



## Service User Involvement in HIV Care

- Bloomsbury Patients Network: founded 1999 with support and encouragement from clinic management
- Advisory Group function initially – quarterly meetings (low attendance)
- Pharmacy problems and survey provided hook to engage more patients
- 2002: Millennium Awards funding, including Kings Fund Leadership training to deliver a programme of health and wellbeing forums and workshops
- 2003 Local Authority continuation funding for events (ongoing)
- Explored feasibility of adapting Brighton Patient Rep volunteer role

## Building Peer Support Services

2004 – Paid Patient Representative role (Band 5) developed to:

- Organise and promote network events (including in-house Newly Diagnosed Courses)
- Meet, welcome and support new and current patients
- Provide peer support, advocacy, signposting to services
- Develop patient resources in-house
- Liaise with clinic management to improve services

## Sharing Success

- Second Patient Rep role created at Archway (sister clinic)
- Talks and support to develop Patient Forums at most London clinics and some services across UK
- Participation in local/national PPI committees/conferences
- Forum Link founded to share experience and offer support
- EJAF proposal to duplicate Patient Rep role in 3<sup>rd</sup> Sector – Health Trainer service and myHIV web resources via THT

## The value of peer-delivered support

- Ability to reach all patients, in a safe, known environment
- Breaking isolation of a new diagnosis, building community by sharing lived experience and solutions (esp. in relation to issues of disclosure, adherence, side effects management etc)
- Creates a holistic service with non-clinical events, courses and workshops
- Potential for improved health outcomes in relation to issues such as adherence. Cost and time savings to clinic due to task shifting

## The rise of the Rep and beyond

- Bloomsbury – 3 part-time reps, 52 hours a week. NDCs, Hep C co-infection workshops, Women's Lunch Club, Choir, Social Events, Christmas Party
- Paid patient reps at Kings, St Thomas, ChelWest – different models for different services – one size does not fit all
- Peer Navigator service in London clinics via Positively UK, Health Navigators in Midlands, N. West, S. West via THT
- myHIV online services – HIV Health Trainers, Counselling, Advice, Community Forums, self-management tools, signposting to face-to-face services
- Soerlandet Hospital Kristiansand, Norway: user-driven clinic

## What the HIV Doctors say

- *"If a patient only sees a clinician, they only get half the story"*  
*Dr Simon Edwards, Lead Clinician at Bloomsbury, 2001-10, 2013-present*
- *"Peer support - both psychological and social - is not only important, it is vital"*  
*Dr Ian Williams, ex-Chair BHIVA, Lead Clinician at Bloomsbury, 1991-2000*

## Useful Contacts & Links

Bloomsbury Patients Network:

Email: [bloomsusrs@hotmail.com](mailto:bloomsusrs@hotmail.com)

Website: [www.bloomsburynetwork.co.uk](http://www.bloomsburynetwork.co.uk)

Support in setting up a Patient Forum:

Forum Link: [www.forum-link.org](http://www.forum-link.org)

Online peer support and services:

myHIV: [www.myHIV.org.uk](http://www.myHIV.org.uk)