Clinician and community collaboration on PrEP in the UK – a narrative

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Background:

- The delay in widespread availability of PrEP has seen renewed grassroots activism from the community sector plus collaboration with clinicians reminiscent of the early days of AIDS advocacy in the 1980s

Methods:

- We document the timeline and benefits of a close relationship between community activists and clinicians in advancing the PrEP agenda

Results:

- Community engagement during the PROUD trial led on to increased advocacy and activism from October 2014 when interim results were published
- Launch of the websites iwantPrEPnow.co.uk (with a click to buy generic PrEP) and PrEPster.info in October 2015 further galvanised clinicians and community advocates into greater joined up action

The benefits of collaboration include/d

- Mutual social media support; advancing the PrEP agenda amongst potential PrEP users and clinicians
- Obtaining GMC input on providing clinical advice regarding generics
- Pushing for free monitoring for current generic PrEP users
- Sharing of therapeutic drug monitoring data
- Community input into staff training and service development such as production and review of patient information – this culminated in the production of a collaborative booklet produced from i-base
- Two way learning; sharing PrEP users perspective and evidence based research

Discussion/conclusion:

- The lack of availability of PrEP in the UK is proving an ongoing challenge to both community advocates and clinicians
- We wish to celebrate the achievements made within the confines of the current political climate, in particular working together to ensure patient safety, shared media work and support
- There is a history of successful clinician / community collaboration in GUM/HIV medicine; we suggest that continued collaboration and innovation is paramount

Addendum:

- In March 2016 a larger collaboration between community organisations and clinicians began
- This has grown to become the United4PrEP Coalition and is open to anyone to join – please email