REACH Project Evaluation
Independent Evaluation – Report
May 2017
Purple Pen...!
Research & Evaluation Consulting
Overview of Report

This evaluation report presents a review of the peer support services delivered by Positively UK to a group of clients who are living with HIV and who have been referred by clinical services.

Positively UK commissioned Purple Pen Research and Evaluation Consulting1 (PPREC) to conduct an evaluation which was completed between March and May 2017. This report has been prepared by Dr Melvina Woode Owusu, with contributions from Dr Stephanie Steels, an independent research consultant subcontracted to PPREC.

PPREC was established in 2016 and is a growing company which specialises in providing independent guidance, support and resources to research, evaluation and audit programmes in the health, social and charitable sector.

Dr Woode Owusu is a medical anthropologist2 and behavioural epidemiologist3 with experience in mixed methods research and evaluation, as well as audit and quality improvement. She has ten years’ experience of local, national, and international STI and HIV sectors and an interest in reducing health inequalities and inequities.4

Dr Steels is a senior lecturer in social work at the University of Leeds and independent research consultant. She has ten years’ experience of health and social care service evaluation and national and international health policy making.

Acknowledgements

This evaluation was supported by PPREC team members, Dr Melvina Woode Owusu, Dr Stephanie Steels and Ms Emma Harvey, as well as the broader peer support, peer mentor, case work, administrative and senior management teams at Positively UK.

Many thanks to the clients who shared their personal experiences, and the clinical and peer support staff, case management team and peer mentors at Positively UK and the Royal Free Hospital, London who contributed to the evaluation survey.

Thank you to the MAC AIDS Fund and Big Lottery Fund who supported the production of this evaluation report.

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1 Purple Pen Research and Evaluation Consulting is a trading name of INFACTION Consulting Limited, founded by Dr Woode Owusu in 2016.
2 BSc Health and Human Sciences (Medical Anthropology) awarded by Durham University in 2006.
3 PhD Epidemiology and Public Health (School of Translational Medicine) awarded by University of Manchester in 2011.
Contents

Overview of report .................................................................2
Acknowledgements..............................................................2
Contents.................................................................................3
Table of tables........................................................................4
Table of figures.........................................................................4
Acronyms and abbreviations......................................................4
Executive summary.................................................................5
Overview of evaluation..........................................................6
  Background...........................................................................6
  Evaluation aim and questions...............................................7
Evaluation framework............................................................8
Overview of interviews..........................................................9
  Primary lines of enquiry for interviews....................................10
Overview of multi-professional stakeholder online survey...........11
  Survey topic areas.............................................................11
Analysis and presentation of evaluation findings........................11
Evaluation findings...............................................................13
  Overview of peer support......................................................13
  Theme 1: Behaviour change and management..........................19
  Theme 2: Interaction between peer support and other services....23
  Theme 3: Opportunities and challenges....................................26
Recommendations.................................................................28
Final thoughts..........................................................................30
Table of Tables

Table 1 Evaluation framework.................................................................8
Table 2 Evaluation sample.................................................................9

Table of Figures

Figure 1 The COM-B Model.................................................................12
Figure 2 Importance of HIV status to peer support workers’ role..................16
Figure 3 Maslow’s hierarchy of needs....................................................20
Figure 4 Word cloud (25 most frequent words used to describe peer support)........26

Acronyms and Abbreviations

<table>
<thead>
<tr>
<th>COM-B model</th>
<th>Capabilities, Opportunities, Motivation – Behaviour model</th>
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<tbody>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>LGBT</td>
<td>Lesbian, Gay, Bisexual and/or Transgender</td>
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<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
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<td>PPREC</td>
<td>Purple Pen Research and Evaluation Consulting</td>
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<td>PSW</td>
<td>Peer support worker</td>
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<tr>
<td>REACH</td>
<td>Retention and Engagement Across specialised Care services for HIV patients in the United Kingdom</td>
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<td>UCL</td>
<td>University College London</td>
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Executive Summary

This discrete evaluation study report presents findings from a three-month exploration of peer support services delivered by Positively UK’s peer support team to clients who are at risk of or who are already disengaged with clinical care, struggling to adhere to prescribed treatment regimens and/or otherwise finding it challenging to live well with HIV.

Through six in-depth interviews with key informant clients and a multi-professional stakeholder online survey, we explored the components and processes by which the peer support service delivered by Positively UK enables people living with HIV to improve and/or maintain their engagement with clinical services. Key areas reviewed included:

1. Behaviour change and management influenced by client engagement with peer support services
2. The interaction between peer support and other services
3. The extent to which peer support services are focused on solving challenges and/or providing opportunities to clients

Four female, and two male clients were selected as key informants and were interviewed by an independent research and evaluation consultant. Interview transcripts were analysed using inductive, thematic coding and emerging themes were reviewed and interpreted alongside survey data.

Both clients and health and social care professionals agreed that peer support is important for the psychological, emotional, and social wellbeing of people living with HIV. Peer support can also provide direct access to much needed financial and practical support which for some clients helps them to overcome isolation, stigma and physical barriers to engaging with clinical care services and adherence to prescribed treatment schedules. It is through addressing the primary challenges faced by this group of individuals that peer support services helped them to achieve improved and/or optimal clinical, psychological, and social experiences and outcomes. The accessibility of peer support in a clinical environment was considered vital for many clients in enabling them to access a seamless and holistic package of professional care in a single, safe setting.

The role of a peer supporter is complex and appears to be dependent on the service user accessing the intervention. The existing service provided by Positively UK responds promptly to the urgent needs of its clients, and where their requirements are beyond the organisations remit, the clinical teams at the Royal London and Royal Free Hospitals, as well as neighbouring charitable services can provide additional support to clients through a referrals system. The service provided by Positively UK is sensitively designed based on experience of working with this client group and involves a range of 1-1 and opportunities to group based peer support sessions and
activities. Clients described both formalised 1-1 and informal peer support as having a positive impact on their knowledge and confidence, physical capacity and motivation to self-manage their HIV. To clients, dedicated peer support workers are problem solvers, advocates, confidantes, information bearers, system navigators and role models and as such have played an integral role in their HIV journey.

There is potential to strengthen both types of support by implementing innovative approaches, notably providing written stories of peoples lived experiences of HIV, offering a structured enrichment-based peer support programme to clients and further involving existing clients in service design and development. To further enhance the integration of peer support in clinical settings, clear referral guidance and care pathways should be agreed and shared between clinical and social care teams. Taking these actions will help ensure that clients continue to receive a holistic and professional care and support service during of a period of their lives when they need it the most.

Overview of Evaluation

Background
Positively UK recognises that the needs of clients vary over the course of their HIV journey and between individuals and groups of individuals. Consequently, the peer support service has developed in direct response to the needs of clients.

Through consultation with Positively UK’s senior management team about the delivery of its peer support services, PPREC gained an insight into how the peer support, mentoring and case management service was designed, how it is currently delivered and ways in which the team may like to develop the service in the future. The organisation currently adopts a person-centred and solution-focused approach to support clients and has drawn on available evidence from research and practice to develop a range of techniques designed to support, motivate, and empower clients.

Positively UK worked with a team of researchers from University College London (UCL) and clinicians at Barts and the Royal London NHS Hospital Foundation Trusts to provide peer support services to the REACH study5. The study aimed to explore, describe and understand HIV outpatient attendance in people living with HIV (PLHIV), and to develop cost effective interventions to optimise engagement in care. Four complex interventions aimed at increasing retention in HIV care were explored, two of which involved the provision of peer support services in clinical settings. The first was a series of 1-1 peer support sessions and the second involved a peer case worker working closely in a multi-disciplinary team consisting of a consultant, specialist nurse, psychologist and social worker. In both cases, the peer support

5 The REACH Study is a mixed methods exploration of patterns of Retention and Engagement Across specialised Care services for HIV patients in the United Kingdom, funded by the National Institute for Health Research.
worker (PSW)\(^6\) assisted with psychological, social, and economic challenges which were found to deter people from engaging in HIV care. Although the REACH study ended in 2016, Positively UK wishes to continue to meet the needs of clients who are at risk of or who are already disengaged with clinical care, struggling to adhere to prescribed treatment regimens and/or otherwise finding it challenging to live well with HIV.

**Evaluation aim and questions**
This evaluation aimed to:

> explore the components & processes by which the peer support service delivered by Positively UK enables people living with HIV to improve and/or maintain their engagement with clinical services.

Key areas for investigation included:

- Behaviour change and management influenced by client engagement with peer support services
- Interaction between peer support and other services
- The extent to which peer support services are focused on solving challenges and/or providing opportunities to clients

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\(^6\) The term ‘peer support worker’ (PSW) describes any individual referred to be clients who offered formalised, 1-1 peer support services either at a REACH clinic or at Positively UK.
## Evaluation Framework

The following framework was designed in collaboration with Positively UK’s senior management team members to guide the evaluation:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Evaluation Questions</th>
<th>Informant Group</th>
<th>Data Collection Method</th>
</tr>
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</table>
| Theme 1: Behaviour change and management | To what extent do peer support services enable clients to develop the resilience and coping mechanisms needed to manage living with HIV and maintain stable engagement with HIV clinical services?  
To what extent do peer support services assist clients in prioritising their health?                                                                 |                                 |                        |
| Theme 2: Interaction between peer support and other services | In which ways do peer support services complement, enhance, or replace existing statutory, voluntary and clinical services available to clients?  
What is the experience of professionals involved in designing, developing and/or delivering peer support as part of the REACH study? | Multi-professional stakeholders | In-depth interviews   |
| Theme 3: Opportunities and challenges | To what extent do peer support services promote opportunities?  
To what extent do peer support services focus on challenges faced by clients?  
To what extent do peer support services challenge/promote a ‘dependency culture’ among clients?  
What is the impact of peer support on clinical and holistic wellbeing of PLHIV? |                                 | Survey                 |
Overview of Interviews

The Positively UK team identified six key informants to take part in confidential, in-depth interviews exploring their experience of peer support, mentoring and/or case work management services. Purposive sampling was used to ensure representativeness of clients who accessed peer support services through the REACH study (predominantly black African, heterosexual women) and ensure a combination of newly and long-term diagnosed.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Peer Support Evaluation</th>
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<tbody>
<tr>
<td>Gender</td>
<td>4 women; 2 men</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>5 black African; 1 white British</td>
</tr>
<tr>
<td>Age</td>
<td>All aged 35-50</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>4 heterosexual, 2 Lesbian, Gay, Bisexual and/or Transgender (LGBT)</td>
</tr>
<tr>
<td>Uncertain Immigration status</td>
<td>5 experienced current/previous immigration challenges</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5 unemployed; 1 employed full</td>
</tr>
</tbody>
</table>

All interviews were conducted at Positively UK offices in April 2017 by the same evaluator and all interviewees were offered a £50 food voucher as a gesture of goodwill. Positively UK reimbursed travel expenses.

Interview questions were based on variables from the Capabilities, Opportunities, Motivation – Behaviour (COM-B model) which suggests that behaviour is the result of the interactions between an individual’s capability, opportunity, and motivation. In the case of the REACH study, the behaviour under exploration was retention in clinical HIV care. For this evaluation however, we were keen to explore how peer support affects service users’ perceived capability, opportunity and motivation to self-manage their HIV infection which has been identified as necessary for both clinical health and mental wellness among people living with HIV.

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Primary lines of enquiry for interviews

1. The meaning and value of a ‘peer’
2. The extent to which shared HIV status is important for clients
3. Involvement with REACH clinics
4. Entry point to peer support
5. Context of peer support received - who, what, when, where, how, feelings and experience
6. Perceived impact of peer support on behaviour management or change (with specific exploration of COM-B variables)
7. Extent to which peer support services met expectations
8. External support provided alongside peer support
9. Issues not addressed or supported by the peer support service and perceptions as to why
10. Opportunities to improve the peer support services available
Overview of Multi-Professional Stakeholder Online Survey

An online survey was designed using a range of closed and open-ended questions to explore the views and opinions of a multi-professional group of stakeholders, Positively UK identified stakeholders as those who were involved in the design, development and/or delivery of the peer support elements of the REACH study.

Survey topic areas
1. Involvement in REACH study
2. Extent to which the REACH study fulfilled its aims and objectives
3. Challenges experienced when referring/providing peer support to people living with HIV
4. Suggestions for improving the peer support as it was delivered during the REACH study
5. Types of peer support
6. Meaning of peer support
7. Potential impact of peer support on engagement with clinical care and clinical outcomes
8. Potential impact of peer support on the holistic wellbeing
9. Description of a situation in which a patient/client benefited from peer support

The survey was designed using Typeform software and was accessible online for seven calendar days; all invitees received one email invitation and two reminder emails to complete the survey.

Analysis and Presentation of Evaluation Findings

Client interview data was transcribed (intelligible verbatim) by a member of the PPREC team and two independent research consultants conducted inductive coding, thematic and interpretative analytic reviews. Once common themes were identified and agreed, the COM-B model was used as an analytical framework for interpreting the qualitative data generated through client interviews. Survey data were extracted from Typeform platform, collated and handled using Microsoft Excel and exported to NVivo Pro for textual analysis.
Findings from the interviews and survey are presented according to the three key themes which guided the evaluation exercise. In addition to these key themes, we present key observations, common themes and useful insights regarding elements of peer support which are well received by clients and which appear to contribute to an improvement in the clients; holistic wellbeing.

The findings presented here relate specifically to the group of clients who were interviewed and the professionals who took part in the survey. While some comparisons may be drawn with published literature on peer support interventions and aligned with the components of the COM-B model, these study findings should be used as a means of highlighting topics which may be important to:

1. Clients with similar demographics who access peer support following referral from a clinical setting and who are experiencing immediate challenges with economic and migration concerns.
2. Health and social care professionals seeking to develop peer support services for similar client groups.

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Evaluation Findings

Overview of peer support

What are ‘peer support’ services?
Clients used a range of terms to describe the people who had offered them non-clinical support through REACH clinics and/or Positively UK. These included:

<table>
<thead>
<tr>
<th>“case worker”</th>
<th>“peer worker”</th>
<th>“peer support worker”</th>
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<tbody>
<tr>
<td>“peer mentor”</td>
<td>“peer”</td>
<td>“social worker”</td>
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In most cases, the terms were used interchangeably, with individual clients using several terms to refer to a single person who had offered them support. Review of the context in which clients used these terms suggests two distinct types of support from peers via Positively UK existed:

1. **Formalised**, 1-1 peer support was provided by a person living with HIV who was relatively more experienced in their HIV journey and who had received training to address the holistic needs of others living with HIV. Clients characterised formalised, 1-1 peer support as being focused on reflection, identifying current challenges and possible solutions, and setting action plans to achieve agreed goals.

   *She was telling me that ‘listen, calm down, relax yourself, I know being positive is not easy but I am positive as well... we’re here to help you, to support you, we’re not going to work against you.’ That’s all what she was telling me that day, I could never have imagined... So, each time I look forward to see her, to talk to her.*

   **Interviewee 4**

   Actually to help us to navigate through the system to get those ESA, child benefit and housing. She’s actually the one who helped us. She would also come to comfort me, talk about the disease, what to expect, about end of life, life must continue, she would comfort, that was also good.

   **Interviewee 3**

2. **Non-formalised** peer support was provided by a person living with HIV who may or may not be in receipt of training but who are at a similar stage in the HIV journey to that of the client. Non-formalised peer support was provided on a 1-1 and/or group basis and was characterised by an emphasis on shared past and current experiences, shared learning and the “distraction time” it offered clients.
Sometimes you can call somebody and remind the person ‘have you taken your tablets?’, ‘Have you do this?’ or, you just say ‘have you taken your vitamins?’... you can help each other, you can go and visit, I can take you out, we can go to the shop and we eat something to make you not feel lonely. You can go to the group, you can go out to seaside, you can go to the Kew gardens, we can do things which can make you forget about the difficulties.

*Interviewee 5*

It’s very very nice to be with other people who are positive… in the group settings, you can learn from other people and learn from their experience… everybody feels free to talk and no fear of judgement.

*Interviewee 1*

He’s a good friend, completely platonic though. He’s been diagnosed a bit longer than me and so we talk about real life while we go shopping in Selfridges… he listens, understands where I’m coming from and I feel really good when I meet with him.

*Interviewee 6*

Clients described both types of support from peers as being equally important to their motivation to change their health seeking behaviour. There appears to be a ripple effect in that the benefits of a single individual being supported by a peer (whether formally and informally) are shared in 1-1 interactions and/or in group settings with others living with HIV; observers are motivated by the progress and achievements of others and so the impact of both types of peer support is mutually reinforcing.

Clients also felt a sense of accountability to their peers and did not want to disappoint somebody who had supported them and/or who they felt cared about their health and wellbeing.

Health and social care professionals conveyed similar sentiments when describing what the term ‘peer support’ meant to them:

*In the context of HIV, someone who is living with HIV supporting someone else living with HIV to find solutions to issues in their life and support them to move forward. For example, helping other people living with HIV move forward after their diagnosis.*

*Peer Mentor, Positively UK*

*Drawing on the shared experience of others who have experienced the same process (in this case illness) to access and derive support be it practical, emotional or social.*

*Clinical Lead, Royal Free Hospital London and Epidemiologist, UCL*
What makes peer support effective?

*I am telling you their assistance was so timely and so good, it really, really saved us… she was in the hospital, so most of the time she was there with us, most of the time she would come to me there.*

*Interviewee 3*

Clients described several common factors which they felt made peer support process effective:

**Accessibility in clinic location**

Being able to access a PSW, regularly, in same location as their clinic appointments was very important to clients, especially in the early stages of their HIV journey.

For many, following the shock and self-stigma associated with their diagnosis, the HIV clinic was the only place where they felt “free”, “safe” and “relaxed”. Providing peer support in this environment meant that clients who were at the start of their HIV journey felt “reassured” about the confidentiality and professionalism of their interactions with the PSW. Clients reported that they implicitly trusted the PSW because they were introduced to them in a formal, clinical and therefore governed space. For all clients, peer support was their first experience of formalised, non-clinical care and so the experience was a new one for them. Clients described the PSW they met at REACH study clinics as part of holistic team of several healthcare providers and felt that the high-quality care they received met their wide-ranging needs.

**A shared lived experience of HIV**

Both clients and health and social care professionals described the importance of a shared lived experience of HIV to being able to effectively deliver peer support:

*A person who is similar in fundamental ways to the recipient of the support; their relationship is one of equality. A peer is in a position to offer support by virtue of relevant experience“ and can relate to others who are now in a similar situation.*

*Senior Case Worker, Positively UK*

*Because the stress I’m going through… what I am facing they would have gone through it.*

*Interviewee 4*

Clients described how their PSW appeared to respond to their needs automatically and “naturally” and several commented that the PSW appeared to “just know” their needs (mostly economic and migration related) without them needing to ask for help. Clients were often unfamiliar with their entitlements and the UK system and so did not know what to ask for:
I didn’t get that kind of help elsewhere, maybe I didn’t ask but I also didn’t know.

Interviewee 3

I didn’t know [the peer support services] would give me money for transport.

Interviewee 4

While clients felt PSWs’ knowledge of how to help them was gained exclusively from an initial client assessment and/or referral forms from their clinician, an alternative explanation is that a PSW’s ability to respond in a prompt and appropriate manner to their clients’ needs results from the interaction of knowledge, training and insight which is in turn gained because of their personal lived experience with HIV:

Figure 2 Importance of HIV status to peer support workers’ role

Shared characteristics
As well as being able to give support that clients needed, PSWs may also serve a modelling role to clients, for example, if they share another characteristic such as gender, sexuality or ethnic background. The importance of common characteristics beyond HIV status was considered important by some professionals who responded to the survey:

[A] peer is someone that shares characteristics e.g. medical condition, gender, sexuality, age, job role etc. Support can encompass means of obtaining help, guidance, working through solutions or self-development. Therefore, peer support for Positively UK, is fundamentally that shared characteristic of HIV status, but could be wider such as sexuality, length of diagnosis and is support around managing any aspect of HIV and one’s well-being.

Management Team Member, Positively UK
However, the importance of sharing multiple characteristics was not shared among clients interviewed as part of this evaluation. Some interviewees specifically felt that a PSW who shared their ethnic background would not be trustworthy and the fear of stigma within their community was a significant barrier to accepting the offer of peer support:

So, at times, I was like ‘why should I see [the PSW]? Why should I? What for?’… based on the community I come from, you know in Ghana⁸ if you’re positive, trust me, they’ve got it in for you. So, like, are they black? Are they white? Because Ghanaians they know -they’ll talk a lot, [there’s] nothing like confidential[ity] or something

_Interviewee 4_

The variation in responses among the interviewees highlights the individual nature of peer support and suggests that having access to or having a choice of PSWs who embody a range of characteristics might encourage clients to accept the offer of peer support more readily.

A survey respondent highlighted that engaging heterosexual men living with HIV in peer mentorship and support work may prove particularly challenging:

_From a caseworker perspective, the main group that were left with a general unmet need were heterosexual men as most of the male peer mentors were MSM – this is a sector wide issue… More recently this has improved but still leaves a population with significant unmet needs…_

_Management Team Member, Positively UK_

Time, continuity, and familiarity
All clients reported (without prompting) that the time which their PSW devoted to them was important to them. PSWs made repeated attempts to personally call clients who rejected their initial offers of support, persisted in the offer of follow-up appointments, and accompanied clients to non-clinical meetings and to access support from other agencies. Clients described how PSWs took the time to listen, empathise and comfort them and appreciated the time they invested in establishing a rapport with them as they felt this enabled them to develop meaningful and personal relationships which in turn deepened the clients’ trust and made for a more positive experience at their clinic appointments. Clients looked forward to seeing their PSWs and spoke about them with warmth and appreciation. Clients contrasted their experience of peer support services with the clinical services they received in the same setting noting that clinical services did not allow for time-intensive activities such as “chatting”. While clients did speak fondly of their clinical team, their descriptions focused on the medical expertise and scientific knowledge offered to them assurances and comfort which were made possible over time:

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⁸The name of the countries, names, and places mentioned by the interviewees has been changed to maintain confidentiality.
You know that doctors always give assurances. So that sometimes even when you are not better off [well] the doctor can tell you that you will be ok… I don’t know how to put it. I mean sometimes your moods are not fine when somebody begins chatting with you and, you know, trying to assure you that you are not the only one and you don’t have to be ashamed of it, sometimes you can get some comfort, you know? … it’s different the way they say it, the way she [PSW] approached us was very different. Although she was telling us assuring words she was also offering us help… she was also offering us help, it was not only words…

Interviewee 3

Because the doctor is not positive, Jenny was positive, so, she knows that when all’s said and done, when you are into something – you know, ‘I’m into it, I know what I’m talking about, I’ve been living with this.’ So, anything she says I quickly grab it… more than my doctor, I don’t know why… maybe because she is positive as well you know, she says ‘you can do anything’ and I believe her.

Interviewee 4

Clients explained that because they repeatedly saw the same PSW they felt comfortable continuing existing dialogues rather than restarting new conversations with new individuals and having to continually overcome the same feelings and concerns:

She knows everything and she really stood by me. She really stood by me. She calls me to ask me, ‘have you gone to your solicitor?’ The last time I saw Jenny then that was really for the appeal.

Interviewee 2

The time afforded to clients is crucial to the development of their relationships with their PSW and in turn appears to maximise the benefit that they receive from the ongoing interaction.
Theme 1: Behaviour change and management

What was the impact of 1-1 peer support?
Clients reported that their adherence to appointments and treatment regimens (where applicable) improved following engagement with a PSW. This was because the barriers to them accessing services previously were removed or minimised as a direct result of their interaction with a PSW and Positively UK.

The primary benefits of 1-1 peer support reported by clients were specifically in relation to:
- capability (through help to overcome specific economic and physical barriers)
- opportunities (by referring clients to group sessions, clients could meet others living with HIV, share their HIV journeys, expand their social networks, and reduce self-stigma and isolation)

Impact on clients’ capability and opportunity
Specifically, clients’ physical capability to attend clinical appointments was enabled by their PSW who facilitated access to hardship funds which most clients used to pay for transport to attend clinical appointments. As the clients report travelling between London boroughs or even from outside of London, the high and rising cost of public transport was a real barrier for five of the six clients interviewed.

As well as meeting financial needs, PSWs supported clients with physical and safety needs such as providing access to food vouchers, supporting with accommodation problems and helping alleviate the stress caused by immigration concerns, which clients felt forced them to deprioritise attending clinic appointments:

*How can I think about seeing this man when I don’t have food and I don’t know where to sleep? Tell me?*

**Interviewee 1**

*Yeah, I needed help, I needed finance, I needed the housing, you see she helped us, even with food, she used to help us.*

**Interviewee 3**

*...because I am not working and still had issues with immigration, so my mind was not settled at all, I was just like, ‘do I need to see this lady [PSW]? Do I need to see her?***

**Interviewee 4**

Only after addressing their immediate physiological needs were clients able to seek support regarding self-esteem, self-stigma, and mental health.

One client described how her immigration challenges were her “main” source of stress, and which coupled with her recent HIV diagnosis led her to feel suicidal. She
described how she consciously disengaged with her medical team and refused to adhere to her prescribed medication to speed up what she described as her inevitable fate – AIDS and then death.

_I thought it was a death sentence… if I end it, that will be the end so there’s no point in me going through all this stress._

_**Interviewee 4**_

This client went on to describe how the multidisciplinary team supported her to calm her suicidal thoughts and begin attending her appointments, accepting peer support and adhering to her medication:

_…so, with the help of the new consultant, Jenny, they keep talking to me, that things will be ok… with HIV I can live years and do anything, I can have a baby, I can do anything._

_**Interviewee 4**_

These descriptions align with Maslow’s hierarchy of needs. Maslow’s original five-stage model, sought to explain individual motivation and a revision of the model in the 1960s and 1970s saw the expansion of the hierarchy with the inclusion of cognitive and aesthetic needs and transcendence needs such as esteem needs and self-actualisation⁹.

Figure 3 Maslow’s hierarchy of needs

Interaction with the peer support team has also been found to impact of clients’ psychological capacity to engage in activities which they report as being beneficial, either in the immediate or longer term. PSWs could pass on their personal

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knowledge and experience of living with HIV which the clients retained. Clients reported that since seeing their PSW, they felt empowered to ask for clarification at clinical appointments, to seek confirmatory blood tests and in the case of one client, seek care from a different provider. These behaviours all contributed to the clients’ autonomy, ability to guide their own care and helped them to navigate the clinical care system.

The multi-professional stakeholder survey responses supported the finding that both formalised peer support (particularly when located and delivered alongside clinical care) and informal peer-to-peer support can have a positive impact on clients’ engagement with clinical care and in turn their clinical outcomes.

> Collaborative working can assist the nurse doctor or clinician to better understand the needs of the patient and assist the patient in developing trust of the clinician through positive approach.  
> **Nurse Specialist, Royal Free Hospital London**

> ...by addressing areas of hardship, housing etc it provides the foundations to underpin good health and good clinical outcomes.  
> **Management Team Member, Positively UK**

> I think that when [peer support] is connected to other peer support services (groups, etc) it can help people living with HIV engage regularly with clinical care services, become informed and in control about their lives, health and treatment and adhere to their medication, resulting in improved health and wellbeing.  
> **Peer Mentor, Positively UK**

> A positive impact for both [clinical care and outcomes] – primarily via breaking down of stigma, improved autonomy, and information  
> **Clinical Lead, Royal Free Hospital London and Epidemiologist, UCL**

**Impact on clients’ motivation**
At the start of the evaluation, it was assumed that peer support enables clients to develop the resilience and coping strategies needed to self-manage living with HIV and maintain stable engagement with HIV clinical services. Clients did report that their interaction with their PSW and/or individuals whom they met through group support sessions hosted by Positively UK provided them with invaluable emotional support which boosted their self-esteem and motivated them to live well with HIV. Clients’ descriptions of spending time with their PSWs on a 1-1 basis and/or with other people who are living with HIV were overwhelmingly positive:
[PSW said] ‘oh Lillian, you’re ok, you look so well, if you didn’t tell me you were positive I wouldn’t know.’ So, you need to see her, it’s ok… she talks to me ‘listen, I am confident now I am positive’, she is positive as well, so, I should feel free to talk to her. ‘Lillian, do this, you can do this, you can get through this, it’s ok’

Interviewee 4

Health and social care professionals also agreed:

…there is nothing more powerful than having a person sit in front of you presenting as healthy, engaged in life and making plans talking about their journey and the sources of support they’ve accessed along the way. People aren’t informed enough about the support (very precious right now) out there.

Psychologist, Royal Free Hospital London

For individuals struggling with their own health, seeing how an individual has overcome these. Motivation to engage and adhere to treatment is critical, but equally important is developing skills to self-manage in a holistic way that begins to move away from a purely hospital and medical model and enables that patient to live positivity

Nurse Specialist, Royal Free Hospital London

Some clients also reported that the physical appearance of their PSW empowered them to adhere to their own prescribed treatment regimens and to follow (as far as was financially possible), a healthy diet to emulate their PSW and to achieve what they believed to be optimal outcomes for somebody living with HIV. The modelling exhibited by PSWs may have a profound impact on some clients who are disillusioned following diagnosis and who sometimes have low or even no hopes for their future.

Yeah, I feel good, I feel so good with them. I feel good with somebody [who] is positive with me, I can talk to her, I can really breathe and they made me to have the confidence. Like Jenny told me she’s been positive for years, and Lorraine about twenty-five years, me I’m just twelve years, so… I look up to them, I look up to them... in all ways, like, how they look and how they’ve been positive for years, how they carry on, like Lorraine says she’s been positive for twenty-five years, that’s what she told me, I couldn’t believe it ‘wow! … when my consultant told me that ‘Lillian, you’re not going to die, you’re going to live.’ – I didn’t believe her. That was my first consultant, Doctor Clark; I didn’t believe her, like, all this time. But when I saw Jenny she looks well and when I saw Lorraine for the past twenty-five years and she looks so well too, then I meet Amber…

Interviewee 4
Theme 2: Interaction between peer support and other services

Peer support as complementary to clinical care
All clients expressed the view that the support they had received from their PSW was a necessary and valued complement to the statutory clinical care they had received. Clients contrasted the type of support they received from clinical and non-clinical services but asserted that it was the joint efforts of the clinical and peer support team which enabled them to overcome the barriers to them remaining in care and to adhering to their prescribed treatment regimens. Once these (mostly) physical barriers were removed, clients felt that their physical and emotional health improved.

Yeah, they [appealed against a home office decision], Jenny has done that, my consultant, my psychiatric doctor, those are the people that helped, those three people.

Interviewee 4

Some clients experienced a comprehensive care package provided jointly by a team of health and social care professionals. These clients reported the transition from consultant to PSW and psychiatrist care to be a seamless and professional service—one which they believed should be standard practice for people diagnosed with HIV and in need of a range of support services. The combination of clinical and social services available to clients meant that where the remit of one professional ended, there was another suitably trained professional to provide the support needed. For example, one client described her referral from her clinician to a PSW and/or group based services:

Actually, the consultant referred me to [the PSW], I need to see her because it was the consultant saying I can't be going all this way, I need somebody to talk to me, I need somebody to put me through, I need somebody to be there for me. I saw my consultant all the time, maybe for four or five months, so, they can't do all the job for me, can't do anything apart from give me the medication. They said they would talk to me, lift my spirit… that's why they introduce me to Jenny.

Interviewee 4

So [my consultant] was like 'you missed like two, three appointments, why?' I say listen, 'I don't have money, I'm not working, things are not really ok for me.' I'm not sick, but just that the financial aspect for me wasn't there. So, they were like, 'oh, are you in this group?' and they say 'have you been to visit to Positive East?' I said 'no', 'what about Positively UK?'

Interviewee 4
In many cases, clients were simply unaware of the services available to them and once engaged in one service – whether clinical or social, they were then referred onto a suite of holistic services which could support their health and wellbeing:

*Actually, she helped us to navigate through the system to get those ESA, child benefit and housing. She’s actually the one who helped us.*

**Interviewee 3**

The critical step was encouraging engagement among this group of individuals who were experiencing very challenging circumstances which often led people to isolate themselves from statutory and social services:

*REACH type patients by definition a challenge to engage thus may not attend when peer support available or decline offer when made.*

**Clinical Lead, Royal Free Hospital London and Epidemiologist, UCL**

Different clients preferred different approaches to being contacted by a PSW which suggests there is value in being able to offer a range of services in a variety of ways. There are a number of different services people living with HIV will need to access to address their needs, and clients sometimes found it difficult to distinguish between services they had received directly from Positively UK compared with other services such as a referral note to obtain food parcels provided by another organisation.

Clients were most concerned with the availability of effective peer support rather than the source, funding agency or provider. Being able to access a variety of support services which can be delivered via the face of a known ‘peer’ was important for clients’ capacity building and in turn their clinical and emotional wellbeing. This view was supported by a social care professional who said:

*Service users presenting with greater need around hardship, immigration and mental health issues, which cannot be met directly by peer support. Issues such as hardship are also fundamental to good health, adherence to medications etc. These require greater work in identifying agencies that can provide support.*

**Team member, Positively UK**

Challenges of providing holistic, integrated care

Two key challenges were identified in this discrete evaluation which might directly and/or indirectly impact on Positively UK’s ability to work within a holistic and multi-agency care model.

**Duplication and cracks**

One issue identified through client interviews presents a sector level challenge often a result of localised funding and changing providers. Whilst providing a range of high quality services, through a variety of approaches was considered optimal for
clients, there is a risk that the efforts of different organisations can be duplicated and/or that some clients may fall through cracks between services in areas where there is no local provision:

Before, I’ve been to, this place, HIV... Body and Soul... before I live in Enfield and then they moved me to down here... sometimes I went to Positively East, but my caseworker is not there, they move, since I’ve moved nobody is taking care of me.

Interviewee 2

This is especially challenging for London based services, as people regularly travel considerable distances between boroughs and from outside London to access specialist HIV care and/or to avoid being seen by members of their local and/or ethnic communities.

Communication surrounding professional boundaries and engagement of clinical staff
Several survey respondents explained the importance of communication surrounding professional boundaries and referrals within an integrated and collaborative care model:

Recognise [their] own limits/boundaries and need to refer on to more specialist help.

Psychologist, Royal Free Hospital London

At one site there was concern that the complexities of the patient group especially around mental health needs was too great for a volunteer mentor and needed an experienced caseworker...

Senior Case Worker – Positively UK

...other members [were] cautious about referrals and acting as a gatekeeper as to who should and shouldn’t be signposted.

Management Team Member, Positively UK
Theme 3: Opportunities and challenges

Peer support services as described by clients appear to give clients the opportunity to gain knowledge about HIV, gain an insight and hope for living with HIV in the future and provide opportunities to overcome the physical and emotional barriers which restrict their clinical health and wellbeing outcomes and experiences. As peer support is by definition, a solution-focused intervention, the focus is mostly on the current challenges which impact on clients’ lives. The most frequent words used by health and social care professionals to describe what ‘peer support’ meant align with the challenge, solution and goal-focus reported by clients.

In addition to helping clients to solve challenges directly related to their ability of self-manage their HIV, clients reported being signposted and referred between organisations and some explained that they felt confident in their ability to navigate information, services and systems independently or with minimal support (compared with when they first entered the system):

…sometimes I go to the group, talk about feminism, the group that talks about Human Rights, tomorrow I am going to the group that is all white people, they are talking about how to be in the parliamentary, how to protest. I just go there to listen and to know, then this thing has opened me, I didn’t know how the system of government here works... I’m well equipped although it’s not enough I’m still going to here to listen to get more confidence. You get confidence. The problem is in this group of people, some of us we are not confident, we are still like ‘Can I?’ ‘Can I not?’ ‘Can I?’ Fifty-fifty. But there are those who are up there, they are one hundred per cent, ninety per cent, they know themselves. Others they are still hiding, they are still hiding pain inside of their heart.

**Interviewee 5**
I go here, I go there, they give me a lot of advice, they help me, they give me a call to come and meet people every month and I get interested. I come every month to Positively UK or to other groups.

**Interviewee 1**

In terms of the duration of peer support, all clients felt the relationship they had with their PSW and/or Positively UK transcended the concern which initially led them to accept peer support. While some clients recognised the positive effects of being able to reflect periodically on their emotional progress as well as their clinical outcomes, others explained they would like to continue their HIV journey with the support of their PSW and aspired to attend group sessions.

One client explained that although he had not visited his PSW regularly, he did wish to continue nurturing a relationship with a PSW so that he would feel more comfortable to request support as needed:

*I haven’t been involved you see. I would like to have them there, so that when I need them I can go. I don’t need it now but there is this guy, he knows I’m undetectable and we want to do bareback so it would be good to talk about that with a mentor – but now I don’t have one because I haven’t been involved.*

**Interviewee 6**

All clients felt that their relationship with their PSW would either continue for the foreseeable future to support them with ongoing challenges or would end when they themselves became a PSW or a social worker which two clients felt was a natural next step for them. These descriptions of hope and planning for the future were quite a contrast from the descriptions clients gave about how they felt when they first began seeing their PSW. This demonstrates the effectiveness of peer support in empowering clients and enabling them to see a positive future for themselves, despite their HIV diagnosis.

Among the client group interviewed, there was evidence that peer support provided a range of services which they could depend on when they needed support. This is not to be confused with a dependency culture being cultivated; this study did not find evidence of a dependency culture being cultivated. A further study could examine this phenomenon in detail by reviewing gathering experiences from people who have engaged frequently with 1-1 peer support services over an extended period.
Recommendations

The current model of offering peer support to clients accessing care at Positively UK has several strengths as described. It could be improved further by creating additional opportunities to clients which boost their capabilities and motivation to self-manage their HIV. Clients were asked what they felt could make peer support even better for themselves and for others and their ideas are summarised below:

Share written stories of other people living with HIV
Clients who attended group sessions report having many positive experiences during the events and afterwards. In contrast, some clients who are unwilling or feel unable to attend group settings benefit from hearing the personal journeys of their PSW and anecdotal stories via their PSW. Existing or former clients could be encouraged to share a written summary of their peer support experience could be made available to clients while they await appointments in clinic or at Positively UK. This would:

• bridge the gap between attending 1-1 sessions and attending group sessions
• encourage clients that there is a supportive community of people living with HIV
• provide example pathways of how different people have gained knowledge, support and benefited from the myriad services and opportunities available through Positively UK and other organisations
• demonstrate to clients that while peer support is individualised, there are also structured pathways which they can engage in if they prefer
• give clients examples of how others have overcome HIV self-stigma and accepted their HIV status
• provide clients with knowledge of entitlements and opportunities which they can raise with their PSW or clinical team

Provide an optional structured peer support programme
While some clients will benefit from the informal and ‘by-need’ nature of peer support, others felt that a general lack of daily or weekly structure in their lives, inability to work or volunteer enforced by a pending immigration status were the single biggest barrier to them engaging with their clinician and the major contributor to their loss of hope. By offering a structured peer support programme to clients, in which clients could be offered a series of small, low-risk but meaningful opportunities on a regular and planned basis through a non-individualised programme – for example a gardening project, a book club, or a certified training course. Such an enrichment programme or initiatives could:

• help clients structure their time
• expand clients’ social networks
• reduce isolation and self-stigma
• equip clients with valuable skills which they could continue to develop once they have left the programme
Continue to create opportunities to involve clients in service development
Service users are currently involved in service development and review through feedback at groups, project steering groups, evaluation and many past services users are now peer mentors and delivering services. Clients interviewed expressed an interest and appreciation of client involvement in service development. It is suggested that current or past service users continue be included in the ongoing development of peer support based interventions provided by Positively UK.

While potential service users may not be willing to engage in such collaborative initiatives, existing or previous clients may have already overcome initial barriers to engaging with statutory and/or charitable services and may view collaboration as an opportunity to “give back”, contribute to the HIV sector and to further reflect on the progress they have made through peer support. Engaging in a service development initiative could:

- provide opportunities for clients to nourish and expand their social network
- help clients meet their need for self-actualisation

In addition, the professionalism and seamlessness of combined clinical and social care can be enhanced further.

Enhance the integration of peer support in clinical settings
To maintain effective communication and engagement, all clinical and peer support teams could receive enhanced training in the remits of each type of service provided within the integrated model. This could be accompanied by reference documents and tools which highlight trigger points and/or a clear pathway for when patients/clients should and should not be referred to another service.

Supporting
Final Thoughts

The role of a PSW is complex and dependent on the dynamic needs of the service user accessing the intervention. The existing peer support service provided by Positively UK addresses the needs of clients as far as is possible within the remits of the organisation and boundaries of the roles of the PSWs who volunteer and are employed by the charity. The service is quick to respond, comprehensive and sensitive to the needs of clients who are at risk of or who are already disengaged with clinical care, struggling to adhere to prescribed treatment regimens and/or otherwise finding it challenging to live well with HIV.

*Accessing peer support when I was diagnosed in 1991 and subsequently has made my journey living with HIV easier, helping me to increase knowledge and develop strategies to survive living with HIV.*

*Peer Mentor, Positively UK*

Clients reported that both the formalised 1-1 and informal peer support had a positive impact on their knowledge, physical capacity, self-esteem and motivation to self-manage their HIV. Clients describe the peer support they have received as invaluable in helping them reconcile self-stigma related to HIV which oftentimes has made them reluctant to engage with clinical and/or social care services.

To clients, PSWs are problem solvers, advocates, confidantes, information bearers, system navigators and role models and as such have played an integral role in their HIV journey. The accessibility of peer support services in clinical settings was reported as beneficial to clients and this integrated care model could prove a suitable approach to delivering a comprehensive care and support package to people who are most in need of confidential, professional, and holistic care services.

*Jenny has done that, my consultant, my psychiatric doctor, those are the people that helped, those three people.*

*Interviewee 4*

Future peer support interventions might consider how they engage with the wider community in which their service users live or spend time, to reduce isolation and stigma through community-based activities as well as clinical settings. There is potential for future interventions to incorporate skills-based workshops and enrichment programmes to support clients in gaining knowledge which in turn might further enable them to volunteer, retrain, gain employment, and/or maintain a social network – all of which are likely to have a positive impact of their ability to attend clinical appointments, adhere to prescribed treatment regimens and ultimately self-manage their HIV.
we are positive

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