

PEER SUPPORT, ADVICE AND ADVOCACY

**THE WORK OF
THE PATIENT REPRESENTATIVES
&
PATIENTS NETWORK**

**THE BLOOMSBURY CLINIC
MORTIMER MARKET CENTRE
APRIL 2010**

" Peer support - both psychological and social - is not only important, it is vital"

Dr Ian Williams, Chair, British HIV Association

Contents

1 Summary – Activities and Achievements

2 The Bloomsbury Clinic & Peer Support

3 Patient Representatives

4 Bloomsbury Patients Network

5 Patient Engagement

6 Future Vision

APPENDICES

7 Case Studies

8 Referral Organisations

9 Bloomsbury Patients Network - Workshops & Forums.

10 Newly Diagnosed Courses - Course Description

11 Positive Self Management Programme

12 Patient Feedback

13 Professional Feedback

14 Biographies and contact details.

*This report covers the period
April 2009 – March 2010*

Activities and Achievements

- Peer support, advice and advocacy
- Open access to all patients
- Over 600 patients accessed patient rep services
- Patients signposted to over 100 organisations
- Close working relationship with consultants, nurses, health advisers and psychology department

- Workshops, forums and focus groups
- Over 400 patients accessed workshops and forums
- Newly Diagnosed Courses and Positive Self Management Programmes
- Acts as a social network

- Data collection - for patient demographic
- Write, design and produce leaflets

- Provide structure for engaging patients in minor service change, major research projects and national policy
- Attendance at management meetings and help to effect clinic change

- Influences local and national policy
- Membership of external committees and advisory panels

Last year over 1000 patients were seen by the Patient Representatives or attended events organised by the Patients Network - more than 25% of the clinic.

The Bloomsbury Clinic

“The emphasis on peer support and patient engagement allows for a holistic approach at the clinic”

Dr Paul Benn, Lead Clinician

The Bloomsbury Clinic at the Mortimer Market Centre has a pool of 30 doctors, 17 health advisers, 15 nurses, and eight clinical psychologists - offering CBT, psychodynamic, systemic and generic therapies - and two Patient Representatives.

The Clinic provides routine follow up clinics, emergency walk in services, reproductive and sexual health treatment advice, renal clinic, hepatitis co-infection, family and transition clinics, plastic surgery, neurology, oncology, dermatology, a dietician, in-house pharmacy and a citizen's advice bureau service.

It also runs the HIV clinic at Great Ormond Street Children's Hospital and consequently has the largest teenage clinic in UK.

There are approximately 3,700 patients increasing annually by about 10% with more than 80% on therapy. Gay males make up about 60% of the cohort and 20% are women. There are over 15,000 appointments a year.

Peer Support

In 1999 two patients - Peter Twist and Garry Brough - set up the Bloomsbury Patients Network and won a Millennium Awards Grant in order to expand service-user involvement in the form of workshops and meetings. Encouraged by Dr Ian Williams they also attended management meetings to give feedback on the service.

In 2004 Garry Brough was appointed the first salaried, part-time patient representative .to offer peer support, advice and advocacy; to co-ordinate user involvement; to engage patients in their care; and to represent patients' interests at management level.

There are now two salaried patient representatives – Angela and Chris – who offer a five day a week drop-in and appointment service, providing positive peer support and helping patients help themselves. This is of increasing importance now that HIV is a chronic manageable disease which patients have to learn to live with for the rest of their lives.

614 clients were seen by the Patient Reps last year on a one to one basis.

Patient Representatives

“If a patient only sees a clinician, they only get half the story”

Dr Simon Edwards, Lead Clinician 2001-10

Neglecting emotional reactions to diagnosis can result in passive victims rather than active survivors. Low self esteem, lack of employment, financial concerns, feelings of not being in control of one's life and other psychological and socio-economic issues, can impact negatively on patients' health and well being. Positive psychosocial peer support can help prevent distress and suffering from developing into something more severe, and can help people cope better at living with HIV.

The Patient Representatives therefore offer peer support, advice and advocacy on a range of issues:

- Living with the virus
- Starting treatment and medication side effects
- Disclosure and confidentiality issues.
- Immigration, employment, benefits, housing
- Dental care and GPs,
- Stigma, discrimination, violence, abuse and criminalisation
- Social and psychological support

They also refer clients to in-house specialist services, external agencies, charities and support organisations.

As the Patient Representatives are also patients at the clinic, they are able to empathise with their clients – they know what it is like to go through the crisis of diagnosis, to live with the virus; take pills every day; deal with side effects; agonise over who to tell; and to how to deal with discrimination, stigma and abuse. They understand how the smallest problem can impact negatively on health and well-being.

The Reps are valued members of the team and work closely with consultants, psychologists, specialist nurses and health advisors - to whom they can refer patients when necessary. In return, patients are referred to the reps, not only for social issues and peer support, but because they may never have met anyone living well with the virus before. The Patient Reps can help dispel patients' fears and preconceptions, correct urban myths, outdated information, negative images in the media and be positive role models.

"I just wanted to thank you for all your help and support. Your approachability, understanding and advice were invaluable in helping me to cope with a very traumatic period in my life. Thank you so much."

Stephen, 47 television producer – diagnosed 2009

Bloomsbury Patients Network

417 people accessed workshops, forums focus groups and courses last year.

The Network holds forums or workshops once a month, and organises focus groups for researchers, and policy makers. Consequently it influences the decisions of external organisations such as the Metropolitan Police, the British Medical Association, Camden NHS, Westminster NHS, Islington NHS, the British Dental Association and the Royal College of GPs - who took the views of our patients back to their annual conference.

Forums have included

- **BHIVA Conference Feedback** - which was led by Dr Ian Williams, Chair of British HIV Association (BHIVA)
- **GPs & HIV** - with representatives from the British Medical Association, the Royal College of GPs, MEDFASH and Camden's Deputy Director of Primary Care.
- **HIV & Dental Care** – the panel included the British Dental Association and Gus Cairns, Editor of *HIV Treatment Update*.

Interactive workshops have included:

- **Building a Support Network** facilitated by Danny West.,
- **Change Your Mind, Change Your Life** a workshop facilitated by David Manning & Garry Brough.
- **Choice is Power** a workshop on positive thinking and life choices facilitated by Darren Brady.

There have also been two highly successful **Newly Diagnosed Courses** and one **Positive Self Management Programme**. These were inclusive, and had a wide range of participants – including a seven month pregnant woman and a married couple.

The most important part of all of these events is the peer support - a sense of belonging and a feeling of safety where people can express their fears, feelings and problems; where they can learn from others' experiences, use others as role models, and realise that they are not alone; that other people are similar and that their feelings are normal; that they can find solutions to life's problems by accessing not only their own strengths but also those of other participants.

“The range of speakers has been very impressive and represent important organisations. It is good to know we can influence national policies and the voice of the patient is being heard.”

Michael, 30, PR Manager – diagnosed 2008

Patient Engagement

“Patient involvement increases patient satisfaction”

The Picker Institute

The Patient Representatives and Patients Network have a long history of helping to effect change at the Bloomsbury Clinic – most notably:

- the opening of the in-house pharmacy
- the phlebotomy unit
- the introduction of evening clinics
- home delivery of medication
- the redesign of Bloomsbury clinic and waiting areas
- patient awareness and understanding to changes in clinic
- on-call doctor service

Patients’ views are regularly sought in major surveys and focus groups – for instance, whether or not to have an in-house GP and future NHS policy. The clinic is also a major centre of research, so patients are regularly surveyed on a variety of issues – such as safer sex, notifying partners, waiting times in clinic and parenting.

As the reps and network interact with over 25% of the clinic’s patients, and are present in the clinic five days a week, valuable feedback, information, outcomes and views are shared at other Clinic meetings, most importantly the monthly management HIV Implementation Group.

In the last twelve months patients’ interests have been represented on several other Clinic committees:

- Refurbishment
- Flu pandemic planning
- Pharmacy Pathways
- Cost Saving Initiatives
- Home Delivery Service
- Electronic Patients records
- Reconfiguring HIV Follow-up
- HIV Service Development

External committees on which patients are also represented include Camden HIV Steering Group, HIV Rights & Responsibilities Advisory Group, Camden HIV Joint Commissioning Group, Westminster HIV Care and Support Tender Panel and the London Consortium’s Public & Patient Engagement Sub Committee, chaired by Peter Twist – the Co-Chairs of the Patients’ Network.

The work of the Patient Representatives and Network amounts to significant patient engagement which undoubtedly influences and informs all aspects of patient care.

Future Vision

“In a time of crisis, psychosocial support is not an optional extra; it is an obligation”

International Federation Red Cross & Crescent Societies

There have been huge medical advancements in the last couple of years. First line medication is now one pill a day and life expectancy is near normal.

However, there is a misconception that these medical advancements have solved all the problems. This is not the case.

Psychological and social issues remain - the shock of diagnosis, fear of rejection, fear of disclosure, low self esteem, lack of confidence, stigma and discrimination. Outdated public perceptions, memories of the 80s campaigns and a negative media image do nothing to help the newly diagnosed come to terms with their diagnosis, manage their condition and get on with their lives.

The earlier the intervention, the more knowledgeable and engaged people are, the more they are helped in this process.

In 2010 – 2011, therefore, we hope to develop more initiatives for the newly diagnosed which are clinic based. This will further aid continuity of care. The more vulnerable patient is far more likely to access support within an environment they already know, where they feel safe and where they know a familiar face – as most participants at our events have previously met with the Patient Representatives. Moreover the team of consultants, psychologists and health advisers can monitor a patient’s progress and offer further support if necessary.

Other proposed activities this year include:

- Expanding the Network mailing list to provide a more effective method of communication between Clinic and patient.
- Setting up of an *emergency fund*
- Furthering our collaboration with outside agencies to provide more courses
- A programme specifically designed for women
- Training volunteers to help with administration of the Network with an eye on future expansion of the service

We will continue to make sure the voice of the patient is heard loud and clear.

.On December 8th 2010 we will be celebrating the 10th Anniversary of the Bloomsbury Patients Network

APPENDICES

Case studies.

"single mother – verbal abuse and stones through the window, three children beaten up at school. Were able to mobilise social services, housing, the police, organise a safe place for her to stay with the children over the week end and get long term support from Body & Soul"

"young man in denial and life in chaos. Cut himself off from support for a year. Paranoid about being seen entering the clinic. Too depressed to start medication and refused to speak to psychologist. Meetings outside clinic for several months. Now has a job, a flat and recently started medication"

"woman on the ward with HIV, cancer, epilepsy and recent heart failure. Had been waiting two weeks for council to find suitable accommodation. Previously had been given a flat miles away from her son's school and on the fourth floor – without a lift. Contacted Mary Ward Legal Centre. Accommodation sorted"

"patient who said he was *living like a pig*. Toilet in flat not working for 3 months. Leaks from flat above. Recently bereaved. Social worker said that Housing Association not returning calls. Persuaded all parties to meet at his flat to remedy the situation. Community Matron also now involved in care."

"young man, made redundant, delays in council paying rent, faced with eviction. Depression, threatened by neighbours and landlord. History of being abused as child and adult. Psychological support found. Council approached who paid rent. New accommodation found and now in part time employment"

"single mother, victim of torture, living in a first floor bed-sit. Bedroom window smashed on several occasions. Landlord refused to do further repairs to window. Worried for the health and safety of her young son. Put complaint in writing to the landlord, copy to NASS and social services. Window repaired"

"Young man presented himself in our office threatening suicide. "Did not want to go on", paranoid and hearing voices. Calmed him down, contacted the on-call doctor who rang his GP and emergency services. Taken into hospital for his own protection. Referred for further psychological support"

"refugee couple, escaped with their lives. Arranged food parcels from Food Chain, monies from Crusaid Hardship fund, co-ordinated care package including finding GP, dentist & optician; English classes and THT refugee mentoring project. Husband has just started lecturing at a university, wife studying accountancy"

Referral Organisations

Including

African HIV Policy Network
 African Health Forum
 Age Concern
 Albert Kennedy Trust

Body & Soul
 British School of Osteopathy

Camden CAB
 Camden Volunteer Service
 CARA
 CWAC
 Crisis
 CRUSAID Hardship Fund

Ealing Gay Group
 Elton John Foundation
 Food Chain
 Fostering and Adoption Association

Gateway Clinic
 Gay Men's Housing Association
 Gay Men's Group
 GMFA
 Gay Sports & Social Clubs

Hep C Trust
 Homeless People's Services

Immigration Advisory Centre
 Lambeth LGBT Officer
 Lesbian & Gay Switchboard
 Lighthouse West
 Living Well
 London Advice Services Alliance
 London Friend
 Long Term Survivors' Group

Mary Ward legal Centre
 Medical Foundation
 Metro Centre
 Metropolitan Police – LGBT officers
 Midmonth
 Migrants Resource Centre

NAZ Project
 Newham HIV Advocacy Project
 OPAM
 Outdoor Lads

PACE – counselling
 PACE – employment
 Plus Friends
 Positive East
 Positively Women

Red Cross Refugee Services
 Rise Community Action
 Riverside Trust

SHAKA Services
 Shelter Housing Aid Office
 Southwark LGBT Group
 Stonewall Housing
 Str8Talk

The Helios Centre
 THT Counselling
 THT Direct
 THT Legal – employment
 THT Legal – immigration
 THT Refugee mentoring project
 THT South London Partnership
 Tyddynbach Trust

Umoja

West London Gay Men's Project
 Westminster Day Centre
 Westminster Housing Options
 Winkfield Road Drop-in Centre

YMCA Positive Health

68 Organisations

- excluding PCTs, PALS, NHS services, citizens' advice bureaux, judicial, social and housing services.

Workshops and Forums

417 people accessed workshops, forums focus groups and courses last year.

- April ***BHIVA Conference Feedback***
Dr Ian Williams, Chair of BHIVA and Dr Tristan Barber.
- May ***Forging a Positive Future - Accessing support.***
Positively Women, Body & Soul, Living Well, YMCA Positive Health, Str8Talk, and the Helios Centre.
- June ***HIV & Dental Care Forum***
British Dental Association, Gus Cairns Editor of HIV Treatment Update. Dr Steve – Dentist and campaigner living with HIV.
- July ***Building a Support Network***
Interactive workshop facilitated by life coach Danny West.
- Sep ***Change Your Mind, Change Your Life***
Workshop facilitated by David Manning & Garry Brough.
- Oct ***GPs & HIV Forum***
Royal College of GPs, BMA, Deputy Director of Primary Care (Camden), MEDFASH and Dr Paul Benn – Bloomsbury Clinic.
- Nov ***Choice is Power***
Interactive workshop on positive thinking facilitated by life coach Darren Brady.
- Dec ***What Can We Do About Stigma & Discrimination?***
Forum with NAT (Stigma Index team), African Policy Network, THT & Metropolitan Police LGBT officers.
- Jan ***Disclosure – How to Tell.***
Interactive workshop facilitated by Chris Sandford.
- Feb ***Free (or low cost) Support in London***
Gay Men’s Group, CARA, Body & Soul, Positively Women, YMCA Positive Health, Str8Talk, THT.
- Mar ***A Brilliant Life***
Interactive workshop to focus on your strengths and increase positive outlook facilitated by Darren Brady.

Newly Diagnosed Course

“What a great course! I have learned so much, both in terms of facts and how to move forward in my life. You have brought humour and sensitivity to a difficult and emotional process and it has been such a positive experience for me.”

Gail, 28, social care worker

Workshops are facilitated by trained facilitators living with HIV.

Course Description

Week 1 **The Impact of Diagnosis**

Sharing experiences - awareness you are not alone - gaining shared understanding - learning coping mechanisms from others' experiences.

Week 2 **Disclosure**

Whether or not to disclose - the perceived barriers to disclosure - what to take into account - why, when and how to disclose - the advantages of disclosure.

Week 3 **Medical Aspects of HIV**

HIV & the immune system - viral load and CD4 - medication and treatment options – fears of side effects – adherence - the advantages of therapy.

Week 4 **Sex, relationships, your health and HIV transmission**

Transmission and infectiousness - other STI infections - disclosure to sexual partners – negotiating/responsibility for safer sex - legal and moral obligations

Week 5 **Coping with emotional issues**

Emotional and mental health issues – coping mechanisms – the importance of support networks - psychological support – things you can do to help yourself.

Week 6 **Looking to the future – living well with HIV**

Explore in greater depth or to clarify points – to discuss any issue that has not been covered – further support sources – how to use what you have learned.

27 people attended the two Newly Diagnosed Courses

Positive Self-Management Programme

Stanford University's Positive Self-Management Programme, or PSMP, is a seven-week course delivered once a week for two and a half hours.

Each session is facilitated by two or three trained facilitators, at least one of whom is a non-health professional living with HIV.

The PSMP provides participants with skills and techniques that allow them to improve and maintain their physical and mental health.

Sessions are highly participative, where mutual support builds the participants' confidence to manage their health and maintain active and fulfilling lives.

Subjects covered by the PSMP include:

- Evaluating common symptoms – acute and chronic conditions
- How to integrate medication regimens into daily life and adherence
- Techniques to deal with emotions such as frustration, fear, fatigue, pain and isolation
- Appropriate exercise for maintaining and improving strength, flexibility, and endurance
- Communicating effectively with family and friends
- Nutrition, relaxation and cognitive techniques
- Sex, intimacy and disclosure
- How to evaluate new treatments or complementary therapies
- Making treatment decisions
- Informing and working with your healthcare professionals
- Positive thinking and making choices
- Building support networks

17 participants enrolled in the first Positive Self Management Programme, autumn 2009

Feedback - the patients

"May I take this opportunity to thank you both for your time, support and more importantly faith that we can embrace our HIV status with a degree of confidence and pride. "

Susan, 39, mother – diagnosed 2009

"Everyone should do this course! I was shocked at my diagnosis and my knowledge of HIV was so out of date that I contemplated suicide. I talked to the Patient Rep and attended the newly diagnosed course. I started therapy after only 4 weeks. I would have been very ill otherwise. I now feel ten years younger and have not been so well for a long time. Now living well with HIV "

Neil, 58, writer – diagnosed 2009

"I was deported from Canada six months ago. My CD4 was below 200. It is already above 350. I am now engaged in training, volunteering and looking forward to a productive and rewarding future. None of this would have been possible without the Bloomsbury Clinic - and in particular the two Patient Reps who held my hand while guiding me through the labyrinth of bureaucracy in my adopted country."

Roger, 46, part-time student – diagnosed 2008

"I should like to extend my thanks for a great event today that was most thought provoking and well constructed. I should also like to share my admiration for your apt skills and gentle approach in presenting this emotionally complex subject matter. Today I was challenged, in a very positive way. Many, many thanks."

John, 49, mental health nurse RN - 1998

"Just a quick email to say how interesting and supportive I am finding the Course. Especially the variety of ages, origins and walks of life in such a relatively small group. The fact that the facilitators are gay and positive, like me, makes me feel more comfortable and reassured as they can talk from experience. This is helping me deal with the numerous questions and anxieties I have as a newly diagnosed person."

Luis, 34, designer – diagnosed 2009

"Thank you so much for running the newly diagnosed group. To meet other people living with HIV has helped me tremendously with the situation and things look nowhere near as bleak as they did a couple of months ago..... I feel that the group is so important and can make such a huge difference to those at one of the most important points in their lives "

John, 28, charity project manager – 2009

"What you are doing at the Bloomsbury Clinic is pretty special. You are creating a rich, diverse and positively fertile environment that is and will have far reaching effect. Thank you."

Darren, 45, trainer - diagnosed 2004

Feedback - the professionals

“I have been really pleased to support the Bloomsbury Patient Network. I believe that there is more to the care and support of someone living with HIV than simply their healthcare and medication, no matter how excellent that may be. The Representatives and Network offer peer support, a social network, and signposting to essential care and support services. I also believe that it is important that the voice of people living with HIV is heard by policy-makers and commissioners, and attending meetings of the Network has been incredibly useful in helping me to understand the challenges, frustrations and successes that people encounter when living with HIV”

Lindsay Jones
Interim Joint Commissioner Sexual Health and HIV
Services NHS Camden

‘It is so important that people with HIV are heard by those of us in the NHS that design and commission services on their behalf. The Bloomsbury Patient Representatives and the Patients’ Network do an excellent job in making sure that what people living with HIV want is fed back to us. More than that, both through one to one work and events that are organised, the Representatives and the Network really are meaningful, supportive friends to people living with HIV and have their interests at heart.’

Ewan Jenkins
Assistant Service Development Manager Sexual Health and
HIV NHS Westminster

“Psychosocial support can be just as important for the health and well-being of someone living with HIV as going to the doctor or taking treatment. This form of support can be of real benefit to people's mental and emotional well-being, and can be the crucial difference between finding every day a struggle and feeling able to cope with and enjoy daily life. It can also be the difference between a person managing well on HIV treatment and someone struggling to cope with a treatment regime.”

Yusef Azad - Director of Policy and Campaigns, NAT

“The collaboration with the Bloomsbury Patients’ Network has helped educate GPs to understand the needs of people living with HIV; to improve their health and well being; and to devise a shared care framework between GPs and clinicians”

Dr Richard Ma – Royal College of General Practitioners.

AUTHOR

Chris Sandford BA, PGCE, MA

Patient Representative.

Administrator of the Bloomsbury Patients Network.

A patient at the Bloomsbury Clinic for 26 years. Facilitates *Newly Diagnosed Courses*, workshops, focus groups and forums. Represents patients' interests at management level. Also a member of the *Camden HIV Steering Group*, *HIV Rights & Responsibilities Advisory Group*, *Camden HIV Joint Commissioning Group*, and *Westminster HIV Care and Support Tender Panel*. Writes, teaches and lectures widely – including for THT, NAT, NAM, London University, Islington NHS and Royal College of GPs. Previously university lecturer and West End theatre director.

COLLABORATORS

Angela Ariho BA

Patient Representative.

Administrator of the Bloomsbury Patients Network.

Joined the team in 2006 as first female patient representative. Also teaches undergraduates and represents patients' interest at management level. Has a degree in *Early Childhood Studies* and diplomas in Hospitality Management, Teaching and Counselling (Level 2). Previous experience includes being a liaison officer for *Centre Peace Women's Project*, a mentor for *Home Start* and a secondary school teacher. Recently elected to the board of CARA – a charity supporting people living with HIV. Originally from Uganda, has lived and worked in London for seventeen years and has two children.

Garry Brough BA

Co-Chair *Bloomsbury Patients Network*.

In 1999 set up the *Bloomsbury Patients Network* with Peter Twist and won a Millennium Awards Grant to expand service-user involvement. Appointed as the first Patient Representative in 2004 to provide in-house peer support, advice and advocacy. Managed the *Central YMCA Positive Health Programme*, developing their national *HIV & Exercise* training. Long term member of the *Pan-London HIV Consortium's Public & Patient Engagement Subgroup* and community representative on two *BHIVA Guideline Subcommittees*. In 2008 he joined the Terrence Higgins Trust as a Health Trainer and is now Membership and Involvement Officer.

Peter Twist LLB
Co-Chair *Bloomsbury Patients Network* .

After establishing the Bloomsbury Patients Network with Garry Brough in 1999, won a Millennium Awards Grant in 2003 and successfully completed the Leadership Programme of the King's Fund. Chairs the *Public & Patient Engagement Sub Committee of the London HIV Consortium* and recently chaired the *Camden HIV Steering Group* – for *their HIV Awareness Day* and *Science and Silence*, part of the Black History Season. Also chairs forums and focus groups for the Patients Network and Camden *Adult Social Care Liaison Group Review Engagement Jury*.

Our thanks to:

Dr Paul Benn FRCP

Lead Consultant in HIV Medicine, Mortimer Market Centre
 Consultant in GUM/HIV, Mortimer Market Centre
 Honorary Senior Lecturer, University College of London
 Clinical governance lead for Sexual Health Services and HIV, Camden PCT (2004-2010)
 Lead Clinician HIV services, Mortimer Market Centre (2010 -)

As Lead Clinician, ensures that HIV services meet the needs of users in close collaboration with the Patient Representatives and Patients Network.

Dr Simon Edwards FRCP

Lead Consultant in HIV Medicine, Mortimer Market Centre
 Honorary Consultant, University College Hospital. London
 Honorary Senior Lecturer, University College of London
 Lead Clinician HIV services, Mortimer Market Centre (2002-10).

Co-chair of the BHIVA/BIS Opportunistic infection guidelines. Member Drug and Therapeutic subgroup of the London Specialist Commissioning Group. Chair of the BASHH HIV Special Interest Group. UCL-P Clinical Lead for HIV infection.

CONTACT DETAILS

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