

**The role of patients acting on
the social determinants of
health, promoting patient
rights and improving patient
experience.**

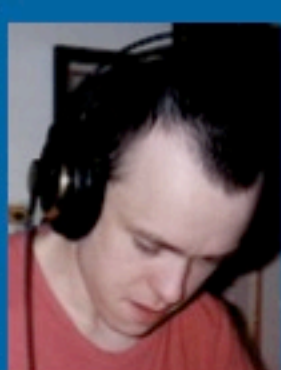
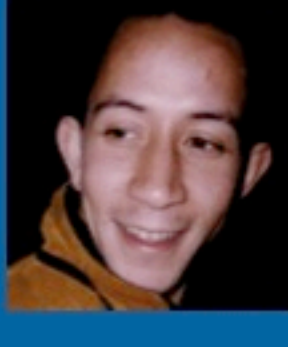
The role of patients acting on the social determinants of health, promoting patient rights and improving patient experience.

People taking an active role in
their health in the NHS:
an HIV positive perspective

Simon Collins
i-Base.info

Context

- **Collaborative approach is essential – from any perspective**
- **Reduce gap between clinical expertise and individual need.**
- **People should be able to receive care as partners in our own health.**
- **We are likely to have the strongest interest in staying alive.**



Andrew, Andy B, Andy C, Chris M, Chris P, Richard, Chris W, Space,
Nick, Dolly, Wesley, Colvin, Jimi, Kevin, Mike, Paul, Mark, Steve.

Wide interest in care



**Limited:
Doctor to
decide**

**Active:
Every
decision**

**This can change over time as knowledge
and information changes**

patient:doctor dynamic

- **Strange situation**
- **Reliance on doctor as gatekeeper to care (treatment, health and life).**
- **Often specialised language – and potential cultural and class differences.**
- **All at a time of personal stress.**

Why take an active role?

- **Active patients can get better care: from appointments to treatment**
- **Interactions with health workers**
- **Access to treatment (choice and new medicines).**
- **Information and understanding.**
- **Shared decision making helps if future outcomes are worse.**

Disadvantages

- **People are not always aware of these options.**
- **Many do not chose an active role.**
- **May be wrong in hindsight.**
- **Often needs confidence and persistence and to overcome fear of being a “difficult patient”**

Personal history.1

- Bereaved 1994. CD4 = 60 cells/mm³
- 1996: CD4 = 2.
- Cachexia, weight 45 kg
- Crypto/microspodia (MST 90 mg/d)
- Multiple OI's: CMV in both eyes
- > d4T/3TC/indinavir
- No expectation of response.

Personal history.2

- **Weight increased >1kg / week**
- **Energy returned**
- **CD4 = 100: stop CMV treatment**
- **CD4 = 200 by year 2.**
- **Switched for side effects (kidney stones, lipoatrophy, toenails) and better formulations (TID > BD > QD)**

AIDS Treatment Project (ATP)

- **1996: 30-40 people with similar experiences**
- **Volunteer phonenumber: “does treatment really work?”**
- **Dr Fax, conferences, internet**
- **“every person is able to make their own treatment decisions”**

Early examples 1997/8

- **3 vs 2 drugs (including research)**
- **indivavir vs saquinavir: 63 vs 43%**
- **Viral suppression > drug resistance.**
- **Use of viral load and resistance tests**
- **Long-term vs short term benefit**
- **HAART for PMTCT**
- **d4T and lipoatrophy**

i-Base (April 2000)

- Medical meetings
- HIV Treatment Bulletin (HTB)
- HTB editions in S. Africa, Turkey, Balkans
- Treatment guides (>35 languages)
- Phonenumber and online Q&A
- UK-CAB



VIH/SIDA
Introdução à terapê
de combinação
Setembro de 2011



O GAT agradece a revisão científica de Maria José Campos, Luis Mendes e Ricardo Fernandes. Edição e revisão: Ana Pires, Gabriela Cohen, Rosa Freitas. Tradução: Mariana Kumpere

www.i-base.info
www.gatportugal.org

primeiras perguntas
a pessoa seropositiva
resistência e adesão
escolha do tratamento

**Rastreo da infeção
pelo VIH e riscos de
transmissão sexual**
outubro de 2013



Revisão Científica: Maria José Campos
Coordenação: Rosa Freitas
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Revisão: Erica Almeida Paolito
Concepção gráfica: Diogo Lencastre

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www.gatportugal.org

**Guide to HIV,
pregnancy &
women's health**
September 2011

i-base
0808 800 6015



HIV i-Base
ISSN 1475-0740
www.i-base.info
Watch for out-of-date information

Diagnosed with HIV in pregnancy
How HIV is transmitted to a baby
Mothers' health
Having an HIV-negative baby

**GUÍA PARA ENTENDER LAS PRUEBAS DE DETECCIÓN Y
EL RIESGO EN LAS PRÁCTICAS SEXUALES**

**TRANSMISIÓN
SEXUAL DEL VIH**



**hiv
+ tedavi
bülteni**

türkiye Ağustos 2011 sayı:2

EDİTÖRDEN	03	olan genç erkeklerin erişkin servisine aktarılmasından sonra sağlık durumları
KONFERANS RAPORLARI	04	
18. Retrovirüsler Ve Firsatçı Enfeksiyonlar Konferansı - CROI		Yanlış hastalıklar ve geç bavyuru - 50 yaş üzerindeki hastalardan oluşan bir gruba ait bulgular
27 şubat - 2 mart 2011, Boston, ABD		
+ HIV/HCV koenfeksiyonunda tedaviyi kullanmaya ilişkin ilk bulgular		
+ Tüberküloz ile koenfeksiyon olan hastalarda ART başlama zamanı: CROI'de sunulan iki çalışmanın bulguları		
+ Anasiden bebeğe bulaşın önlenmesinde lopinavir/ritonavir monoterapisi		
+ Temas öncesi ve sonrası profilakside topikal jeller: bavyuru ve isen çalışmalar		
+ Korunmasız antiretroviraller: ağzından kullanılan temas öncesi profilaksi, jeller ve tedaviye ilişkin çalışmalar		
+ IPVEX çalışmasından etkinliğe ilişkin başka analizler		
KONFERANS RAPORLARI	15	
12. HIV Tedavisinin Klinik Farmakolojisine İlişkin Uluslararası Çalıştayı		
13-15 Nisan 2011, Miami, ABD		
+ Oral kontraseptiflerin düzeylerini azaltıyor		
+ Lopinavir/ritonavir rifabutin düzeylerini değiştiriyor		
KONFERANS RAPORLARI	17	
17. İngiliz HIV Birliğinin Yıllık Konferansı		
6 - 8 Nisan 2011, Bournemouth, İngiltere		
+ Chelsea ve Westminster kohortunda uzun vadede ilelene güncellenen hastaların ve HIV kontrol altına alan olguların sıklığı ve özellikleri		
+ Perinatal olarak edinilmiş HIV enfeksiyonu		
PATOJENEZ	20	Tedavinin yavaşlatılması HIV rezervuarlarını azaltmasa da, bağırsaktaki bağışık yanıtında bir rolü olabilir
		Etki kontrol olgularından elde edilen CD4+ T hücrelerinde düşük düzeyde HIV replikasyonu
TEDAVİ	22	
		FDA nevirapin XR'i onayladı
		Kürresel Fon, tedavi almamakta olan hastaların sayısını arttırdığını bildirdi
PROFILAKSİ	23	
		Günlik Truvada kullanımına ilişkin FEM-PEP bulguları çalışmasını hasta ailesi derledi: ana döşem analizi, aktif kol ve plasbo kolunda enfeksiyon bulgularını benzer olduğunu gösterdi
ÇOCUK SAĞLIĞI	24	
		Altı aylıktan küçük yaşta lopinavir/ritonavir başlanan bebeklerde uzun vadede akıbet
TÜRKİYE'DEN SAYFALAR	25	
		Söyleşi
		Pozitif Kişi
		Türkiye'den Çalışmalar
		Bunları Biliyor musunuz?
I-BASE YAYINLARI	35	



i-Base.info

UK-CAB (2002)

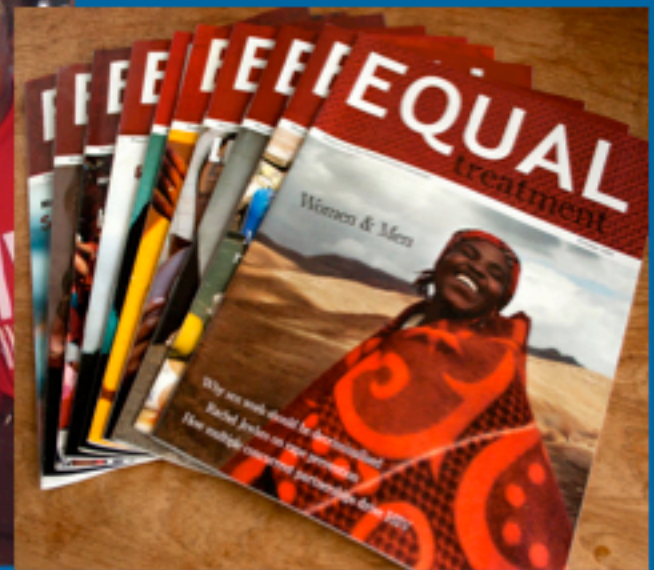


- Network of UK activists.
- Community Advisory Board ~ 600 members/120 organisations
- BHIVA guidelines and conferences
- Four meetings/year + online forum
- Language: HIV positive (not infected)
- www.ukcab.net

Global

- **“none of these drugs are for Africa”
ECAB meetings (1997/8)**
- **>10 million people on ART (2013)**
- **Generics and patents (Yusef Hamied,
Cipla: \$10K/year to < \$1 a day**
- **Secondf-line drugs, new drugs, etc.**
- **d4T (neuropathy, lipoatrophy)**

Treatment Action Campaign

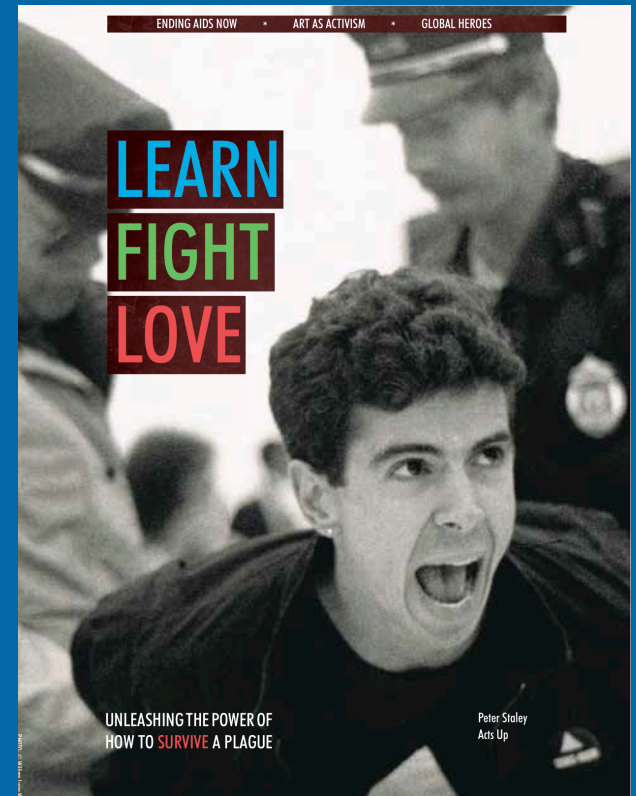


Conclusion and summary

- **Powerful examples of where medical advances change peoples lives**
- **Powerful examples of where activism (community, health workers, politicians) show that change is possible.**

Further watching

- And the Band Played On
- Angels in America
- Blue (Derek Jarman)
- Fire in the Blood (Global access)
- How to survive a plague (ACT-UP/TAG)
- Philadelphia
- Precious
- United in Anger (ACT-UP)



Thank you

Time for questions

Thanks to Polly Clayden, Memory Sachikonye
and Marc Ennals at i-Base.