Relative merit: keeping the HIV research program real

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This is a paper about "value". Specifically, it's an attempt to get beyond obvious statements of the "Research is important, let's have more of it" kind, and to ask some direct and maybe tough questions about value, meaning, utility and relevance in clinical [2]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. research, social research and fundamental science.

I am not presenting this as an argument: hermetically sealed, QED. One of the points of this paper is that "we", and by this I mean a sort of collective community of researchers and the people who use it, are sometimes wary of owning 'the personal', or of 'opinion', preferring instead, the refuge of, "As Brown and Green have shown …", carefully-tabulated data, or hiding behind the high-minded words of this or that theorist or researcher.

What follows here is personal, subjective and opinionated: a set of thoughts, propositions and questions which have occurred to me as variously a journalist, advocate, and policy wonk, some of which I feel to me quite urgent.

Let me start with a proposition I'd imagine as shared and uncontested by this audience: "Research into HIV is valuable". But what do we really mean by this? After all, "value" is in some ways a pretty relative concept. Depending on your point of view, a piece of research might be valuable because someone is paying you for it, or because you need to get published, or because an arcane question fascinates you. It might be political ammunition, or alleviate your diarrhoea.

It would be naïve in the extreme to assume or expect that research is only ever entirely altruistic, focused exclusively on its relevance for people with HIV – though one rather hopes this last is at least in the picture. But sometimes, the reasons why particular research questions get asked, and others don't, are deliberately or otherwise obscure to the people being asked to participate in that research. We don't expect the 'researched' to question its motives. More bluntly, bad questions sometimes get asked at the expense of more relevant or important ones – and it seems to me that in this world of competitive funding, and where policymakers, educators and researchers seem to be making more, rather than less demands, on HIV positive people as a collective "research entity" we need to be more honest, anyhow, in owning that this is a problem.

The 2005 National Centre in HIV Epidemiology [3]The branch of medical science that deals with the study of incidence and distribution and control of a disease in a population. and Clinical Research tells me there are 14,840 people living with HIV/AIDS in Australia. It tells me that 1,100 of these are women, 85 percent of the newly-diagnosed are gay men, and 50 percent are on antiretroviral [4]A medication or other substance which is active against retroviruses such as HIV. therapy. The HIV Futures IV survey tells me that 32.8% percent of people with HIV/AIDS surveyed own, or are buying a flat, and that 19.8 percent of pos folk reported receiving "some" of their everyday social support from their pets.

Scientists delve into microbicides, molecular targets, hormones, haplotypes, and viral fitness. They peer into the brains of monkeys or mice. Clinicians inhibit CCR5, shear genes [5]The most basic unit of genetic information., compare dosing. At least once a month, I receive another article or press release touting this breakthrough molecular compound, or that novel nucleoside.

A drug company pays market researchers to investigate positive peoples' attitudes to their drugs. Community organisations weigh up PREP and vaccine trials. A researcher records experiences of lipoatrophy: after three years of lobbying and equivocating, an Australian study into a possible treatment for it begins to enrol.

Recently, I learned that lesbians were comparatively knowledgeable about sexually transmitted infection. (The notable exception: that many thought the virus [6]A small infective organism which is incapable of reproducing outside a host cell. commonly associated with cold sores couldn't cause herpes on your genitals. This was cast by the researchers as a deficit, but if it is, I'd have a good guess it isn't one shared only by lesbians). A gay man

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called Brendon told researchers that his sexual adventurism is apparently what makes him different from the "unthinking" and "boring" folk of the world. And two years ago, an enthusiast for Deleuze and Guattari — French theorists of capitalism and desire — invited me to consider a "productive conceptualisation of gay men's casual sex assemblages".

HIV Futures IV says just over 33 percent of people have ever participated in a clinical trial [7]A clinical trial is a research study to answer specific questions about vaccines or new therapies or new ways of using known treatments. Clinical trials are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people. Trials are in four phases: Phase I tests a new drug or treatment in a small group; Phase II expands the study to a larger group of people; Phase III expands the study to an even larger group of people; and Phase IV takes place after the drug or treatment has been licensed and marketed. , seventeen percent in the past two years, a testament to the long list of new drugs and compounds in the research pipeline, but also to the slow devolution of clinical research from national centres and large studies to smaller, more privatised projects proliferating in general practice.

I can find no similar figure for social research. I suspect the answer might be similar if not higher, though it seems the question hasn't been specifically asked.

The point of all this is that, whatever might be said about the state of HIV research in Australia, it is almost certainly not the simplistic case that we just "need more of it". Nor can some genuine problems in our research sector can be answered with a generic appeal for more/better/different/improved structures for its oversight by government – although I do have considerable sympathy with the view that the current situation, in which everyone seems to want input but no one seems to have responsibility, is neither justifiable nor sustainable.

The problem with 'value'

It's almost a cliché to note that in some academic practice, there's a good deal of suspicion about, if not open hostility toward, 'valuing'. On this, much has been said which is both true and useful. It has also provided something of a free kick for populists, conservatives and whingers who have made cheap tactical and rhetorical gains out of the ridiculous argument that the entire "academic post-modern left" really just wants a world in which, to use the words of William S. Burroughs, "Nothing is true. Everything is permitted".

But I do I think that for various historical and cultural reasons, especially when it comes to social research, "value" operates in some unacknowledged ways: both for researchers, the researched, and those who use the research.

Sometimes, the "value" of a piece of research to community organisations is baldly political: a fact that I think can place researchers and community both in an uneasy position, when it comes to the question of interpreting data. Quantitative researchers, in some cases for good reasons, can be reluctant to get into the business of 'interpreting' the findings of their research too far. Community organisations, on the other hand, have interests which are sectarian and political – and there have been some interesting tussles over what does, or doesn't get said publicly about certain research findings, particularly when it comes to such matters as unprotected sex, drug use among gay men and other politically touchy topics.

There is also a constant demand from policymakers, community groups and educators that "research" be mobilised to answer an ever-proliferating set of highly-specific questions and sometimes, reflect perceived need. Research is seen as an advocacy tool – not always unjustifiable, provided that everyone is able to negotiate this carefully, and steer clear of the trap of constructing their research in order to confirm particular outcomes.

In many ways, policymakers and community may "over-value" research, according it intrinsic, almost mystical powers. If one can defer to "the research", we don't have to take the same responsibility for our arguing and making policy on the basis of our own political or philosophical convictions. Research becomes a sturdy referent in a complex world, which is always more reliable than (say), the empirical [8]Based on experimental data, not on a theory. evidence of our everyday lives and experiences, or just our common sense. "Research" neither can, nor should, be asked to take this role. I am all for evidence-based decision making. But those of us who use research in our daily work have to take responsibility for our own practice, and not just expect the research community to do our advocacy for us. We should not be afraid of common sense – or of defending what we believe in its own right. Sometimes, I say and do things because I believe they are right – regardless of what the research might say.

Some reasons why research gets done

It's obvious many factors can determine what research gets done: the marketplace; academia; the need to keep a general practice viable, to name three. These aren't always "illegitimate" reasons, but often, however, they are obscure to the people being asked to participate in the research.

So, for example, GPs in clinical practice are not uniformly obliged by ethics [9](In clinical trials) The process of determining that a proposed clinical trial conforms to a wide range of moral, scientific and ethical standards, to ensure that participants in the trial are not abused, mistreated or unfairly taken advantage of. Before a clinical trial can go ahead, it must be given approval via an independent ethics process. committees to disclose to potential trial participants the amount of money they may be paid by industry studies to recruit patients.

In one recent instance, a pharmaceutical company conducting market research through a third party argued it did not need to disclose who was funding the research, mischievously suggesting this would bias [10]When a point of view prevents impartial judgment on issues relating to the subject of that point of view. In clinical studies, bias is controlled by blinding and randomization. their sample in favour of people who had only positive attitudes towards the pharmaceutical industry. The research involved the collection of relatively personal and invasive information about peoples' experiences of HIV – but the company was initially resistant [11]HIV which has mutated and is less susceptible to the effects of one or more anti-HIV drugs is said to be resistant. to informing the participants as to who was really collecting the data, and why.

In basic science, debate has been simmering as to whether consenting to have one's samples and specimens collected as part of a national research databank obviates the need to consent for individual research being conducted on those samples – regardless of the nature of that research.

And I was once involved in the saga of a Phase I [12]A clinical trial designed to establish whether an experimental drug is safe for humans to take. Phase I studies determine the metabolism and pharmacologic actions of drugs in humans, the side effects associated with increasing doses, and look for early evidence of effectiveness; these studies may include either people with HIV, HIV-negative volunteers, or both study of an obscure immunological compound, which went ahead in spite of some serious scientific and clinical reservations about its validity. The initial protocol [13]A study plan on which all clinical trials are based. The plan is carefully designed to safeguard the health of the participants as well as answer specific research questions. A protocol describes what types of people may participate in the trial; the schedule of tests, procedures, medications, and dosages; and the length of the study. While in a clinical trial, participants following a protocol are seen regularly by the research staff to monitor their health and to determine the safety and effectiveness of their treatment had been so poor it was a laughing stock. But somehow, this dubious project found an alarming trajectory, as if, despite all the reservations and deep scepticism, nobody wanted to be the one to go out on a limb say, "This is not good research and it shouldn't proceed". The trial did proceed, but was eventually stopped for serious safety reasons. It literally took injury to several individuals for the project to be buried, a sharp lesson that researchers and their advocates, and I put myself squarely in this frame, might place somewhat more trust in the empirical weight of their accumulated and collective wisdom and knowledge. Doubt is an entirely valid arbiter. We are none of us, perhaps, very good at naming research when it is self-evidently "bad". At worst, we tacitly allow it to go ahead because it might – however unlikely – "do something", as it was put it to me at the time.

Competition

"Competition" in the research world can be fierce. Often, this means "competition" for a patient group or research population or a small number of potentially valuable patients. One of these groups is the antiretroviral-naïve: a small, sometimes vulnerable, and definitely valuable group of people in Australia, where treatment rates have at some periods soared close to 80 percent. A number of HIV treatment workers report concerns or questions from newly-diagnosed individuals who have felt under considerable pressure from their GP to participate in treatment-naïve studies. We're squeamish about naming this, but it's another argument as to why ethics committees need to get tougher on researchers about disclosing the money paid to recruit people into studies.

"Competition" is an often-unacknowledged pressure on research, and may sometimes mean that trivial, marginal, or unimportant questions get researched simply because someone has an interest in paying for them. One example is head-to-head post-marketing studies, which may require a long-term commitment from participants – but often have endpoints which are, truth be told, much more important to drug companies than positive people, or ask no-brainers which have long been answered in the empirical world of everyday clinical practice.

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It would be hard to argue that these individual studies are unethical. But asking people to participate in studies motivated more by the needs of industry and research centres is not exactly benign, particularly for a positive population which is already over researched, with a growing number of people, quite literally, wanting their blood.

There are similar competitive pressures on social research.

In social research, politics can also be a selective pressure. Much HIV social research, for example, has been driven by the broader political project of the gay and lesbian movement. At its best, this research can be revealing and illuminating – and an important riposte to social, cultural moral and political prejudices. At its worst, however, it is little less than propaganda: defensive and pre-emptive. There is great nervousness and defensiveness, for example, about research which highlights the potential harms of drug use – as if to acknowledge this is by definition the first step on a slippery slope to "just-say-no" campaigns and moral rectitude. But the opposite – to ignore the harm and spin the data—is patronising and equally unhelpful; politics of the worst kind.

As both the gay community and the HIV epidemic have 'grown up' it's pertinent to ask whether all the research conducted on the topic of gay sexuality can be justified merely by appeals to 'marginality'. I don't think that 'gay' is always as marginal as some would have us believe. Nor is there an intrinsic marginality attaching to the so-called culturally and linguistically diverse (an officious, dehumanising and patronising term, particularly egregious as an acronym: CALD). Just exactly what a "CALD person" is I do not know, but it is a term used with depressing regularity, effacing the 'person' behind the bland abstraction of the acronym, and subsuming all particularity into a meaningless 'them' to be brandished at conservative governments like a weapon: surely just a more politically palatable version of the sin of "othering". We need to challenge the assumptions behind these claims.

Use and value

Some time ago, it was put to me by a community advocate that the Beck Depression Index should be incorporated into the HIV Futures questionnaire to "demonstrate" that large numbers of people with HIV are depressed.

The claim that large numbers of people with HIV are depressed isn't new, and Futures shows a perhaps surprising number of people on antidepressants – not, I stress, necessarily proving that all these people have depressive illness. But I argue now as I did then that there is a real danger if we start requiring of research projects such as Futures that they should be vehicles for reflecting or confirming the perceptions, needs or prejudices of community or service providers.

That community participation can add uniquely to the research process is incontestable. But surely this comes with responsibilities. The first is to make sure that the claims made on research and research funding are legitimate and justifiable. Advocates need to be sure of our ground if we are arguing that a particular research question needs answering. Community representatives don't just have some intrinsic quality of being able to "channel" what the community "needs" just by virtue of "lived experience" – and many "researchers" are themselves "community", with equally legitimate experiences. We have come to fetishise personal experience as an incontestable font of truth – but the tendency to universalise from the experiences of a few is an ever-present danger. And for all the constant talk of the "positive voice", the reality is, there are many "voices" — and we need to get better at hearing some of them, even the ones which are saying things that some may not wish to hear.

Educators, policymakers and sector workers often respond to a perceived lack of information by saying, "We need to have some research into this". But the problem isn't always a lack of research. Sometimes, policymakers and educators – and I include myself in this – are reluctant or perhaps nervous about interpreting and drawing implications from existing research. By and large, we make poor use of what's there. Teaching people how to do literature searches, abstract useful general principles from particular or specific studies, and auditing available materials, are all ways to avoid the wasteful repetition and duplication of research questions – and it is pleasing that there is now some serious attention being paid to these practical questions.

My second point is that community representatives have a responsibility to ask harder questions about the intrinsic or assumed value of some individual research projects. I don't mean that community advocates should assume the role of pseudo social scientists. Rather, I think there is an obligation to make sure that the claims of any piece of research are legitimate: that the question really is pertinent, and more importantly, that it's answerable.

- What's the bang for this research buck? Are there other, more pressing questions, we should be asking?
- Is there a natural limit to how much we can know, or realistically need to know, about any given topic? Has the

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question been asked before?
How useful might this research ultimately be to the population being researched?

Community has been quite timid about asking direct questions, in particular, about the value of qualitative research. With its often-intimidating, abstract, technocratic or esoteric language people seem nervous about cutting through to 'common sense'. But it is legitimate to ask questions such as: "Who will benefit from this project?". What limits exist to the claim to be "finding meanings" in human behaviour? Is the repeated claim to "marginality" any longer enough to justify the research? What if I were to say to you that perhaps there is no special case or "meaning" in anal sex, any more or less than any other human sexual activity? Or that to conclude, as is so often the case, that the meanings may be multiple is in many cases just a banality of the first order. Or, what if I put it to you that gay men's sexuality is in many ways over-articulated and over-researched and yet for all this, still poorly theorised – with uncertainty about its application in education or policy practice? If it's unethical to make unsupportable claims in clinical research, what special responsibilities do social researchers have, given that evaluating and measuring the veracity of its claims can seem much harder than in clinical or basic science?

Researchers and their community advocates owe it to HIV positive people to question some of the assumptions on which much research continues to stake its claims of authority and relevance.

Recently, the research sectors have been held hostage by an unhelpful debate about the nature of "strategic" HIV research. The national research institutions have been given instructions from government to carry out only "strategic" research. Yet it seems to me that there is more, rather than less, certainty, as to what "strategic" research is. "Strategic" – surely a Don Watson weasel-word if ever there was one – now seems endlessly malleable, as research institutions and community-based researchers wrestle the push-me-pull-u of internal and external competition, tight budgets, other national health priorities, the collapsing of HIV, sexual health and hepatitis, an ever-proliferating demand for 'evidence' from government and policymakers, and myriad new directions in HIV and its treatment.

What's remarkable is that we have managed to maintain a level of focus as much as we have.

But it's more important than ever that we get beyond the usual rhetoric of "more, please" and push for a shared sense of responsibility for co-ordinating a meaningful and relevant research agenda, whose outcomes are valued, and which can be justified, not just among researchers, but for those people who are giving up their blood, their time, their tissues, their personal stories, to the research project.

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