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Claire Maxwell, Peter Aggleton, Ian Warwick

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# Involving HIV positive people in policy and service development: recent experiences in England

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## **Involving HIV positive people in policy and service development: recent experiences in England**

### **Abstract**

Although the 'Greater Involvement of People Living with or Affected by HIV/AIDS' (GIPA) principle was first articulated over a decade ago (UNAIDS, 1999), relatively few studies have examined the extent to which it is being implemented. A study was undertaken in three areas of England to establish the types of user involvement mechanisms in place for HIV positive people to influence service and policy development. Drawing on group discussions with thirty-eight people living with HIV and six HIV professionals across the three geographical research sites, as well as interviews with eight professionals with expertise in this area, this paper illustrates variability in opportunities for involvement. Also identified are a range of (innovative) methods for facilitating HIV positive people's greater participation in service planning and delivery, as well as some of the challenges encountered by people living with HIV and service providers when implementing GIPA. The paper concludes by identifying some specific strategies for improving user involvement in HIV service provision.

**Keywords:** GIPA, involvement, HIV, AIDS, England, policy

## Introduction

At the 1994 Paris AIDS Summit, the 'Greater Involvement of People Living with or Affected by HIV/AIDS' (GIPA) principle was declared. GIPA recognised the contribution that people living with HIV could make to tackling the epidemic and called for the creation of spaces in which positive people could be involved and actively participate 'in all aspects of that response' (UNAIDS, 1999: 2). A subsequent UNAIDS Best Practice document on GIPA suggested a six-tier pyramid outlining possible levels of involvement (UNAIDS, 1999). At the minimum level of involvement, HIV positive people can offer feedback on services received, while further up the pyramid they can become more 'visible' through public speaking, or more actively and directly involved in the response to the epidemic as carers, peer educators and so forth. At the tip of the pyramid, a relatively small proportion of people living with HIV may work to gain access to forums in which service and policy decisions are made, and where their HIV status affords them the recognition of expertise (UNAIDS, 1999).

Cornu's (2003) study of positive people's involvement in non-governmental organisations in four majority world countries between 1998 and 2001 concluded that while involvement at any level had a positive impact, people living with HIV were most likely to be only 'accessing' services (i.e. as beneficiaries) or occasionally volunteering within these organisations, rather than holding positions as paid employees or taking part in strategic decision-making (the latter representing a greater degree of participation). Based on what was observed in this study, Cornu (2003) offered a different framework

for describing the various types of 'involvement' to that offered by UNAIDS (1999). This emphasized access to services, inclusion, participation and greater involvement.

Despite increasing public awareness of the epidemic and the funding scale-up to tackle HIV/AIDS which has occurred since the GIPA Declaration, commentators continue to remark that 'to date, the involvement of positive people has been very tokenistic' (Asia Pacific Network of People Living with HIV/AIDS, 2004: 2). The International Community of Women Living with HIV/AIDS (2004) has argued that despite the 'rhetoric about challenging the stigma of HIV, few organisations take [the] obvious step' (p. 2) which is to involve people living with HIV 'in all levels of decision making' (p. 2). Roy & Cain (2001) have noted that 'surprisingly little attention has been paid in the literature' (p. 421) to positive people's involvement in policy development and service delivery. Only a relatively few studies describe the involvement of positive people in initiatives and organisations. Studies have focused on assessing the 'positive consequences' (Ramirez-Valles & Brown, 2003: 90) (which might include an increase in self-esteem and safer sex behaviours among those who become 'involved' in service delivery and development, as well as supporting services themselves to tailor programmes and make the support they offer more relevant to those living with HIV), as well as the 'obstacles' (Roy & Cain, 2001: 426) and 'negative effects' (Cornu, 2003: 100) of involvement. The barriers and negative consequences of involvement discussed in the literature often overlap, but include such issues such as the need (often) to disclose one's HIV status (which may increase the risk of people experiencing discrimination), or the fact that people who might want to

become involved in service delivery and development can already be in employment and may therefore have little spare time or put themselves at risk of 'burn out' (Cornu, 2003: 110).

In the United Kingdom, despite increasing commitment to 'patient and public involvement' in health and social care (Department of Health, 2001), little research has focused specifically on the participation of HIV positive people in service and policy development (for an exception see Anderson, 2005). The study reported on in this paper aimed to gain an overview of positive people's involvement in organisational and policy strategic decision-making in three English cities. In addition, the study sought to identify opportunities and barriers to participation with two groups of respondents – HIV professionals or those responsible for patient and public involvement, and people living with HIV.

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## Methods

### *The sample*

The study aimed to offer a geographical overview of HIV positive people's involvement in health and social care policy and service development, as well as eliciting the views of national stakeholders with expertise in this field. Using principles of purposive sampling (Robson, 2002), three geographically contrasting research sites were chosen: site one - London (one area of the English capital city which has a history of developing positive people's involvement); site two - a small city in the south of the country (with a

relatively low number of HIV positive people when compared to the other cities nearby); and site three - a large city in the North of England (where the largest number of people living with HIV outside London live – The UK Collaborative Group for HIV and STI Surveillance, 2005).

In each of these sites, two professionals with an overview of how HIV positive people were being involved in policy and service development were interviewed. Professionals were selected if they had formal responsibility for facilitating positive people's involvement and/or were responsible for patient and public involvement in health and social care policy and service development. In addition to these interviews with professionals, a group discussion with people living with HIV was conducted.

Complementing this purposive geographical sample, were in-depth interviews with eight professionals with expertise in the area of positive people's involvement. These professionals were selected because they offered either a national HIV voluntary sector perspective (four respondents), a local HIV voluntary sector perspective (three respondents), or a local sexual health and HIV commissioning view (one participant). One of the local HIV voluntary sector professional respondents interviewed was also the HIV positive person representative on a national working group who advised the UK government on their sexual health and HIV strategy. Two of the national HIV voluntary sector participants interviewed specialised in promoting the rights of specific groups of people living with HIV - Black Africans, and children and young people.

Finally, in order to gain further insight into an 'example of good practice' as defined by the Department of Health (2004) in relation to positive people's involvement, a fourth focus group discussion was convened with seven people drawn from across London and the south of the country, who were 'patient representatives' at their local HIV clinics. The 'patient representative' role within those HIV clinics involved one or two HIV positive people, who were also service users, facilitating feedback from other patients to the service managers and campaigning for changes to provision, organising events for service users to meet and provide support to each other.

#### *Data collection*

In each of the three research sites, a professional working in a local HIV organisation acted as a link between the research team and people living with HIV who were invited to take part in group discussions. Given the nature of the current epidemic of HIV in England (The UK Collaborative Group for HIV and STI Surveillance, 2005), one of the local HIV organisations approached by the researchers targeted their support to the Black African community (research site one). The two service providers collaborated with in the other areas provided a broader range of services to anyone infected or affected by HIV. In the first two sites, the local service provider invited all people living with HIV known to the organisation to participate in a group discussion at a specified time and date. In the third city, the manager of the local HIV voluntary sector organisation identified a specific group of positive people to be involved in the discussion who he felt represented the various faces of HIV



and levels of service user involvement – this included a Black African man, a Black African woman, three self-identified gay men, and an HIV-negative carer. Of these six participants, four were members of the organisations' service user forum and so were involved in strategic decision-making, while two of the group members were recently diagnosed HIV positive people and were new users of the service. All group discussion participants across the three research sites received a voucher of £20 to cover travel and other expenses.

In recognition of their workloads, interviews with professionals were generally conducted over the telephone (N=10). Face-to-face interviews were conducted with one professional who asked to be interviewed face-to-face as well as with the link professional from each local HIV organisation. [Following consultation with the HIV-positive participants, link professionals also](#) joined in the group discussions in the three research sites. [All potential professional respondents agreed to participate in the study when approached by the research team.](#)

The group and interview schedules were developed following a literature and policy review of 'user involvement', with a specific focus on people living with HIV. The group discussion guide was piloted with an HIV positive person, as well as an HIV professional, who also commented on the interview schedule for professionals. The following topics were the focus of discussions with respondents: experiences of, benefits and challenges in, facilitating service user involvement; and new ideas for improving positive people's participation.

### *Data analysis*

Interviews and group discussions were written up from notes taken during interviews. With participants' consent, an audio-recording of interviews was also made to later clarify any unclear or missing data in notes. A broadly inductive approach to analysis was undertaken. Using a 'template approach' (Robson, 2002: 458), points relevant to the broad study themes were manually coded and clustered to identify sub-themes or recurrent issues of concern. The analysis was also guided by a focus on the different modes of involvement highlighted in the literature including: using services; consultation; peer education; involvement in service and policy decision-making. A search for negative instances was undertaken prior to feeling confident that each of the analytic categories cited was adequately saturated (Glaser & Strauss, 1967).

## **Results**

### *Sample characteristics*

Overall, thirty-eight people living with HIV and 14 professionals participated in the study. Six professionals were drawn from the three geographical research sites, four respondents worked nationally on involving HIV positive people in policy development, and the remaining four participants worked in three different localities (two other cities in the north of England and London) with HIV positive people around user involvement in local service and policy

improvement. Of the 38 people living with HIV recruited to the study, 21 were women (all but one of whom described themselves as Black African), four self-identified as heterosexual Black African men, and 13 as White, gay men. The group discussion participants ranged in age from 30 to 58 years and had been diagnosed as HIV positive from as recently as four months ago, to over 20 years ago. Furthermore, three of the professionals involved in the study identified themselves as being HIV positive (one White gay man and two White heterosexual women) during the course of the interview. The research team was therefore able, through this sample, to gather the views and experiences of a range of key sub-groups of people affected with HIV in England. Two under-represented groups in the study, however, were men who had acquired HIV through heterosexual transmission (in particular, White men), and injecting drug users.

#### *Evidence of GIPA in action?*

Approaches to positive people's involvement in service and policy development varied widely across the three research sites.

In site one (which had a history of positive people's user involvement), considerable commitment to the principle could be observed. Through the local HIV Partnership commissioning body for the area, 'a range of patient and public involvement methods have been developed' (local HIV commissioner). A users' subgroup had been resourced to contribute to the work of the HIV Partnership, and consultations were under-way at the time of the study to

examine how both the sub-group, but also other people living with HIV could be involved in making commissioning decisions for the next financial year.

The commissioning group had committed 'a recurring budget item for patient and public involvement [as they recognised the] need to resource these ideas' (local HIV commissioner). This included ring-fenced funding within current grants made to local organisations by the commissioning body which had been ear-marked for the development of user involvement. A small grants scheme had also been established for voluntary sector organisations not receiving a distinct grant from the HIV Partnership, in order to facilitate further engagement of users in policy and service development. This funding commitment recognised the need to involve the various groups of people living with HIV in the area, who might need different strategies to enable them to make a contribution to policy and service development. Finally, the HIV Partnership had also funded an organisation to train HIV positive people to accredit local HIV clinics as 'patient-friendly'.

In contrast, mechanisms for the involvement of people living with HIV in service and policy development in the other two research sites were rather different. In the second geographical location studied, a smaller city in the south of England with a lower number of HIV positive people compared to nearby towns, people living with HIV appeared to have few opportunities to become involved. The local HIV voluntary sector organisation commented that they had tried a number of approaches to involve service users in the management and development of their service, but with little effect. One of the main support workers for people living with HIV in the area complained that the local health and social care agencies felt she was able to represent

the 'patient voice' at strategic meetings. 'The [local health commissioning body] ask me to be the patient voice – as a tick box; but what do they do about [patient views that I represent] – nothing!' (voluntary sector HIV support worker). A White gay man living with HIV involved in the group discussion facilitated at this research site commented, 'it has more impact if a positive person says it than a voluntary sector organisation person...we want to be asked...and we need to see something happen!'.

The professional who was responsible for 'patient and public involvement' (a statutory responsibility under section 11 of the Health and Social Care Act, Department of Health, 2001) argued that while general opportunities for involvement were made available, specific work with people living with HIV should be the responsibility of the local voluntary sector providers. The patient and public involvement lead for the local health commissioning body argued, 'I give advice on user involvement, I don't do it directly...the organisations that work with the people we wish to consult are best placed to find out how they want to be involved'.

In the third research site, a city in the north of England with one of the largest HIV positive populations outside London, considerably more activity appeared to be underway. The involvement of people living with HIV seemed to be driven by the main HIV voluntary sector organisation in the area, which was attempting to increase the involvement of people living with HIV both within their own organisation, and externally, in wider service and policy development structures. Internally, the organisation offered a wide range of involvement opportunities which included: regular feedback questionnaires on their services; one-off consultation events on topics such as the city-wide

sexual health and HIV strategy; quarterly review meetings for each service to which all users were invited; a volunteers programme; a service users forum whose make-up aimed to reflect each sub-group within the HIV population ('there is a mathematical formula for determining who can sit on the group – based on cultural background and gender to reflect the service user population of the organisation...it is more like an expert reference group' – local HIV voluntary sector organisation manager); and the opportunity to become an elected member of the organisation's management board.

The same organisation had also developed mechanisms for non-service users to participate in local service and policy development, as well as processes that would ensure users' views would be passed on to key stakeholders outside their organisation ('local Members of Parliament receive mailings from [the organisation] every three months' - local HIV voluntary sector organisation manager). Importantly, the local voluntary sector organisation was organising a series of workshops and consultation events to gather views, which would then be used to inform a conference that brought together people living with HIV with service providers and commissioners to develop the locality's future HIV strategy.

#### *Other suggestions for innovation*

Discussions with people living with HIV and professionals revealed four further strategies for promoting user involvement, which did not appear to be common practice, but respondents argued could in the future make a real contribution to the involvement of people living with HIV in service provision.

First, similar to service user forums in local voluntary sector organisations, a number of Genitourinary Medicine (GUM) clinics and outpatient services were reported to have 'patient representatives' who offered peer support to other HIV positive people, developed mechanisms for eliciting feedback from users of the service, and in some cases were invited to join the clinic's management meetings meaning they became involved in strategic and service decision-making. The patient representatives often worked voluntarily, but some clinics had made this a resourced post.

'Patient reps. can provide peer support [to other people living with HIV during their clinic] meetings....reps. can let patients know what issues there are on the horizon – restrictions on treatment, move to use of General Practitioners, streamlining of services, different prescribing practices at different hospitals' (patient representative, London). Another patient representative working in a clinic outside London explained he had helped inform other HIV positive people about which General Practitioners and dentists locally had been on an HIV training course.

The HIV positive patient representatives interviewed for this study identified a number of benefits to this model of involvement. Patient representatives could, for instance, organise to train 'patients to help them talk with others who have been newly diagnosed' (patient representative, London) or 'about the structure of the clinic, how it functions and what range of services are available' (patient representative, from a city outside London). However, the group discussion held with patient representatives also led to the suggestion that they could provide training for clinic staff, 'nurses may not know about [what] being HIV-positive overall [means], it is more likely that

someone who has been living with HIV for many years knows that [and can share this with them]' (patient representative, London). One patient representative in the group described a piece of work he had undertaken, and the other group discussion participants felt this could be further developed and result in useful outcomes - help newly diagnosed patients to record and reflect on their 'patient pathway' and feed back any issues to the HIV outpatient service's management board.

A second initiative which HIV positive study respondents said they would welcome, but only a few of them had actually experienced, was having an 'open or health awareness day for services in the local area, which would not necessarily be associated with HIV, and might include lecturers, alternative therapies, pampering activities, proper activities for children...I don't mind being asked my views then' (Black African woman living with HIV, research site one). These relatively informal consultation events were viewed positively by respondents as they felt services 'offer a package – so we can contribute but we also get something back or leave feeling refreshed' (Black African woman living with HIV, research site one). This suggestion also emerged during Anderson's independent consultation with HIV service users, providers and commissioners in south London on improving HIV service user involvement in health and social care services - 'special events away from service settings' (2005: 16).

Two final suggestions were made for involving HIV positive people. Only a few study respondents had experienced them, but each held the potential not only to improve opportunities for people living with HIV to become involved in service and policy development, but also the quality of the



contribution that could be made. One suggestion made was to develop 'mystery shopping' initiatives (a technique initially developed by the marketing sector) which involves a group of HIV positive people working in conjunction with service providers to develop a set of 'good practice' criteria on which HIV positive people base their assessment of local services which they visit anonymously (similar to the 'patient-friendly' clinic accreditation initiative being funded by the HIV commissioning body in research site one). The second suggestion put forward was that service users should be involved in the recruitment of staff, by serving on interview panels for instance (as a few of the HIV clinic patient representatives had done).

#### *Challenges to positive people's involvement*

Four key, inter-related, barriers to promoting involvement of HIV positive people in service and policy development emerged in discussions with respondents: lack of proper resourcing for the work; lack of adequate feedback processes; lack of clarity in the purpose of some 'consultation' exercises and inappropriate structures for facilitating user involvement; and professionals' concern about ensuring those who became involved were 'representative' of the whole population of people living with HIV.

Many study participants identified the first two barriers through expressions of frustration that service user involvement was significantly under-resourced (in terms of recompense financially or in kind for the time involved), and that service users rarely received any feedback on how their comments had helped to shape policy and services. Positive people

interviewed in research site one explained that in order to secure the funding to run a support group for Africans living with HIV, they had been required to model the support group as a service users' forum who were expected to comment on strategy documents. Not only did the HIV positive people in the group feel that their level of need was great enough to warrant the provision of a support group without having to participate in consultation exercises, but also that involvement of this nature should be voluntary. Furthermore, 'we say what we want, but it doesn't happen...we comment on a draft policy and then look at the final document and can't see how it's different!' (Black African woman living with HIV, research site one). Similarly, a professional responsible for user involvement at a local voluntary sector HIV organisation in the north of England (not the same city as the third research site) said, '[the local health commissioning body] holds closed consultation meetings with HIV-positive service users...but we [local voluntary sector HIV organisation] have to put a lot of effort in to get a good cross-section of people – we bribe them with food – as there is an expectation from the [health commissioning body] that we do service user involvement, and we are afraid that if users don't come it will reflect badly on us...but we don't hear feed back from the meetings, and never get anything written back - neither do the users!'.

Frustrations at the lack of proper feedback from contributions made were also heard in interviews with professionals specialising in HIV positive user involvement. '[Statutory organisations give us] a form to be completed rather than [allowing us to] feedback in whatever format easily represents users' views...[statutory organisations] need to devote time and energy to this process and people need to see what they say gets acted upon – this

encourages them to get involved again in the future' (voluntary sector HIV organisation manager, London). Another professional who was the user involvement lead for a national HIV organisation explained that services and commissioners 'often forget to budget for the feedback part of the process'.

One professional working locally in London with HIV positive people introduced the third barrier to promoting user involvement, 'what is the [policy consultation] process trying to achieve?...service commissioners need to unpick this...[and they] need [to allow for a proper timeframe as well as a clear outline of what they want comments on – not just as an afterthought...'. The local statutory lead for patient and public involvement in research site one explained, 'the problem for the [local health commissioning body] has been that too many services have had to develop very quickly – leaving no time for patient and public involvement work from the beginning – so users only tend to be involved in the monitoring of a service...that's not really the principle of section 11 [of the Health and Social Care Act, 2001], but the Department of Health is working against us with constantly changing services'.

The lack of well thought-out, planned and timely involvement opportunities was linked to what participants felt was a shortage of locally, regionally and nationally-developed set of structures for facilitating a range of involvement opportunities for people living with HIV. 'We never see opportunities for contributing at a national level' (Black African woman living with HIV, research site one), while a White gay man in research site two commented, 'I haven't seen any information on how I could become involved'. 'I want opportunities to contribute our views on other local issues – immigration status, housing to local planners – we are only [given the option]

to discuss issues related to health services' (Black African man living with HIV - research site one).

Many respondents noted that statutory organisations appeared to lack a strong commitment to user involvement and often 'plugg[ed] people into set-up structures' (Roy & Cain, 2001: 431). 'You can make a lot of noise about something – but can the person you are making the noise to do anything about it?' (White gay man living with HIV, research site two). With the exception of a few local and national HIV-specific organisations or strategic partnerships ('we feel a sense of ownership here, we feel welcome, able to talk to the staff, we have a sense of belonging; at [another local service] I would be less likely to say anything [get involved] – I would just sit quietly' (Black African man living with HIV, research site three), many study participants reflected that the context in which service user involvement occurred represented a significant challenge to effective participation. Statutory organisations especially appeared to expect positive people to fit into current organisational structures - 'we need to challenge the current format of committee meetings [if we really want to involve service users]' (professional responsible for user involvement in a national HIV organisation). One other respondent, a voluntary sector worker responsible for local user involvement in an area of London commented that service users needed to be involved in developing the terms of reference of a strategic planning committee, and that 'users often come from a difficult, painful place – but this is always denied in the involvement process – this needs to be acknowledged rather than [professionals] just sitting down and getting on with business of the meeting'.

A final barrier identified during discussions with professionals involved in facilitating user involvement appeared to be that some of them, as well as other service and policy managers they worked alongside viewed users who spoke on behalf of HIV positive people as being 'stroppy and difficult' (voluntary sector worker responsible for local user involvement, London), 'having their own agenda' (professional responsible for user involvement in a national HIV organisation), and not being 'representative' of the wider group. 'Some people are quite effective at representing themselves instead of their communities... some people who come forward [to share their views] are more of a hindrance than a help – they have so much anger and personal issues' (local HIV commissioner, research site one). One London-based patient representative suggested a reason why professionals might have this impression. He explained that giving patients a greater voice 'can cause a lot of aggravation in some services – it's a rocky road...it can be scary for staff to have patients with big gobs [mouths]...staff do their work with the best of intentions, but they are often used to a top-down [organisational] structure, and it takes time to get used to a bottom-up approach'.

Debate around how people 'representing' the views of HIV positive people could claim to speak for all affected by HIV highlighted firstly, the importance of offering a diverse array of consultation and involvement mechanisms in order to ensure the voices of a wide range of sub-groups of people living with HIV were heard in various fora, and secondly, that this area of work needs to be properly resourced. Offering a range of opportunities to become involved was seen to be necessary as positive people had varying amounts of time, energy, capacity and skills to participate. 'People living with

HIV are such a diverse group – want to do different things and be involved in different ways’ commented a professional responsible for positive people’s involvement in a voluntary sector organisation in the north of England (but a different city to research site three). A local sexual health commissioner in another city in the north of England explained, ‘people living with HIV are often in work already, are tired, want to get on with their lives, and forget about being HIV positive’. A professional responsible for developing user involvement among Black Africans living with HIV across England commented, ‘[we] need to remember the communities people come from and assess what their history of involvement is – to determine understanding and their training needs’.

## Discussion

This paper aims to contribute to, and build on the few studies which have examined the greater involvement of people living with HIV in service development, delivery and evaluation to date. The overwhelming message from the respondents who took part in this study was that they would welcome greater exchange of experiences with others working nationally and internationally on effective strategies for involving HIV positive people in policy and service planning was needed.

The research reported on in this paper examined initiatives in place in three English cities for people living with HIV to become involved in service and policy development. While one of the research sites (site two) reported

almost no user involvement in policy and service development, the other two areas offered a relatively wide range of opportunities, most of which were structurally embedded in the local sexual health and HIV strategy. Positive people's involvement in one area of London had been developed through the strategic HIV commissioning process led by the statutory sector, whereas in the third research site, a city in the north of England, the impetus for developing involvement opportunities for people living with HIV appeared to have come from the main local HIV voluntary sector organisation.

From interviews with HIV professionals with a national overview, it appeared as if one or the other, the voluntary or statutory sector, tended to have taken the lead on developing mechanisms for consultation and participation. Regardless of where the initial impetus came from, both sectors made important, and seemingly complementary, contributions to offering opportunities for involvement that could usefully inform policy and service development. The statutory sector could make available resources, as well as structures that enabled positive people's views to be incorporated into strategic plans, and importantly, offer sustainable and continuous opportunities for involvement. Meanwhile, the voluntary sector was more easily able to access people living with HIV, especially those in more marginalised groups, and these organisations appeared to be most able and willing to offer a wider range, of usually less formal, mechanisms for participation.

Taken as a whole, the findings from this study point to three strategies that might lead to the fuller involvement of people living with HIV in service provision in England. First, adequate resources need to be made available to

develop user involvement beyond a 'tick box' activity. Study participants suggested a range of resources which would facilitate HIV positive people to become more involved – a discrete post in the locality or organisation; a pleasant place to meet, with food and on-site childcare; payment for participating in a meeting or consultation event; timely re-imbursement of travel expenses; and good quality feedback to service users. Second, a range of methods for involving people should be employed, which should also offer opportunities for both one-off and continuous participation. Linked to this principle, HIV positive people should not only be actively involved in determining their immediate care, but should also have access to opportunities for contributing to local, regional and national policy and service developments. Finally, the importance of timely and accessible feedback was emphasized by participants throughout the study, and was seen as key to promoting future motivation for user involvement.

It is important to recognise that the study reported here was of a relatively small-scale nature and only aimed to provide an overview of HIV positive user involvement in service and policy development in three English localities. The first research site, for instance, only represented one area of London and would not have captured all user involvement initiatives underway given that the local HIV commissioning body was funding a number of organisations to undertake work in this area. Furthermore, while views were sought from at least one professional who facilitated user involvement and a group of HIV positive people in each locality, further discussions with other professionals and users would have likely resulted in additional insights into the history, current practice, barriers and opportunities for participation in



service and policy development within each research site. However, the complementary sample of experts in positive people's involvement did ensure that the findings from the three research sites could be set alongside developments in other parts of London, two other cities in the north of England, and nationally-led initiatives. Given that study participants commented it was particularly challenging to involve more marginalised sub-groups of HIV positive people (such as White, heterosexual men and Black men who have sex with other men), future research would benefit from the time and resources to involve such groups in a similar study.

Overall, this paper makes a contribution to the limited literature examining whether and how GIPA is being implemented in practice. Commitment to GIPA appeared variable across the research sites this study focused on, but most study participants argued there were clear benefits to HIV positive people being involved in service and policy developments, both for themselves and for the services they access. Two of the three research sites offered a number of interesting approaches to involving positive people, representing different levels of participation, and four further ideas for innovation were also suggested by respondents. Despite UK government commitment to 'patient and public involvement' across health and social care, involving people living with HIV appears to still require statutory support at a national, regional and local level.

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For Peer Review Only

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