The Patient Voice

Patient engagement and the work of the Patient Representatives

Bloomsbury Clinic
Mortimer Market Centre
2014
Achievements
January to December 2014

“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, 37 - Film Technician

- 1,034 patients were seen by Patient Representatives
- 1,987 patients made use of one-to-one peer support, advice and advocacy or attended Bloomsbury Network events
- Patients were signposted to over 80 external organisations
- 953 patients attended Bloomsbury Network forums, workshops, courses and events
- 500 people have completed the Newly Diagnosed course since it started in 2009
- 800 patients receive a weekly Newsletter from the Bloomsbury Network
- Active patient representation on Bloomsbury Clinic management meetings
- Membership of external committees and advisory panels
- Engagement of patients in service change, major research projects and national policy

Over 953 patients attended Forums, Workshops, Courses and Social Events

- 5 Bloomsbury Network Forums - 262 patients
- 4 Motivational Workshops - 87 patients
- 4 Hepatitis C Co-infection Workshops - 32 patients
- 6 Newly Diagnosed Courses - 92 patients
- 11 Women’s Lunch Club - 150 patients
- 30 patients sing in the Bloomsbury Choir
- 140 people attended the Summer Picnic in Regent’s Park
- 100 people attended the Christmas Party
- 45 patients attended exhibition previews at the British Museum
- 15 patients participated in a guided tour of Bloomsbury and Fitzrovia
Patient Representatives and the Bloomsbury Network

1. The Patient Voice

This report is about the patient voice; about patient engagement, about how lived experience is just as valuable as the expertise of health professionals; about how peer support can help and support people living with HIV.

Patients, their partners and their families have unique experiences, skills and abilities that enable them to offer expert advice about their treatment, support needs and how services can better meet their future needs.

Our aspirations are to engage the patient in their care and build self-esteem and self-confidence through information and peer support; to support self-management and improve quality of life; to promote an equal and reciprocal relationship between professionals, people using services, their families, significant others and the public.

This Annual Report describes the support, advice, advocacy and engagement activities that have been delivered to people living with HIV by the Patient Representatives and the Bloomsbury Network over the past 12 months.

2. Patient Representatives

There are three Patient Representatives based in the Bloomsbury Clinic who offer confidential one-to-one peer support, advice and advocacy for those HIV patients registered at the Bloomsbury Clinic. They are key members of the multi-disciplinary team and in 2014 the Patient Representatives directly supported 1,034 patients. All the Patient Representatives are living with HIV.

- Chris - diagnosed 30 years ago
- Angela - mother of two negative children and diagnosed 17 year ago
- Cristian - in his 20’s and diagnosed 2 years ago.

3. The Bloomsbury Clinic

The Bloomsbury Clinic at the Mortimer Market Centre is an NHS funded clinic providing HIV clinical care, treatment and support to patients and their significant others. There are three Patient Representatives who provide peer support, advice and advocacy, coordinate user involvement, represent patient interests at management level and facilitate and support the work of the Bloomsbury Network.

- Based in central London at Tottenham Court Road close to transport hubs
- 4,567 HIV positive patients
- 18% female
82% male, of which over 80% are men who have sex with men
83,182 patient appointments a year
85% of patients are on antiretroviral medication
97% of patients have an ‘undetectable’ viral load
Research, trials and teaching links with University College London Medical School
Inpatient Ward at University College London Hospital
Largest teenage clinic in the UK
Multi-disciplinary team of 3 Patient Representatives, Doctors, Nurses, Psychologists and Health Advisers.

“The Bloomsbury is such an important place... it is not just about getting my medical needs looked after - I come here for support, inspiration, new information about issues relating to HIV, and most of all to feel that I am part of a community.”
Anthony, 32, writer

4. The Value of Peer Support

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 psychosocial issues can impact negatively on patients’ health and psychological well being. Psychosocial peer support can help prevent distress and suffering from developing into something more severe, and can help people live positively with their HIV diagnosis.

The Patient Representatives offer confidential one-to-one peer support, advice and advocacy on a range of issues:

- Living with the virus
- Disclosure and confidentiality issues
- Dealing with fears of rejection
- Starting medication and the fear of side effects
- Fears of stigma and discrimination
- Fears of violence, abuse and criminalisation
- Social and psychological support
- Finding a GP, Dentist and other NHS services
- Advice on immigration, employment, benefits and housing
- Referral to in-house specialist services (e.g. Psychologists, Health Advisors) and external agencies, charities and support organisations (e.g. Social Services, Third Sector).

“If a patient only sees a clinician, they only get half the story.”
Dr Simon Edwards, HIV Lead Clinician - Bloomsbury Clinic
5. Education, Empathy and Empowerment

Patient Representatives play a vital role in educating, motivating and empowering patients. They are valued members of the Bloomsbury Clinic Multi-Disciplinary Team and work closely with Doctors, Nurses, Psychologists and Health Advisers.

- They can empathise and are positive role models
- They are living positively with the virus
- They take medication every day with no visible side effects
- They have experience of psychological and psychosocial issues such as the crisis of diagnosis, disclosure and fear of rejection, stigma and discrimination
- They understand how the smallest problem can impact negatively on health and wellbeing
- They can help dispel fears and preconceptions, challenge urban myths, out-dated information and negative media coverage.

“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.”

Stephanie, 27 - Mother

6. Psychosocial Support Case Studies

Woman diagnosed in antenatal clinic
- She considered termination and suicide, dropped out of college and stopped working. She suffered post-natal depression and isolation due to fear of gossip because she was advised not to breast-feed. She did not leave her flat and could not cope with opening her mail. Her benefits were stopped. The Patient Representatives organised free groceries, powdered milk for the baby and advice about benefits. She attended the Newly Diagnosed Course run by the Bloomsbury Network and was helped with subsidised childcare. She is back in college, working part time and volunteering and her son is now two.

Young man struggling with diagnosis
- Became depressed and cut himself off from family and friends. Suffered severe paranoia. Fled the country to study - in denial, isolated and depressed. His CD4 cell count fell sharply. He would not engage with the clinic or psychological services. The Patient Representative met with him 12 times outside the clinic. He began to re-engage with services and started medication with no side effects. He is now ‘undetectable’ and has a new job, new home and new partner and has agreed to be referred to the in-house Psychology team.

Refugee couple
- No money, no clothes, no food. The Patient Representatives arranged food parcels and charitable funding for furniture and co-ordinated a care package which included finding a GP, Dentist and an Optician. They arranged English classes and support from a refugee mentoring project, which led to the Refugee Council accrediting the husband’s overseas
qualifications. He is now working as University Lecturer and his wife is studying accountancy and working as a Care Support Worker.

**Young man with a serious and very rare reaction to HIV infection**
- Spent seven months in hospital and was in a coma for two months and paralysed. He is now learning to walk again. The Patient Representatives supported him and his family with ward visits, information and organised benefits and when he was discharged home they arranged free groceries and additional financial support. When he was well enough he attended the Newly *Diagnosed Course run by the Bloomsbury Network and was an inspiration to everyone.*

> “In a time of crisis, psychosocial support is not an optional extra; it is an obligation.”
> *International Federation Red Cross & Crescent Societies*

### 7. Patients Top 10 Concerns

Although people living with HIV often have more than one concern there are a number of issues that consistently concern them. In 2014 the top 10 concerns that patients asked Patient Representatives to help them with were:

1. Social isolation 33.4%
2. Fears around disclosure 27.3%
3. Fears of discrimination 27.3%
4. Medication issues 21.8%
5. Counselling 17.6%
6. Housing 15.9%
7. Physical health 14.3%
8. Sexual health 12.1%
9. Benefits 10.6%
10. Employment 10.1%

### 8. Who used the Patient Representatives Service

The Patient Representatives supported people from over 60 countries. Approximately half were gay men or men who have sex with men and 28% were heterosexual women. Although only 18% of people living with HIV who attend the Bloomsbury Clinic are women, a disproportionate number used the services of the Patient Representatives.

- 42.1% - UK born
- 49.3 % - Gay or MSM (men who have sex with men)
- 28.1% - Heterosexual female
- 21.3% - Heterosexual male
- 1.3% - Not specified
9. The Bloomsbury Network

The Bloomsbury Network was set up in 1999 by two patients on a volunteer basis to improve engagement with clinical staff and services and to improve the patient experience. The Network is a not for profit membership organisation and operates independently of the Bloomsbury Clinic through a Volunteer Steering Committee. The Network produces a weekly newsletter and offers educational forums, motivational workshops, courses and social events. Network activities are administered and facilitated by the Patient Representatives.

The Network has a website (www.bloomsburynetwork.co.uk) and a twitter feed (@bloomsusrs) which patients can use to find out about upcoming events and support services. The Chair of the Network and our Patient Representatives are full and active members of the Bloomsbury Clinic management team.

The Patient Representatives and the Bloomsbury Network have a track record in effecting change and improving patient services at the Bloomsbury Clinic. Some of the improvements that have taken place are:

- On-call doctor service
- Opening of the in-house HIV Pharmacy
- Opening of the phlebotomy unit
- Introduction of evening clinics
- Home delivery of medication
- Redesign of the Bloomsbury Clinic (waiting areas and clinic rooms)
- Improved patient awareness and understanding of clinic changes.

“I must acknowledge your strength and dedication. Thank you so much for the encouragement and support. I pray that the Lord will continue to keep and strengthen you. You’ve touched my life in a positive way.”

Olori, 27 - Nurse and Mother

10. The Bloomsbury Network Forums

The Forums take place regularly throughout the year and start with a number of presentations followed by an Expert Panel answering questions from patients. They are co-produced by the Bloomsbury Network and the organisations represented at the forums, e.g. BMA (British Medical Association), BHIVA (British HIV Association) and NAT (National AIDS Trust).

- 5 Forums per year - 84 participants at each Forum
- Held on Thursdays between 6.00 pm and 8.00 pm at the Mortimer Market Centre
- Refreshments available before, during and after each Forum
- Participants complete an evaluation form to provide feedback on the effectiveness of the Forum and make suggestions for future topics.
2014 Forum Programme

- **Recreational drugs and HIV** - What impact do recreational drugs have on people living with HIV? Where can we turn for help? Speakers from Antidote (http://londonfriend.org.uk) and the CNWL Club Drug Clinic.

- **Growing Older with HIV** - What are the challenges that lie ahead? What are the psychosocial implications? Speakers from Positively Ageing Forum, Public Health England, Bloomsbury Clinic and the Bloomsbury Network.

- **A Medical Update** - The latest news about new treatments and research from the worldwide spring conferences. Speakers from BHIVA (British HIV Association - www.bhiva.org) and the Bloomsbury Clinic.


- **The Future of Living with HIV** - The Bloomsbury Clinic’s response to new treatments, research, guidelines and developments. Speakers Dr Laura Waters and Dr Diarmuid Nugent from the Bloomsbury Clinic.

“I’ve found all the forums extremely interesting, helpful and informative. The range of speakers has been very impressive, and represent important organisations - which we, in turn, can influence... It is good to know we can influence national policies and the voice of the patient is being heard.”

*Thomas, 34 - Marketing Director*

11. Hepatitis C Co-infection Workshop

These workshops are co-produced with the Bloomsbury Network, the Bloomsbury Clinic Lead Hepatitis Consultant and Specialist Hepatitis Nurse, and the Hepatitis C Trust (http://www.hepctrust.org.uk). They are for HIV patients who have recently been diagnosed with Hepatitis C, or are about to start treatment, or who are struggling with issues around HIV co-infection.

2014 Workshop Programme

- The impact of a Hepatitis C diagnosis
- Understanding Hepatitis C, context and medical
- Treatment options
- Transmission and risk factors
- Self-management - what can we do to help ourselves?
- Support networks - website, leaflets and organisations.

- Facilitated by people living with Hepatitis C and/or HIV
- 6 Workshops a year - up to 15 participants at each Workshop
12. Motivational Workshops

These Workshops give patients an opportunity to look at non-medical issues that are important to them in a new and creative way.

- Facilitated by people living with HIV
- 4 Workshops a year - 25 participants at each Workshop
- Held on Saturdays between 10.30am and 1:30 pm at the Mortimer Market Centre
- Participants have refreshments and lunch in a local restaurant
- Evaluation forms provide feedback on the effectiveness of the workshop and suggestions for future workshops.

2014 Workshop Programme

- Building Self-Esteem and Confidence - participants explore powerful tools to build self-esteem and confidence and unlock self-expression and fulfilment.

- Telling Others - an opportunity to explore fears around telling other people. Where do these fears come from? Do we have a legal or moral obligation to disclose? Facilitated by Chris Sandford, Patient Representative.

- An Introduction to Meditation and Yoga - how yoga and meditation can help deal with stress and help strengthen the immune system.

- Love, Sex and Relationships - What kind of relationship do you want? What are the risks of transmission? Is HIV a barrier to finding love?

“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.”

Tom, 29 - Retail
13. Newly Diagnosed Course

This course has been co-produced by patients and Patient Representatives. It is for patients who have recently been diagnosed with HIV or who are still coming to terms with their diagnosis. The course provides information, peer support and advice and is participatory.

Course Programme

- The impact of diagnosis
- Disclosure - telling others
- Medical aspects of HIV and therapy
- Love, sex, relationships and transmission
- Self management - keeping you immune system in good shape
- Building support networks.

- Facilitated by Patient Representatives and people living with HIV
- 6 Courses a year - 15 participants on each Course
- Held over 3 consecutive Saturdays between 10.45 am and 4.45 pm at the Mortimer Market Centre
- Participants have refreshments and lunch in a local restaurant.

“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

Course Evaluation

- Participants complete survey forms at the beginning and at the end of each course and these are used to evaluate the impact of the course on the psychological wellbeing of participants.
- Satisfaction with the course is high and participants report improved knowledge and confidence after completing the course.
Average ratings over 5 satisfaction questions covering:
Time available for Q&As, length of sessions, material covered, facilitators, overall usefulness of course

Overall Satisfaction with Course

- Overall Satisfaction
  - Very dissatisfied: 3%
  - Dissatisfied: 27%
  - Neither: 70%
  - Satisfied: 3%
  - Very Satisfied: 2%

Average ratings over 5 confidence questions covering:
Emotional state, dealing with status, telling others, dealing with sex & relationships, outlook for the future

- Average score: 2.46 pre-course, 3.93 post-course
- 59.6% improvement in average score

Overall Confidence

Q1. How comfortable do you feel about your HIV diagnosis

- Average score: 2.44 pre-course, 3.67 post-course
- 50.3% improvement in average score
Q2. How satisfied are you with your ability to get more information about HIV

- Average score: 4.12 pre-course, 4.71 post-course
- 14.3% improvement in average score

Q3. How confident do you feel about disclosing your HIV status

- Average score: 1.83 pre-course, 3.58 post-course
- 95.8% improvement in average score

Q10e. Confidence in the future

- Average score: 2.70 pre-course, 4.42 post-course
- 63.8% improvement in average score
14. Social Events

Highlights of 2014

- 140 people attended the Summer Picnic in Regent’s Park
- 100 people attended the Christmas Party
- 45 free places to exhibitions at the British Museum
- 15 patients took a walking tour of Bloomsbury and Fitzrovia followed by lunch in a local restaurant. This was led by one of our patients who is an official London City Guide.

Women’s Lunch Club

- 150 women in total attended 11 meetings of the Club
- The Club is both educational and social and is for mothers of young children and people who are socially isolated
- Subsidised travel and child care is available
- Recent events:
  - Talk from Winnie Sseruma, who has addressed the United Nations on women’s issues and presented a TED talk
  - Talk from Sam Culpeck, star of Channel 4’s The Undateables, who talked about dealing with stigma, discrimination and finding love
  - Screening by Body & Soul (http://www.bodyandsoulcharity.org) of their film Undefeated about a group of teenagers dealing with HIV at school.

Bloomsbury Choir

- 30 members of the Choir meet every Tuesday between 6.00 pm and 8.30 pm at the Mortimer Market Centre
- The Choir was featured in an article in The Guardian Newspaper.
- Maria, the musical director, welcomes anyone who wants to try their hand at singing and have a fun and exhilarating evening.

“Sometimes I miss my family who live far away in Argentina... so I join in the activities. The Network for me is like a foster family - where I always meet old friends and make new ones.”

Virginia

15. Influencing Service Change, Policy and Decision Makers

The Bloomsbury Network actively promotes the needs of people living with HIV within the wider community and also works at a local, regional and national level to influence, guide and inform policy and decision makers. Some key areas of involvement have been:
• UCL - teaching, presenting and delivering lectures to medical, psychology and nursing students
• London School of Hygiene and Tropical Medicine - teaching and facilitating workshops
• Queen Mary, University of London - delivering lectures to epidemiological students
• British Medical Association - speaking at events
• MEDFASH (Medical Foundation for HIV & Sexual Health) - Committee Member
• Royal College of General Practitioners - facilitating workshops
• British HIV Association (BHIVA)
  - BHIVA Standards of Care for People Living with HIV - contributor and speaker
  - Standards for Psychological Support for Adults Living with HIV - Committee Member, contributor and speaking at events
• British Association for Sexual Health & HIV (BASHH) - speaking at events and facilitating workshops
• National Aids Trust (NAT) - Committee Member and speaking at events
• All Party Parliamentary Groups on Sexual Health & HIV - Committee Member and speaking at the Committee
• Interviewed by The Guardian and The Independent newspapers
• Interviewed by BBC Television and Radio
• ABC of HIV - contributor to the Chapter on Peer Support & Patient Engagement
• Member of UK CAB (HIV Treatments Advocacy Network) - advisory body to BHIVA
• NHS England’s HIV Clinical Reference Group - Committee Member
• Stop Aids, National Tour - speaker and UK Representative.

“It is so important that people with HIV are heard by those of us that design and commission services on their behalf. The Bloomsbury Patient Representatives and the Network do an excellent job in making sure that what people living with HIV want is fed back to us.”

Commissioner

Thanks

Our work would not be possible without the encouragement and support of the clinical, nursing and administrative staff at the Mortimer Market Centre; from the CNWL executive team and Sexual Health and HIV management team, the London Borough of Camden, The Robert Grace Trust and private donors.

And of course... our thanks must go to those people living with HIV who attend the Bloomsbury Clinic and who give us such invaluable support and such positive feedback. Your courage and determination is inspiring.

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