Conference Abstract

Online support scores highly for patient satisfaction and demonstrates improvements in HIV knowledge and engagement with healthcare

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Abstract

Background: With over 8,000 registrations during the 3 years since its launch, a UK-wide interactive online service has become the largest network of PLHIV in the country. Its innovative use of free interactive tools and online support via paid staff, volunteers and peers has made it a destination for information and support for newly and long-term diagnosed alike.

Methods: Snap-shot surveys are emailed to all members who have registered within quarterly periods. The data from the first two quarters (April – September 2013) was analysed for satisfaction levels and areas of improvement reported.

Results: 2,500 emails sent yielded 250 responses (10% response rate). Outcome percentages are reported only from those where an improvement could be made in each area.

The highest ranking areas for improvements experienced were 'Improved knowledge of HIV' (77%), 'Improved knowledge of CD4/VL' (69.5%), Improved lifestyle' (69%), but there were also significant improvements in confidence around 'asking questions at Clinic' (63.5%) and 'discussing HIV status with others' (41.4%).

Although they were fewer in numbers, there were also members who reported having started to attend clinic appointments, registering with a GP or informing their GP of their HIV status, where they had not been previously doing so.

Members were asked if they used the site tools (36.7% did) and what was most useful to them personally. The top responses were information pages, CD4/VL tracking graph, appointment reminders, medication reminders and online discussion boards.

Overall satisfaction rating for the site was 90%, with 57.5% having used the site in the last 3 months. The online discussion boards also scored highly, with satisfaction at 82.5%, and 49% using the message boards in the last 3 months.

Conclusion: Accessing online community support via computer and/or smartphone can complement clinical support and significantly enhance patients' engagement with their own health and the services they receive. Patients are comfortable storing personal data and health information online.

Keywords

online; HIV; health; support