South London HIV Peer Support

Provider and User Focus Event

18 January 2013

CAPS
PO BOX 24632
London E9 6XF
Charity No. 1095756

METRO
N106 Westminster Business Square
1-45 Durham Street
SE11 5JH
Charity No. 10707582

Contents

Executive Summary:

The following report aims to capture a consultation event hosted by Catholics for AIDS Prevention and Support (CAPS) and METRO on 18 January, subsequently followed up by interviews with some of those present or who were unable to attend on the day.

The event was a response to general and specific uncertainties faced by HIV Peer Support Services in South London, most specifically those commissioned by the South London HIV Partnership (SLHP) and was attended both by providers and users of such services and independently facilitated by Peach Consultancy.

The main focus of the report is to respond to uncertainties by examining the type of beneficial outcomes that can be supplied to commissioners of peer support services – groups in particular – and to develop a general outline of a model that can meet current and increasing demands to prove effectiveness through outcome measurement without compromising service quality or focus.

The report states that though there is little direct academic research evidence to support the effectiveness of HIV peer support groups, a body of evidence pertaining to a more general, larger group of services which encompasses HIV peer support services does exist. Using this evidence, the report suggests methods of organising services to best and most efficiently standardise and gather such outcomes. Most specifically, a joint approach is put forward to reduce duplication and centralise outcome gathering and measurement. By approaching peer support services in this way, it is hoped that a balance can be reached between using resources to provide much needed services and ensuring such services are having their intended positive effect.

Context

On 18 January 2012, METRO and CAPS hosted a consultation event for providers and users of HIV Peer Support in South London. The event was attended by representatives from the following organisations:

- METRO
- CAPS
- Terrence Higgins Trust (THT)
- Body and Soul
- Southwest London Fellowship (SWLF)
- African Advocacy Foundation (AAF)
- French African Welfare Association (FAWA)
- Positively UK
- African Positive Outlook
- Living Well (provided content but could not attend)

Service users of some of these organisations were also in attendance.

The aim of the event was threefold:

1. ***To respond positively to current uncertainty regarding the shape of future Peer Support services in South London:*** Many of the participants are currently providers of peer support to the South London HIV Partnership (SLHP). The current model of peer support for the SLHP is a pilot Hub and Spoke administered by THT. Organisations contracted to provide support are CAPS, METRO, Ernest Foundation, FAWA, Positive Parents and Children, AAF, SWLF, and THT. Most of the support provided is in the form of open access peer support groups. Currently these services are under review, and although there appears to be commitment to fund Peer Support Services, as well as a commitment to conduct a PPI exercise concerning their form, there is concern among group providers that groups may be discontinued for lack of research evidence of their effectiveness. With respect to this concern, the aim of the event was to consider a combined response to any forthcoming PPI exercise, as well as to examine any available evidence or respond coherently to its lack.
2. ***To look at ways of providing Peer Support outcomes in line with current commissioning requirements:*** Not only will any future SLHP Peer Support Service require measurable outcomes, but all Peer Support Services are facing this challenge. More specifically, the move of Public Health into Local Authorities (LA) and the need to provide outcomes in line with the Public Health Outcomes Framework (PHOF).
3. ***To find a common provider voice and find ways of working in partnership in the future:*** With the above and general challenges facing both providers and service users due to the current economic climate, a strong and unified provider voice and vision is needed.

This report is, thus, largely a recording of the issues raised and agreed on during the event held on 18 January. Relevant documents used for this event have been attached as appendices.

In addition, some service users and providers in attendance were contacted for brief interviews during the writing of the report to further clarify and expand upon issues raised during the event.

This report does not attempt to record the activities of the event or the individual conversations 'as they happened'. Instead, it is a statement that coherently combines the views expressed into a whole that all participants and interviewees are able to endorse. To this end, the following providers have signed their name to this report as expressing an agreed vision of the future of HIV Peer Support in South London:

- METRO
- CAPS
- Terrence Higgins Trust (THT)
- Body and Soul
- Southwest London Fellowship (SWLF)
- African Advocacy Foundation (AAF)
- French African Welfare Association (FAWA)
- Positively UK
- African Positive Outlook
- Positive Parenting and Children (PPC)
- Living Well

As well as these providers, those service users in attendance on the day also had the report circulated to them and agreed to endorse it as a vision of Peer Support services in South London.

Evidence:

In Autumn 2011, a review of HIV Health and Social Care services by Lambeth, Southwark and Lewisham (LSL) concluded that there was very little evidence supporting the effectiveness of peer support groups for people living with HIV (PLWH)[1]. A further review of services in Southwest London conducted the following year concluded the same.[2] These findings are perceived by both the provider and service user communities as being largely responsible for the current uncertain state of peer support services as currently funded by the SLHP. Thus, while other SLHP services are being rolled over for another financial year until re-specification

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[1] Review of HIV Care and Support Provision (LSL) – November 2011. Young, Peck, et al.

[2] NHS South West London Health and Social Care Needs Assessment for Adults Living with HIV in South West London, 2012. Pyper et al.

and re-tendering, Peer Support Services are in an ongoing state of uncertainty, operating at 3-month contract extensions.

More than this, the larger cohort of providers saw the movement of Public Health (PH) to Local Authorities (LAs) and the introduction of the Public Health Outcomes Framework (PHOF) as further adaptation pressures to Peer Support Services due to the new and varied outcome requirements they entail.

Largely it was felt that the traditional and grassroots model of peer support, favouring open access, semi-anonymous attendance at discussion groups, did not lend itself naturally to gathering and providing the types of evidence of outcomes increasingly being called for, and that the lack of evidence cited was due to this rather than to any inherent ineffectiveness. One-to-one interventions like Stanford's Positive Self-Management Programme (PSMP) were acknowledged as able to record outcomes because of their structured natures. *However, it was stressed that these two styles were not interchangeable. Each offered different styles of support for PLWH at different stages of their diagnosis and according to their disposition.*

Given this dichotomy between group and one-to-one interventions, discussions held at the 18 January event and in interviews dealt largely with the question of evidence supporting peer support groups. This is to be taken as the assumed context unless otherwise stated.

The following examination of evidence will thus be divided into three sections: 1) Available, 2) Possible, 3) Considerations

1. *Available Evidence:*

There was general agreement with the two reviews cited that there was a general lack of academic research evidence available supporting the effectiveness of peer support groups for PLWH. However, there is compelling evidence that supports:

- **The GIPA Principle**: GIPA stands for Greater Involvement of People Living with HIV. This is a principle endorsed by UNAIDS in 1999 and backed by 42 Governments, including the UK. GIPA states that Groupwork, Sharing and specifically Leadership by PLWH is effective in empowering PLWH. More than this it is understood as an ethical requirement in terms of service provision and policy planning. There was thus general agreement that the nationally and internationally endorsed GIPA principle, is evidentially important as supportive of Peer Support Group provision.

- **Social Support**: This is an 'umbrella term for a variety of pathways linking involvement in social relationships to well-being'. The way in which Social Support and its 4 distinct categories can be applied to peer support can be seen in the following chart[3]:

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[3] Dutcher, M.V., et al., 2011. *"Positive Examples": A Bottom-Up Approach to Identifying Best Practices in HIV Care and Treatment Based on the Experiences of Peer Educators.* AIDS PATIENT CARE and STDs Volume 25, Number 7

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TABLE 3. PEER ACTIVITIES CATEGORIZED BY SOCIAL SUPPORT

Informational support	Emotional support	Instrumental support	Affiliational support
Share personal story[a]	Share personal story[a]	Assist patient in navigating resources	Facilitate activities/outings (conferences, cookouts, game nights, etc.)
Communicate health information	Listen to fears, complaints, problems, etc.	Interpret medical jargon	Facilitate or connect clients with support groups[a]
Teach clients how to read and understand labs	Reassure clients' that they are not alone, that they are not the only person living with HIV	Remind clients of appointments; make and reschedule appointments	Encourage clients to seek support from family and friends
Share information about dealing with opportunistic infections	Help clients deal with disclosure issues	Connect with case managers	Augment social networks
Communicate importance of taking medication (adherence)	Connect through physical contact (giving a hug)	Refer to other resources (housing, mental health, substance abuse support, child care, etc.)	
Teach healthy eating habits	Reassure clients that they don't have to die	Provide transportation to appointments	
Share information on managing side effects	Reassure clients that they can live a "normal" or productive life with the diagnosis	Follow up with clients who do not show up for appointments	
Guide clients on what questions to ask providers	Commit to being available, provide client with their full attention	Complete paperwork or track down documents that will allow clients to see providers	
Teach about how to have safer sex (risk reduction)	Let clients know there is hope	Order medication refills	
Share information about HIV 101	Aid self-esteem	Visit client at hospital	
Facilitate or connect clients with support groups[a]	Encourage effective coping	Assist clients in getting child care	
Encourage attendance at workshops/trainings	Facilitate or connect clients with support groups[a]	Assist clients in finding jobs	

[a] Activities appear under two or more support methods.

It is possible to classify HIV Peer Groups as providing the above types of support. Social Support is evidenced in academic research as effective for supporting good health and well-being, Implicitly therefore, HIV Peer Support groups claim as evidence, all the existing research that demonstrate those benefits which come under the umbrella term of Social Support. Moreover, it was felt that on-going attendance at the groups themselves was evidence that social support is being successfully provided, and is of on-going actual relevance to PLWH. As such peer support groups are useful as means for supporting the health and well-being of PLWH.

Providers were clear that the following specific aspects of social support can be evidenced from group activities:

a) *General emotional Support:* Peer support provides emotional support for PLWH, helping them to identify, tackle and address issues such as self-esteem, and the feelings of isolation and loneliness often felt particularly by those recently diagnosed, and increasingly by older PLWH. Peer support provides "a sense of welcome" and belonging for service-users, introducing them to others who are dealing with or have dealt with similar issues, helping to alleviate anxieties over specific practical issues such as long-term health prospects and issues to do with medications and their possible side-effects. Service providers and users also described the emotional and psychological reassurances that can only be obtained when meeting somebody who has already faced what they are facing.

b) *Positive self-image*: Peer support allows PLWH "a chance to be themselves and admit to their HIV status without fear of judgement." For many newly diagnosed patients especially, it provides a safe space in which they can begin to come to terms with their own identity as a person with HIV. The opportunity peer-support provides for encouraging positive self-image develops emotional tools such as the confidence to access services or the confidence to navigate situations that require the disclosure of HIV status to others.

c) *Continuous support*: Peer support was celebrated for providing a holistic, continuous emotional support base for users rather than only intervening at moments of crisis. As such it also addresses broader emotional issues that may directly or indirectly relate to HIV such as bereavement, sero-discordant relationships, depression, and anxiety. Sigma's 2007-8 national needs assessment of PLWH '*What do you Need?'* found that 27% of respondents "felt unhappy about their friendships" and that 41% had "experienced difficulty with their friendships in the last year." 32% of respondents "reported a complete breakdown or loss of friendships and poor communication between them and their friends." Peer support must then be considered an important resource for those respondents who have experienced such difficulties in maintaining friendships since their diagnosis. This should be considered especially important given findings in the same report showed that "Friendship" ranks very highly as a source of help in managing a broad range of issues that directly or indirectly affect the ability of PLWH to address a wide range of basic needs. Peer support augments social networks that may have become strained, addressing the need for support that friendships provide, at a time when they are most needed. The friendships and space for completely open interaction that peer support groups provide have also been spoken about in terms of assisting those PLWH who are currently employed, to remain in work. For some they are the only opportunities they have where they feel they can be completely 'themselves'. They are an important place, and space, where an employed person can come, and surely contribute in terms of maintaining a 'normal life' with all the stresses and strains that modern day work entails.

Furthermore, it was reported by service-providers, that the support of peers within groups often developed into friendships beyond the boundaries of the support group, with many service users taking a highly active role in supporting peers, in a variety of ways, outside of scheduled meetings and activities. Lastly, the development of new friendships often facilitates access to other settings and groups where social and material support can be found. The peer support group can enable a greater integration into 'wider society' for individual members, by way of 'accompanied introduction' or the through the formation of new contacts through the 'non-HIV' networks that other members already belong to (e.g. social circles; church and faith groups; hobby based groups; employment opportunities; sports; and other health related groups such as AA).

In these ways, the benefits of peer support groups provide a potential 'added value' that extends well beyond the more narrow confines of specific HIV related outcomes.

d) *Empowerment:* A consistent theme throughout the consultation event was the empowering effect of peer-support. Attendants stressed not only the value of learning from and being supported by peers, but of imparting knowledge and supporting others. Users are thus empowered through peer support as a facilitating means that is less hierarchical than traditional notions of service user and provider but instead allows for greater involvement in the provision of support for PLWH.

e) *Being of use to others*: There was a broad agreement of the value of what one speaker termed "being of use to others." What was meant by this was a general description of the many ways that peer support groups, by drawing on the strengths, skills and experiences of their members, can enable service users to find value through supporting each other. This is a context that values and encourages the skills of the peer group members and affords opportunities for these skills to be developed further and be put to positive use. A real sense of personal meaning can be found through these kinds of mutual help and service, and this undoubtedly contributes to the person's sense of well being, self-esteem, and mental health. The reality is evidenced especially, (though not exclusively) within those peer support groups that rely upon the voluntary service of their members to function.

f) *Learning together:* The pedagogical function of peer support was described by both service providers and users. Peer support services were characterised as places where service users share and exchange knowledge and skills for managing HIV and the many issues that are influenced or exacerbated by diagnosis. In this sense peer-support, in bringing together a group of people with many different experiences of dealing with HIV, provides a pool of informational resources for PLWH.

g) *Practical Skill Sharing and Knowledge*: Peer support provides an atmosphere in which service users can share practical skills and advice relating to managing HIV

and general health and wellbeing. Service users explained the value of a less formal atmosphere where they could ask questions they would not feel comfortable asking their doctor. In this setting newly diagnosed members have access to the more advanced skills and knowledge of other, more experienced members. In addition, by working together and sharing advice, peer-support users can more easily stay up to date on recent treatments, health information, and services

h) *Translation*: Several providers raised the issue that some of their service users faced significant language barriers. For smaller groups with less staff especially, the diversity of users meant that groups did not need to rely entirely on the translation skills of staff and facilitators, but could make use of a pooled knowledge base including language skills. Moreover, peer groups also prove helpful in translating literature regarding treatments and health advice, translating jargon into the common language of a group where a shared level of understanding and interpersonal comprehension has been worked over time.

i) *Holistic Support and Advocacy:* Providers and users alike repeatedly reported the importance of peer support in identifying practical difficulties in addressing a number of needs that affect the ability of PLWH to manage their condition. The context of peer support is not structured in such a way as to address already delineated needs, instead users are empowered to *work through* the intersecting difficulties that they face, including housing, employment, immigration, education and welfare benefits. As such, peer support empowers users to be able to recognise their own needs in order to negotiate the various effects of HIV on many different aspects of their lives. The flexibility of the peer support group to respond to the needs of individuals as they arise for the person, is a strength. Again, the value of peer-support might be recognised for its harnessing of the experience of other PLWH as a pool of expert knowledge in negotiating the complexity of these interrelated effects.

j) *More confident disclosure:* It was commented that peer support is the context in which many service users first tell other people they are HIV positive. Peer support provides a place where PLWH can 'admit' to their status "without fear of judgement." This supportive environment allows people to become more comfortable with disclosure. Opportunities to 'process' one's thinking, and consider the varied complex issues that pertain to different sets of relationships (e.g. family, spouse, children, employers, health professionals, friends and colleagues etc…), are invaluable for assisting PLWH to carefully consider issues of disclosure. Again learning from the experience of others cannot be underestimated. This also positively impacts risk reduction behaviour by furnishing service users with the confidence to better disclose their positive status to potential partners. Furthermore, it enables users to, by giving them the confidence to disclose to their GP or other healthcare provider, to access other services more beneficially.

k) *Fewer missed appointments:* Another benefit that was mentioned was a decrease in the number of missed appointments made by service users as they progressed through peer-support programmes. Again, it was pointed out, this was a consequence of the increased confidence of service users with respect to accessing services.

l) *Support in reducing isolation and maintaining mental health.*
   The reduction of isolation has already been mentioned, but deserves specific mention in regard to mental health issues. Service users with dementia, or those who are socially isolated, or those who are unable to share their own HIV status with others, are at risk of a deterioration in mental health. Many report the benefits of the Peer Support Group in terms of reducing their need to access mental health services. Some report that they feel that there are insufficient services that are sensitive to the particular mental health issues that arise for PLWH, and for them the Peer Support Group functions at times as a kind of 'lifeline'.

The above benefits are both outcomes of peer support group interventions and are evidenced as being effective in supporting good health.

Most of the above benefits have been expressed positively, but some are also the product of the question 'What would happen if I did not attend the Peer Support Group?' and are expressed as negative consequences. Benefits can sometimes be evidenced as positive statements, but are also expressed for some by stating a fear or anxiety, if the peer support group was not available.

Owczarzak and Dickson-Gomez (2011) have noted that for many Community Based HIV Organisations there is a tension between the requirement to deliver upon specific targets or outcomes set by external health agencies and funders, whilst at the same time maintaining the ethos and values inherent to the 'grass-roots' service provider. They show that the requirements of external agencies' (e.g. for data and evidence, or to deliver a specific program in a proscribed way) can conflict with the particular needs of service users in a given organisational setting. Maxwell, Aggleton and Warwick (2008), note that statutory organisations in particular, often expect PLWH to fit in to pre-existing structures and systems. In other words, the GIPA principle can often be 'suffocated at birth' when the demands of funders take undue precedence, or there is an insufficient appreciation of or commitment to this principle. Both studies conclude that in order to more effectively implement the types of health and well being outcomes desired by both funders or statutory agencies and Community Based HIV Organisations, there is a greater need to integrate community partners in all stages of policy development, research design and service delivery. Maxwell et al., propose that 1) adequate resources need to be made available to develop service user involvement beyond a 'tick-box' activity; 2) a range of methods or tools should be employed when seeking greater user

involvement; and 3) that timely and accessible mechanisms for user feedback are key to ensuring continued involvement of PLWH.

Participants at the January conference shared some similar convictions, as well as frustrations. The variety of peer support group provision was viewed as a collective strength. Many of the support groups already collaborate and co-operate. Each peer support group would need to identify which of the supports/benefits listed above align with the groups own aims, ethos and 'style'. They would need to identify which supports/benefits they felt able to provide for their service users. All the service providers present, and the service users, emphasised the importance of an approach that could respond creatively, and flexibly to the needs of individuals.

- **Case Studies**: All providers were keen to point out that there was no lack of individual case studies that evidence the importance of peer support groups in individual lives. In keeping with the evidence of actual benefit that seems to be 'common sense' when one considers the consistent attendance and use of peer support groups, service users and providers also considered that many of the benefits of peer support are self evident if one listens to the stories and accounts of individual members. Undoubtedly, individual cases are indicative of a wider 'trend' or more general outcomes. Thus group membership, and the stories (or cases) of individuals point towards both the needs of the wider group of PLWH, and attest to the specific ways in which people are helped via the provision of peer support groups. Within most peer support group provision, given limited resources, it may be difficult to bring together individual case studies to form generalizable academic evidence. However, that does not mean that there is no evidence, and individual cases provide important data on the social and actual relevance and beneficial outcomes of peer support groups.

2. *Possible Evidence:*

It is important to distinguish between a lack of available evidence and the possibility of providing evidence. Participants at the 18 January event agreed the following could be provided were proper outcome measuring templates provided by or ideally designed in partnership with Commissioners:

- **SLHP Hub and Spoke**: Providers from this stream were keen to point out that much work had already been done on developing outcomes for these groups. However, uncertainty over the future of the service as well as a lack of clarity surrounding the method of recording had delayed their implementation.
- **PHOF**: It was agreed that outcomes (or information) relating to the PHOF could be gathered by peer support groups to support LA's need to report back to Public Health England, though many of these were only tangentially related to HIV-related peer support

3. *Considerations:*

All participants felt that the above methods of outcome gathering could not be noted without raising some issues with respect to the limits of evidence and outcomes gathering and the need to look towards the broader context in which peer support exists:

- **Intrinsic Value**: It is hard to underestimate the intrinsic value of sharing time and experiences with people in similar situations and difficulties. This value, essential to the GIPA Principle is already evidenced by academic Social Support research. The fact that PLWH seek out and use peer support groups demonstrates that they matter. We are relational beings, and it is through these relationships of mutual support, understanding and acceptance, that PLWH can overcome many of the challenges associated with living with HIV and AIDS. When people are 'artificially' bound by a health concern, particularly one where stigma and shame plays a large role, the provision of funding to enable people to form these networks of support is essential as a counter-balance to the inequalities and exclusion that they actually endure in society. It is surely a necessary duty of those charged with eliminating health inequalities.

- **Proof through use**: Although this relates to the above point, it nonetheless needs to be made separately as well. Namely, it needs to be marked that attendance at a peer support group is itself a form of proof that clients find the sessions valuable and engaging. Many clients who attend such groups have few other social outlets and are hesitant to engage those that are available. The fact that peer support groups remain continuously and well attended by PLWH cannot but be proof of their usefulness to those attending.

- **De-focusing Provision**: The nature of peer support groups is generally informal and relaxed. Given this, there was concern among both providers and service users at the event that too rigorous a focus on outcomes could change the nature of the type of service provided by peer support groups. All outcome measurement practices would need to accommodate and mould themselves to the service they seek to measure, rather than the reverse.

- **Outcome waste**: The following section of the report will look at ways in which peer support providers can measure outcomes based on both the work done in the services and the needs of commissioners, particularly in relation to the new PHOF. However, it is necessary to note beforehand that there was much discussion at the event and during interviews of concerns among providers of misusing resources trying to catalogue and achieve outcomes. Any funding given to providers, it was felt, is best spent providing services, and there was concern that provision could possibly suffer if too many outcomes were required or if too much emphasis were placed on recording them. With this in mind, provider resource has been factored into the proposed ways forward that will follow.

Proposed Models of Peer Support:

The latter part of the 18 January event was spent consolidating the issues discussed above with the aim of determining general principles of any Peer Support service for the SLHP. In the interviews that followed the event, participants were again given the chance to comment on any factors they thought ought to be in place in any service. The following is thus a catalogue of the general principles that were agreed on the day or stated during interviews. It is not a service proposal as such, but rather an inventory of what both providers and service users feel ought to be part of any service that is commissioned in future:

1. **Joint Working:** It was felt that providers ought to work together within a larger, single peer support service. The advantages of this are:
    a. *Reduction of duplication:* Were a single Peer Support Service commissioned as a consortium of smaller providers, areas of expertise could be delineated to ensure that there was no duplication. More over, a jointly organised service would also work to ensure proper geographic coverage as different providers could, through central administration and distribution of funds, share space and resources as required in order to ensure equality of access.
    b. *Consolidation of outcome measurement:* Given some of the above caveats, it was thought that a larger service could have a single, integrated outcome measurement tool. A jointly organised service would thus have an intake/assessment function with pan-service outcomes as well as sub-service specific outcomes determined through assessment. Dividing outcomes in this way could help reduce the burden of measurement and gathering on group providers.

    It must also be noted, however, that joint-working in the ways described above is not intended to compromise any organisation's independence or expertise. Rather by reducing duplication and consolidating necessary administrative functions, it is believed that participant organisations will be better able both to provide unique services while ensuring outcomes are recorded and measured properly and without unnecessary resource drain.

2. **One-to-one versus group support:** Both providers and service users felt that one-to-one support was useful and necessary, but that it provided a very different type of support from that found in groups. Moreover, there was some concern that because one-to-one models are more naturally equipped to provide outcomes based on the length and style of the intervention (Stanford's PSMP and METRO's MetroSafe programmes were cited as examples) that they were in danger of being favoured by commissioners tasked with providing outcomes to meet new criteria. From this it was felt that a combination of one-to-one and group provision could be integrated into the single service suggested above. It was noted, as well, that because one-to-one services are more fitted to providing outcomes, that such a service could sit centrally, within the assessment/intake function, as a core service, with groups acting as satellite services. In the best case scenario, the one-to-one service could be the 'outcomes service', with groups providing necessary specialised and back-up support, based on outcomes gathered during provision. This of course would not preclude exclusive use of groups by service users, but merely provide a template for provision and

outcome measurement where a central one-to-one service gathered data that justified and allowed freedom within group provision.

3. **Which Outcomes?:** As has been referenced above, the need to provide outcomes must be balanced with the necessities of providing a focused, client-oriented service as well as the resource limitations on the individual providers. In developing the idea of primary, pan-service and secondary, sub-service outcomes, the following example can be given:
   a. *Primary:* Here could be gathered key, relevant information from the PHOF – were the client accessing the peer support through the First Point SLHP service all of this and more would be pre-gathered – as well as specific information determining which more specialist service would suit and the resultant outcomes template to engage
   b. *Secondary:* As determined through assessment, the secondary outcomes would comprise those determined as most relevant according to the model of Social Support and GIPA as outlined above, as well as those specific to a given demographic and group's area of expertise.

Building on this model, a client could, for example, access peer support as a parent wanting support specifically geared to this issue. An initial assessment may indicate other issues (adherence, healthy living, etc.) which could be dealt with specifically in a one-to-one programme or less specifically in a parents group. The client could choose both one-to-one and group support, or only one-to-one or only group support. Should the client choose both, only the secondary outcomes (those determined by the peer support group as its specialist outcomes with highlights made known to it based on the incoming individual's assessment) would be transferred to the group, with the primary outcomes staying with the one-to-one programme. However, should the client not want one-to-one support, this information, though with less expectation of being dealt with specifically, would be transferred to the group as part of the client's profile. Similarly, should the client decide to only have one-to-one support, the more specialist issues would be dealt with during it, with the specialist group facilitators able to provide support to the one-to-one mentor if necessary.

The above is only an example of how such a system could work based on i) providing the flexibility and choice of one-to-one and group support, ii) acknowledging the specialist nature of group support in dealing with specific issues, iii) providing a system geared to gather the most possible outcomes in the most rigorous manner possible though without compromising user experience as central.

4. **Centralised information gathering and handling:** This is implicit in all of the above though needs to be stated explicitly. It is to be noted that the current hub and spoke model of peer support within the SLHP is based on this assumption of a central provider/administrator responsible for gathering information and reporting to commissioners. The proposals generated from the 18 January event thus support this model, though with more sensitively developed outcomes templates and division of expertise.

5. **More usage of volunteers:** It was noted that some groups currently use volunteers in their provision, while others do not. However, in accordance with the GIPA principle and from opinion gathered on the 18 January event, it was felt that a more standardised and active volunteer participation mechanism would be beneficial to any peer support service. These volunteers could work as mentors in one-to-one support services or as group helpers (as is currently the case in some groups). However, by standardising volunteer involvement and allowing people to enter peer support as volunteers or to become volunteers as part of their support journey, ownership and patient involvement could only be increased to the benefit of the SLHP as a whole. Outcomes relating to volunteering would thus be part of the centralised outcome template.

Conclusions and Recommendations:

To summarise, the event hosted by CAPS and METRO on 18 January succeeded in unifying the event's attendees who formed a representative cross-section of providers and users of peer support in South London.

This report represents a common vision endorsed by all those in attendance or who were interviewed after the fact.

It is recommended that this report is taken into account in any upcoming PPI and re-specification process as being indicative of the combined expertise of South London providers and service users as represented at the 18 January event.

Main considerations drawn from the information given in detail above are:
- There is evidence to suggest the type of support provided by Peer Support Groups is effective. This falls under the banner of Social Support and going forward outcomes for individual groups should be determined through these categories and according to each group's specific area of expertise.
- The current diversity of provision is a positive strength, as is the work already undertaken over the past several years. 'Re-inventing the wheel', rather than building on the strengths of existing provision is not likely to be resource efficient.
- The GIPA principle, which is endorsed by UNAIDS and backed by the UK government recognises peer support groups as effective interventions for PLWH, and that this principle be applied as an ethical requirement at all levels of policy formation and service delivery
- The joint commissioning of discrete providers under a single service banner would help reduce duplication, allow for better geographical representation through administrated recourse sharing, and unburden single providers through central outcome measurement systems and reporting in line with the PHOF and other reporting necessitates
- Both one-to-one and group support are not only necessary but complimentary methods of support

- Better consideration needs to be given to the use of volunteers in the provision of peer support services through the development and standardisation of roles, allowing for measured personal development

- There needs to be a reasonable limit placed on the amount of outcomes supplied by service providers. In an era of limited funds, it is especially important to ensure that resources are spent providing services rather than 'continually proving' their effectiveness. To this end, a balance needs to be struck to ensure that quality service provision based on established and tested models remains primary despite the growing need to measure effectiveness. The task of data and evidence collection therefore, must be approached more creatively than before, and must be flexible involving mixed methods. We suggest that fund-holders and commissioners will have greater confidence that service provision is effective if they can engage more fully, directly, and co-operatively with service providers and service users at the 'grass-roots' level. We urge the commissioners to re-align themselves as advocates for PLWH, rather than 'demanders of' PLWH.

For more details, please contact

METRO
Scott Lupasko
tel: 020 8305 5000
fax: 020 8305 5001
email: scott@metrocentreonline.org
web: www.metrocentreonline.org

CAPS
Vincent Manning
email: secretary@caps-uk.org
web: http://www.caps-uk.org/