Which of these would you wager is pure science fiction, and which currently being developed in the lab? Such is the speed and excitement of today’s bio-medical research – sprinting from the starting gun that was the Human Genome Project – it’s sometimes hard to tell. In a unique collaboration, fourteen short story writers have been invited to explore the increasingly grey area between the fantastical and that which is already within our reach. Closely collaborating with scientists and ethicists working at the frontiers of their respective fields, each writer has been tasked with predicting some of the potential ‘ethical side-effects’ of this groundbreaking work. Not all progress, after all, is progressive. And dark forces are afoot that threaten to hijack what many declared would be ‘the century of biology’.

the AUTHORS
Jane Feaver
Simon Ings
Annie Kirby
Toby Litt
Sara Maitland
Adam Marek
Gregory Norminton
Sean O’Brien
K. J. Orr
Justina Robson
Jane Rogers
Dilyse Rose
Sarah Schofield
Simon Van Booy

the SCIENTISTS & ETHICISTS
Prof Martyn Amos
Dr Melissa Baxter
Dr Jane Calvert
Prof Sarah Gilbert
Dr Jane Haley
Prof Stephen Lawrie
Dr Nick Love
Dr Ian McGonigle
Dr Ainsley Newson
Prof Burkhard Schafer
Dr Simon Stott
Dr Nihal Vrana
Prof Joanna Wardlaw
Dr Angharad Watson
Prof Bruce Whitelaw

STORIES from the FAR SIDE of RESEARCH
EDITED BY RA PAGE
BIO-PUNK

Stories from the
Far Side of Research

Edited by
Ra Page
Introduction

Commissioning an anthology of short stories is rather like conducting a series of laboratory experiments. You start with a hypothesis – that the theme of the book, some burning issue out here in the non-fictional world, can have genuine, new light shed on it by fiction writers; you then establish certain experimental parameters – clarifying what the authors can and can’t write about; finally, you make sure that laboratory conditions are preserved throughout – that the ‘Petri dish of fiction’ is hermetically sealed and the drama inside plays out as if it were in the real world, but with no confusion or contamination leaking between the two. The results are typically scientific too: diverse, unpredictable, sometimes even game-changing.

With this particular experiment fourteen authors were invited to respond to exciting new areas of bio-medical research so as to explore, through fiction, potential social or ethical dilemmas that might arise from them. Scientists and bio-ethicists were attached to each research area, and accompanied the author who chose it in the development of their story – from an initial consultation, through to writing an explanatory afterword to the finished piece.

The parameters given to the authors were straightforward. Firstly, the stories needed to be scientifically accurate; they had to be based on current research and stay consistent with the theory and practice as it now stands – the consulting scientists and ethicists had recourse to correct errors in the drafting process, as well as address issues of likelihood in their afterwords (see Dr Sarah Gilbert’s response to Jane Feaver’s...
vaccine trial story). Secondly, the stories had to be set within the confines of a fictional society that ostensibly had its citizens’ best interests at heart.

As with all experiments, some tests fail immediately. The agar stays clear; the Petri dish a dud. Early in this experiment, one author we approached – himself a well-seasoned SF writer – responded to the commission by saying, flatly, that there was nothing to write about. His argument was with the very idea of bio-ethics – that rapidly emerging, interdisciplinary study whose set of concerns offered an umbrella concept for this commission. Bio-ethics, he argued, so often poses a series of ‘ethical concerns’, the answers to which are ‘trivially obvious in terms of generally accepted norms of conduct and policy. Of course, these norms can be criticised and can change, but in lots of the topics [posed in this commission] the “ethical problem” only arises if the problem is posed in terms of much more controversial, and much less widely held, positions such as animal rights or Roman Catholicism.’ Bio-ethics may be a growth industry, but nothing much was growing in this Petri dish.

Putting aside this respondent’s considerable underestimation of what he calls ‘much less widely held positions’, it was a worrying start. Some of the authors invited (and some of the fictional characters they created) were indeed of a religious leaning and/or championed animal rights. Theirs may well be ‘less widely held positions’, and the experiment may well be rigged from the start, to get a desired ‘outrage result’.

Early returns from other writers, however, suggested there was more to the bio-ethics question than the ‘trivially obvious’. Fairly deep-seated dilemmas were pointed to at opposite ends of the bio-medical process. In K.J. Orr’s Amazonia-set ‘Elegy for a Bio-Pirate’, we are confronted with a paradox at the very onset of research: should we invest in the utilization of a traditional medicine even if such ‘investment’ is likely to destroy both the knowledge base (shaman-led village tradition) and the environment (the rainforest) that have preserved the medicine and all knowledge of it thus far? Dilys Rose’s airport-set ‘EFEMERI’ considers dilemmas at the other end of the spectrum: an alternative application for a technology originally developed for medical purposes (MRI brain scanning). In between these two bookends, stories returned exploring ever more bizarre consequences of ‘well-meant’ bio-tech: Adam Marek’s ‘An Industrial Evolution’ considers one woman’s attempt to save an entire species with the help of inter-species genetics, but asks whether preservation is always the right thing to do; Simon Van Booy’s ‘Flesh and Blood’ examines the consequences of simply knowing too much about ourselves; Toby Litt’s ‘Call it “The Bug”…’ considers a world segregated according to its access to life-preserving implants.

With the help of the bio-ethicists, some stories also shone a light onto apparently ‘non-trivial’ problems in the current legal system, either where bio-technological progress has left the statute book behind, or where the law has embraced it too quickly: Sarah Schofield’s story explores the legal loophole exploited by manufacturers of over-the-counter supplements, and Justina Robson examines the grassroots phenomenon that is DIYbio – both areas where arguably more regulation is needed. Dr Jane Haley, on the other hand, notes the first case of an fMRI-based ‘lie detection’ conviction in a court of law (in India), and the fact that the UK has yet to test its admissibility, whilst the US has so far rejected it.

As the patterns in each Petri dish start to flower and unfurl, certain similarities present themselves. Holding each story up to the light and comparing it to the next, we notice a shared, deep-rooted contradiction in the way many characters (and arguably the society they occupy) relate to science: the rational brain appreciates perfectly well that science progresses according to the ‘best methodology available to us’; but the irrational, instinctive brain still struggles to trust science, to put its faith in a process that isn’t just difficult to comprehend, but inherently riddled with
uncertainty. The more natural, 'human' impulse, it seems, is to fill this gap, and join the dots, not with painstaking self-education and inductive argument, but with an easy dollop of drama. As Simon Ings' character puts it, ‘Any story [...] is better than no story at all.’ Indeed we regularly splash ‘story’ all over science so as to ‘humanize’ it, making its players subject to all-too-human ambition. Yet, by making science more recognizable, and therefore easier to trust, we paradoxically apply to it motives and characteristics that are entirely mistrustworthy. We prefer a single, deranged boffin to countless, anonymous lab technicians. We prefer an unlikely anecdote about a little-known natural ‘cure’, to peer-reviewed, published clinical trials. Because mad boffins and miracle remedies are, by definition, story elements; long, drawn-out drug trials with contesting interpretations are not.

The manifestations of this paradox are various and many-coloured. Sarah Schofield’s ‘Shake Me and I Rattle’ examines how our love of anecdote leads to a dangerous proclivity for alternative remedies, diet pills and ‘snake oil’, for want of a better term. Whilst the consultant on her story, Dr Angharad Watson strives to thrust these woolly anecdotes back under the hard light of reason: ‘If something is claiming to do what a drug does,’ Watson asks, ‘why isn’t it a drug?’

Simon Ings explores the other danger of humanizing the science ‘story’ – that of glamourising it, expecting too much of it, becoming a fan. The problem with fans, Ings argues citing the state-led corruption of Soviet genetics, is they have no patience.

Another problem with fans is their unshiftable belief in ready-made, off-the-peg cures – magic bullets, designed by evolution, and merely waiting for us to find them. Rather like the elusive ‘eureka moment’ in science breakthrough stories, the characters in this collection (and indeed many real-life ‘science fans’) trade in past examples of the magic bullet, and convince funders and investors of the existence of new ones. Usually these bubble up from the headspring of traditional medicine: the silverfruit tree that survived Hiroshima and deters all known pests (gingko biloba), the Amazonian arrowhead poison deployed as a paralysing agent in early anaesthetics (curare), the malaria-fighting bark extract brought back from Peru by Jesuit missionaries (quinine)... these examples have a mythic status in research circles. And new candidates are always being lined up. The Linckia starfish is perhaps the latest, thanks to its ability to both regenerate lost limbs (as a newt, tadpole or axolotl might), and also generate from a detached limb, as an entirely new organism.

Hope is important, of course. ‘Found cures’ are not just myths, and bio-mimicry has become a watch-word for many areas of research (see Annie Kirby’s story of a tadpole-derived ‘magic cream’). After all, if evolution is the best designer, why not try to smuggle out a few knock-offs for humans to try on? But hope, as several contributors here point out, can be dangerous, damaging. And scientists are as much to blame for fuelling ‘fandom’ as anyone. Bio-medical scientists have two masters, after all – the funders on one side, who crave hope, respond to it and invest in it; and the general public (i.e. potential patients) on the other side, whose expectations need to be managed. The former is often served at the expense of the latter. As Dr Ian McGonigle argues in his afterward to Ings’ story, an ‘epistemic rift’ begins to open up between what science says is possible in the lab, and what the general public realises is likely in the real world. Scientists are in danger of creating a fiction of their own, in fact, if sobriety and caution aren’t sufficiently exercised in the way they communicate to the rest of us.

We called this project ‘Bio-Punk’ in an attempt to create a third archetype in the over-humanized science ‘story’ – dangerous though all these archetypes are – that is to say, an alternative to the ‘science fan’ and ‘megalomaniacal boffin’. Unlike the fan, who allows for overzealous state-meddling, or the mad boffin, who represents the opposite – the unaccountable individual – a bio-punk is a member of a
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grassroots movement that organizes against an enemy far more powerful, these days, than states or individuals. I speak, of course, of corporations.

Vast, hidden libraries of coded information are currently being unlocked by genomics and, if we're not very careful, the keys to these libraries will ultimately fall into the hands of private companies — even though the secrets they contain belong to, and concern, all of us. The bio-punk believes in the common ownership of this vital knowledge, and calls on states and individuals to lobby against the likes of Craig Venter and his corporate-centipede of private investors (Celera Corp, JCVI, etc).

Drawing a parallel between genetic code and computational code, the bio-punk calls for the open-sourcing of all genetic information, indeed all bio-knowledge, most of which remains hidden from general view in pay-to-access research journals, even when it isn't patented. (The University of Manchester's John Rylands Library, for example, spent a staggering £5,929,803 last year on subscriptions to academic journals). Dr Nihal Vrana, discussing implant technology, suggests private ownership of life-extending technology could lead to an untenable level of social segregation in the future — one that can only lead to revolution. If the secrets of the genomic libraries are privatized, an untenable level of segregation may come about even sooner than that. The best way to avoid it, we contend, is with the help of bio-punks; people like the Human Genome Project scientists who strove to beat Celera Corp to the sequencing finishing line. Whilst paying heed to the dangers of 'bio-error' (in scenarios like Justina Robson's 'Madswitch') we should also be careful not to buy into too many scare stories surrounding common ownership of research information or indeed grassroots engagement projects (like DIYbio). The media seem very quick to respond to this latter phenomenon by applying the 'anti-terror' rhetoric of the Bush-Blair era so as to convince us that the bio-punk is just another iteration of the mad scientist: the mad scientist turned terrorist. In fact, this rhetoric isn't limited to the popular press. In November 2011, the US National Security Advisory Board for Biotechnology (NSABB) called on the editors of Nature and Science to censor key passages of two research papers on the H5N1 virus in the fear that the information might fall into the wrong hands — a decision that sparked immediate controversy in the scientific community, including the researchers concerned, who argued that the benefits of publishing the research in full outweighed the risks. The World Health Organisation backed the publication of the papers in full, and eventually, in March this year, the NSABB reversed its recommendation.

Individual scientists, taking up the bio-punk mantel, regularly call for open access, and free information, even to the extent of eschewing Nature and Science (subscriptions for which are over £100 per annum for individuals, and thousands for institutions) for free-access journals like PLoS One. Universities increasingly find themselves on the other side of this fence, however, and have generally dedicated intellectual property offices that continually encourage their researchers to patent everything they possibly can (with the universities themselves taking up to 60% ownership of these patents). This in turn leads to even greater secrecy within the scientific community, and the muzzling of seemingly all concerned with non-disclosure agreements. As government funding for academia declines (the UK currently ranks at only 41st in the world in terms of government funding for H.E.), universities are forced to explore other ways to generate revenue, and the exploitation of intellectual property seems the obvious route. The development of MRI — as explored in Dilys Rose's story — is a prime example of a technology that was greatly developed in UK universities, but not patented by them; indeed MRI is held up as a cautionary IP tale for UK universities.

It is in this context that the radicalism of the bio-punk — committed to the giving away of knowledge for the benefit of all — should be considered. Indeed it's worth remembering

1. More on JCVI's recent work on pp. 9-12.
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the words of Jonas Salk, perhaps the original bio-punk, whose discovery of the polio vaccine in 1952 has almost completely eradicated the disease, and spared humanity hundreds of thousands of infections. When asked in a televised interview who owned the patent to the vaccine, Salk famously replied: ‘There is no patent. Could you patent the sun?’

Every experiment needs a control, and this one was no different. Initially we expected this role to be filled by the opening passages of Jane Rogers’ story — a light-hearted canter through the prejudices, misunderstandings and snobberies that still abound in the non-science community, even in the higher echelons of academia. We assumed the ‘active ingredient’ being tested by this anthology in particular was the scientific input, and for much of Jane’s story, common ignorance is allowed to go untouched by the consultation process, like empty agar in a control sample.

But as other stories started to come back, it occurred to us that we might have got this quite wrong. This was a commission to explore ways in which unforeseen ethical issues may arise from research; what we were actually doing therefore, in all cases, was testing an absence: what happens if we don’t foresee and prevent a moral or social problem. In other words, all of these stories were controls. The real experiment — where the fruits of bio-ethics and social conscience will be truly tested — is taking place out there.

Dinner at High Table
or
An Erudite Vindication of Pure Research

Jane Rogers

‘RICKY,’ CHARLES was saying, ‘Yes, our own dear Professor Richard Finn has this very week had the dubious honour of saving mankind from extinction.’

I rarely go in to formal hall. Once or twice a term, just to show willing. It’s still a male preserve, and I always make a fool of myself. And Charles, while not yet completely plastered, was well on his way. There was a rumble of affarthing and table thumping. Charlie gave me a wave.

‘Do go on,’ I said. ‘Where is Rick, anyway?’ Rick being one of the few habitués of the table with a more sophisticated attitude to women than that of a prep-school boy — possibly because he’s a biologist. At any rate, he understands matters of the flesh with a pleasing thoroughness. Although I had not had the pleasure, since he got hitched to wife number three.

‘In the States, Cynthia m’dear, in the US of A. Saving the planet. Lend me your pretty ear and I shall reveal...’

My ear is old, Charlie. Old and bored and tired, and for all I know, ugly too. A boy brought my soup; broccoli and stilton, good. That horse-faced idiot from Ancient History was sitting opposite me, picking food out of his beard. I tried not to look.
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He takes off his shoes and his socks, leaves them on a rock.

Closer to the bank the water is slow, but further out, he feels something like a tug, as if he’s hitched his wagon to a freight train and is being pulled along. He swims a while, and then just lies flat, stretches his arms out to either side — up above him the empty sky — lets the current carry him, watches with detached amusement as his trouser legs inflate, looking like puffed up waterwings.

He isn’t prepared for just how shallow the water will get before it reaches the lip. He feels the bottom against his back, tries to flip over to see where he is and what needs to be done but finds it too shallow even for that; dry season. He pushes himself onto his knees, and sits, surveying the scene.

He is still a few feet from the edge. The noise seems far away. Reeds nudged lazily in slow-flow currents, side to side.

Now he stands, takes it all in — the gorge dead ahead in its glory, emerald green rolled out like a carpet covering the land. A few steps and he is almost at the edge, on the brink, the slow waters at his ankles, the slick reeds beneath his feet.

From the bank — a commotion unrelated — no need to turn his head. Just focus on edging forward. Motion now, arms waved in the air. He doesn’t really care but he turns to look. She is shouting at him, her mouth in odd distortions, looking like a crazy person. He cannot hear a word.

Afterword:

Ethnopharmacology

Dr Ian Vincent McGonigle
Department of Anthropology, University of Chicago

SOME OF THE Western world’s most successful drugs have come from plant sources: quinine, taxol, ephedrine and digoxin to name a few; and more than a third of the world’s top-selling drugs are either natural products or their derivatives. Amazonia is a particularly good ‘hot-spot’ for finding such bioactive material, as plants living in tropical forest habitats contain lots of chemicals, mostly to protect themselves from viral and fungal infection, as well as from animal and insect predators. One of the most famous drugs to come from Amazonia is ‘curare’, an arrowhead poison used by indigenous peoples for hunting. Due to its useful paralytic effects, curare became instrumental in the development of the general anaesthetic in Western medicine. Curare blocks the acetylcholine receptors that initiate muscle contraction and this discovery, and the pharmacology studies that followed, ultimately led to the development of the modern muscle relaxants that are now used by anaesthesiologists in medical surgery. In Amazonia however, ‘medicine’ is usually practised by shamans (local healers), and it is usually the shamans that hold the most knowledge of which plants have toxic/therapeutic value, how to find them, and how to use them most effectively.

The task of finding such drugs is the object of ethnopharmacology. Ethnopharmacology practice may thus be defined as ‘the search for new drugs from traditional medicine’, placing it at the nexus of natural product pharmacology and social anthropology — being concerned with ‘social’ and ‘biological’ issues conjunctively. And for ethnopharmacologists looking to find ‘new’ drugs in Amazonia,
gaining privileged access to shamans' local knowledge is often essential. As the current laws protecting indigenous knowledge allow researchers and companies to claim intellectual property rights over biological resources and traditional knowledge once they have been 'slightly modified', 'illegitimate' plundering of such knowledge has led to the coining of the term 'bio-piracy', used to designate those adventurer scientists who go off-the-grid seeking to find 'wonder-drugs' in traditional societies, hoping to take a sample away with them back to their commercial or academic laboratories. Sufficient modification for legal proprietorship may be as little as a subtle alteration to the chemical structure of the active compound or the use of a semi-synthetic chemical analogue (a slightly modified version of the original compound). And so bio-pirates may only need a small sample in order to identify the chemical structure of a 'wonder drug' – if one were found...

In K. J. Orr’s story, the mysterious 'wonder drug' is reputedly like Ayahuasca but with some bark extract additive. Ayahuasca is a particularly important Amazonian medicine. It is a hallucinogenic brew that has been utilised in rituals by indigenous and mestizo Amazonian people for over 300 years. Ayahuasca is usually composed of two plants: a vine (Banisteriopsis caapi) and leaves of the Psychotria viridis bush, which contain a psychoactive compound called DMT (a close analogue of the natural neurotransmitter serotonin). These leaves and vines are boiled in water for over ten hours and a dark, bitter viscous preparation is produced, ayahuasca, which is traditionally drunk during shaman-led rituals. The brew causes hallucinations or 'visions' during which participants may have a 'spiritual transformation' or undergo 'spiritual growth' or 'healing'. Visions may at times be extremely distressful as well as euphoric and insightful and the shaman plays a central role in guiding the participant throughout the ritual. Other plant or animal materials may be added to the ayahuasca brew during its preparation however, and these different ayahuasca brews may be used differentially to target specific illnesses.

In the story, there is an anti-viral compound addition that can be extracted from tree bark. This is perfectly scientifically possible: Tree bark, in particular, is known to contain bioactive compounds in order to stave off infection (for example, quinine\(^2\)). Moreover, such additions to the ayahuasca brew are not without precedent: Mestizo Shamans in Amazonia are known to 'experiment' with different animal and plant material additions in their ayahuasca preparations. Furthermore, as referred to in the story, there is a growing body of mainstream scientific evidence that hallucinogens may be beneficial in the treatment of depression; and indeed, ayahuasca has also been used to treat addiction in several clinics in South America. The molecular basis that underlies any possible therapeutic effects from psychedelics such as ayahuasca has not yet been fully elucidated, but scientists agree that such psychedelic drugs mimic the natural serotonin molecules that are involved in mood, perception and reward signaling in the brain. By stimulating the same types of pathways – via serotonin receptor and transporter proteins – such 'serotonergic' drugs may hold potential for the treatment of related psychological disorders, such as depression and addiction, or indeed for the development of related therapeutics and practices. There thus remains great opportunity for Western science to find a truly transferrable medicine that could be globally used in medicine...

In light of these exciting possibilities, it is important to bring into question the ethical problems that inher in the development of 'novel' medications through the utilisation of indigenous, traditional medical knowledge. In particular: does

2. Quinine originated from the bark of Cinchona trees. Originally used by the Quechuas of Peru and Bolivia, quinine was first brought from South America to Europe by Jesuit missionaries. Quinine was widely used to treat malaria in the West, until its replacement by synthetic analogues in the 1940s. Quinine interferes with the reproductive cycle of Plasmodium falciparum, the causative agent of malaria. See also pp. 47-67.
anybody exclusively own such knowledge or is indigenous knowledge just ‘local common sense’ of no particular value? Should an indigenous medicine belong to the community forever, or should the drugs of tropical forests be considered the common heritage of all of mankind? Should indigenous people be rewarded for their role in drug development? Or could their very recruitment in the drug discovery process disrupt their communities irreversibly, as has been the case in past interventions by missionaries, forest loggers and colonial elites? These are big questions that should be tackled through interdisciplinary research spanning social, biological and philosophical schools; good bio-ethics necessitates such collaborative efforts.

Flesh and Blood

Simon Van Booy

I waited for David in the place we had agreed at twilight. November is a month of long nights. I leaned on the dark wall that runs the length of the Embankment. Pigeons pecked at the ground in small groups. The river was high because of heavy rain, and it swallowed the low stone steps from long ago, when currents of people had moved along the river's shoulders, working, eating, and washing their clothes. I imagined people stopping on the steps to talk, children sitting, watching boats, wondering what their lives would be like, worried about small things. David liked to speak of those times, long ago — when the only way to learn anything was by talking with others. To love someone then, he said, you didn't need to match them in any way, nor have any common interests — or even be attracted to them. The only qualification was that you simply couldn't be apart.

I attended university from home, and never actually met my fellow students and teachers. Now that I'm a few years out, I think I would have liked to walk around the park with other students after lectures, saying whatever came into my mind — even if I regretted it later. I told David when we first met a few weeks ago, that I yearn for a life of mistakes.

Waiting for him at the water's edge, it would have been easier for me to climb down onto one of the lion's heads, and then jump into the Thames — rather than confess the truth of how I had been deceiving him. I leaned over the wall and looked at the water. I saw my body in the air. He would arrive amidst the commotion. People shouting and pointing at the river. A woman has fallen in. A woman has been carried