and independent academics. Especially not when that information could be used to second-guess, or criticise, the regulatory decisions made in the first place.

But more than that, these problems have persisted because there haven't been enough people, from outside medicine, peering in and asking us the embarrassing questions. Time

and again, at public events and over email, people have asked me: why are people allowed to withhold trial results, and why didn't I know about this before?

The best answer I can give you is that it takes a few dozen pages – a good hour of your life – to get a good understanding of why this problem even matters. Then it takes a few hours more reading to trust me when I say that the problem hasn't been fixed, despite the protestations of industry and regulators to the contrary. In fact, I don't think of myself as an angry person, but this is where my patience breaks down: it's bad enough that these issues persist in medicine, passively; but when people then actively claim that they don't exist, they are standing in the way of efforts to fix things and move forwards.

This, I think, is why people throw the book across the room so often. When they read, for example, in the last chapter, 'Better Data', about the Ethical Standards in Health and Life Sciences Group – the great and the good of British medicine and academia – who stand up and say outright that there is a robust regulatory framework around trial results, people are rightly appalled. I get emails on that one paragraph, spitting fire. People gasp when you put that organisation's quotes up on slides at public talks. And yet, when I've tried to talk to the people who represent doctors and academics in the Group – to explain the harm that they've done, not just to medicine, but to our collective reputation – they seem to struggle.

So this, in a very roundabout way, is why I wrote the book: I think we in medicine need your help, the public, to see the wood for the trees. I think we need you to make us fix these broad, bird's-eye-view issues, where we have failed.

But there's a cheerier reason. I've always thought that explaining how science goes wrong is the best way to explain how science really works. There is a beauty in the clever ways that trials can be rigged by design, and it speaks to the reasons we do trials in the first place: because we want them to be fair tests of which treatment works best.

And before you even get that far, to understand how evidence-based medicine has been perverted, you have to understand how it's supposed to work in the first place. I'm constantly staggered that this isn't taught in schools, explained on television, and understood by all normally educated people, as the parts of the body or the plays of Shakespeare are. Given so many patients' endless preoccupation – quite understandably – with side effects, it's amazing to me that there aren't clear and accessible explanations of exactly how we monitor and measure side effects flying off the shelves already. Secretly, that's what this book is, too: a basic primer in epidemiology, the science we use to find out what's good for us, or bad for us, in medicine. But a primer with bad guys, to keep you reading.

Lastly, it's a book because it had to be. There are lots of things in science that you can explain in twenty minutes, and there's nothing wrong with that. There are lots of books that are a string of twenty-minute vignettes: fair enough, if you want to gorge on one writer's vignettes. But the interesting thing to me, about the problems in *Bad Pharma*, is that they are all interrelated. That means they all reinforce each other, but it also poses some interesting challenges when you come to explain them. Computer programmers talk about 'dependency issues': you need to define A, B and C, in a program, before you can define G, H and I. In medicine, and in *Bad Pharma*, you have the same problem, but you often also need to know a little bit about H and I to understand A and C. Things like this preoccupy me, and create rooms filled with post-it notes and string. It also explains why there's a tiny bit of repetition, here and there, because it's a book that had to be accessible to people who know nothing about the subject area, as well as people who think they know it backwards.

My publishers have asked me to talk about how I wrote the book, but as you can see, that will rapidly descend into talk of tools. What follows is more detail than anyone needs, and probably more than I should confess.

Broadly speaking, my life is spent hoovering up information, loving it, filing it, and using it. I read a lot through Feedly, which lets me subscribe to multiple journals, blogs and other news feeds. I also pick things up from Twitter, mailing lists, conferences and conversations. When I stumble on anything I might want to use again – an academic paper, an insight, a thought, an explanatory framework, an author I want to read more from – I store it in a service called Evernote, which synchronises my notes across my phones, tablets and laptops. I'm obsessed with devices and systems, and I'll cheerfully spend four hours automating a task that could be done by hand in two minutes.

In Evernote, then, I have piles of things in queues, waiting to be pulled off and worked on: a bank of ideas that would work for single articles; a pile of 'bad graphs' that I've not got a use for yet; piles of notes for books I'll write one day; ideas for academic studies someone needs to do; and so on. When I sit down to work, I can go to those piles, and get going. Meanwhile, any academic papers also go into Zotero, an amazing free and open-source reference manager that lets you store papers in a hierarchy by subject (and builds bibliographies very neatly, when you've cited hundreds of them).

People sometimes ask how long it took to write *Bad Pharma*, and there's no clear answer, because it can't be disentangled from this ongoing game of populating the giant, delicious, monstrous, synchronising ecosystem of knowledge that lives and breathes across all these electronic devices and services. Sometimes I feel overwhelmed by the sheer scale of the

information that's available to us all now: it can make some people feel quite anxious (it makes me feel like I want to live for ever). But working in this way has made me realise that putting a frame around disparate facts, and constructing an argument, is the one thing that humans will probably always be needed for.