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Go to the Edges of the Map

We're not in this to be liked, we're in this to be heard

– Tej Samani

Now we come to the heart of the matter. A small rebellion is all well and good, but the real treasure lies out of sight, off the edges of the map, in spaces, conversations, and actions that others daren't touch. Every pirate, historical or modern, knows this.

This is the transition from one or two righteous moments of resistance to a whole new way of thinking and being. Change comes from the fringes, and being a pirate is often about acting in opposition to mainstream practices and opinions. It's not about being controversial for the sake of it, there are good reasons some things aren't popular or don't work, but as the world changes, there's a continual need to shake free of the past and reinvent how we live, work, play, consume, and interact with the planet.

Creativity, innovation, and 'transformation' are what the world wants and needs, but precious little attention is given to what really gets you there. The truth is that you can't reach new territory if you already know it; it requires a willingness to step into the unknown and feel your way through the darkness without being tempted to rely on what feels safe and familiar. Like breaking small rules that are just habits and hangovers, we need to cultivate a willingness to step across boundaries and find inspiration in unusual places.

One brief example from last year showed me both the need and the appetite for this. I was invited into a discussion with a group of students at University College London's School of Pharmacy, led by my friend and occasional collaborator Oksana Pyzik. Oksana is a Senior Teaching Fellow, an expert in global health, and a fierce

campaigner against fake medicines. The purpose of the session was to come up with some new ideas for her Fight the Fakes campaign, and she was keen to bring in some fresh thinking and strategies to increase public awareness and engagement around this little known global health threat. How could they be more pirate about it?

The problem is this: 1 in 10 medical products worldwide, from antibiotics to chemotherapy drugs are fake or of extremely poor quality.[1] They have no health benefit and may even have serious consequences ranging from poisoning, to disability to death. While fake medicines are a global problem, they are more prevalent in countries with weak

regulatory systems where it is easier for criminals to slip contraband across state lines. However, trying to understand the extent of this problem and the scope of solutions from a classroom in central London, has its limitations. The Fight the Fakes campaign is global in nature with over 38 partners across the world, but the conventional multi-stakeholder approach which is intended to bring a variety of perspectives to the table, is still limited by members all being on the same side of the law.

This is where it can pay to build some unlikely alliances to try to get closer to the source of the problem. I suggested that instead of having the conversation just with a group of university students studying the same subject, why not open it up to those who can teach you something new about the problem? Invite in some ex-drug dealers, or others who understand the motivations, challenges, and advantages of working within unofficial channels? They would no doubt offer entirely different insights along with a dollop of realism.

Oksana loved the idea, but voiced that she'd be hesitant to take it forward to her head of department.

Unbeknownst to the group, the head had actually slipped into the back of the room, heard the whole discussion and stood up to announce that it was something she'd be happy to try. Seeding this idea felt like a good day's work. It was helpful to have me in the room to put the suggestion forward because sometimes an unconventional idea lands much better when it comes from a fresh voice.

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https://www.who.int/publications/i/item/study-on-public-health-socioeconomic-impact-substandard-falsified-medical-products-978-92-4-151343-2

The question then is whether you can run with the radical idea and stick it out through the initial stumbling blocks: the awkward silences, confused expressions and reprimands that may come when you stop adhering to normal patterns. The loneliness that comes when you start to diverge from your peers can be exhausting. Oksana's initial reluctance surfaced because she had grown weary of challenging middle management to take greater risks on creative projects and felt that her maverick reputation was starting to work against her politically. Whereas in the past she would have been the first to explore unchartered territory, this time she succumbed to the protection of doing it by the book.

And she isn't alone. This is the point when most of us would probably hesitate and fall back into something that feels familiar, because all of those uncomfortable feelings send us the signal 'this is wrong'.

But ask yourself this question: do you really think it's wrong, or is it just different? In the long term, staying within limited patterns of thinking and expectations can be more trying than conservative management itself.

If all of this sounds a bit like another way of saying get out of your comfort zone (though that is inevitable), it's intended to go much further. Going to the edges of the map is about a willingness to really engage with the full extent of your imagination – to be more visionary, to turn the world upside down, to consider the opposite of what is usually done. To partner with 'enemies', make mischief with misfits, and be a lot less fucking predictable. Not for the sake of controversy, but because regularly stepping outside of and crossing boundaries can enrich your life in ways you can't imagine until you start doing it. It is about relishing the feeling of being surprised and even shocked, remembering how much more you have to learn, and realising that is a good thing.

It is also about how to navigate the edges when you get there. How to maintain the integrity of a radical new idea while also making it real? Otherwise it's just dreaming. How and when should you compromise? We've seen just how negatively polarising opinions can affect society, and that is not the point either. Change requires cooperation, and activism as total opposition can fall down very quickly. Pirates enact a delicate duel between what would be ideal, and what can be made real. Sometimes

gaining the ground to 'prove' your new model means working in an establishment setting. It is a precarious place to be, but it's what differentiates pirates from mere rabble rousers.

But first, where to find inspiration?

Skewer the skeletons and toast the taboos

A useful way to slip off the edges of the map is to confront the skeletons in your closet. If your team, company or sector has a bad reputation for something that no one is talking about, can you bring it out of the closet and seize it as an opportunity to explore a whole new area in which to innovate? Just by surfacing the one thing no one dares speak, you will surprise people, and surprise is the spirit we want; it is one of the easiest ways to get people to remember you.

In Sam and mine's experience, most organisations barely scrape the surface of the potential for creative thinking. Creativity is deeply enhanced by diverse thinking, and diverse thinking is generally under-practised and underappreciated. Without dipping into any kind of moral argument, suffice to say that teams with a diverse array of life experience, inclusive of more marginal perspectives, have a clearer sense of what is in the closet, and taboo for the mainstream. Therefore, they have lots of rich, untapped content to draw on.

For example, most of us are not very comfortable talking about serious illnesses like cancer, let alone talking about it in a way that goes beyond platitudes. But engaging with the subject in a more nuanced way can lead to exciting new endeavours. In January 2017, a young London-based artist named Sarah Davis was diagnosed with Hodgkin lymphoma. After undergoing the standard chemotherapy treatments, and emerging on the other side, Sarah soon discovered there was one conversation topic that nurses and healthcare professionals did not want to talk about.

'After many rounds of chemo and a stem cell transplant I found myself living in a completely different body. Many after-effects of treatment were made clear to me

*from the start, whereas others were left completely off the table. Namely, sex –
especially sex for pleasure!*

*During cancer your body is dismantled. You are slowly put together piece by
piece. Afterwards not everything fits the way it used to. I found having sex was
uncomfortable and things that gave me pleasure before now caused pain. I cannot
fault the support I had regarding fertility but my quest for pain-free sex led to
confusion, embarrassment, and disregard. I was angry and knew I couldn't be alone in
this.'*

It was only when Sarah joined Macmillan's London Cancer Community – an
initiative developed by the charity off the back of their 2017 report on cancer
inequalities in London 'Mind the Gap' [2]– that she decided to raise the issue of
inadequate support around sex and intimacy. After speaking with Sarah, Macmillan
Engagement Lead Emma Quintal decided to do some further research and find out
whether this was a widespread issue across the community.

*'We found substantial evidence around health professionals' reluctance to have
these conversations with patients, and similarly, patients not feeling that perhaps their
GP or CNS is the right person to ask. We do not expect clinical professionals to be an
expert on sexual issues as a result of cancer, but we do expect them, at the very least,
to initiate a conversation and signpost to other sources of support if necessary.
Unfortunately, women affected by cancer have told us that this is not happening.'*

As a result, Emma is now supporting Sarah to tackle the issue by running sex
and cancer workshops, but when raising sensitive or taboo issues, it's important to
consider how you go about it. Rather than go running headfirst into a deeply personal
topic and letting Sarah's experience lead the way, they decided first to host a focus
group, 'Let's Talk About Sex & Cancer', providing women with the opportunity to
discuss the impact of cancer on their sex lives.

This was done last year in partnership with Sh!, an award-winning
female-focused sex shop in Hoxton, East London. The workshop took place inside
their shop, recognising that a clinical setting was part of the problem. Macmillan staff
attended to support if there were any clinical questions, but really it was a chance for

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[2] https://www.macmillan.org.uk/_images/4057%20MAC%20Report%202017_tcm9-319858.pdf

the women to open up, describe their experiences, and explain what would help them. In addition to the lack of advice and signposting from cancer professionals, the focus group highlighted an inability to discuss sex post-cancer with family or friends, or raise it in a public setting (still very much a taboo); that sexual issues were having a serious impact on personal relationships; and that cancer's detrimental impact on body image and confidence due to scarring from surgery, has an impact on sex.

Emma said:

'There was a moment when everybody was talking about the physical impact on their bodies – one woman revealed her scar, which in turn led others to… it was a very powerful moment.'

Now that the initial information has been gathered, their aim is to run a programme of sex and cancer workshops with Sh!. Or in the case where a sex shop might be barrier to attendance, a few of the women have volunteered to host them elsewhere in their own communities. This initial pilot will focus on women with the view to tailor and cater to the needs of different audiences in the future such as LGBTQ+ individuals, and also couples. The workshops will offer practical demonstrations from the Sh! sex shop team, offer the opportunity for women to share their experiences/challenges or tips/solutions and ask the professionals any questions (plus at least one hour socialising session).

According to Cancer Research 50% of people born after 1960 [3] will develop cancer at some point in their lives so there is no good reason whatsoever for this subject to stay in the closet. I met Sarah at an event Macmillan hosted at City Hall marking two years since the beginning of their Cancer Community. The event showcased the stories and solutions that had emerged following a collaboration with ethnographer Dr Adam Gill of Wilding Health. Adam's research uncovered that there were three broad themes accentuating cancer inequalities in London: navigation of the system, emotional support, and language barriers. The event's 'hack session' that I ran with Adam focused discussions on these three areas but with an additional pirate layer. We asked everyone, *'How would you take a risk/rewrite the rules or be more pirate to*

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[3] https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk#heading-Three

support people to navigate the system and get the right care?' Sarah's sex and cancer workshops were highlighted as an example.

Lourdes Colclough, Engagement Manager for London said:

'Our London Engagement Team work with seldom heard groups so we constantly need to find creative ways to engage with people falling through the net of cancer care. The sex and cancer project was about tackling taboos and uncomfortable conversations – the workshop was a place where women could meet that was fun and safe with no clinical labels.'

Yet the event did highlight how much their team in London have already internalised a different way of doing things. The conference itself was interspersed with live music and poetry, and at least half of the speakers were members of their cancer communities. They showed a commitment to hear the truth, from the source, regardless of what it might say about how good or bad the system is.

In giving a voice to seldom heard groups, you find the skeletons, but beyond that, there is treasure.