



HIV Activism at 30

How has HIV activism in England changed since effective treatment (ART) became available?

Robert James:
Associate lecturer Birkbeck College,
BHIVA Hepatitis Group member,
Birchgrove chair, HTU Readers
Panel, Lawson Unit Patient Rep,
milliners model, NAT volunteer,
UK-CAB.

Background : HIV activism was intensely studied in the era before there was any effective treatment, particularly in the US. Academic work on HIV activism now focuses almost exclusively on those advocating for treatment availability in low income countries. No research on activism in England appears to have been done for over 20 years and there is almost nothing on HIV activism in any Western country in the era of effective treatment.

Methods: 14 health care professionals (6 doctors, 4 allied health professionals, 4 policy workers) and 14 activists in England were interviewed. 8 activists were living openly with HIV and 6 were HIV negative, untested or not open about their status. All of the people interviewed were involved in HIV guideline writing, policy work or lobbying at a national level. The interviews were transcribed and then analysed using qualitative thematic analysis with mix of pre-existing and content derived codes.

Results: All felt that activism has changed from earlier in the epidemic and was much less confrontational now. The reduction in conflict between activists and clinicians made working together easier but there was concern from clinicians that the 'spark' of activism had been lost. For activists, discussion and negotiation were seen as successful in terms of producing desired outcomes and examples were given. HIV patient reps exist at a number of clinics now and are involved in NHS governance.

Conclusion: English HIV activism is now almost entirely about engagement and not protest. Activists are 'knowledgeable negotiators' who operate inside the systems and processes of government and medicine. HIV activists have significant respect and there is an expectation of high competence in activists both in the clinical world and by state bodies. HIV peer support has become more clinic focussed with the formation of patient groups and the demise of many community based groups. The successful joint working between activists and clinicians has influenced both activists and clinicians, adding social understandings to clinicians work and medical ones to activists work. The closer working relationships provide a better shared understanding about issues and less conflict. Conflict whilst tiring to manage can also lead to new solutions in merging different frameworks of understanding and these alternative solutions may be lost.

Protest : we don't march anymore



The first march of people with HIV- Pride 1985

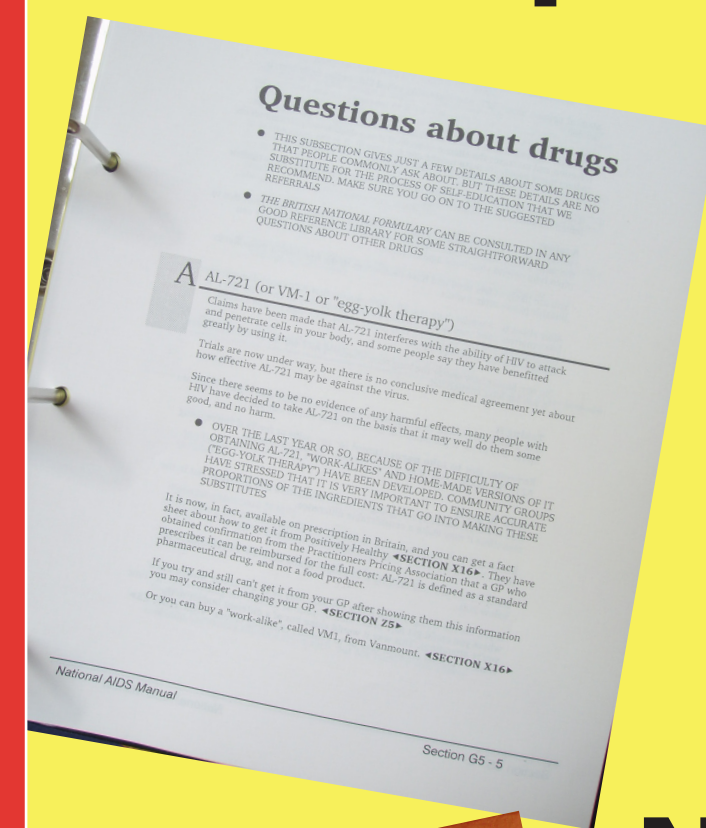
"I don't see so much evidence of activism now in the way that one did ten years ago. You don't have people marching or chucking red paint over people that you did then." Clinician

"engagement, does it make a difference, I'd say, absolutely, and I can give you examples." Activist

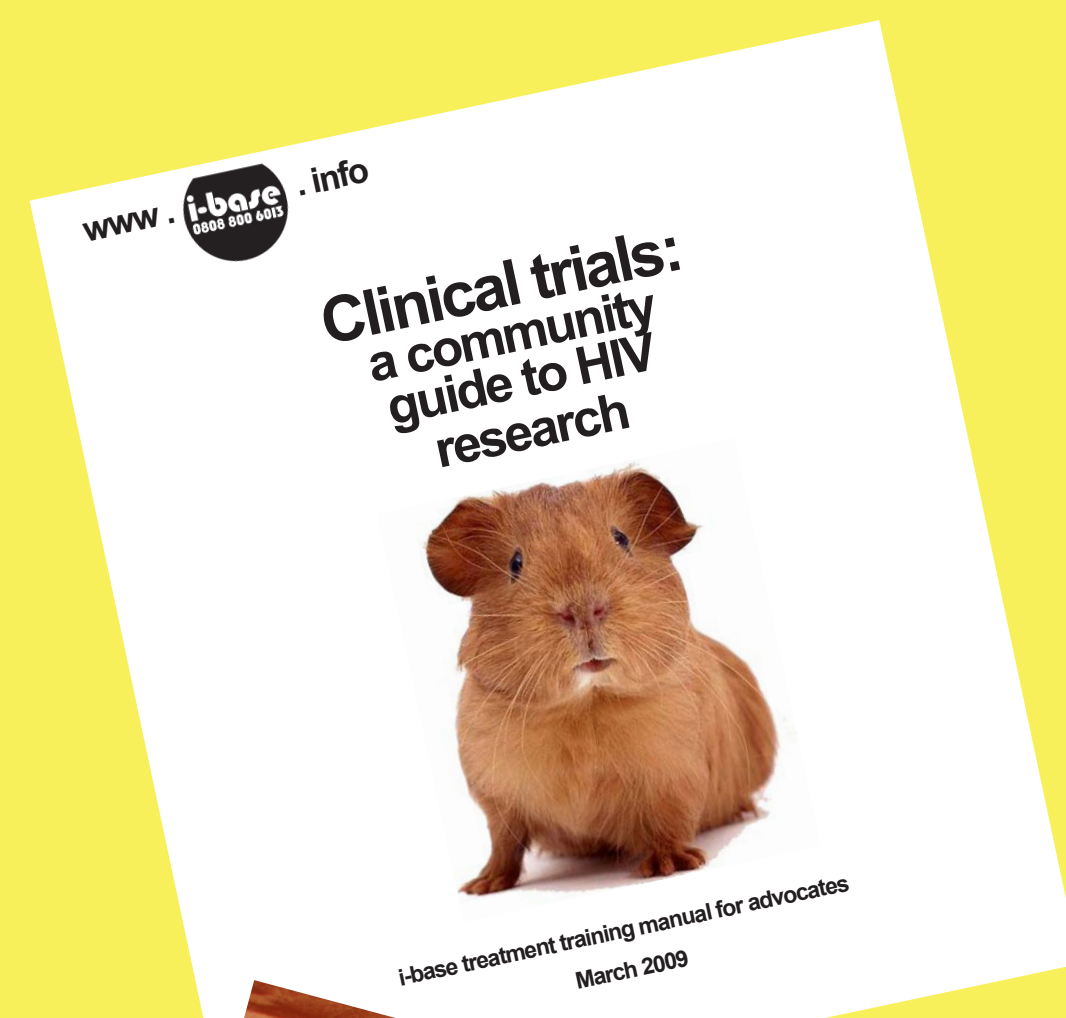
"I think the difference between modern HIV activism and old style HIV activism is, a lot less of it is confrontative." Activist



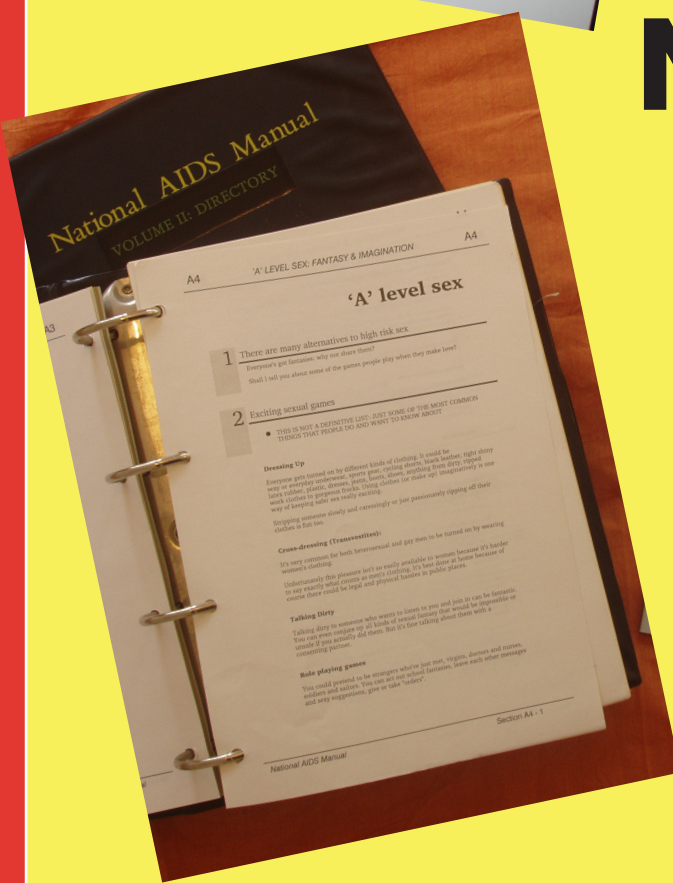
Activist produced treatment information : from egg yolks to i-base



"the main focus is actually to get people to the point where they can take control of their own decisions." Activist



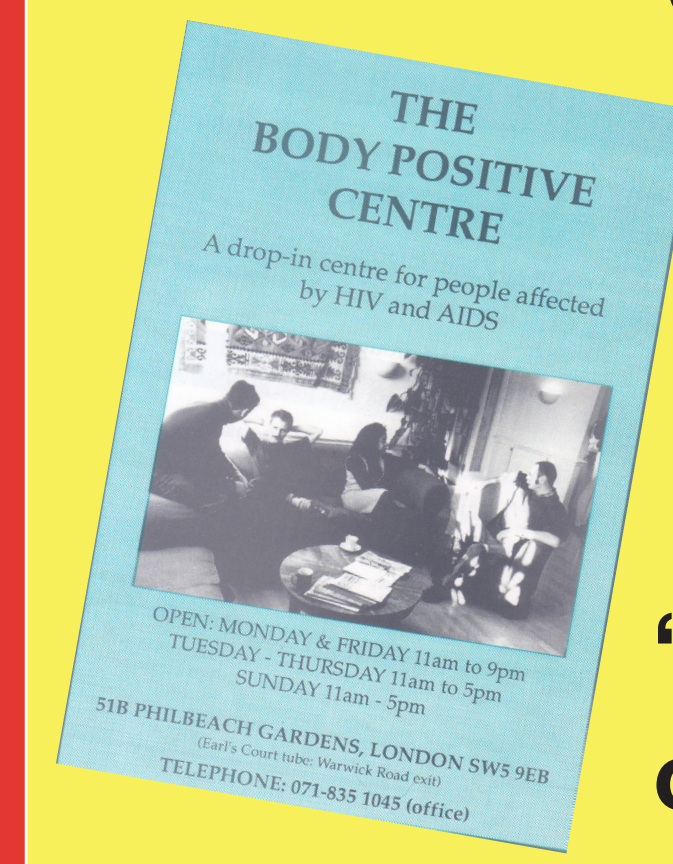
NAM : from sex to drugs to lifestyle



"I think patient the literature is great and I use it because it's graded for beginners, intermediate and advanced. I find it really useful for teaching different groups of people." Clinician



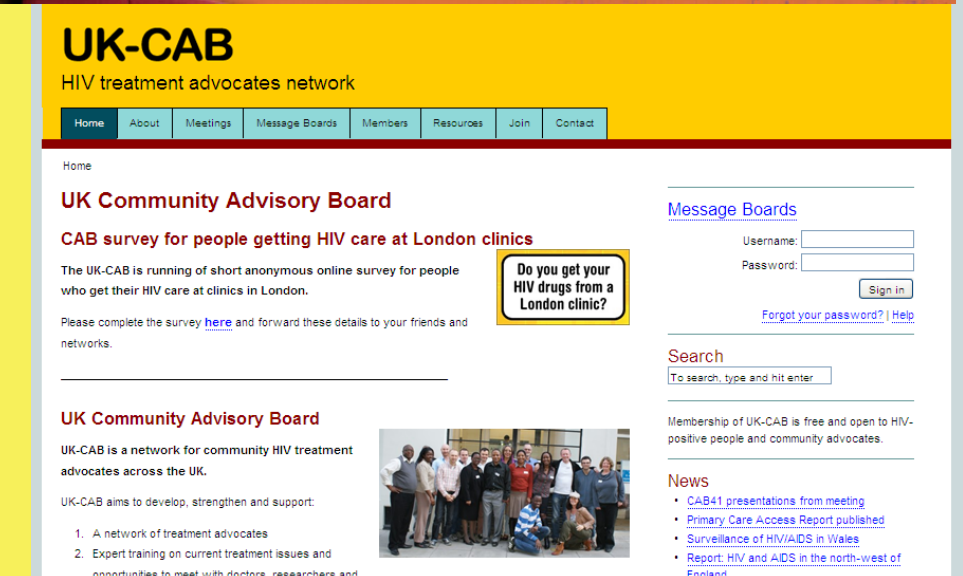
Support : Drop-ins to log-ins



"[There has been] a shift from the helpline to more email requests and more information requests through the website." Activist



"You don't have to go on a march in Whitehall. You can sit down and write an email to your MP, and they will take notice of it if you're a constituent." Activist



Patients : a role, a rep or an expert?

"a bit weird being in a management meeting one minute and then the next minute having one of the staff there pop a proctoscope up my behind." Patient Rep

"I think whoever is in that position needs to be meeting-savvy." Clinician

"People just won't listen to you these days if you rant and rave. So you have to get yourself onto the right committees and know the right people to talk to and understand how you can exert some influence." Activist



Pictures are merely illustrative and not necessarily the people quoted.

With thanks to all the doctors, nurses and activists who agreed to be interviewed.

And to David Rowlands at Baseline, i-Base, NAT, NAM, THT, UK-CAB, Edwin Bernard and Jonathan Grimshaw for the use of images. Funded by a doctoral bursary from the AHRC.