The importance of peer support in HIV care

myHIV and Online Peer Support Volunteers (OPSV)

Alex Sparrowhawk
Membership & Involvement Officer
myHIV Objectives

- Empower people living with HIV to manage their own diagnosis and increase their knowledge of HIV
- Support people living with HIV with all aspects of, and during all stages of their diagnosis
- Reduce feelings of isolation and a lack of confidence that some people living with HIV experience
- Sign-post people living with HIV to appropriate support services when required and facilitate a safe space to engage in peer-led discussions
myHIV self-management tools

Online Counselling
- Book sessions and manage bookings with Online Counsellors

Online Health Training
- Learn practical steps to manage living with HIV

Online Advice
- Obtain assistance navigating legal problems and benefits

My Medication
- Learn about your drugs and set text/email reminders

CD4 and Viral Load Tracker
- Log and track your results

My Appointments
- Set reminders

My Personal Notes
- Record questions for consultants, side effects etc.

My LifeCheck/Test my Knowledge
- Test knowledge about living healthy with HIV and complete e-learning modules

My Favourites
- Save useful myHIV pages and information in your own library
myHIV community forums

- A space to speak to other people living with HIV about the topics that matter
- Live chat in the "ShoutBox" used to facilitate online peer support sessions and general discussions
- Threads include 'My Diagnosis', 'My Treatment', 'Relationships' and 'Other Health Conditions'
- Provides a space to promote campaigns and volunteer/job opportunities from THT and other HIV organisations
- Two regional sections provide a space to sign-post local community services, clinical services and a "would like to meet" section
myHIV Online peer support and the role of OPSV

- Accessible 24/7, flexible around service users daily routine and schedule
- Allows service users to remain as anonymous or open as they wish, unlike other online support networks i.e. Facebook groups
- A peer-led community with membership exclusive to people living with HIV
- Compliments traditional HIV support and care services
- Provides access to a HIV community for those living in isolated circumstances
- Daily peer support sessions facilitated by HIV+ volunteers within the "ShoutBox" facility and topical discussions in the "Group Chat" function
**myHIV Peer Support Survey Results: August 2015 - Respondents Information**

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>Year myHIV account created</th>
<th>Last time used the community forum</th>
<th>Time most likely to visit the community forum</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980-95: 14%</td>
<td>2011: 29%</td>
<td>2+ years ago: 13%</td>
<td>Anytime during the day: 37%</td>
</tr>
<tr>
<td>1996-2010: 44%</td>
<td>2012: 19%</td>
<td>1+ year ago: 12%</td>
<td>6-10pm: 46%</td>
</tr>
<tr>
<td>2011: 7%</td>
<td>2013: 24%</td>
<td>6+ months ago: 14%</td>
<td>10pm-12am: 9%</td>
</tr>
<tr>
<td>2012: 9%</td>
<td>2014: 13%</td>
<td>2-6 months ago: 23%</td>
<td>12-7am: 3%</td>
</tr>
<tr>
<td>2013: 11%</td>
<td>2015: 15%</td>
<td>1-2 months ago: 14%</td>
<td>7am – 12pm: 4%</td>
</tr>
<tr>
<td>2014: 7%</td>
<td></td>
<td>1+ weeks ago: 14%</td>
<td>12-6pm: 2%</td>
</tr>
<tr>
<td>2015: 9%</td>
<td></td>
<td>Today: 10%</td>
<td></td>
</tr>
</tbody>
</table>
Survey Results: Importance of factors when accessing online peer support

“Please rank the following in order of importance to you when using the myHIV community forum online peer support”

1. The service is easily accessible
2. I don’t have to travel to a specific place or venue to get support
3. I feel in control of my privacy and confidentiality
4. I don’t have to wait to use the service
5. I can be anonymous to others if I wish
Survey Results: Importance of factors when joining online peer support discussions

"Which of the following are important to you when joining the discussions hosted by the OPSV?"

1. Knowledge of HIV
2. Experience of living with HIV
3. Communication style
4. Interests other than HIV
5. Age group / age appropriate to you
6. Sexual orientation
7. Gender identity
Service users responded that they “always” or “mostly”...

- **77%** felt confident enough to join the online peer support sessions.
- **85%** felt welcomed by the OPSV when joining online peer support sessions.
- **69%** felt included during online peer support sessions.
- **77%** felt the OPSV achieved the right balance between HIV specific and general discussions.
- **82%** felt the OPSV provide good information and signpost helpfully to others.
- **87%** felt the OPSV were enthusiastic and made their sessions enjoyable.

Survey Results: OPSV performance
Survey Results: Personal benefits of using online peer support

- 70% could better manage living with HIV
- 70% were more confident talking to others about HIV
- 73% were encouraged to share experiences of living with HIV with others
- 65% felt less isolated or alone
- 73% were more knowledgeable about treatment and care
- 68% were more confident talking to their clinic team

Service users “agreed” or “strongly agreed” that by joining in online peer support sessions...
Difficulties and Solutions when Delivering Online Peer Support

Difficulties

- Engaging all high risk groups e.g. BME and perception of cliques
- Absence of body language, "text" speak and language issues e.g. sarcasm
- Technological Issues i.e. poor system performance

Solutions

- All service users are treated with dignity and respect and empowered to live healthy lives.
- Avoid jargon and slang, maintain awareness of the audience – including 'silent' participants.
- Manage service user expectations and maintain open and honest communication
- Ensure all service users are welcomed and introduced in discussions
Beyond personal benefits: How Peer Support can progress social change

Diagnosed HIV+ September 2013 and joined myHIV and the community forums

Publically revealed HIV status via social media and own blog – talking openly about life with HIV

Began OPSV training with Terrence Higgins Trust and started Peer Support volunteering in July 2014

Initiated plans for HIV social support group with other HIV activists following the termination/relocation of services in the local area

Thrive NE due to convene first social 7 December 2015
Thank you

Alex Sparrowhawk
Membership & Involvement Officer

‘The forums are a life line to me. They make a huge difference to my life.’