

Out of Hours

Dangerous Ideas:

SAPC competition winner!

MAKING A PITCH

Since 2012, the Society for Academic Primary Care has run a competition at their Annual Conference called the Dangerous Ideas Soapbox. The soapbox offers primary care clinicians and researchers a platform to share a dangerous idea that they believe needs to be heard by the academic primary care community. Submissions are judged prior to acceptance based on how challenging and cutting edge they are. Those chosen are presented through lightning pitches (2 minutes, 1 slide) in the soapbox session, after which the audience can debate the ideas presented with the speakers before a final vote to decide that year's most dangerous idea.

CHALLENGE THE AUDIENCE

In summer last year I presented my idea that health research should be crowdfunded through Kickstarter, inspired by conversations with patients and members of the public involved in research. This challenged the audience with the idea that publicly funded research should have public backing before we're allowed to get our hands on the money.

Kickstarter is a crowdfunding platform. You don't have a product available that people choose and you then sell, as you would in a shop. Instead, you ask for investment up front from potential 'backers' and if you don't secure enough promised custom then your product does not get made. You have to make a pitch, which outlines what you intend to produce, convince people to invest in you — and you have to get the necessary number of backers within a time limit.

What if, after passing peer review, rather than being given the funds for your research, you had to make a pitch on such a platform? What if we had to ask patients to commit to our project and only if we got enough support would the funds be released? Patients after all, as taxpayers, are paying for this research and this would give them an explicit vote with their cash.

MY IDEA OF CROWDFUNDED HEALTH RESEARCH

This idea is actually very consistent with current policy and with the funders' currently stated philosophy, which claims a patient-driven research agenda, supporting research reflecting patient priorities, and

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conducting research that engages patients. So let's put our money where our mouth is and give patients the purse strings.

Yet, despite this being a natural evolution of our claimed approach, most people I've mentioned it to have thought this was crazy or it sent them into palpitations — and that's why this is a genuinely dangerous idea.

DO WE TRUST THE PUBLIC?

This idea also provokes some difficult thinking. It forces us to ask whether we really want patient-driven research — and if not, why not? Do we not trust them with the money, because we don't trust the public to know what research is needed? Or do we not trust ourselves to communicate to the public what research is needed and justify why our studies should go ahead?

It's also a dangerous idea because it carries genuine risk. If you fail to do a convincing pitch and win over sufficient patient backers, you don't get access to the funds. But there's a motto that's used in Silicon Valley that I think is apt here — Fail Faster. Maybe if you can't drum up support in advance, you need to stop and reconsider your research plans. Think about the 45% of publicly funded trials failing to meet recruitment targets once they're up and running, and spending public money.¹

TRULY PATIENT-DRIVEN RESEARCH

This kind of patient-supported research might actually help with exactly those problems of recruitment and retention. Think of platforms run by and with patients, such as PatientsLikeMe.² Patients choose what they want to research, and the site has 250 000 'data donors' engaged and participating in studies — how many trials can claim the same?

This model would therefore not only

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bring to life the idea of 'patient-driven research', but it could also herald a new way of working with patients, for patients, sharing ideas and sharing responsibility, with their commitment to help us see research through.

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The SAPC (@sapcacuk) will be holding their 45th annual scientific meeting on 6–8 July 2016 at Dublin Castle.

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2. PatientsLikeMe. *Live better, together!* <https://www.patientslikeme.com/> [accessed 8 Mar 2016].