



Supporting

**Improving well-being:
The effectiveness of
peer support**

We can help. We are positive.



POSITIVELY UK

January 2014

Positively UK

Foreword: Why we wrote this report

Over 25 years ago, two women living with HIV, put up hand drawn posters in HIV clinics and gathered a group together in their living room to offer each other support. Such were the humble origins of Positively UK and our model of peer support.

Today Positively UK provides peer led support to over 1,000 people each year through information, mentoring, guidance, advocacy, groups and workshops. Our aim is to improve the physical, emotional and social well-being of people living with HIV; good health and quality of life is determined by all three, they are equally important and often over-lapping.

We can only achieve this if we work collaboratively. That means collaboratively with all those accessing peer support in sharing their insight and strategies for managing HIV, other health and social care services providing a wider range of specialist services, and HIV clinics to ensure people living with HIV access the best clinical care possible.

HIV is now considered a long-term medical condition and treatments now mean people living with HIV can have a comparable life-expectancy with people who are not HIV positive. However HIV brings particular challenges in managing those medications and their side effects, managing sexual health when living with a communicable condition, and managing the psychological impact of living with a condition that is still met with stigma.

This research was designed so we could understand more the role of Positively UK's peer-led services in enabling people to better manage and improve health and well-being:

- What is the perception of Positively UK's peer support?
- How does our peer support enable people to better manage their health?
- How does this support complement clinical care?
- How does this support impact on well-being?

We believe access to good quality peer support is vital for people living with HIV. This report sets out to demonstrate that, and how our work contributes to both the NHS Outcomes Framework in managing long-term conditions, and Public Health Outcomes Framework in improving well-being. We hope this report will be of benefit to all Positively UK's donors in demonstrating the value of their investment, and as a useful resource to anyone seeking to establish local peer-led services. Nobody should face HIV alone, and we hope this research encourages everyone to understand the value of peer support now and in the future.

Allan Anderson
Chief Executive



How we did it

The research upon which this report is written from was an online survey distributed to people who have used, or are currently using, Positively UK's peer support service. Participants were also recruited through internal local meetings and word of mouth.

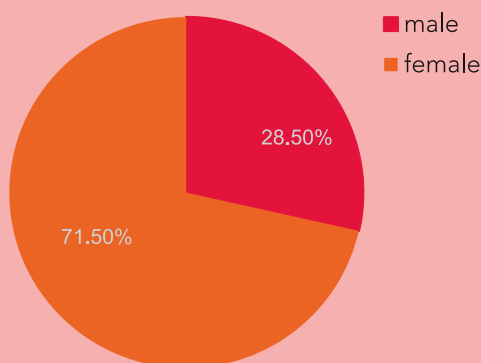
The survey was also offered as a paper version to those without access to the internet. In total we received 122 paper surveys (89%) and these surveys were entered into the online survey by Positively UK volunteers. The survey opened on 27th June and closed on 11th Nov 2013.

Who we reached

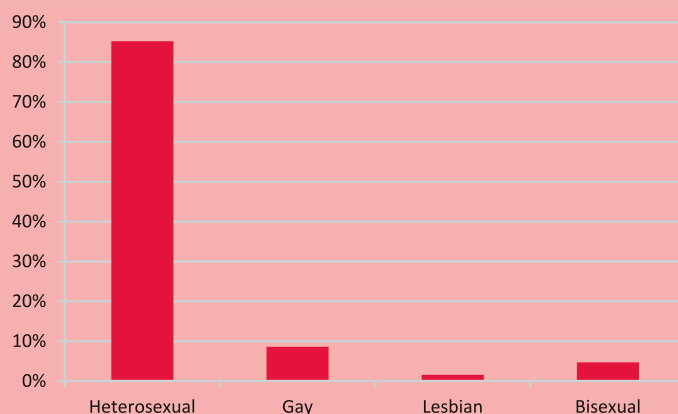
137 people completed the survey in total. It was not possible to achieve an entirely representative geographic split and most of the respondents lived in or around London where Positively UK directly delivers one-to-one and group support. The population reflected the people who access Positively UK's support services.

- 71.5% surveyed were female (n=98) and 28.5% were men (n=39)
- 64.7% were Black-African (n=86) and 7.5% White British (n=10)
- 85.2% surveyed were heterosexual (n=109) and 8.6% gay (n=11) 4.7% bisexual (n=6) and 1.6% lesbian (n=2)
- Average age of respondents – 46yrs 7mths (range 15-73yrs)
- Average length of time living with HIV – 11yrs 2mths
- Average length of time accessing services from Pos UK – average 5yrs 11mths

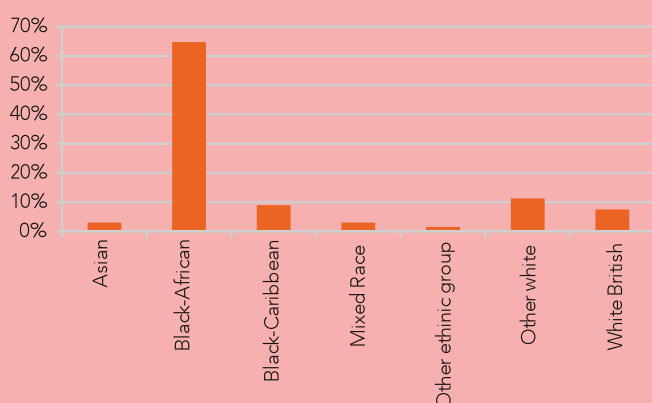
Gender



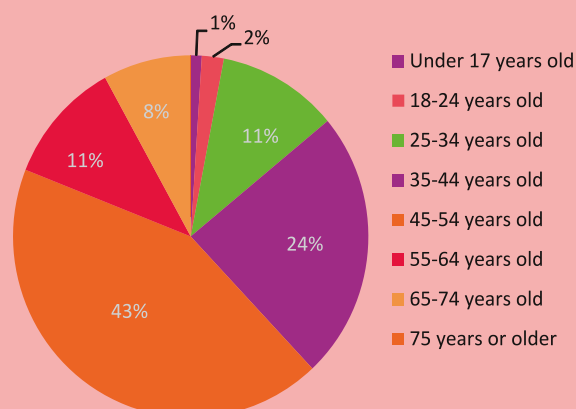
Sexuality



Ethnicity

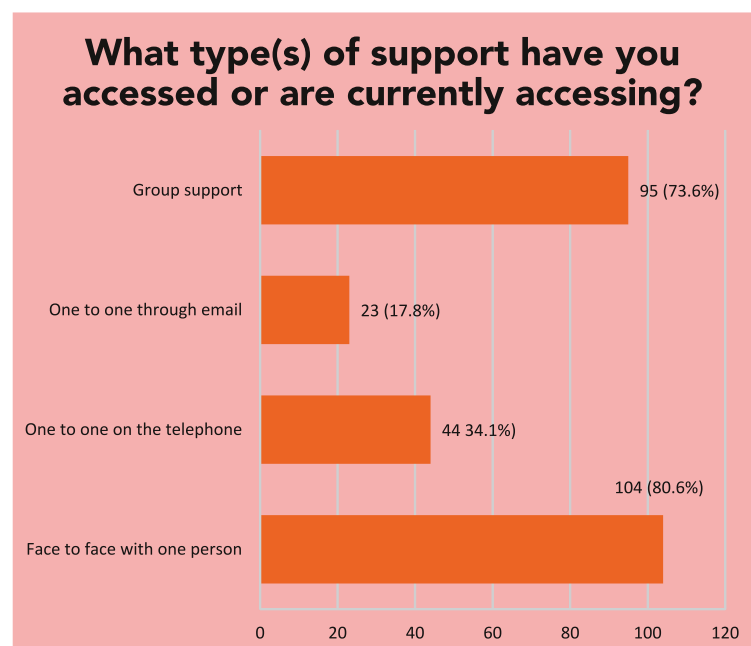


Age



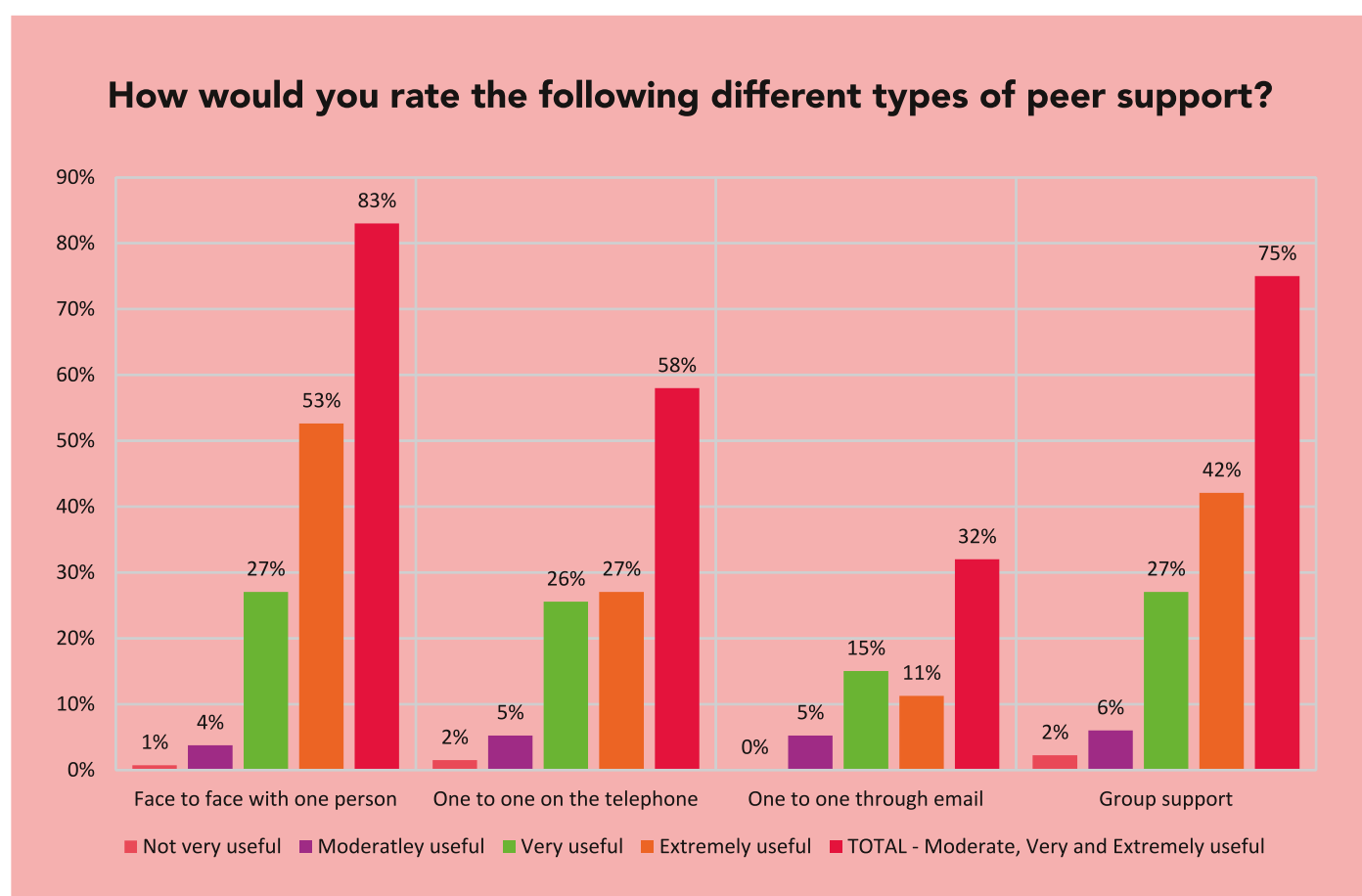
Peer Led Support

People can currently access peer-led support in a number of ways through one-to-one face to face, over the telephone or via email, and through a range of support groups. We asked people what type of support they currently accessed.



"Nothing beats talking through a problem with someone who understands what you are going through"

To understand people's perceptions of the support interventions we asked people how useful each medium was.



- 83% found support with another person face-to-face useful; 53% describing it as extremely useful
- 75% found group support useful; with 42% describing it as extremely useful

What we found

1) What is the perception of Positively UK's peer support?

- 97.8% of respondents (n=131) stated they would recommend Positively UK's peer support service to other people

"Without Positively UK I wouldn't have been the person I am today. Through the support groups I was able to make friends; I now have a social life. I also got advice and got help with immigration matters. Through the motivation I received I have went back to school, have gained a BA and look forward to getting back to work"

2) How does this support complement clinical care?

NHS Outcomes Framework has 5 domains, the second being 'Enhancing quality of life for people with long-term conditions' and this evaluation focuses on the parameter:

- Ensuring people feel supported to manage their condition

Domain 1

Preventing people from dying prematurely;

Domain 2

Enhancing quality of life for people with long-term conditions;

Domain 3

Helping people to recover from episodes of ill health or following injury;

Domain 4

Ensuring that people have a positive experience of care; and

Domain 5

Treating and caring for people in a safe environment and protecting them from avoidable harm.

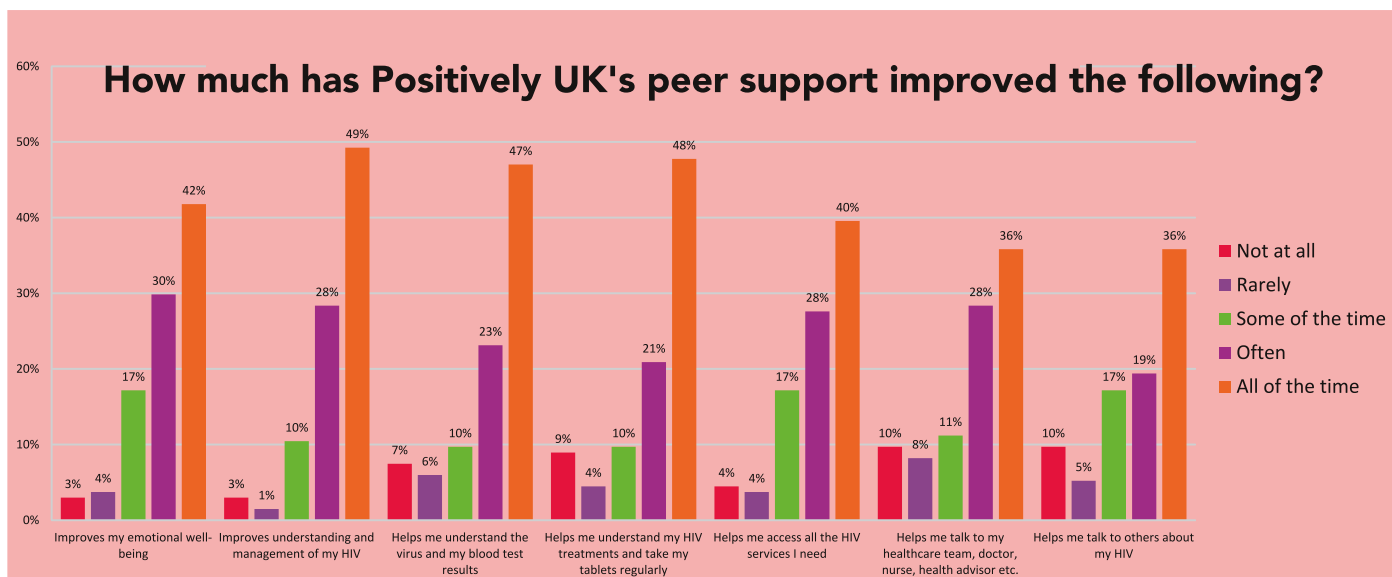
This research proves that Positively UK's peer support service contributes to helping people manage HIV as a long-term condition, by improving a number of aspects of life including:

- 89% said that peer support improved their emotional well-being
- 88% said that peer support improved their understanding and management of HIV
- 84% said that peer support helped them access all the services they need

Above figures = total improvement some, often and all of the time.

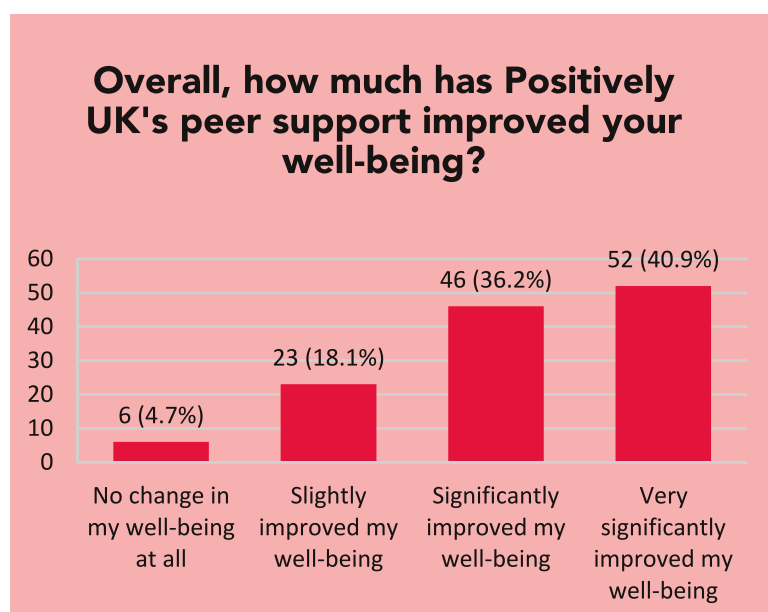
"...I have gained self-esteem"

"I have learnt to be positive about life"



3) How does this support impact on well-being?

- 95.2% stated Positively UK's peer support had either slightly, significantly or very significantly improved their well-being



"I am a living testimony; because of their services one feels valued, respected, and they value confidentiality"

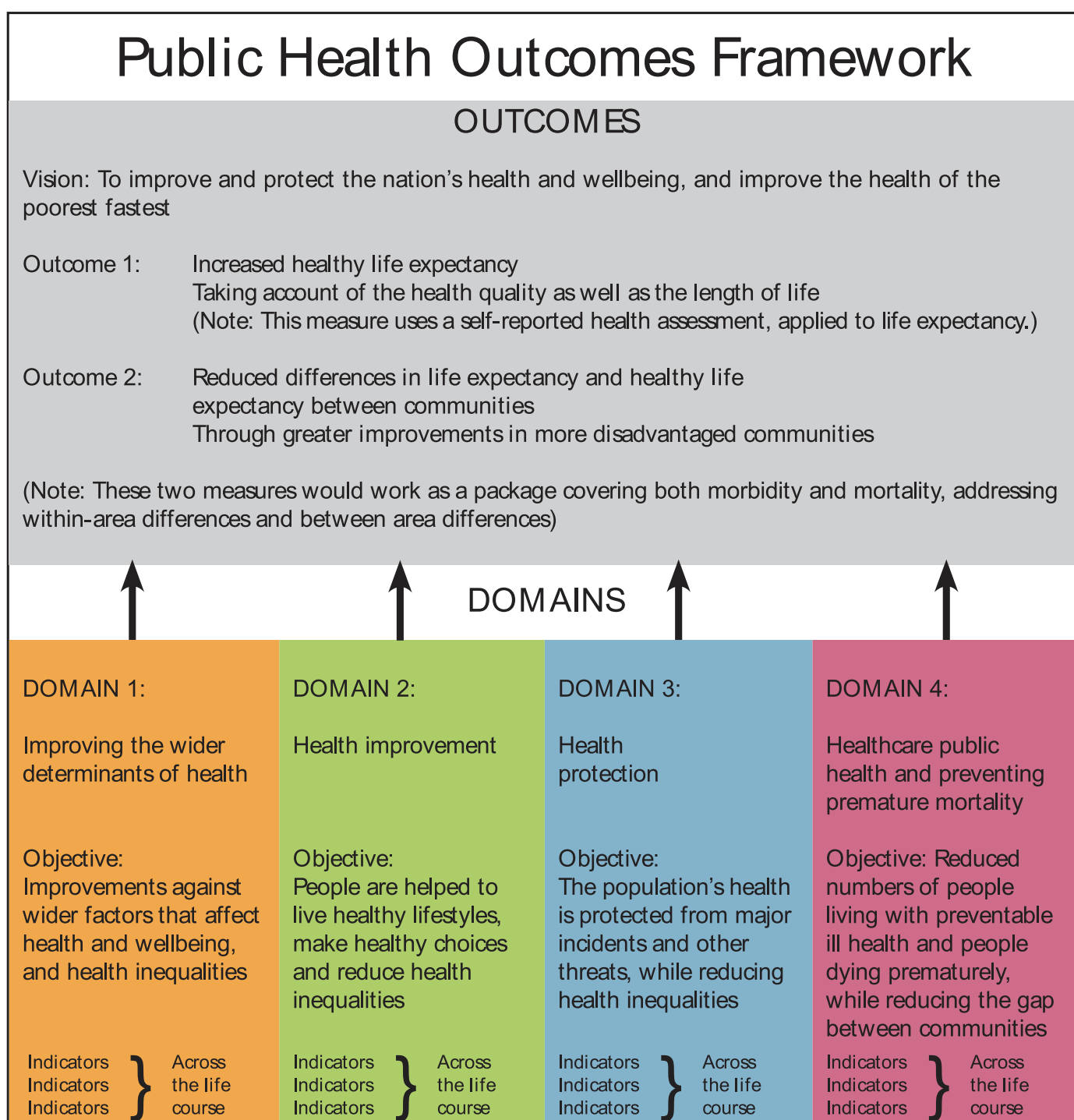
"The treatment workshops helped me to improve my understanding of HIV and treatment. I am now aware that it's important to have a say in terms of my treatment"

95%
improved
their overall
well-being

"Positively UK supported me a lot in the early years of my diagnosis. Meeting people with the same problems made me confident in dealing with the condition and has aided me on my career"

Public Health Outcomes Framework has 4 domains, the second being 'Health improvement' which breaks down to an objective: "People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities"

This study measured how Positively UK's peer support service helps people live healthy lifestyles and make healthy choices



Warwick Edinburgh Mental Well-being Scale (WEMWBS)

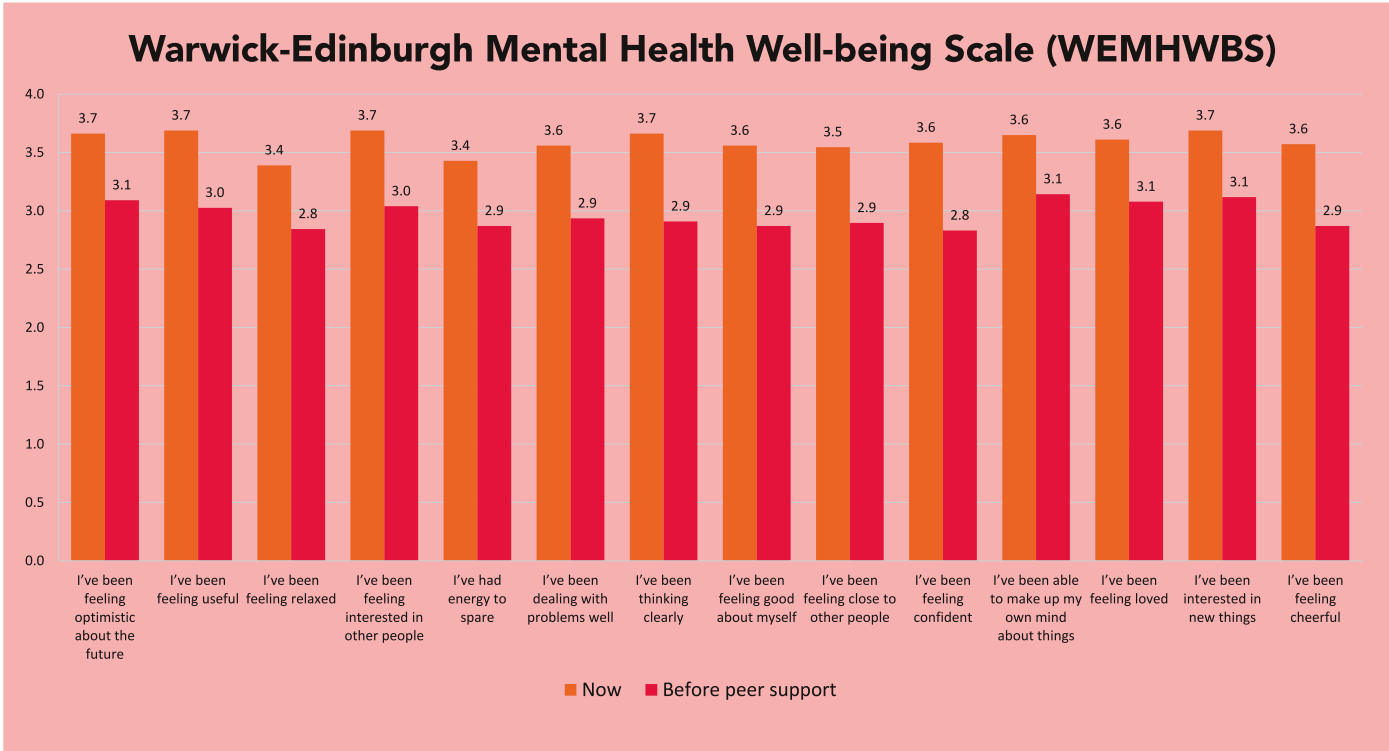
The Warwick Edinburgh Mental Well-being Scale (WEMWBS) is a scale that assesses positive mental health (mental well-being). A 14 positively worded item scale with five response categories, it covers most aspects of positive mental health (positive thoughts and feelings) currently in the literature, including both hedonic and eudemonic perspectives.

We asked our respondents to complete this 14 question scale twice. The first time reflecting on their feelings now and the second reporting on their feelings 2 weeks prior to accessing Positively UK's peer support service. The 14 questions have scores for the scale, 1 point for None of the time and 5 points for All of the time. The highest score is 70 and lowest 14.

The average score reported on how the respondents were feeling now was 50.3 out of 70 and in the 2 weeks prior to accessing peer support only 41.5 out of 70 an improvement of 12%.

Warwick Edinburgh Scores - NOW	
TOTAL	6210
AVERAGE SCORE	50.30 (out of 70)
RANGE	27 to 70
Warwick Edinburgh Scores - BEFORE PEER SUPPORT	
TOTAL	5060 (out of 70)
AVERAGE SCORE	41.50
Range	14 to 70
Improvement (scores)	9
	12%

The result is significant at $p \leq 0.01$



Each scale is out of 5, total 70. On every parameter Pos UK's peer support had an impact in improving well-being.

We also conducted a survey of healthcare professionals in the 10 London clinics in 8 hospitals where peer support is offered by Positively UK asking them of their perception of the service and how they think it complements clinical care. The hospitals are Chelsea and Westminster, Ealing, Homerton, Newham, Northwick Park, Royal Free, Royal London and St Mary's.

- 100% of HCP's were satisfied with Positively UK's Peer support (80% extremely satisfied and 20% very satisfied)
- 80% said that peer support either significantly (20%) or very significantly (60%) improves well-being
- 100% said they would recommend Positively UK's peer support to colleagues

What does this mean?

Positively UK's aims are 'improving the physical, emotional and social well-being of people living with HIV'; we consider good health to be determined by all three, they are equally important and often over-lapping.

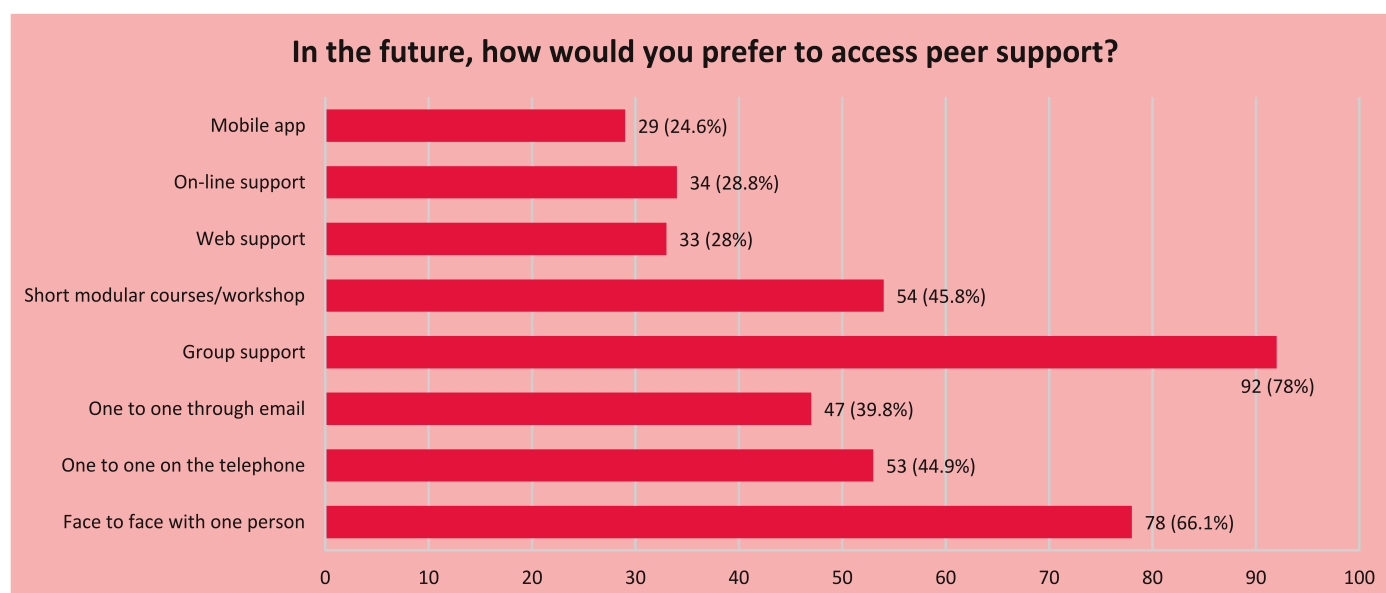
Results show Positively UK's peer support service contributes to achieving these goals especially emotional and social well-being.

9/10

Nine out of ten said peer support improved emotional well-being.

Future

Most of the respondents prefer group support (78%) and face to face with one person (66%) One to one over the telephone scored higher than one to one through email (45% vs 40%)



Still looking at how people would prefer to access Positively UK's peer support service in the future, trends were very similar with male and female respondents and unsurprisingly women slightly prefer group support and short modular courses.

Generally the trends were similar when analysed by other factors such as sexuality, with slightly more heterosexuals preferring group support.

What this means for:

People Living with HIV	Nearly everyone who accessed peer led support at Positively UK benefited and said they would recommend it to a friend. Accessing peer support and talking to others living with HIV can help emotionally and practically. Good peer-led support will work with you to identify your needs, and want you to be honest and open with them. If it's something they can't help with they will help access a service that can offer the right information and support.
Healthcare staff in HIV clinics	The BHIVA Standards of Care in standard 9 have already identified the need for 'self-management services including access to peer support'. This evaluation demonstrates how peer-led support can complement the role of clinical staff in supporting patients and improving patient outcomes. While peer-led support can be accessed via referral, it does work best when integrated into the clinical setting, providing a seamless transition between the clinical and peer led support, particularly for those who feel vulnerable about accessing services outside the clinic. Clinical staff have a role to play in working with local groups and possibly in future in directly commissioning peer support within the clinical setting.
Voluntary and community groups	The evaluation data shows there is a role for peer led support in supporting people living with HIV, both in better managing their HIV and improving their emotional well-being. When developing peer led programmes a range of interventions should be provided to meet the needs of the diverse population. Groups should also seek to develop links with key agencies notably HIV clinics, but also look wider, to promote access to a wider range of services including expert-patient programmes, benefits advice, social services etc. Voluntary and community groups need to demonstrate the effectiveness of services and it is hoped the evaluation tools and approach used in this study can be adopted and revised as necessary.
Commissioners and those who pay for peer support services	<p>Peer-led services can support commissioners in meeting their goals and improving the health of people living with HIV.</p> <p>Within the NHS Outcomes the evaluation demonstrates people are better able to manage their treatments and be involved in their healthcare through improved relations with clinical staff. Support also increases knowledge and thereby supports people to make informed choices about their health and well-being.</p> <p>For Public Health this evaluation demonstrates outcomes in Improving Well-Being. In addition if people understand HIV and adhere to treatments there is a reduced risk of onward transmission.</p> <p>When commissioning services, a range of interventions should be provided to meet the needs of the diverse populations living with HIV. Tenders should also consider links with clinics and other support services.</p>

For additional information on mental health needs see Positively UK's reports:

- States of Mind: Improving mental well-being in the HIV community
- Commissioning Effective Services for Women Living with HIV

Both available at www.positivelyuk.org/publications

Acknowledgements

This project has been supported by an educational grant from MSD and the secondment of A K Gilbert, researcher, and employee of MSD.



Many thanks to all the participants who took part in the survey.

References

Warwick-Edinburgh Mental Health Well-being Scale (WEMHWBS)

Statistic cited throughout this report come from the Positively UK peer support survey. Percentages have been rounded up for ease of reading, therefore individual figures and totals may vary slightly.

All free-text comments from the survey are written as they appeared, though minor style and grammatical corrections were made in some places.

Contact us

Whether you are newly diagnosed or have been living with HIV for years, Positively UK is here to support you. Our front-line staff and volunteers all have a firsthand understanding of the issues you may face as they are living with HIV themselves. To find out more about our services, access support, or just talk to someone else living with HIV, contact us via the information provided:

Telephone: 020 7713 0444

Helpline: 020 7713 0222

Email: info@positivelyuk.org

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