Peer Support for People Living with HIV in Wales: Scoping and Feasibility

Authors: Sue Channon, Adam DN Williams,

Carlos EA Alvarado, & David Gillespie,

Centre for Trials Research, Cardiff University.

The work was funded by Public Health Wales.

"Care is needed to make sure that any top-down approaches to stigma reduction are not about exerting control over people living with HIV. It should always be about human dignity."

AIDS 2022 conference, "Getting to the Heart of Stigma"

EXECUTIVE SUMMARY

Background: In June 2022 the Welsh Government released its draft HIV Action Plan for Wales 2022 to 2026, setting out 26 actions to eliminate new HIV infections, improve quality of life and end stigma by 2030. An integral part of this plan is to develop and deliver a peer support service for people living with HIV in Wales as part of the 'Living Well with HIV' priority for action. Peer support (PS) takes many forms, but its defining ingredients are a reciprocal, equal relationship between peers who share a common experience, for example living with a particular health condition, which means they can relate to each other's experience in a way that others cannot. A summary of the best available evidence, published in 2021, showed that adding PS to routine medical care can make a positive difference to retention in care, antiretroviral therapy adherence and viral suppression.

The 2017 UK National Standards of Peer Support in HIV provide clear guidance on equity of access to PS, the importance of training and support of mentors and ongoing evaluation, all of which have been incorporated into the 2018 British HIV Association standards of care. Although there have been efforts to introduce a peer support programme in the past, Wales does not currently have a national peer support service for people living with HIV. As part of the HIV Action Plan working group, Public Health Wales commissioned Cardiff University to conduct a brief scoping study to explore the potential for developing a service in Wales.

The aim of this study was to utilise the experiences and views of service users and providers, alongside the research evidence, to identify factors that might help or hinder the development of PS for people living with HIV in Wales. Establishing a high quality, co-produced, sustainable PS service requires several stages over time, this study is part of the first stage.

What did we do: Between April and July 2022, we conducted:

1. A systematic review of the current published research relating to HIV peer support.
2. An online survey exploring the views of people living with HIV in Wales about a PS service.
3. Interviews with service providers who have experience of designing, setting up and/or delivering PS services for people living with HIV in the UK.

Key findings:

Systematic review of the current literature relating to HIV peer support [15 studies]

In addition to the evidence that PS can have a positive impact on clinical outcomes, PS can also be an effective approach to decrease enacted and self-stigma, depressive symptoms, and anxiety. A PS service that meets the UK National Standards can be applied in the UK to decrease HIV-related burden and more studies are needed to continue evaluating the impact on quality of life and effectiveness of the approach in the UK.

Online survey amongst people living with HIV in Wales [n=154]

The people living with HIV who completed the survey had a positive response overall to the idea of the development of a HIV PS service. Many were interested in either using or helping deliver such a service. However, it would not suit everyone and so it would need to be one part of a range of support on offer.

The service model needs to be adaptable with options including in-person, virtual and group elements taking place in community and clinic settings. Managing confidentiality is paramount and a clear connection between the service and the healthcare team would provide legitimacy and safety.

The main benefit of PS from a service user perspective is derived from sharing experiences. Confidentiality of HIV status is the big challenge across the board for those using and volunteering alike. Wales has some specific issues to deal with in setting up an All-Wales PS service, including geography and funding.

Interviews with service providers with experience of peer support services in HIV [n=13]

There was significant support amongst service providers for the development of a PS service in Wales. The interviews generated some key themes about any proposed service:

1. Some core principles of the service (ethos, sustainability, it's place in the wider system, model of delivery and training)
2. The necessary structures within a host organisation (people living with HIV included at all levels of the organisation, community led, highest level of ethical practice),
3. Understanding the context in Wales (stigma, the impact of previous PS services, the need for a new host organisation, service delivery challenges, prioritisation, clinical services)
4. Understanding what success would look like, operationally and in terms of outcomes.

For Wales-based service providers in particular, their responses were very much informed by the failure of the previous PS service, it has made many people wary. A new service will need to overcome this narrative through co-design with service users and local providers, clear communication, strong and steady integration with the existing system (particularly clinical services) and a robust, transparent system of monitoring and accountability.

Conclusions: The development of a peer support service for people living with HIV in Wales would be broadly welcomed both by people living with HIV and service providers, but it must be done with significant care and with the long-term in mind. This development will start the process of bringing Wales in line with the British HIV Association 2018 standards, that everyone living with HIV should have access to quality-assured peer support.

TABLE OF CONTENTS

Glossary of terms

Abbreviation	Description
ART	Antiretroviral therapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
CFIR	Consolidated Framework for Implementation Research
GCP	Good Clinical Practice
GP	General Practitioner
HB	Health Board
HIV	Human immunodeficiency virus
IMTP	Integrated medium term plan
NHS	National Health Service
PHW	Public Health Wales
PIS	Participant Information Sheet
PLWH	People living with HIV
PS	Peer Support
PSS	Peer Support Service
QoL	Quality of life
RE-AIM	Reach, Efficacy, Adoption, Implementation, Maintenance
SHC	Sexual Health Clinics
SMREC	School of Medicine Research Ethics Committee
SOP	Standard Operating Procedure
THT	Terrence Higgins Trust
UKHSA	United Kingdom Health Security Agency
UNAIDS	Joint United Nations Programme on HIV/AIDS

Acknowledgements

The authors would like to thank everyone who contributed to the study: all the people who took the time to tell us their views and experiences via the survey; those who generously agreed to be interviewed and also provided valuable feedback individually and during meetings; and the members of the Wales branch of the British Association of Sexual Health and HIV who welcomed us to their meeting and shared their experiences of HIV services in Wales.

We would like to recognise the supervision provided by Dr Athanasios Hassoulas and Dr Jane Nicholls for the systematic review led by Dr Carlos Alvarado and presented in Chapter 2. We are also very grateful for the contribution made to the study by Lisa Power and Gian Molinu who gave up a lot of their own time to help with the development of the project.

Throughout the report, we have endeavoured to adhere to the People First Charter, which recommends terminology for research and publications related to HIV (https://peoplefirstcharter.org/). Language matters, and we hope to have written this report in a way which matches the inclusive and respectful nature of the Centre for Trials Research and Public Health Wales. We are very aware that we are a team of four people who are not living with HIV so we may not get it right, but we are willing to learn.

We know this is only a start and that much, much more needs to be heard from people living with HIV, but we hope this work helps as a conversation opener.

The project was funded by Public Health Wales. The Centre for Trials Research receives funding from Health and Care Research Wales and Cancer Research UK.

Author information:

Dr Sue Channon (she/her)
Senior Research Fellow
Centre for Trials Research
Cardiff University
Email: ChannonS2@cardiff.ac.uk

Adam DN Williams (he/him)
PhD candidate / Trial Manager
Centre for Trials Research
Cardiff University
Email: WilliamsAD7@cardiff.ac.uk
Twitter: @AdamDaleNewman1

Dr Carlos EA Alvarado (he/him)
Student MSc Psychiatry
Cardiff University Medical School
Email: AvalosAlvaradoCE@cardiff.ac.uk

Dr David Gillespie (he/him)
Senior Research Fellow
Centre for Trials Research
Cardiff University
Email: GillespieD1@cardiff.ac.uk
Twitter: @DaveGuk87

Chapter 1

INTRODUCTION

1.1 CONTEXT

On June 15th 2022, Welsh Government launched their draft HIV Action Plan for public consultation (https://gov.wales/draft-hiv-action-plan-wales-2022-2026-html). This plan put forward actions aiming to eliminate HIV, improve quality of life, and tackle stigma associated with HIV. The plan was underpinned by three core principles:

1. That there should be zero tolerance of HIV-related stigma.
2. That plans for implementation of new initiatives and services will be informed by, or developed with, people living with HIV. Alongside this there will be a recognition of contextual differences by sexuality, ethnicity, age, gender, and location, to ensure that no one is left behind.
3. That all new initiatives and services will be subject to ongoing monitoring and evaluation to make sure they meet the actions and principles laid out in the plan.

The importance of peer support is recognised in the plan, including the acknowledgment that Wales does not currently have a dedicated peer support network for people living with HIV. As stated in the action plan, this report, and the work it describes will be used to inform the potential principles and structures of an HIV peer support service for Wales, acting as a starting point for future development and dialogue between the community of people living with HIV and service providers.

Definition

There are multiple definitions of peer support and the form it takes will vary by context, for example, one-to-one or group support, online, chat or text-based, structured, or informal etc. Common features are the description of a reciprocal relationship in which people are equal partners, and from which both (or all in a group setting) can benefit; the peers share common experiences or characteristics e.g., age, health condition, such that they can relate to each other's experience in a way that others cannot. The aims of peer support in the context of a health-related condition are to provide social support, information and promote behaviours to improve personal health, through acting as a role-model and signposting to services.

National Standards

Peer support is integral to the British HIV Association (BHIVA) standards of care (2018) which draw on the 2017 UK National Standards of Peer Support in HIV (National Voices, 2017). These standards identify the importance of support "to empower people to live well with HIV by promoting self-management strategies which allow them to make better health and life choices for themselves" (P3). Peer support is included in all the key themes covered by the

BHIVA quality standards, with measurable and auditable outcomes identified. There are four core standards in the 2017 UK National Standards of Peer support in HIV. Each standard includes a rationale, the competencies and skills needed by those providing the support, the expected outcomes and finally the auditable indicators which will demonstrate how the standards have been implemented and how quality is being maintained:

1. Everyone living with HIV should have access to peer support that is timely, easy to access and meets their needs.
2. People who provide peer support will be living with HIV and have access to training, support, and personal development.
3. Peer support will include robust monitoring, measuring and evaluation processes.
4. Children and young people living with HIV will have access to child and youth centred peer support.

This report will focus on peer support for adults living with HIV and so will include the first three standards but not the fourth standard. Whilst there are many commonalities in ethos and approach between peer support for children and for adults, there are specific requirements for peer support for young people, not least the safeguarding and consent issues, that merit particular attention which is beyond the scope of this project.

Evidence base

A recent systematic review of randomised controlled trials of peer support for adults living with HIV, which provides a high-quality summary of the best evidence so far (Berg et al 2021), concluded that adding peer support to routine medical care improves outcomes for people: The evidence indicates that peer support is associated with better retention in care, antiretroviral therapy adherence and viral suppression. These findings suggest that peer support is an effective approach for enhancing people's self-care and improving the connections between people living with HIV and the HIV services available.

Work by a Cardiff University MSc Psychiatry student, Dr Carlos Alvarado, has extended this review and is reported in chapter 2. This review incorporates a wider range of studies and focusses on stigma, mental health, and quality of life outcomes, as these were the outcomes with greatest uncertainty in the Berg et al systematic review, while at the same time being described as important benefits from engaging with a peer support service. In addition, the review maps the included interventions onto the UK National Standards for Peer Support in HIV, to understand the extent to which any of the interventions described in the published literature may be readily adaptable to a UK setting.

Peer support in the UK

Peer support is consistent with the Healthier Wales strategy (https://healthier-wales-our-plan-.pdf) which recognises the importance of supporting self-management and taking a whole system approach, including communities, to enable people to manage their own health and wellbeing. There have been previous efforts to introduce peer support for people living with HIV in Wales, via the Terrence Higgins Trust and Project 100, which between 2015 and 2019 delivered HIV peer support training across the UK, including Wales. However, for many and varied reasons, explored in chapter 4, these services have not become established across Wales, so whilst there are a few individuals providing peer support either informally or as part of a wider service brief, Wales does not currently have a national peer support programme for people living with HIV. There are several models of successful peer support services delivered in the UK which Wales can learn from and reflections from some of these service providers. Table 1 provides a summary of services identified which have publicly available guidelines, evaluations and reports related to Peer Support Services in the UK (it is not an exhaustive list of all potential services available as this varies by place and over time).

1.2 PROJECT OUTLINE

The approach taken in this project is based upon the framework of actions for complex intervention development as outlined by O'Cathain et al (2019). It is a prudent exploration of acceptability and feasibility, building on stakeholder experiences to identify the nature of a potential peer support service for people living with HIV in Wales and any barriers or facilitators of its development. Establishing a high quality, co-produced peer support service that is sustainable in the longer-term requires several stages over time, and this is the first stage in that process. Ethical approval for this project was received by Cardiff University's School of Medicine Research Ethics Committee (SMREC 22/19). Cardiff University acted as data controller and all data were stored following Cardiff University security and protocols.
The following three chapters each describe one of the components of the project and the concluding chapter brings the information from those components together:

Chapter 2 provides a summary of review work building on the systematic review of peer support for people living with HIV, focussing on stigma, mental health, and quality of life, and mapping the interventions included onto the UK standards.

Chapter 3 describes the results of a survey of people living with HIV in Wales to explore the acceptability of the idea of peer support.

Chapter 4 summarises the findings from interviews with UK providers of established peer support services, those in Wales who have previously offered this peer support and clinical service providers.

Chapter 5 is a synthesis of the results across the different groups of stakeholders and identifies potential theoretical frameworks which could be used to inform a future service development.

Table 1. Summary of Guidelines and Toolkits relating to Peer Support Services in the UK

Organisation, "Title", (Year)	Explanation of PS	Structure of service	Recommendations
IRISS and Evaluation Support Scotland, "Supporting Peer Support" (2013)	Not provided	• **Set it up:** Encourage forethought about what people want to get from the group, this can include an application process or a joining questionnaire. • **Dis-own it:** Insist the group controls 'direction of travel' from the beginning. • **Build trust and confidence**: Openly discuss issues around confidentiality and sharing, resolve as a group anything else that arises. • **Use processes that work:** Use multiple activities. Keep a consistent structure while using a variety of techniques within that structure. • **Stay regular and clear on commitment:** A regular meeting keeps the topic for support on the priority list. If you can, be clear about the lifetime of the group. • **Chill out:** Have an informal atmosphere for a good learning environment. • **Try cut out the middleman:** Set up ways and encourage the group to communicate directly with each other rather than through a facilitator.	• The knowledge is in the room: Use facilitation and minimal training. Support everyone to be confident in what they know. Use processes which get people sharing their knowledge. • Keep it concrete: Link the group to a task the group members complete. This way it's not an add on - it's a support to do something we have to do anyway. A focus on the concrete rather than the abstract helps to embed learning into day-to-day work outside the group.
Brigstowe, "Positive Voices Midway Project Evaluation" (2016)	Not provided	• **One-to-one Peer Support:** A service enabling people recently diagnosed or struggling to come to terms with their diagnosis to meet with a trained volunteer mentor who is also living with HIV. The mentor & mentee meet once a week to share experiences, give advice, set goals together, as well as to provide information based around the mentees' diagnosis. The mentoring relationship is time limited to promote independence, lasting up to 6 months. • **Recently Diagnosed Workshops:** A series of workshops to provide HIV related information to people recently diagnosed delivered by professionals and PLWH. Aim to promote wellbeing, prevent a future crisis, & provide the opportunity for participants to meet & connect with other people experiencing similar situations. • **HIV Awareness Training:** Training sessions to empower professionals with the skills and knowledge they need to work confidently with people living with, affected by, or at risk of HIV. Topics covered include HIV transmission, prevention & treatment; testing/support services; and stigma & discrimination as well as a PLWH sharing their testimony.	• Continue to consult on service design and delivery with PLWH and maintain constant dialogue on equitable inclusion. • Continue to review any barriers to accessing services, and work with PLWH to minimise these. • Improve engagement with under-represented groups, especially those with high levels of stigma. • Review peer mentor training and support maintaining boundaries & preparation for ending the mentoring relationship. Ensure there is space for mentors and mentees to reflect on challenges of mentoring. • Consider developing follow-up support for mentees who have completed the mentoring relationship. • Consider how to share learning from this project with other organisations implementing PS for people living with long term conditions.
Mind, "Developing peer support in	PS happens when people who have similar experiences of	This **toolkit outlines six core values** essential to any form of PS (group, one-to-one, online).	• Evaluation of any PS service is essential. • PS services should be integrated into or offered alongside all mental health services across England and Wales.

the community: A toolkit" (2017)	something difficult come together to support each other. People involved in PS will also have other shared characteristics, experiences, and interests.	**1. Experience in common**: Peers share similar backgrounds, experiences, or goals. **2. Two-way interactions:** Peers have opportunities to give and receive support. **3. Safety:** Have structures in place to create physical and emotional safety. **4. Human connection:** Peers develop meaningful connections with each other. **5. Choice and control:** Peers have choice and control in how they are involved. **6. Freedom to be oneself:** Peers feel able to express themselves. When developing a PSS, **key decisions** need to be made about how things will be organised: • Facilitation and coordination: Who? Why? What kind of role? • Membership type: Who is PS for? How are people included? • Leadership and decision-making: Peers making decisions? Are leadership roles paid? • Organisational support: What kind of support do we have, or want? • Focus of peer support: Do we do activities? Do we invite people to talk to us about mental health or other topics of interest?	• Evidence-based values are needed to underpin successful community-based peer support. • Despite evidence that PS is cost effective, it is not cost-free. • A range of PS options should be provided, including projects for and by marginalised communities. • All PS should offer a range of opportunities & support to give people choice about the type of support they do/don't access. • PS should be co-produced. It's vital that people with lived experience of problems lead or are fully involved in decision-making in all aspects of peer support project design and delivery.
Positively UK, Guide to Peer Support Services in HIV Clinics (2022)	PS is a relationship in which people see each other as equal partners and where the focus is on mutual learning and growth. There is a hope and a belief that through sharing and support we can transform our lives and the lives of our communities for the better.	Setting up peer support 'in-clinic', the following questions need to be considered: • **What resources are available to you?** • **Who are your champions?** • **What already exists in your Trust?** • **Does your Trust have a Volunteer Service that could support you?** • **What are your mentors going to do?** (Peer Educators, Peer Navigators, Peer Support Volunteer)	**Practical issues to consider:** • Space: are there rooms available for 1-to-1 work at varied times/days each week? • Booking system: who will organise appointments? • Access to info: what info will peers have access to? Levels of privacy. • Note taking: to what extent will peers be recording conversations, where data stored, how accessed and by who? • Training: how will peers be trained for particular roles and who will organise ongoing training? • Support and supervision: who will support peers and how/when and by whom will supervision be provided?

Chapter 2

A QUALITATIVE SYSTEMATIC REVIEW

Lead author: Carlos Eduardo Avalos Alvarado

2.1 INTRODUCTION

Over 37 million people have been diagnosed with HIV up to 2020 and 1.5 million new diagnoses were identified in that same year (UNAIDS 2021), showing that HIV remains an important public health issue. In 2014, UNAIDS established the global 90-90-90 targets, that by 2020 at least 90% of people with HIV would know their diagnosis, 90% of them would have access to treatment, and 90% of them would become viral supressed (Joint United Nations Programme on HIV/AIDS (UNAIDS) 2014). In 2020, it was estimated that 84% of people living with HIV knew their diagnosis, 73% had access to treatment, and 66% were virally supressed (UNAIDS 2021). Although not meeting the target globally, regions like the UK have exceeded those targets with 94% of diagnoses known, 98% on treatment, and 97% virally supressed (89% of all the people living with HIV in the UK) (National AIDS Trust 2021). Despite the progress made in the UK, there is still much more to be done. In 2020, in England, there were 2,780 people newly diagnosed, 670 of those were late HIV diagnoses (defined as a CD4 cell count less than 350 cells/mm^3 upon or within three-months of diagnosis) and there was an estimated mortality rate of 630 per 100,000 population living with HIV (UK Health Security Agency 2021). Moreover, the COVID-19 pandemic has restricted the access to early diagnosis and treatment services (Brown et al. 2021) leaving over 6900 people living with HIV dropping out of care services in the UK (UK Health Security Agency 2021).

HIV and Stigma

One of the most common factors with negative impact on reaching the 90-90-90 targets is stigma. Stigma is the process by which a group of individuals is labelled as socially undesirable, and these individuals are devalued due to attributes or behaviours deemed to be “deeply discrediting”. Stigma has been shown to lead to exclusion and social marginalisation, and we can see how this may lead to people living with HIV being left on the outskirts of society. Stigma has multiple forms, internalised and external stigma, social and structural (Turan et al, 2017). People living with HIV who experience stigma tend to have poorer affective and behavioural health and well-being (Earnshaw et al. 2013) as well as a detrimental impact on various health-related outcomes (Rueda et al. 2016). Stigma has shown to be also detrimental to the psychosocial wellbeing of family members (Domlyn et al. 2020). With current HIV treatment helping people achieve a near-normal life without the risk of transmitting the virus (Eisinger et al. 2019), HIV related stigma has reduced but it does continue to exist and cause damage to people's lives. In the vast majority of low- and middle-income countries, stigma prevails as a barrier to accessing early diagnosis and treatment (Rueda et al. 2016). In high-income countries, specifically in the UK, almost a third of people living with HIV reported experiencing discrimination even from health care workers (Geter et al. 2018). When intersecting living with HIV with being a member of a minority group such as a particular ethnicity or sexual orientation, those reports of stigma heighten (Hedge et al. 2021), making it more challenging to provide proper detection and treatment approaches. Initiatives such as Fast-Track Cities, a global partnership, are making efforts to get to zero new HIV infections, zero preventable deaths and zero stigma by 2030 by working with people living with HIV, healthcare workers and governmental organizations (Fast-Track Cities 2021).

HIV, Mental Health, and Quality of Life

Being diagnosed with a chronic condition can be challenging, and HIV/AIDS is no exception. Mental health problems were one of the first HIV-comorbidities identified (Brown et al. 1992). Even though the problem had an early identification, it has not been fully addressed until recent years by a global call for action and prioritizing mental health, irrespective of the cause of the mental health disorder (Patel et al. 2018). Specifically, people living with HIV are more commonly affected by depression, anxiety, post-traumatic stress disorder (Bantjes and Kagee 2018) and substance use disorder (Shadloo et al. 2018). Rates of self-reported mental health symptoms in people living with HIV are high, presenting themselves as less physically active, less engaged with social and personal activities, having problems with controlling their emotions, and feeling less satisfied with their lives (Memiah et al. 2021). Even though a HIV diagnosis is often associated with the onset of these mental health difficulties, there is a need to understand the pre-diagnosis mental health status of any patient and also, of those who seek testing, to fully understand the role of the diagnosis in the person's mental health (Bantjes and Kagee 2018). The identification and addressing of these issues are challenging since they can present themselves in various forms depending on different factors such as the age of onset (Halkitis et al. 2017; Vreeman et al. 2017) and gender (Waldron et al. 2021). Therefore, there is a gap in understanding the impact other factors such as biological, environmental, and psychological factors have in worsening HIV outcomes such as mental health (Senn et al. 2021). Once the patient's unique challenges are identified, it is important to evaluate the approach necessary to address the issue. In recent years, many non-pharmacological interventions (such as a visit to a health professional for psychological treatment or psychological counselling) have been implemented and seem to be effective in reducing HIV-related mental health issues, improving retention in care and prognosis (Rooks-Peck et al. 2018). These interventions need to be more integrated with the standard-care and shaped around the cultural nuance in every region (Nakimuli-Mpungu et al. 2021).

Mental health and quality of life are outcomes that help understand the burden of the disease and the impact factors like stigma have on recovery. Mental health has gained more attention since the COVID-19 pandemic. Higher incidence rates of mental health issues, and worsening of those already existing, has necessitated a re-evaluation of how health services approach this issue (Hossain et al. 2020). These changes also translate to patients with chronic conditions including HIV (Lesko and Bengtson 2021). People living with HIV experience high rates of mental health deterioration including suicidal behaviour (Catalan et al. 2011), making them a more vulnerable population than other chronic conditions (Niu et al. 2016). Mental health problems have been associated with poorer adherence to ART and, consequently, less likelihood of obtaining viral load suppression (Akena et al. 2012). These factors mixed with a high-stigmatization context can translate into a poor quality of life (Desai et al. 2020). When non-pharmacological approaches are added to the treatment framework, people living with HIV tend to improve their general wellbeing and have better ART outcomes (Yellin et al. 2018).

Peer support and HIV

There is a need to implement strategies that could help improve the quality of life and well-being of people living with HIV by strengthening their confidence and coping mechanisms. Peer-support (PS) comes as an alternative to other non-pharmacological approaches to achieve that objective. It has been used in many contexts irrespective of the mental health condition, with results that encourage healthcare systems to incorporate PS into today's mental health treatments' standards (Shalaby and Agyapong 2020). PS is the creation of a familiar bond between people with similar conditions. The method of delivery is diverse: it can include informal sessions where people living with HIV with the same diagnosis gather to talk about the burden the disease has on them and to create support networks; formal sessions might be part of their healthcare delivered by trained staff with the same diagnosis, with basically the same purpose but including more education and creation of a healthcare-related support network. Further research is needed to compare different PS approaches against standard care and between each other (Mahlke et al. 2014).

In HIV, the aim is to establish a safer and enriching environment for people living with HIV. PS has been shown to improve quality of life for people living with HIV across a range of diverse outcomes (Van Tam et al. 2012). One of those outcomes includes the capacity to decrease the severity of internalized stigma and the burden it comes with (Kellett and Gnauck 2016). It has shown promising results in improving coping mechanisms to better manage stigma (Kamen et al. 2016) and adherence to treatment when compared to regular clinical follow-ups (Berg et al. 2021). Understanding the impact peer-support has on stigma, mental health, and quality of life could help to shape a well-structured complementary programme.

In the UK, the National Service Framework in 1999 increased the emphasis on ensuring a person-centred service with access to high-quality health services and to local support-programmes (NICE 1999). These standards opened the door to incorporating peer-support as an important asset towards recovery and improving the quality of life of people living with different conditions. Now, the NICE guidelines include peer-support as part of the treatment options for several mental health conditions and, most importantly, legal frameworks have been applied to ensure the correct implementation of patient-centre strategies. Legislation like the Care Act (Department of Health & Social Care. 2016) and others alike in England (Department of Health & Social Care. 2011), Ireland (Government of Ireland. 2020), Scotland (Scottish Government. 2017), and Wales (Welsh Government. 2012), promote the implementation of peer led programmes to support patients with various conditions including mental health aiming towards a common goal: improving the patient's quality of life. Nevertheless, when searching for papers reporting the experiences and results from independent and governmental programmes implemented in the UK, no study was found delivering this information. Moreover, no information was found regarding the adaptability of peer-support programmes to the UK.

Rationale

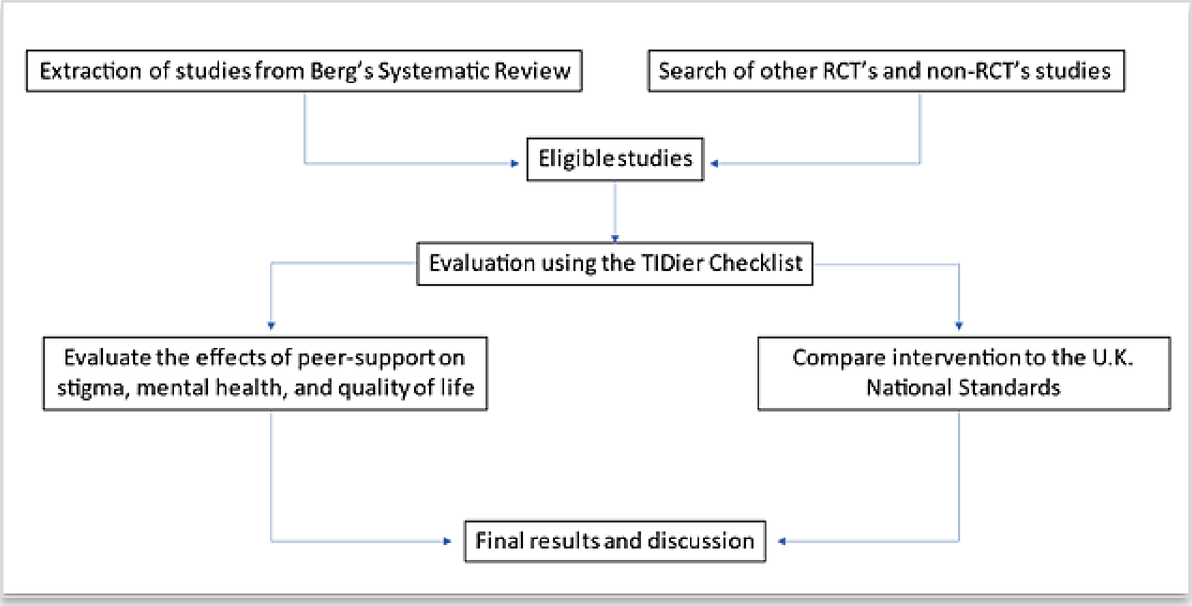
As outlined, stigma is strongly linked to mental health and quality of life. These three variables seem to be co-dependent of each other and addressing them together with one single intervention could be highly beneficial for people living with HIV. Peer-support has shown promising results improving all these three variables and seems feasible to implement in HIV-standard care. Nevertheless, most of the interventions that explore any of these variables do it separately and have not evaluated the effect over the three variables in one assessment. A systematic review and meta-analysis of randomised controlled trials (RCTs) evaluating the effectiveness of peer support for people living with HIV was published by Berg and colleagues in 2021. It included 20 RCTs comprising 7,605 participants from nine different countries (no RCTs were conducted in the UK). The most common point at which peer support was delivered was when individuals were newly diagnosed and/or were treatment naïve, however, some trials were intervening at other points (e.g., targeting individuals who inject drugs, people on ART, people who were on ART but known to be not adhering to treatment). The studies demonstrated benefits of peer support for retention in care after 12-months of follow-up, antiretroviral therapy (ART) adherence at three-months of follow-up, and viral suppression at six-months of follow-up. Other key outcomes from RCTs included in this review (ART initiation, CD4 cell count, quality of life, mental health) contained too much uncertainty to draw firm conclusions regarding effectiveness.

The objective of this review is to assess available global evidence on the impact peer-support has on mental health, stigma, and quality of life of adults living with HIV and evaluate how those results can be translated to the U.K.'s context. An assessment of Berg's systematic review will serve as a starting point to evaluate current evidence and use ADAPT Guidance (Moore et al. 2021) to extrapolate the information in considering how it could be implemented in the UK context.

2.2 METHODS

This review is divided into three stages. The first consists of analysing each of the RCTs included in Berg's systematic review and determining which RCTs met the inclusion criteria that will be described in the eligibility criteria section. The second stage consists of conducting a detailed search on the subject to widen the results, including more RCTs and adding non-RCTs studies. The third stage consists of analysing all the studies that met the inclusion criteria and run them through the TIDieR checklist to analyse how the results can then be applicable to the UK's setting by comparing them to the UK National Standards. Details of each process will be included in each of the upcoming sections. The qualitative systematic review section was conducted using the Cochrane Handbook for Systematic Reviews (Higgins et. al. 2019) and the PRISMA checklist (Moher et al. 2009) for evaluation. A diagram depicting the process of this review is presented in Figure 1.

Figure 1. Review process



Eligibility criteria

Study designs considered as eligible were randomised control trials (RCTs) and non-RCTs. Participants included in each study should be 18 years old and above with a diagnosis of HIV, irrespective of the stage.

Interventions had to be based on any of the forms of peer-support programmes. Peers had to be individuals with proper training prior the beginning of the study. Specifically, training had to be imparted by specialists and peers should have completed the number of hours proposed by the authors. Therefore, details on the training period in RCTs must be presented in the publication. If not, providers must be listed as "trained" when mentioned. Those papers that did not include that characteristic were excluded.

All the outcomes included should be explicitly measured in each paper. Primary outcomes for this review include stigma, mental health, and quality of life. The results of these outcomes must be based on quantitative measurements, excluding those who present qualitative data such as interviews, and opinions.

Sociodemographic factors were not considered as excluding factors. Studies published in English and Spanish were included due to the latter being the author's native language. Every publication considered was a full-text publication available online. Preliminary reports and briefs were also considered if they met the other eligibility criteria.

Search strategy

Searches were conducted in the following electronic database: MEDLINE (OVID), PUBMED, and PsycINFO (OVID). The used keywords and how they were used are listed in the Appendix. Moreover, articles were also obtained from other sources of information such as Google Scholar and Scopus. Searches were completed in December 2021.

Selected studies

Adding to the database search results, papers from Berg's systematic review that met the inclusion criteria were also included. All the studies that met the inclusion criteria were saved as PDF documents and had their citation imported into EndNote X9. The screening process for inclusion was conducted by the author.

Risk of bias

RCTs evaluation of bias was conducted using the second version of the Cochrane risk-of-bias tool for randomized trials (RoB 2) (Sterne et al. 2019). Non-RCTs evaluation was conducted using the Risk of Bias in Non-randomized studies – of Interventions (ROBINS-I tool) (Sterne et al. 2016).

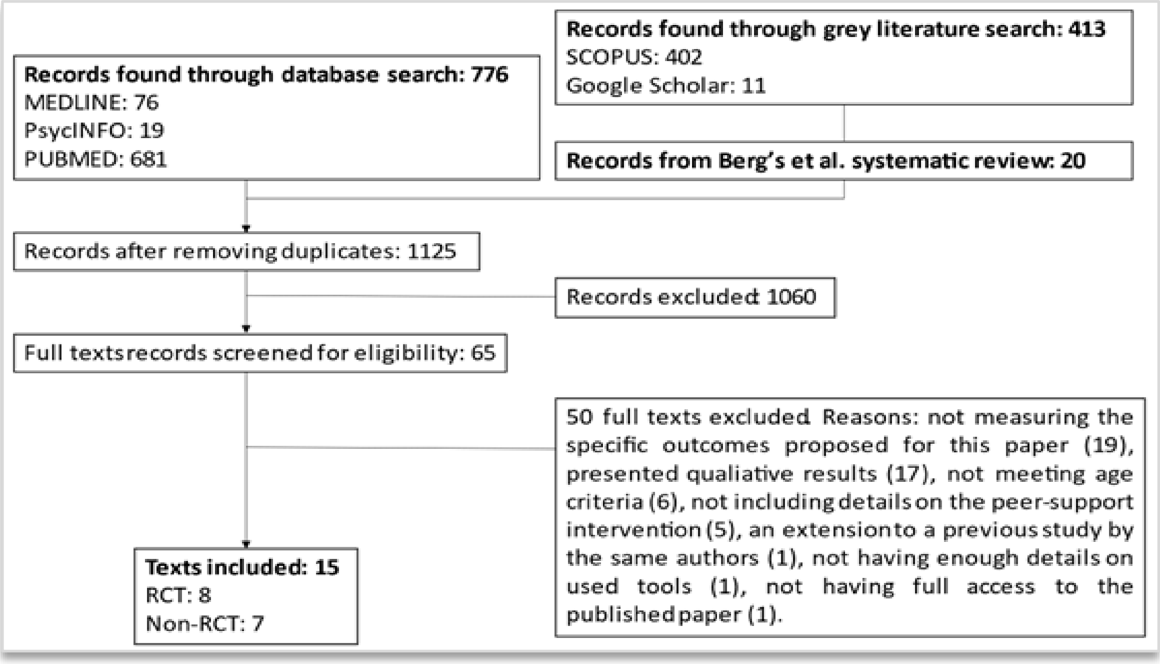
Data analysis

PS interventions evaluated in RCTs and non-RCTs were characterised using the TIDieR checklist (Hoffmann et al. 2014). This checklist was used due to its capacity to evaluate the completeness of interventions' reporting so that they can be replicated in other studies or scenarios. It consists of 12 items that explore as many details of the intervention as possible to evaluate it from a publisher and reader perspective. These interventions were grouped by themes and, subsequently, each intervention was mapped onto the UK National Standards for Peer Support in HIV (Positively UK 2017). The decision to use this document is because it has the aim to ensure consistency throughout every health-care system in the UK so that it can provide a better quality of life to people living with HIV. This guidance includes four items as standard including access to peer support, trained people who provide peer support, monitoring/measuring/evaluating, and child and youth centred peer support (NB. this review focusses on peer support for adults and hence we have not appraised the interventions against this latter standard). Every mental health, stigma, and quality of life outcomes were evaluated and reported. These results are the basis for conducting this narrative synthesis.

2.3 RESULTS

Figure 2 presents the PRISMA flow diagram of literature review process. Of 1125 records, 65 full texts were screened and 15 were included considering RCTs (8) and non-RCTs (7). A total of 49 studies were excluded. Most of these studies included peer-support as an intervention for people living with HIV but did not measure the outcomes proposed for this review (19). Other reasons for exclusion were presenting qualitative results (17), not meeting the age criteria (6), not including details on the peer-support intervention (5), one was excluded since it was an extension to a previous work conducted by the same authors (1), not having enough details on used tools (1), and another one was excluded since no full access to the published paper was obtained (1).

Figure 2. PRISMA Flow Diagram.



Studies included

A summary of all the RCTs is listed in Table 2. Eight studies were included with 5 of them being obtained from Berg's systematic review (listed as the first five). A total of 3003 participants were included across the eight studies. The other three studies included in that systematic review were excluded because they evaluated variables that were not the focus in this review. A total of seven non-RCTs are listed in Table 3. A population of 2412 participants resulted from all the seven interventions.

Table 2. A summary of the RCTs included.

Study	Population (3003)	Intervention	Control Group	Outcomes
Brashers et al (USA) (2016)	Confirmed diagnosis of HIV infection, lacked a history of HIV-associated dementia, and were English literate. Total: 98	"Living with HIV/AIDS: Taking control": Face to face individualized educational session with the aim to reduce uncertainty and give PLWH the skills to manage it. Six weekly sessions.	Standard care, including educational efforts afforded to them as part of the usual treatment	1. Illness uncertainty 2. Social support 3. Depressive symptoms 4. Self-advocacy
Cabral et al (USA) (2018)	PLWH, 18 years of age or older, identified as belonging certain ethnicities, and had certain risk factors. Total: 348	Based on the social support framework that peers, as PLWH, could provide a unique supportive role. There were 7 one-on-one educational sessions for 60 minutes every 1-3 weeks up to 6 months.	Standard care in accordance with the standard procedures of the clinic site.	1. Time to 4-month ap in care 2. Viral suppression 3. Health-Related Quality of life
Giordano et al (USA) (2016)	PLWH at least 18 years old, able to speak English or Spanish. Total: 460	Adapted intervention from a programmatic intervention for outpatients newly entering care at Tomas Street Health Center. Two in-person session in the hospital, each lasting between 20-45 minutes, followed by 5 telephone calls after discharge over 10 weeks.	Based on Project Respect. It consisted of educational sessions regarding safer sex education and drug use.	1. Retention in care. 2. Biological adherence markers 3. Health-related quality of life measures.
Ruiz et al (Spain) (2009)	Adult (18 years and above) PLWH on ART and attending scheduled appointments for disease monitoring disease units. Total: 240	One-on-one educational session was conducted by trained peers discussing treatment, strategies to achieve adherence, and managing risk behaviors. After that, follow-up visits were conducted in 4 different times over 6 months.	Same procedure as the intervention group but it was conducted by a health professional.	1. ART adherence 2. Viral load 3. Psychological distress
Rotheram-Borus et al (South Africa) (2014)	Pregnant women diagnosed with HIV. Total: 1200	Eight sessions divided into 4 pre-natal and 4 post-natal, post-birth assessment, 6-month assessment, and 12-month assessment. Each meeting with peer mentors covered different topics about the disease and how it affects different aspects of their lives.	Standard clinical care.	1. Risk Behaviors. 2. Infant health. 3. Healthcare. 4. Depression. 5. Social support.
Van Tam et al (Vietnam) (2012)	PLWH at least 18 years old who were ARV-naive. Total: 228	Educational sessions were conducted based on a checklist prepared by the authors. Peer visits twice a week for two months and then once a week until completing 12 months.	Standard care including adherence counselling and readiness training provided by the medical staff.	1. Quality of life 2. Stigma
Webel et al (USA) (2010)	Adult females living with HIV. Total: 89	Based on the Positive Self-Management Program (PSMP) for the content of the sessions	Participants received a copy of *HIV Symptom Management Strategies: A*	1. Symptom intensity.

		conducted by trained peer-leaders. In total there were seven sessions over seven weeks.	*manual for people living with HIV/AIDS.*	2. Medication adherence. 3. Quality of life
Wouters et al (South Africa) (2014)	Adult PLWH on ART. Total: 340	Two visits per week by trained peer-supporters. It is based on family dynamics and there was a total of 36 sessions over a period of 18 months.	Standard care.	1. CD4 count. 2. Mental health

Table 3. A summary of non-RCTs included.

Study	Population (2412)	Variables of study	Results/Conclusions
Asrat et. al. (Ethiopia) (2021)	PLWH currently on ART. Total: 29	The effects of a group-administered peer-intervention in depressive symptoms.	Peer-group-intervention is feasible to reduce depressive symptoms, improve coping mechanisms against stigma and improve the quality of life of PLWH.
Aung et. al. (Myanmar) (2021)	PLWH. Total: 1006	Impact of peer-counseling against standard counseling in HIV knowledge, stigma, antiretroviral adherence, barriers to care, social support satisfaction and attitudes regarding both counseling processes.	Peer-counseling shows promising results over standard counseling in improving HIV-related health outcomes like lowering stigma.
Chime et. al. (Nigeria) (2019)	PLWH attending antiretroviral clinics. Total: 840	The effect of peer support in self-stigma.	Peer-support may not be sufficient to combat self-stigma.
Kemp et. al. (South Africa) (2016)	Men living with HIV. Total: 66	The effect of peer-support in HIV knowledge and attitudes, stigma, disclosure, adherence, and linkage to care.	Peer-support helps improve wellbeing by educating those involved and improving their confidence to deal with stigma and re-engage with their communities.
Lifson et. al. (Ethiopia) (2015)	Adults newly enrolled in HIV care. Total: 142	The impact of Community Health Support Workers in knowledge of the disease, quality of life, perceived social support, and stigma.	Peer-support program has shown to be helpful in improving PLWH's health. For instance, after 12 months, there were significant improvements in all the variables studied.
Masquillier et. al. (South Africa) (2015)	PLWH on ART. Total: 294	The influence of peer-support and treatment buddying in stigma.	Treatment buddying seems to decrease felt stigma better than Peer-support.
Molassiotis et. al. (Hong Kong) (2002)	Symptomatic PLWH. Total: 35	The differences between cognitive-behavioral therapy and peer-intervention when assessing mood and quality of life.	Both interventions helped improved mood and quality of life. CBT group was the one with the best results.

Study methodology and Risk of Bias

RCTs

The Risk of Bias Evaluation of the RCTs was carried out using the Cochrane risk-of-bias tool for randomized trials (RoB 2) as shown in table 4. Two of the studies had a high risk of bias due to lack of information in two or more domains and one of them because it did not report the missing outcome data nor presented details in whether the results were biased or not. One study was considered of uncertain risk since it did not report the management of missing data but had other information that indicated that results were not biased by this data. The other five RCTS scored a low risk of bias. The study carried out by Giordano et. al. had details of the methodology section in a supplementary file.

Table 4. Risk of bias summary for RCT studies using RoB 2 tool.

Domain	Brashers 2016	Cabral 2018	Giordano 2016	Ruiz 2009	Rotheram-Borus 2014	Van Tam 2012	Webel 2010	Wouters 2014
Randomization process	+	+	+	+	+	+	+	+
Deviations from intended interventions	+	?	+	+	+	+	?	+
Missing outcome data	+	?	+	+	+	?	-	+
Measurement of the outcome	+	+	+	+	+	+	+	+
Selection of the reported result	+	+	+	+	+	+	?	+
Overall risk of bias	+	-	+	+	+	?	-	+

NB. Red (-): High risk of bias, **Yellow (?):** Uncertain risk, **Green (+):** Low risk of bias

Non-RCTs

This evaluation was conducted using the Risk of Bias in Non-randomized studies – of Interventions (ROBINS-I tool) as shown in table 5. Only one of the studies got a low risk of bias. Two of them resulted in a severe risk of bias presenting moderate risk in two domains including confounding and measurement of outcomes as well as a severe risk in the selection of participants. Both studies shared similar characteristics where confounding was expected, and the measurement of important variables were sufficient so that considerable residual confounding was not expected. When evaluating the selection into the study, both studies were very strongly related to the intervention and outcomes and could not be adjusted in analysis falling into a severe risk. The other four studies had moderate risk where different domains had the same denomination due to minimal influences that did not alter the result. One common characteristic throughout almost all the studies was that there was no information regarding deviation from the intended intervention and the statistics and management of missing data.

Table 5. The risk of bias assessment for non-RCT studies using ROBINS-I tool.

Domain	Asrat 2021	Aung 2021	Chime 2019	Kemp 2016	Lifson 2015	Masquillier 2015	Molassiotis 2002
Confounding	LOW	MODERATE	MODERATE	MODERATE	LOW	LOW	LOW
Selection of participants	LOW	SEVERE	MODERATE	SEVERE	MODERATE	MODERATE	MODERATE
Classification of interventions	LOW	LOW	LOW	LOW	LOW	LOW	LOW
Deviation from intended interventions	LOW	?	?	?	?	?	?
Missing data	LOW	?	?	?	?	LOW	?
Measurement of outcomes	LOW	MODERATE	LOW	MODERATE	LOW	LOW	LOW
Selection of the reported result	LOW	LOW	LOW	LOW	LOW	LOW	LOW
Overall risk of bias	LOW	SEVERE	MODERATE	SEVERE	MODERATE	MODERATE	MODERATE

NB. Orange: Severe risk of bias, **Yellow:** Moderate risk, **Green:** Low risk of bias, **Gray:** No information

Study location and settings

RCTs

Most studies were conducted in the USA (4). The others were based in South Africa (1), Spain (1), and Vietnam (1). Two of the 7 RCTs were conducted in one clinic where participants were recruited from those facilities and the interventions were carried out in their facilities as well. The other five varied from three to 12 HIV-specialized clinics; one of them even recruited participants from different settings outside the clinics including housing and support groups.

Non-RCTs

Five studies were conducted in the African continent and three of them in the south of the Asian continent. All those on the African continent were set in Sub-Saharan countries including Ethiopia, Nigeria, and South Africa. This region has the characteristic of still presenting high rates of prevalence, low rate of retention with as low as 18% of people living with HIV with continuous care, and high rates of stigma up to 66%. The Asian countries included Indonesia, China, and Myanmar the latter being the country with one of the highest prevalence rates among all Asian countries. This region also presents high HIV prevalence and low rates of continuous treatment. All the interventions were conducted in healthcare facilities including hospitals and clinics. Only one of them ran sessions on a community basis, meaning that the participants was able to choose where he/she could meet with the peer-supporter. The regions where the studies took place were low- to mid-income areas, mostly catalogued as rural.

Participants

RCTs

All the interventions included adults, 18 years and older, living with HIV. A total of 2663 participants were part of the 8 studies. Participants enrolled voluntarily after receiving complete information about the studies. Most of the RCTs specified in the inclusion criteria that participants should be newly diagnosed with HIV or were recently initiating ART. The other studies just defined the participants as those who have an HIV diagnosis. The definition of newly diagnosed consisted of receiving an HIV-positive test result as part of the study's screening or before the enrolment process but not yet receiving any kind of medical care. One study only included newly HIV-diagnosed participants identified as part of a particular minority ethnic group (Cabral et al. 2018). The study from Vietnam explicitly indicated that they were considering participants from rural and urban settings while the other studies included only patients from urban setting due to the clinics' locations (Van Tam et al. 2012). Two studies included only female participants, and one of them focused just on pregnant women (Webel 2010; Rotheram-Borus et al. 2014).

Non-RCTS

Like the RCTS, all participants were adults living with HIV. The inclusion criteria were not specified in detail in most of the studies. Nevertheless, they did include those who were receiving ART in the healthcare facility where the interventions were being carried out or who were newly diagnosed in the same setting. Taking into consideration the seven studies, a total of 2412 participants were part of the interventions (ranging from 29 up to 1006). As mentioned before, the interventions were all based in low- to middle-income regions.

Interventions

RCTs

All the interventions focused on giving informational support using instruments such as brochures and face-to-face sessions conducted by peer-supporters. The purpose of the informational support was to teach about HIV, how ART works, and the challenges this diagnosis could bring to their personal lives. Other interventions also included instrumental

(Brashers et al. 2017; Cabral et al. 2018) and emotional support (Van Tam et al. 2012; Giordano et al. 2016; Cabral et al. 2018). Some authors also included techniques such as role-playing (Brashers et al. 2017) and goal settings with action plans (Giordano et al. 2016) as part of the intervention.

Instrumental support consisted of helping participants find useful resources either to find more information on websites or specialized groups, or to learn how to seek help when needed, including help in support groups or medical attention. Emotional support consisted of peer-support to talk about personal issues and those meetings were held in the participants preferred setting. Sessions ranged from 1 to 16 and were administered mostly in hospital settings or as visits to homes (Van Tam et al. 2012).

The duration of each session was not specified in all the interventions. The studies that included that information gave an average of 64.37 minutes of sessions' duration (30 minutes to 120 minutes) (Ruiz et al. 2010; Webel 2010; Giordano et al. 2016; Cabral et al. 2018). Added to the sessions, some authors used follow-ups in the form of phone calls (Giordano et al. 2016; Cabral et al. 2018) or home/preferred location by patient visits (Ruiz et al. 2010; Van Tam et al. 2012; Cabral et al. 2018). These follow-ups were provided up to 18 months after finishing with the sessions.

Non-RCTS

The content of the interventions was very similar to the RCTS. Sessions were focused on teaching people about the disease, what to expect from treatment, changes that it could make to their lives including their families and friends and using role-playing as well. Interventions were not as detailed as in the RCTs. All of them used group counselling as the main approach. Number of sessions ranged from 1 to 8 sessions. Most of them were weekly-based sessions and measurement were carried up to 3 years after initiation and follow-ups up to 12 months (Molassiotis et al. 2002; Lifson et al. 2015).

Six of the studies used standard therapy as the control group and only one of the studies compared peer-support intervention to Cognitive-Behavioural Therapy (CBT) (Molassiotis et al. 2002). All the interventions used peer-interventions in the form of face-to-face sessions. Only two of them specified the type of therapy given including interpersonal therapy (Asrat et al. 2021) and focus groups (Chime et al. 2019). The others just described their intervention as peer-support.

Peer-supporters

RCTs

Trained peer-supporters were leading the interventions and they were people living with HIV who are currently on ART with good therapeutic adherence. They were required to be at least 12 months in ART with good adherence irrespective of the amount of time they were diagnosed with HIV. Supporters were selected from the health-care facilities and those who met the criteria to participate in the training were invited. Those who accepted received training and were evaluated either by the authors or external trainers to ensure that they successfully finished the training sessions and could act as peer supporters.

Two out of seven studies did not give specific details on the peer-supporters experience on the subject or how they were trained to conduct the sessions (Van Tam et al. 2012; Brashers et al. 2017). The other 5 studies indicated that training was given from 4.5 days up to six weeks and was conducted by trained peer-supporters or specialized trainers. One of the studies had one of their authors as the person in charge of training peer-supporters (Ruiz et al. 2010). The training sessions included workshops, role-playing, and real-life interactions. The focused themes of training were cognitive, behavioural, emotional, and communicational aspects. Peer-supporters were also trained to document sessions and to give support when need in- or out of sessions.

> Non-RCT
>
> Peer supporters were people living with HIV with a good record of attendance to ART sessions. Only two papers specified the number of facilitators used (8 (Chime et al. 2019) and 12 (Asrat et al. 2021). All papers named their facilitators as 'trained' but only one of them specified how the training was carried out (Asrat et al. 2021). The 12 chosen candidates in Asrat's paper received intensive group interpersonal therapy guided by the WHO manual. This training included helping them improve their organization of ideas and how to translate them into practice mainly by using role play. All of them were assessed at the end of the training to verify that they were ready to start providing the intervention. Training days were specified only in two papers and were of 5 (Kemp et al. 2016) or 7 days (Asrat et al. 2021). There were no further details on the type of training and how they were carried out.

Measurements and outcomes.

RCTs

All the papers included at least one of the outcomes proposed in this review. Four papers studied mental health (Ruiz et al. 2010; Rotheram-Borus et al. 2014; Giordano et al. 2016; Brashers et al. 2017), five papers studied quality of life (Ruiz et al. 2010; Webel 2010; Van Tam et al. 2012; Giordano et al. 2016; Cabral et al. 2018), and one paper studied stigma (Van Tam et al. 2012). Other outcomes measured included social support, uncertainty, biological instruments and adherence to treatment, alcohol and substance abuse, family functioning, risk behaviours, infant health status and bonding, and symptom intensity.

The tools used to measure mental health included: The Center for Epidemiologic Studies-Depression (CES-D) which evaluates depressive symptoms in the past week such as restless sleep, poor appetite, and feeling lonely (Brashers et al. 2017); the Patient Health Questionnaire Depression scale (PHQ-8) that measures depressive disorders in clinical settings (Giordano et al. 2016); and the 12-Item General Health Questionnaire (GHQ-12) evaluates psychological distress (Ruiz et al. 2010; Rotheram-Borus et al. 2014). All studies reported that those receiving peer-support interventions had decreased depressive symptoms and psychological stress over time when compared to the control groups.

The tools used to measure quality of life included: The SF-8, a shorter version of the 36-item health questionnaire and measures the quality of life based on physical and mental health parameters (Cabral et al. 2018); the SF-36 Health Survey which is the more detailed version of the before-mentioned tool measuring the same parameters (Giordano et al. 2016); the Medical Outcomes Study HIV Health Survey (MOS-HIV) that measures the quality of life by considering physical and mental health in people living with HIV and was specifically created to target this population in clinical trials (Ruiz et al. 2010); the World Health Organization's Quality of Life Instrument in HIV Infection (WHOQOL-HIV-BREF) that is targeted to people living with HIV and measures their quality of life through the evaluation of their physical and mental health, social relationships and the environment (Van Tam et al. 2012); and the HIV/AIDS-targeted quality of life (HAT-QoL) which is a five-dimensional tool measuring quality of life (Webel 2010). Four out of five studies reported that there were no significant differences between the intervention and control groups. One of them reported that there was a significant improvement over time in quality of life of patients who receive the peer-intervention, especially those who were stage 3 or 4, when compared to the control group (Van Tam et al. 2012).

The tool used to measure stigma was the Internal AIDS-Related Stigma Questionnaire, a 6-item psychometric scale that measures negative perceptions and degrading thoughts of HIV patients (Webel 2010; Van Tam et al. 2012). The study presented by Webel et. al. found that stigma was negatively related to quality of life. Therefore, peer-interventions helped improve the quality of life of people living with HIV and decreased stigma over time as a result. On the contrary, the study of Van Tam et. al. showed that there was no significance difference between the peer-support group and the control group when measuring AIDS-related self-stigma.

Non-RCT

In contrast to the RCTS, stigma was the most measured outcome in the non-RCTS papers being presented in five of them (Lifson et al. 2015; Masquillier et al. 2015; Kemp et al. 2016; Chime et al. 2019; Aung et al. 2021). Only three of the papers studied quality of life (Molassiotis et al. 2002; Lifson et al. 2015; Asrat et al. 2021) and just one studied mental health (Asrat et al. 2021).

The tools used to measure stigma included:

- India Stigma Index, tool adapted by the authors to measure enacted and internalized stigma of people living with HIV and specifically in the Indian population (Aung et al. 2021);
- AIDS-Related Stigma which was also adapted by the authors from a similar study conducted in 2017 in South Africa and measured stigma from low to high (Chime et al. 2019);
- Stigma Scale for Chronic Illness evaluates the enacted and internalised stigma of people with chronic diseases and, even though it was first applied to neurological diseases, has been extended to any condition that can be categorized as chronic (Kemp et al. 2016);
- HIV Stigma Scale which has 40 items measuring stigma in patients with HIV including personalized stigma, concerns when disclosure, self-image and the community's attitude towards people living with HIV (Lifson et al. 2015);
- Berger's HIV Stigma Scale presented by Wright in 2007 (Wright et al. 2007) that included a shortened 10-item scale to measure stigma in youth living with HIV (Masquillier et al. 2015).

Four of the studies obtained a statistical significance in decreasing both enacted and internalized stigma with a p ranging from <0.042 to <0.001 (−0.24, CI [−0.34, −0.14]) with up 97% of reduction from baseline. The study from Chime et. al. found that there was no significant difference between stigma measured in the support and non-support group (p=0.709) with an X^2 of 0.140.

The tools used to measure quality of life included: the WHOQOL-HIV-BREF as described above that evaluates the physical and mental health, social relationships, and the environment of people living with HIV. In these studies, it was translated to Ethiopian (Asrat et al. 2021), Chinese (Molassiotis et al. 2002), or left with the original language (Lifson et al. 2015).

Two studies showed that there was a significant improvement in quality of life both having a statistical significance of p<0.001. On the other hand, the study presented by Molassiotis et. al. showed that there was an improvement of 5% but did not reach statistical significance with small effect sizes (0.11 and 0.07) (p was not listed in a numerical figure).

The tool used to measure mental health was the PHW-9 which is similar to the tool mentioned before in the RCTs but with one additional item. It is also used to measure the severity of depression, and monitors changes under treatment (Asrat et al. 2021). The study showed that there was a significant reduction in depressive symptoms (p<0.001).

Meeting the UK National Standards

The information provided by the authors in their publications served as the base to analyse whether the interventions could be applied to the UK setting. Four categories are prioritized in the standards. Since this review is taking into consideration only adults, the fourth category "Child-Youth Centred Peer-Support" was not considered in the evaluation. Both RCTs (table 6) and non-RCTS (table 7) papers were evaluated under the remaining three categories of the UK National Standards.

For the first category "Access to Peer-Support", all the interventions gave access to every person living with HIV who was willing to participate. No major restrictions were made in any of the exclusion criteria. The interventions were provided in a well-timed period of the diagnosis and were easily accessible for every participant.

For the second category "Trained people who provide Peer-Support" there were mixed results. All of them stated that peer-supporters were trained individuals but some of them did not specify how the training was performed. Two out of the eight RCTs and three out of the seven non-RCTs papers did not include those details.

The third category "Monitoring, measuring and evaluation processes" had mostly negative results since only four papers (one RCT and three non-RCTS) provided details on the monitoring system they used. These details included recording of the sessions and post-session external evaluation of each session plus records of the follow-ups. The majority of RCTs had not enough details on the matter by only stating that sessions were supervised with no further details, while the other non-RCTs papers did not included any information at all.

Table 6. RCTS and the UK National Standards.

Study	**National Standards**		
	Access to Peer-Support	**Trained people who provide Peer-Support**	**Monitoring, measuring & evaluation processes**
Brashers et al	+	?	?
Cabral et al	+	+	?
Giordano et al	+	+	?
Ruiz et al	+	+	?
Rotheram-Borus et al	+	+	+
Van Tam et al	+	?	?
Webel et al	+	+	?
Wouters et al	+	+	?

NB. (+): Detailed information, (?): No detailed information, (-): No information.

Table 7. Non-RCTS and the UK National Standards

Study	**National Standards**		
	Access to Peer-Support	**Trained people who provide Peer-Support**	**Monitoring, measuring & evaluation processes**
Asrat et al	+	+	?
Aung et al	+	?	-
Chime et al	+	?	-
Kemp et al	+	+	?
Lifson et al	+	+	?
Masquillier et al	+	?	-
Molassiotis et al	+	+	-

NB. (+): Detailed information, (?): No detailed information, (-): No information.

2.4 DISCUSSION

HIV is still a prevalent chronic condition that carries a heavy burden to those diagnosed (Pandey and Galvani 2019). Advances in treatment have helped improve the prognosis of HIV and has enabled those living with HIV to live a full life. However, stigma is still highly prevalent even in high-income countries where healthcare coverage is wider and more accessible to people living with HIV (Vermund and Leigh-Brown 2012; Herron et al. 2022). Stigma has been linked to depression and, therefore, poorer quality of life (QoL) (Luseno et al. 2021). These three outcomes are closely inter-related and addressing one could impact on the others (Charles et al. 2012). Evidence has showed promising results for non-pharmacological approaches such as peer support (PS) when combined with ART when considering those three outcomes (Rao et al. 2012). The results presented on this review support this statement. Even though mixed results were found on the improvement on QoL, some limitations in those studies with negative results were found that can explain the need for more studies. On the other hand, strong evidence was found regarding how effective PS is when improving mental health by decreasing depressing symptoms and anxiety, as well as improving stigma by decreasing the negative effect it has on people living with HIV. There is sufficient data to improve implementation of PS in the UK by using the National Standards.

Peer support and stigma

Stigma related to HIV is still prevalent and is recognized as a critical barrier to improve the QoL for people living with HIV (Greenwood et al. 2022). It is considered as one of the most important actors that delays a proper diagnosis, does not allow for a timely seeking or continuance of treatment and, therefore, end up negatively affecting the prognosis and wellbeing of people living with HIV (Logie and Gadalla 2009). Going through different databases, stigma was the least studied outcome in RCTs out of the three outcomes presented in this review. On the other hand, in the non-RCT studies included, stigma was one of the most commonly measured outcomes. This difference could rely on the fact that stigma is still a difficult variable to measure (Van Brakel 2006; Earnshaw and Chaudoir 2009) and most of the tools used to accomplish that had to be modified to be applicable to the target population in each study.

PS has been shown using both quantitative and qualitative data to decrease the rate of perceived and self-stigma. The importance of educating people living with HIV about the condition, how their environment may react after the diagnosis, how to cope with negative circumstances that might present in the future and showing them that they have a support system of people with the same condition are the most important characteristics that participants highlight as benefits of PS (Mburu et al. 2013; Namuleme 2015; Paudel and Baral 2015). When comparing those receiving PS to those in the control groups (who mostly receiving no intervention at all), the participants receiving PS showed a progressive improvement on how they perceived stigma, stating that they felt less ashamed of their condition and got less affected by how the community perceived their condition by giving them 'hope' (Harris and Larsen 2007). These results were also reflected in the quantitative data with significance difference between groups. Better results were shown as time progressed and were maintained even after the intervention had finished as shown in the follow-up results of the studies included and those positive results could be extended to the family members of people living with HIV (Ma et al. 2019).

In contrast, there were two studies included that had different results. The study presented by Chime et. al., showed that there was no statistical difference in self-stigma between PS group participants and the control group that did not receive any intervention (Chime et al. 2019). The population chosen for the PS group was a population that was already part of a PS healthcare facility. In this study stigma was evaluated qualitatively, there is no information on how long they have been participating in the interventions, the level of self-stigma they had before starting their participation and no detail on how the sessions were conducted. Many of the comments had a strong religious element that could have had an impact on the result (Vigliotti et al. 2020). Other comments described that being well-informed about HIV thanks to the PS groups helped them manage stigma, hence the mixed conclusions for the qualitative measurement. The study carried by Van Tam et. al. showed that there was no difference in stigma between the peer-support and the control group since the mean scores of both were very similar (Van Tam et al. 2012). Nevertheless, the authors also pointed out that among those participants whose quality of life changed over time, there was a statistically significant association with stigma but did not have a strong correlation coefficient. One limitation that could have influenced the result was the high withdrawal rate that could have impacted on the statistical power and effect size, despite the randomization between groups.

A qualitative study conducted Uganda in 2016 compared PS with economic empowerment while receiving ART (Kellett and Gnauck 2016). Both interventions helped reduce stigma, but the authors reported that economic empowerment had a greater impact in the target population. This is important to point out since PS is not the only community-based intervention that can be used in addressing stigma in people living with HIV. Hence, there is an increasing need for implementing more studies to compare, evaluate and determine the effectiveness of PS in different contexts, consider comparisons to a range of interventions or perhaps by combining it with some other community-based intervention.

Some differences have been found on how certain sociodemographic characteristics such as gender could affect the effectiveness of PS (Maragh-Bass et al. 2021) when addressing stigma but more studies are needed to explore this in more detail. Stigma is highly sensitive to the context where someone is spending their day-to-day activities and how they are perceived by the community. Education, employment, economic resources, religion, community-based beliefs, healthcare access are some factors that play an important part on modulating how stigma can influence the person's life (Armoon et al. 2021). Therefore, results for PS may vary from region to region and population depending on how well implemented the intervention is for the specific target population. This emphasises the importance of considering what can be modified, maintained, or added from other's experiences of PS programmes and help shape them specifically, in this case, for the UK.

Peer support and mental health

Adjusting to a new diagnosis of a chronic condition, accepting it, and taking the decision to start treatment can be difficult. people living with HIV have higher odds for developing or worsening mental health issues, most frequently depressive symptoms, and anxiety (Hoare et al. 2021). This negative impact has been amplified due to the COVID-19 pandemic since people living with HIV were reporting worsening of health-related issues including mental health (Santos et al. 2021). Therefore, actions to address mental health in this population are important and must be implemented in every treatment decision (Remien et al. 2021).

PS has shown promising results in improving both outcomes by addressing the roots of what worsens symptoms of depression and anxiety. People reported that PS has helped them improve their confidence making them feel less anxious about what others may think and they have also experienced fewer depressive symptoms (Mosack et al. 2016). These results have exponential potential when it comes to clinical outcomes, ensuring the maintenance of ART.

Improving mental health related outcomes has been linked to improving adherence to treatment, better CD4+ counts, and, ultimately, lower viral loads (Glynn et al. 2019; Stockton et al. 2020). All the studies included in this review showed that PS does positively address depressive symptoms and anxiety. This is a promising start, but more work is needed to understand the relationship between mental health and PS for people living with HIV, across contexts and populations, to ensure that we understand the fit between the intervention, the mental health needs of the people receiving it and the timing or circumstances e.g., in relation to diagnosis or life course.

Peer support and quality of life

QoL is the variable in this study that is the most sensitive to changes in the environment of people living with HIV (Basavaraj et al. 2010). Stigma, mental health, and other factors such as sociodemographic factors can highly influence quality of life and, therefore, is one of the most valuable goals to improve (Khademi et al. 2021). Both stigma and poor mental health can have negative impact on QoL with an indirectly proportional association (Chambers et al. 2015; Rueda et al. 2016). In this review, mixed results were obtained. Out of the eight studies that had QoL as a variable, only three had a statistically significant result showing that PS can improve QoL.

In the case of RCTs, four out of five studies showed the PS did not present a significant change in the QoL of people living with HIV when compared to the control group. These findings need to be considered in the light of some study design factors. All these studies had quality of life as a secondary outcome (Ruiz et al. 2010; Webel 2010; Giordano et al. 2016; Cabral et al. 2018). Some used measures that were not HIV-specific (Giordano et al. 2016; Cabral et al. 2018) so their sensitivity to change might have been compromised. There were small sample sizes (Webel 2010, Molassiotis et al. 2002), no control group (Ruiz et al 2010), limited populations e.g., recently hospitalised patients (Giordano et. al. 2016) or very heterogeneous populations with multiple changes in peer supporters making it difficult to build a relationship (Cabral et al.2018).

Studies that presented a statistically significant improvement in QoL did have that variable considered as part of the primary outcomes (Van Tam et al. 2012; Lifson et al. 2015; Asrat et al. 2021). The three studies included QoL as part of a cluster of variables related to it including stigma, depressive symptoms, and anxiety. These results were congruent since they also showed that PS helped decrease stigma, decrease depressive symptoms and anxiety, and, therefore, decreased quality of life with a high statistical significance. These results are similar to those presented in the Berg's systematic review published 2021 (Berg et al. 2021). This interaction between stigma, depressive symptoms, and anxiety, with QoL can be seen in many other chronic conditions (Holubova et al. 2016; Li et al. 2020) so it can be expected that if PS does improve the first two variables, then it can also improve QoL. Nevertheless, more studies are needed to draw conclusive statements on this matter.

The UK National Standards

The UK National Standards were published to shape a more uniform application of PS in the treatment of HIV. Even though it is intended to be applicable to the UK context, the studies included in this review showed that, despite the numerous socioeconomic and sociodemographic differences, the implemented interventions do meet the National Standards and can serve as potential basis for improving those in the UK. All the studies ensured the participation of every patient willingly to participate with no discrimination on sociodemographic characteristics, the severity of the disease, or any other specific circumstance that could leave them out of the intervention. This fits well with the first standard considering the universality of access. On the second and third standard, trained staff and monitoring respectively, there were mixed results as often there were insufficient details to make a judgement. Nevertheless, they did have trained peer-staff working with them with many of the papers specifying how the training was carried out. More details were needed in the monitoring aspect of almost every paper. The lack of mention of these aspects limits the ability to translate the intervention into practice but also helps acknowledge that this is the focus for further research if results are to improve. In this review, the fourth standard was not measured since the population used was those over 18 years old so was outside the scope of the review.

The ADAPT guidance

PS has shown promising results under the premise of a cost/effective approach to improving the quality of life of people living with HIV, improving their mental health and decreasing stigma. The ADAPT guidance was developed as a tool to use the information obtained from different contexts and apply it to build an intervention accordingly to the new target population. It has four steps considering the rationale for intervention (step 1), adaptation (step 2), piloting and evaluation (step 3), and applying the intervention (step 4). This review had the purpose of evaluating whether the studies of PS from across different regions could be applicable to the UK The results presented in this review do support the first step of the ADAPT guidance. They give a basic rationale to start developing PS interventions and could help implement new experimental studies in the UK.

Limitations

This study had limitations including the small number of papers that met the inclusion criteria. These papers were mostly from low- to middle-income countries and many of the from rural areas making it more challenging to extrapolate the results to the UK context. Moreover, there was not a standardized use of the measuring tools resulting in a more diverse and, in some case, not replicable results in some areas. The narrower definition of mental health in this review to just depression and anxiety could also have limited the interpretation of the results in this area.

2.5 CONCLUSIONS

PS appears as a cost-effective approach to improving mental health and reducing stigma for people living with HIV. The results in relation to QoL are more uncertain but this may well reflect the limitations of the studies and therefore needs further work. Even though this study did not evaluate the cost of implementation, the background information obtained from every paper emphasized that this intervention had low economic burden to both people living with HIV and the health-care facilities.

It is important to acknowledge that improvements to stigma, mental health and QoL will have a major impact on engagement with care, taking treatment and having an undetectable viral load. PS based interventions set on different regions can be applied in the UK by making some adjustments based on the characteristics of the population and healthcare system. The UK National Standards is an important guidance tool to better help shape more effective interventions.

Despite sociodemographic differences, interventions being carried out in other parts of the world do meet the National Standards and can be used as examples to implement similar peer-based interventions. This implementation has a great potential to also have a positive clinical impact since improving mental health, stigma, and quality of life can improve treatment adherence and physical-health-related outcomes. Therefore, more studies are needed to explore the results of ongoing PS interventions applied in the UK and identify what changes and improvements can be made.

Chapter 3

EXPLORING COMMUNITY ATTITUDES TOWARDS A HIV PEER SUPPORT SERVICE

Lead author: Adam DN Williams

3.1 BACKGROUND

When developing any intervention or service, it important that the intended population is central to the design and development of the intervention / service. For peer support this is more integral as it will be the community who will have to engage to provide the service. With that in mind it was important that this work gained insight from people living with HIV regarding any potential service. Within the time frame of the project, we would not be able to complete a comprehensive examination of views of the community, but initial work could be conducted to gain insight. This work aims to identify community attitudes towards establishing a Wales-based peer support service for people living with HIV and components of the service felt by the community to be essential to be included in its development for success.

3.2 METHODS

Design and Development

To achieve the aims of this project a survey was selected as the method for the data collection. The development of the survey started with considering Proctor's Implementation Outcomes (Proctor et al 2011). As this work is a scoping feasibility project not all the elements were appropriate and so the survey would focus on elements of acceptability, feasibility, and appropriateness. It was felt that these three elements would allow us to start the introductory work of gauging attitudes of those living with HIV towards a potential peer support service. The initial survey questions surrounding acceptability were adopted from the existing Behaviour Intervention Rating Scale (Elliot & Van Brock Treuting, 1991), with some questions related to feasibility and appropriateness being used and some adaptation to better fit the current needs. The survey was agreed by the research team and provided to a stakeholder group for review with further edits made. The final survey consisted of 4 sections:

1) About you (age, location, experiences of PS), 6 questions
2) Acceptability of Peer Support, 4 questions
3) How to Deliver Peer Support in Wales, 8 questions
4) Demographics (ethnicity, sex, gender, sexuality) 4 questions

Questions included open and closed questions, along with Likert-type scales where appropriate (the survey is available for viewing in the appendix). The survey was focused on anonymity and did not collect identifiable information. It was developed on the Qualtrics platform, selected because it is designed for this type of survey. Cardiff University holds a license and the researcher had experience of the platform and its features.

Ethics and Data Protection

Ethical approval for this project was received by Cardiff University's School of Medicine Research Ethics Committee. Cardiff University acted as data controller and all data will be stored following Cardiff University security and protocols.

Inclusion criteria and Recruitment

The survey was designed to be completed by people living with HIV and living within Wales. Electronic adverts were created and posted on various social media websites, Facebook, and Twitter. The advertisement posts consisted of a brief introduction with QR code and link to the survey for full details. Sexual health clinicians, Public Health officials, NGOs, and charities were also contacted to assist with disseminating the adverts and survey, using their connections to improve awareness of the project along with the survey to increase reach. The survey was live from April 4th, 2022, to May 30th, 2022.

Procedure

From the adverts, the links or QR code could be followed to access the survey. Upon entering, the full information sheet was presented for individuals to read, with consent taken. Only those consenting proceeded to answering survey questions. At the completion of the survey, individuals were asked if they would like to engage in further work on developing a peer support service for Wales and could follow a link to a separate page to provide their email address and indicate which elements they would like to be contacted about in the future.

3.3 RESULTS

Demographics

The survey received 166 views with 154 (93%) completing the survey. All questions were optional, so the number of responses and denominators are provided for descriptive data presented. Most respondents were male (90/154, 58%), aged between 20 to 81 years (mean age 50 years), and 66 (43%) lived in Cardiff area. Approximately half (54%) were from a white ethnic background and in terms of sexuality the largest group were those who identified as homosexual (74/154, 48%). A full breakdown of results is available in the appendices. According to the most recent available data on people accessing HIV care in Wales (from 2020), there are 2448 people accessing healthcare for HIV in Wales, so this survey represents 6% of the population (UKHSA, 2021). In comparison to the 2020 data the survey sample has engaged more of those from the older age groups, with most aged 50-64 (42%, 65/154). For ethnicity, the survey lacks representation of Black/African/Caribbean and Asian communities in comparison to those seeking care. There was also a lower percentage of white individuals compared to those seeking care (54% versus 74%). However, this variable had the highest levels of missing data, with 37% (57/154) of respondents choosing not to provide this information so these discrepancies are difficult to interpret. The variable of sexuality also had a high level of missing data (36%, 55/154), 48%, (74/154) identified as homosexual, 8% (13/154) as heterosexual and 5% (7/154) as bisexual. In a question exploring where HIV treatment was received from in relation to residence, most received care within their home health board (58%, 90/154), a quarter travel to a different health board in Wales, (26%, 40/154). Four (3%) individuals reported receiving care outside of Wales with 20 individuals (13%) not providing this information.

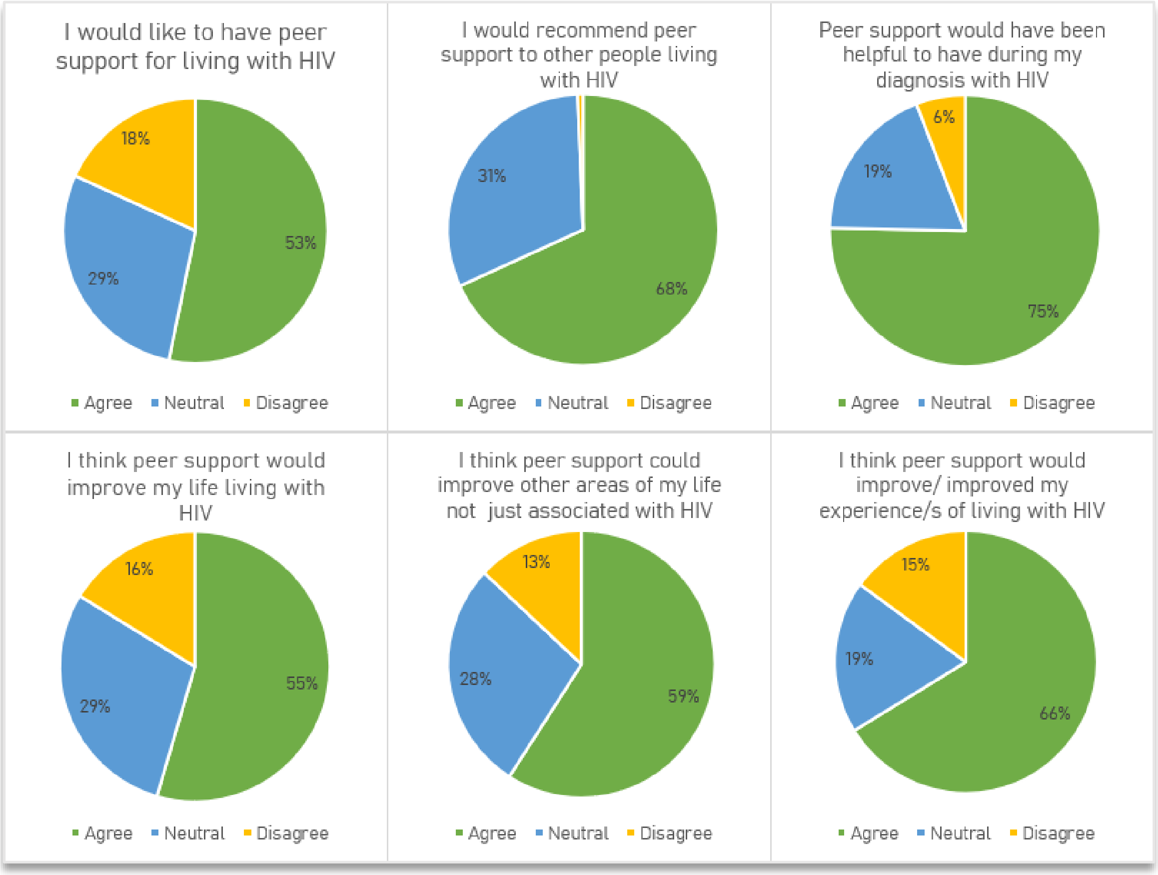
Previous experiences of peer support

We explored respondents' experiences of PS: The majority had no experience of PS (70%, 108/154), 17% (26/154) had previously received PS (this was for any reason, not exclusive to HIV) with 6% (9/154) having received training to be a peer supporter. Of those with experience of PS, we asked them to provide brief details about the support they had received and/or delivered and 17 provided a text response. Of those receiving PS, the majority described a positive experience of the support they received, most referencing their support originating from Terrence Higgins Trust (THT) services, with the support occurring in Wales. Some explained receiving PS for conditions other than HIV. The COVID-19 pandemic was cited as stopping PS services used but it is unclear if these have restarted. Not all experiences of PS were positive, with reports of finding the situation "devaluing and opinionated". From receiving PS, some people went on to train and deliver PS. Training occurred through various organisations including helplines, THT, Body Positive. Some descriptions within this section highlight that there may be some misconceptions around what constitutes PS e.g., people described experiences with medical professionals.

Desire for a peer support service

Of those who responded to the survey, half indicated that they would like to receive PS for living with HIV (53%, 82/154) and believed that it would improve their life (55%, 84/154). Two thirds believed that PS would be beneficial to improving experiences of living with HIV (66%, 102/154), as well as being beneficial to life generally (59%, 91/154) and 75% believed PS to be beneficial if provided at the point of diagnosis (115/154). Two thirds of respondents would recommend PS to others living with HIV (68%, 105/154) and would be willing to act as a peer supporter (68%, 104/154). It is important to acknowledge that not everyone viewed PS positively, with a quarter of respondents not requiring or wanting to receive PS (27%, 41/154) with around 15% not believing that PS would be beneficial. Some respondents took a neutral response towards peer support. Results are presented in Figure 3.

Figure 3. Pie charts representing attitudes towards a HIV peer support service.



Designing a peer support service

When asked how a potential PS service should be delivered, there was strong support for including a one-to-one element, ideally in person (82%, 126/154) but virtually through online or via telephone was also acceptable (58%, 89/154). Group-based support would also be welcomed, with half of the respondents wanting this to be offered in person (51%, 79/154), and 32% wanting a virtual group option (49/154). When asked if they would like an online forum, the majority responded 'yes' (44%, 44/101), closely followed by the response 'maybe' (40%, 40/101). As for the location of a PS service there was no overall preference: Community and clinic settings received similar levels of endorsement (community 66%, 101/154; within a clinic setting 62%, 96/154). Other potential settings for PS included workplaces, educational establishments, public access areas (cafes, libraries), and virtually including webchat or telephone. Clearly a set model for delivery would not work for everyone and would depend on individuals needs and circumstances. Some respondents suggested that connections should start within clinics, providing legitimacy and safety at the outset, and then branch out into the community, highlighting the systemic and evolving nature of the design and delivery of this kind of service.

PS services often involve a degree of "matching" to try and ensure there is a sense of a similar/shared experience. All bar three respondents thought this would be beneficial, at least in some circumstances, and they were then asked how important this matching was for certain characteristics (see table 8). Sexuality was deemed to be the most important characteristic to match for, with 45% categorising it as essential (55/122) and 43% (52/122) believing it important in some instances. Gender was identified as the next most important characteristic with 37% (45/122) identifying it as essential and 45% (55/122) believing it important in some instances. Age, ethnicity, and religion were viewed as important to match in some instances (66%, 81/122; 43%, 52/122; 47%, 57/122). When considering these findings, it should be acknowledged that these will reflect the respondent's demographic profile.

The final question relating to designing a PS service queried the best method for informing people living with HIV about the PS service. Most believed the best method was through HIV clinics and by clinicians (92%, 113/122), as well as by General Practitioners (59%, 72/122). Dissemination through online means was a popular choice (71%, 87/122) along with the use of posters and leaflets within settings such as pharmacies (53%, 65/122) (with one suggestion of information being provided with medications either through collection or delivery methods) and social spaces (63%, 77/122).

Table 8. Importance attached to characteristics for matching peers with supporters.

Level of importance for when matching peers with supporters? [n=122]

Characteristic	Essential		In some cases		Not required	
	N	%	N	%	N	%
Sexuality	55	45.1	52	42.6	15	12.3
Gender	45	36.9	55	45.1	22	18.0
Age	16	13.1	81	66.4	25	20.5
Ethnicity	13	10.7	52	42.6	57	46.7
Religion	16	13.1	57	46.7	49	40.2

Perceived benefits of peer support

Respondents were asked to present what they believed would be the main benefits of providing a PS service, 92 provided an open text response. It was clear that there was a consensus around the main benefit of PS being its nature of sharing experiences, with these being split between practical and emotional elements. Practical support included providing advice with the practicalities of living with HIV, such as medications and adherence, clinics to attend, support available.

> *"[Peer support would] be a chance to share your HIV experience with someone going through the same thing as you. Would be able to chat about different meds [medications], and each other's experience of side effects. Also be good to chat about things you may not be able to talk about to your family or friends."*

Examples of emotional support benefits that a peer could provide were having someone to discuss their feelings who understands the situation, having lived through it and understanding the difficulties of dealing with stigma within society, along with dealing with conversations with family and friends.

> *"Alleviate fears, discuss coping methods, discuss family and friends' attitudes."*
>
> *"Have someone to relate to feel like you can freely discuss about HIV, have a social group away from others that may not know it makes a positive difference to mental health too."*

Particularly for those newly diagnosed, it would help alleviate the isolation and loneliness experienced from receiving a diagnosis. There was an emphasis in the responses on PS being most beneficial to those newly diagnosed with HIV, assisting them in their transition into a new lifestyle.

> *"At the point of diagnosis this peer support would have been useful, to help understand what was going on, that I wasn't going to die, that I could live a good healthy life, instant support in a world where HIV was frowned upon and still is."*

Some expanded on this, adding that this type of service would not be useful to them at their current stage of life, being happy and healthy living with HIV. The focus on support being provided to those newly diagnosed was believed to be required to challenge the stigmas and assumptions held and help them to understand "*what a HIV diagnosis really means*".

Potential challenges and negative impacts of providing peer support

When asked if they predicted any potential challenges or negative impacts from a PS service, 91 provided an open text response. Some of the challenges predicted included operational issues such as recruiting peers, time required by those volunteering time, ensuring appropriate training and support is available for peer supporters. But the main type of challenge reported referred to the relationship and dynamic between supporter and service user. This included ensuring the personalities worked well together and resulted in a positive relationship, but also monitoring the relationships between people to replace supporters if the dynamics do not work. Other issues included willingness of supporters to be open with experiences, maintaining privacy/confidentiality and supporting the supporters. Despite the challenges identified, many expressed beliefs that these could be overcome, and the impact of the service would be positive and meaningful to many people.

Few responders included specific negative impacts, but those provided included situations of burn out among supporters, having to regulate emotions, problems of confidentiality around status being shared and the potential development of dependency by service users on supporters. One individual commented that PS itself is not a good model, believing it generates issues and that professional support would be a better option. However, many of the potential negative impacts identified were followed with how these issues could be avoided with appropriate training. Some did not foresee any challenges or negative impacts from delivering a PS service.

Predicted challenges of recruiting peer supporters

We specifically enquired about predicted challenges to recruiting people living with HIV to act as peer supporters. The majority of those who responded believed that there would be some challenges to recruiting peer supporter (52/92), 26 disagreed and believed that there would not be challenges to recruiting, with 5 people believing there could be challenges for some groups, but people would be eager to volunteer. Seven individuals were unsure.

The recruitment challenges identified often focused on privacy and confidentiality, with the required sharing of their HIV status to strangers being a key barrier. Additionally, it was highlighted that any group setting poses the potential for someone to meet a person they know or even the person who transmitted HIV to them. Other common challenges raised were time, capacity, and personal situation which may result in less people volunteering. Some raised the point around payment as this may improve the numbers of who offer their time. Matching people by characteristic was also highlighted as a potential challenge, as there is a limited pool of people living with HIV so when filtering by characteristics such as age, gender, religion, it may result in very limited options. Some did suggest that there would be an eagerness by homosexual or bisexual men to participate, with difficulties finding heterosexual peers willing to act as supporters (due to numbers and stigma). Those not expecting there to be challenges believed that people, usually like themselves, would be eager to act as a peer supporter and provide their time and share experiences, particularly if there was flexibility to allow services to fit around personal circumstances.

Specific challenges in the context of Wales

We asked respondents if they could foresee any challenges specific to developing a PS service in Wales. Some people did not foresee any challenges, but four main types of challenge were identified from 61 comments: recruitment/engagement, confidentiality/ HIV status sharing, geographical issues, and funding. Challenges related to recruitment have been described above but were raised again as a prominent issue in relation to Wales, along with engaging people to use the potential service. Efforts would need to be made to ensure engagement continues over time, possibly by developing social elements and not being overly focussed on negative aspects. Confidentiality and HIV status sharing was a prominent problem raised throughout the survey and this came through again in relation to identifying specific problems in developing PS in Wales. Geographical challenges are very specific within Wales, with responders identifying a need to provide support for travel, due to the rurality of much of Wales, with limited public transport options to allow for engagement. Additionally, it was identified that different opinions and stigmas surrounding HIV will be held within differing regions of Wales, with work needing to be done to address these. Lastly, funding was identified as an ongoing challenge, with previous services being discontinued due to difficulties maintaining funding.

3.4 DISCUSSION

Overall, there was a positive attitude towards the development of a HIV peer support service, with many respondents being willing to be engaged in the service and others recognising that, even if it would not help them in their lives currently, they would have appreciated the support during the time of diagnosis. However, it is important to note that PS is not for everyone, one type of support does not suit all, and so other types of support must be provided. In the development of the service, it was clear that there needs to be a fluid model with multiple elements to tailor to everyone's needs, including in-person, virtual and groups elements. Challenges identified largely centred around confidentiality of HIV status, with it being identified as a barrier to both people using and volunteering for the service. The privacy policy regarding status and group membership needs to be carefully considered and transparent to those using and volunteering for any potential service.

The limitations of this survey need to be considered in these results. It is part of a small, rapid scoping study that only used social media dissemination over a few weeks and did not directly contact people e.g., via clinics because of time constraints, so it only provides a very limited insight into the views of people living with HIV in Wales. Whilst it was a relatively good response rate in these circumstances, the demographics of the respondents show that there are some groups of people who are under-represented e.g., those from Black and Asian communities. In contrast there is an over-representation of people aged over 50. These skews in the respondent group may underpin some of the responses e.g., in answering the question about the importance of matching where characteristics of ethnicity and religion were not seen to be important to match on and an over-representation of the willingness of people living with HIV to act as a peer supporter. A survey can only explore relatively basic information and although open text offers opportunities to share more complex information, the subtleties of peoples understanding, and experience of peer support services can be lost in this one-way process. For these reasons it is important not to consider these results as definitive, but rather a good starting point to open the discussion about peer support with people living with HIV in Wales. It indicates an interest and willingness to engage with the topic which is going to be crucial in the development of a co-designed PS service and on a practical level, 27 people have expressed a willingness to be contacted about potentially getting involved in the development of such a service. Any ongoing work needs to ensure continued integration of the community within the development of any service as they will be major contributors to any services' potential success.

Chapter 4

INTERVIEWS WITH STAKEHOLDERS WORKING IN THE HIV SECTOR

Lead author: Sue Channon

4.1 BACKGROUND

This chapter describes the results from the stakeholder engagement work, primarily conducted through interviews but also from attending the Wales government HIV action plan meetings (27/1, 22/3, 27/4/22) and the BASHH Wales audit meeting on 2nd March 2022. The purpose of the work was to identify enablers and barriers to establishing a Wales-based peer support service for people living with HIV and potential components of a service model if there was community support for its development.

4.2 METHODS

Design

A list of stakeholders was drawn up in collaboration with the HIV action plan group members and the BASHH group membership. Two broad groups of stakeholders were identified: People with experience of delivering or working alongside peer support services (PSS) for people living with HIV and NHS HIV service providers in Wales. We sent email invitations to the identified stakeholders asking if they would be willing to participate in an interview and also to suggest other stakeholders who might be interested and willing to participate.

The semi-structured interview topic guides were based around the relevant constructs of the Consolidated Framework for Implementation Research (https://cfirguide.org/): this included questions centred around PSS characteristics (including model of delivery and underpinning theory for PSS providers), their experience of PSS as a service provider, the HIV service context in Wales, relevant organisational factors, potential barriers and enablers of PSS for people living with HIV in Wales, important outcomes of PSS and evaluation.

4.3 RESULTS

Demographics

Thirteen interviews were completed between April and June 2022, six with NHS service providers and seven with PSS stakeholders, (12 individual interviews and one which was an interview with two members of the same team). All the interviews were recorded, transcribed, anonymised, and uploaded into NVivo 12, a qualitative data analysis computer software package. The data were analysed thematically, and the main themes are described here with quotes from the interviews included. The content is summarised in five sections, linked to the constructs in the CFIR model:

- Intervention-focussed: What are the core principles of a peer support service?
- Inner setting: What do we need to look for within the structure of the organisation/NGO that could host this service?
- Outer setting: What do we need to understand about the context of HIV services in Wales?
- Processes: What do we need to make a PSS a success? How do we know if peer support has been a success and what should we measure?

Given the size and nature of the community, it is difficult to maintain interviewees anonymity, and so to reduce the ability to link quotes (and thereby identify participants) the quotes used are not identified by participant number but are simply identified as NHS or PSS.

What are some of the core principles of a peer support service?

There are some core principles underpinning the PSS which can broadly be described as ethos, sustainability, place in the wider system and model of delivery:

Ethos: A central tenet of the service needs to be that it has the people living with HIV at the heart of it, with the key principle of "nothing about us without us "integrated into all the different aspects of the service. This applies across the board, from the delivery of the peer support to the design of the service and the organisational structures around the service, such as a steering group. The needs of people living with HIV should be identified by the community itself: Only by establishing this as a clear focus of the service will the sense of community be generated, which will in turn enable others to join. This benefit of identifying with a community of people with the same lived experience is the power of peer support, distinguishing it from any other. This does not preclude people not living with HIV from working in the service, but the service needs to be predominantly delivered by and for people living with HIV.

Sustainability: For people to have confidence and trust in the service they need to know that the service is secure and will be available in the longer-term.

> *"I think it's really important that whatever Wales decides to do in this area that they make a commitment to it, you know, and they commit to it as a sort of medium to long term project, not just something that's just gonna be for a couple of years. Because it takes time to sort of you know build up those relationships. And I think particularly Wales where there isn't much NGO presence anyway, it's gonna take time to build that up as well …. The action plan is to 2030 so I would say that you know that really, we should be looking for a commitment to that, to that to that point." (PSS)*

> *"Wales loses support services so quickly due to lack of funding. So, when the Big Lottery Fund, for example, if funding support services, it is for a five-year period. It was great.*

> *You had amazing responses to five years. But then as soon as that ended, no health board, public health Wales, Welsh government. No one was willing to pick up the tab. So, then they would just end. So, it's for Wales to do it properly. They need us to secure the funding long term and not just temporarily because it does make a massive impact on people's lives." (NHS)*

Building a peer support service requires time and commitment from a wide group of people, particularly people living with HIV; it is not a short-term project as it needs to grow organically from a series of small-start-up projects, to test the water, try out different approaches in different areas of Wales and work out what works for which communities.

> *"I think you've got to do some sort of pilot and see how it works. And then, in my mind, the natural progression of a support system is that you test it somewhere and then it spreads out...Because word of mouth is going to be really, really important." (PSS)*

> *"Because ideally the perfect model for something like this is you would have your peer support manager at the top, you would have that. You would then have localized coordinators so you would have North Wales, mid Wales, South Wales, West Wales. You will have a coordinator that's based relatively local to where they are. They would then be overseen by the top. Those people then would be the local connection for the clinics. They would be the ones managing the peer mentors and the referral sources." (PSS)*

It will build on its own success, but in order to do that there needs to be a clear source of funding of the core organisational elements in the medium-long term in order to develop to the point where it can look for additional sources of funding to grow. The history of the service in Wales suggests that it will not succeed if the funding requires NHS financial commitment at any stage in its development.

Place in the wider system: It is important to understand the position of peer support in the wider systemic context: This includes the national setting, the need for an HIV-focussed NGO, the relationship between peer support and the NHS provision and the boundary with social welfare needs and governance.

All-Wales: The development of a PSS for people living with HIV in Wales needs to be an All-Wales service. The different challenges across the regions may require bespoke solutions but there was agreement that the service needs to have an All-Wales identity. This does not mean starting from scratch: there are many different models of PSS for people living with HIV already in operation which can potentially be integrated into a Wales PSS, but the service must be based in Wales to have credibility and be acceptable to stakeholders.

> *"If they can demonstrate that they understand the different commissioning and landscape in Wales. If they can demonstrate they understand, sort of what some of the particular issues are for people living within Wales, you know, but at the same time, you know, we all recognize stigma is not specific to Wales and clinicians are, whenever anything comes along in HIV, whether it's a guideline or a strategy or whatever it is , pretty reluctant to sort of start reinventing the wheel. And so, I, you know, I think that question has to go to people living with HIV in Wales." (NHS)*

> *"If you had that middle management, if they were Welsh or they were based in Wales, they know how it works. They know the health boards, they know how the NHS works in Wales, cause its very different Wales, Scotland, and England. How it all works, local authorities, funding all of that is very, very different. Local government everything. So, if you had that middle management that was based in Wales, they'd already know the groundworks and then you'd have your localized coordinators." (NHS)*

HIV-focussed NGO: The service needs to be led and managed by an NGO in Wales which has HIV as its main identity. There needs to be a fresh start in terms of the lead NGO: PSS for people living with HIV has a complex history in Wales (see below) and a new PSS provider who can establish a mutually beneficial relationship with clinical services and people living with HIV is a key requirement.

> *"I think it's about building up relationships, it's about going in and talking to clinics about what you're doing for us, as an NGO to go into the clinic and talk about what we do and the value of that." (PSS)*

Organisationally independent of Clinical Services: The stakeholder consensus was that there needs to be a close and effective working relationship between the PSS and clinical services, but it needs to be clearly delineated from the clinical service.

The reasons for this separation ranged from the practical (organising space in clinic), to financial (the competing demands on the NHS budget making it unlikely to ever be prioritised) to the more person-centred aspects and perceptions of the role e.g., around confidentiality, boundaries and what some described as "professionalisation", which would loosen the sense of shared identity from mentor to mentee.

> *"I think if there was an organisation... if there was somebody who... who could kind of manage it in that sense it would have to be in conjunction with whatever's going on with the clinics." (PSS)*

> *"I mean there there'd also have to be separation. So, I think for a lot of people there is nothing really between the medical and the community. Peer support is that sort of*

> *stop gap between those two things that are happening and so they can't be seen as two into one thing." (PSS)*
>
> *"I think sometimes it being part of the clinical services is negative. Some people would prefer not to have a sort of medicalized sort of ..for it to be able to talk freely and about things that they might think they wouldn't want to disclose as part of their sort of clinic records. Even though we do say it's confidential, but then also as well people have sort of concerns about confidentiality like with the questionnaire that's the good sort of example who's going to look at this, who's going to know that. So sometimes that's great to have that anonymity." (NHS)*
>
> *"I think it's probably better if it doesn't sit within services because that's gonna be very hard to then standardize across Wales. So, and to really give focus because services always have other pressures, and I just worry that peer support could fall to the bottom of the pile when you're just thinking about trying to have enough clinic appointments. So, I suppose if I had to sort of say, where would it sit? I'd probably say not in services but with close liaison with services*." (NHS)
>
> *"I'm not clinical and not talking to them in language that's gonna make them feel any sort of barrier." (PSS)*

Boundaries and governance: In terms of the service being delivered, there need to be clear boundaries between a PSS and other types of services e.g., welfare advice, support with asylum claims etc. This was something the peer support providers were very aware of and had taken a range of steps to manage (described in the later section on the host organisation). Whilst there are several robust and successful peer support services run by other organisations in Wales e.g., MIND it was not felt that linking an HIV PSS to these services would create the sense of community and identity.

Delivery of PSS requires a robust governance structure to ensure that all stakeholders have confidence in the service safeguarding everyone's wellbeing across all their areas of work.

Alongside this there is a need for ongoing evaluation of the service, either with an independent evaluation partner or built into the plan of the lead organisation, to ensure the service can evolve and improve. That evaluation needs to be driven by the specification of the service which should be based on the needs of people living with HIV.

> *"…peer mentoring experience can be, could be very damaging. So, I think I would want to know I would want to feel that there was governance and oversight, and I would feel nervous about something that didn't have any." (NHS)*
>
> *"…make sure that its outcome focused in respect of what people want." (NHS)*

> *"I'm as guilty as anyone else, really. That we don't always think about the outcomes at the beginning. We leave it till you get the spec and then you madly think, well, what we're gonna do with this. So, I think from my perspective, it would be important to involve patients in telling us what they would want. So, it would be important that we can facilitate that feedback and that patient engagement as to what would be meaningful to them, what would be the most supportive and productive."* (NHS)

Model of Delivery and Training: One of the main themes emerging from the interviews was that there was no need to re-invent the wheel in the design of PSS. Whilst there is a need for a new organisational structure fit for purpose and based in Wales, there are already a range of options for the model of delivery of PSS for people living with HIV, with some very helpful guidance provided by several UK agencies, in particular Positively UK (https://positivelyuk.org/) and Brigstowe (https://www.brigstowe.org/). These organisations provide training for peer supporters and the websites of both organisations offer a comprehensive overview of establishing peer support in this area. Terrence Higgins Trust (https://www.tht.org.uk/) provide online, text-based discussion forums for people that can be accessed by people in Wales. Different models of PSS have different emphases, for example describing them as more client-centred or goal-focussed. There may be a view that it should be focussed on working with the newly diagnosed but several stakeholders expressed the view it needs to be more widely considered than that and offered across the life-course; for example, one stakeholder mentioned that there has been little work looking at the experiences of older people living with HIV.

> *"…think there would also need to be then a clear vision of who it's for. Are we reaching all the demographics that need it and how do we know that it's effective as well and what it's delivering because you just don't want it to be a tick box thing."* (NHS)

> *"We still got a long way to go in the NHS to sort of really kind of understand what people growing older with HIV really need. And one of the one of the things that peer support can really do is actually help to sort of facilitate a more bottom-up approach to understanding, you know, how we can better support people as they get older with HIV."* (PSS)

There may also be different practical elements such as the relationship with the clinical service and direction of contact (for example mentor to mentee, vice versa or with clinician as the link). A decision about the exact nature of the PSS in Wales can be determined in the future, by the people living with HIV in Wales and other stakeholders in a consultation led by the lead NGO, which can build on the experience of these organisations. What is important is that before the service is offered there is a clear service delivery model, including underlying principles, whose needs it is meeting and how, coupled with training which is quality assured.

There were a range of issues related to training that people felt were important to consider. The model will be based on lived experience and that is its strength. However, it does leave trainee mentors potentially vulnerable, as training can have a significant impact on the wellbeing of some mentors, through re-visiting previous difficult experiences in order to consider what others might be wanting to talk about. The qualities of the trainers are vital in managing this and all the other complexities of this area, thinking about people's readiness, suitability etc. There were also mixed views on the nature of the training: Most people felt that the training needed to be quite detailed, some thinking that actually an accredited training was the way to go. One person however raised a counterargument to this, saying that it was important not to train the genuine peer response out of people; that it was their lived experience that mattered. So, the agreement was that the training needs to be to a high standard, but the precise nature of that training is to be determined.

Staffing of a PSS generally includes at least one co-ordinator of the service, in a paid role, (or potentially one role shared between people), who does the matching of mentors to mentees, supervision of mentors, and who themselves receives supervision.

> *"…maybe somebody just to coordinate. So, one paid role and that's maybe a few days a week. You know if you've got minimum finance umm, you can still, you can still do something meaningful with somebody for a few days a week in relation to being able to then schedule something as a as a monthly event or as a as a weekly mail out for things you know just to start to engage and connect with people." (PSS)*

There was no consensus amongst the stakeholders on whether mentors would be paid or volunteers, with both positions having vigorous support. Those who believed the mentors should be volunteers felt that payment in some ways devalued the service, professionalised it to its detriment and impacted on retention of mentors. There were also the practicalities that if someone is being paid there was a risk of a negative impact on matching as there would be pressure to allocate mentees:

> *"The value of this service is the fact that the volunteers living with conditions using their time because they believe in what they're doing. It's something they wished that they had had when they were there, and that's why they're trying to do it. The second there is financial remuneration …basically by paying you cheapen the service." (PSS)*

In support of the role being paid was the view that only by paying can the role be open to all and avoid inequities as for some on lower wages it would not be possible to offer time as a volunteer. The important factors were finding a model that best engaged, supported, and retained the mentors to ensure a safe and sustainable model.

> *"How is the program going to really maximize retention of those volunteers and support them and engage them in other activities around HIV, make them really feel part of a team? And so that they don't come and go. And I think they will come and go inevitably; I think we've seen the same as some of the prep peer supporters… You know, people come and go, their circumstances change. They may not be able to do it, but I think we need to just have that awareness of that pitfall up front, because what we don't want to risk…. we really don't want to offer something to our patients, and those who are most in need because that's who we're talking about, and then pull the rug from under them and say, well, I'm sorry, we now haven't got enough peer supporters and you'll just have to go back to what you were doing. So, I think it's about sort of sustainability." (NHS)*

What do we need to look for within the structure of the organisation/ NGO that could host this service?

One of the known barriers to developing a PSS for people living with HIV in Wales has been the lack of an obvious NGO to co-ordinate and deliver the service. Several stakeholders identified the synergy of development between the host NGO and the PSS. If the NGO is trusted and is felt to relate to the wider system of support for people living with HIV, then stakeholders are more likely to trust (and therefore use or recommend) the PSS. As the PSS becomes more well known, and service users report its value to peers, clinicians etc then they will trust the NGO that hosts it.

> *"You know this is a group so you need that knowledge of that provider and the knowledge of what can be offered so that it's second nature to you that you mention it to the patient." (NHS)*

> *"I think if you're if it's an NGO you're offering you know a good quality service then and you're you know you're offering solutions and support that's working for patients then they're going to go back and report that back to their clinics."* (PSS)

Also, with one of the goals of peer support being to empower people living with HIV, they may become more public on social media, campaigns etc, normalising living with HIV, which will help build the community, raise the profile of the NGO and PSS, and potentially lead to opportunities to apply for funding etc. This virtuous circle of awareness building and outreach requires an effective NGO which understands and is embedded in the Welsh context and has the capacity to grow. Some felt it was beneficial if the NGO can operate as an umbrella service for interlinked provision across health and social care e.g., services for asylum seekers living with HIV etc: Certainly, there was consensus around the importance of not functioning in a silo and being mindful of the other services available for people living with HIV.

The NGO should have people living with HIV working at all levels of the organisation and its focus should be community-led. The community of people living with HIV is very diverse but often HIV services become identified with one particular group which can be alienating for people who are not part of that group so the NGO must reflect the diversity of the community they are part of. Similarly, there will be a few well-known voices in the area who have a lot to offer but there will be benefits in having some less experienced people involved as well.

> *"I think basically what will happen if a lot of people won't engage in it and you get a sort of cohort of quite vocal people who will kind of grab it and then a lot of the people who really kind of possibly would really benefit from it, won't be on board." (NHS)*
>
> *"…having done the training for [****], I mean, there's definitely overrepresented groups, so gay males are massively over-represented, but actually as it went on, there's definitely a lot more black, African black Caribbean women, still a real lack of heterosexuals (PSS)*
>
> *There are both the advantages and the disadvantages of having people that are established and are well known in relation to those topics and areas of influence and interest. And so, I would say be careful of having somebody that is, that has been doing it all, done this for a very long time and comes with particularly if they come with organizational baggage. Well, this is how we did it that that kind of thing." (PSS)*
>
> *"It would be really great to have something that comes with a fresh perspective based on experiences, challenges and opportunities." (PSS)*

The organisational behaviour of the NGO will be taken as an indicator of how it would manage peer support by people living with HIV: Stakeholders identified the need for consistently ethical practice, evidencing organisational sensitivity and awareness of the importance of confidentiality across all its activities. The NGO will need to be well-managed and with clear transparent processes and accountable to their stakeholder community.

> *"…it's not to say that I don't think something like that could work again. I just think we need to have a sort of complete transparency that we've got a really sort of solid, robust NGO that's got experience of delivering this, that will work to the evidence base, that will liaise with services, and to sort of for awareness, for feedback and to work together on recruitment, you know and referral into peer support. So, because that's a crucial link, clinicians are a crucial link to getting people into peer support and with some accountability. So again, an NGO that's prepared to produce robust reports annually or whatever, to sort of show the work they're doing, report back and be open to development." (NHS)*

What do we need to understand about the context of HIV services in Wales?

Stigma: The history of stigma of living with an HIV diagnosis permeates all the contextual layers surrounding the person and the health and social care they receive. On an individual level, people living with HIV might elect to receive their care away from their home area, either because they do not want anyone in their hometown to know their diagnosis or because they feel connected to the service where they were first diagnosed and so stay with it even when they move. On a societal level there continues to be very poor understanding of HIV, both in the general community and within health and social care, even within medical, nursing and dental providers, such that the stigma and ignorance continues to affect people's day to day life. This is not a situation peculiar to Wales but not having a dedicated NGO to educate and campaign has potentially exacerbated this situation here. Different regions in Wales may be facing different types of challenge: in some areas the lived experience is of a profound lack of understanding and service, described by one stakeholder as being like going back to the 1950s; however, the lack of knowledge generally holds true throughout Wales and is a major barrier to people living well with HIV.

> *"…somebody said, oh well, it's... it was like thing of a gay disease, isn't it? And I just went, sorry? Genuinely its 2022 and you made that comment. So, until there's something out there to challenge the stigma - you know, a great place...it needs to be... it needs to be powerful. It's great for Gareth Thomas to say he's come out as HIV and have a couple of articles for a short while. It's great for one or two other people to come out as HIV. But they don't last long. There isn't that impact on the general community stuff. And that's not supported by Welsh Government or not seen to be supported by them. There needs to be something more." (PSS)*

> *"I really hope that there's some really practical stuff being done about stigma. And for me, a starting point is some sort of public campaign or some sort of public information resource. Because, as I said, you know, my biggest thing about... my first thought straightaway was… went back to those adverts and stuff I saw...when I was a kid about, you're going to die. It has power...it has an impact on people." (PSS)*

> *"One of the problems with it is it is, it's the legacy, isn't it? It's the early legacy still hanging over and really dominating peoples thinking about it so let's rub that out. Yeah, it is filtered through into common knowledge and it is so toxic." (PSS)*

Previous peer support services: There have been attempts to introduce peer support services in Wales in the last decade, but these have failed, and this has left many people with a powerful narrative about peer support in Wales that any developing service will need to overcome.

> *"In the past, when I've talked about it, it had always been met with oh we've tried that. It never worked. Oh, we've never had anybody interested. No, that it's a waste of time." (PSS)*
>
> *"…seeing the impact of lost services across different parts of Wales. The damage it can do to your reputation and people wanting to engage is massive." (NHS)*
>
> *"The biggest barrier was the people that had been working there previously." (PSS)*

Specific conditions for success are described in more detail in section 4 but, with a key message coming through from stakeholders about not repeating the same mistakes, it is important to consider the reasons identified for the collapse of previous projects. The main points of failure described by stakeholders could be depicted broadly as poor communication, a lack of connection between the peer support service providers and the clinical services and accountability. In several health boards the PSS did not create a relationship with the clinical teams who in practice were the link with service users; there was a sense from the clinical services of the PSS "parachuting in" with no development work or consultation and consequently there was a failure to build trust in the PSS provision.

> *"What I remember about it was there wasn't a particular presentation or a launch or I don't remember being sat down with the staff or being told about it." (NHS)*
>
> *"I think we just got, I think we possibly got email communication, but it was already, this is what we're doing. Can you suggest patients who would like to be involved in this?" (NHS)*
>
> *"I think it was, I think probably what was missing at that time was that link to clinicians or to anybody who was in contact with people living with HIV as to the fact they were there, what they can offer and how to refer in. And so I think with better, I think over just over the last couple of years, we're all more aware of peer support and what it is and how it can help and why it's important for our patients. And so, I think if that was something like that was relaunched, not necessarily the same thing but something similar. I think there's a much better chance it would work." (NHS)*
>
> *"I think poor experiences in the past, and there's a lack of trust because there were services here and the long-term survivors here are kind of like, yeah, you know, you create services and then they go away again." (PSS)*

Although some health boards commissioned PSS, there was a lack of monitoring and evaluation of the service, within both the management of the PSS and the NHS, which essentially meant that there was no accountability for the service.

> *"Not having maybe, the right oversight from a managerial perspective as well as a clinical perspective in terms of, you know, making sure that that we do the contract monitor and we do check what's happening*." (NHS)

There are small pockets of excellent PSS provision, but this is down to the skills and commitment of the particular individuals involved. This is a situation that continues in one particular health board, where the peer support service for people living with HIV is going strong. However, the collective memory of the service providers' community means that it will be important that the PSS provider is new to the role in Wales, providing an opportunity for a clean slate.

Service delivery challenges: Alongside organisational failings there were also more individual level aspects of developing a PSS in Wales that meant the service had to be discontinued. Moving straight into a face-to-face peer support service meant that issues of confidentiality were often difficult to manage and consequently people had negative experiences in the mentoring relationships, as well as some difficult emotional responses to the role of mentor.

> *"I think I'd have concerns about the one-to-one things. I think the one-to-one model, I think that's got a lot of issues in terms of potentially being quite negative and destructive to people and it's very difficult you know particularly if we're linked in as a service and coming to be responsible for that and make sure that in terms of safeguarding you know. Potential for manipulation. All sorts of things we'd have to that that's difficult and I think that's very challenging. I think the group work face to face is also difficult, but then I don't know, there are discussions about group work virtually where people can retain their anonymity. You know what I mean? Anonymity might definitely work. And I think that would be sort of something that people would find acceptable post COVID. I know it would exclude potentially people who haven't got technology and access to that. So that that might not be that inclusive as it could be." (NHS)*

> *"I think as well its interesting over the years we've had groups of patients who have asked for group support in the past and have THT involvement and then subsequently fallen out and have, you know, been quite sort of nasty to each other and don't talk to each other. And then in the clinic and allegedly said things about things to others." (NHS)*

> *"…the sort of imbalance that might happen that somebody who's in a good place becomes a sort of support, moves into the peer support rule. And actually, then that could have a negative impact on them." (NHS)*

Some of these issues could potentially be addressed by taking a more gradual approach, possibly in a group setting (e.g., online, and anonymous initially). With relatively small communities of people living with HIV in Wales, these experiences underline how important it will be to develop services step by step, with care and good communication across the service.

> *"Because you need to build the need and the want and the understanding of what that is and then you will be able to get the one-to-one services. But especially now that we're on a digital platform, is having a safe place where people can go face to face if they want to. But then you can have a computer setup like this, and people can join via Teams, camera on or camera off it's up to them but still be included in that community and it can be based anywhere in the country. The more rural places can join in. People from North Wales who may not want to be in a North Wales group because they might know somebody, can join a South Wales group and then they don't have fear of anyone finding out who they are." (NHS)*

> *"I'd start off by working with the clinicians from all the HIV departments. Uh, I'd want them to identify individuals that they feel would be OK to be taking part in it as well as then putting it out generally on social media and anywhere else." (PSS)*

> *"It's boundaries, boundaries, boundaries, boundaries. Say it's so, so key running this kind of service, especially in a city where there is a small …. it's a small community and then when you look at the LGBT community, primarily bi and gay men, that's also small. So, there's a lot of crossover there. And I'd say you know what's key is having your policies, having your procedures in place, having the mentors understand those and be able to follow those. But also having that open conversation of, OK, so we matched with somebody… and like, oh, it's somebody you previously been with or somebody you've been chatting to on Grinder or your next-door neighbour. And like, that has happened and, you know, thankfully, and I think that's again down to us encourage an open conversation. Our mentors are able to tell us that and then we can, you know, check with the mentee, is this appropriate for you to continue mentoring this person or should we switch" (PSS)*

> *"And if relationships need to end because of something going wrong, then we know how to end it in ways which aren't going to be damaging to either party. And making sure, obviously you get always as constructive an outcome as you can from anything that might be an adverse sort of incident." (PSS)*

Clinical Services: The clinical teams working with people living with HIV are, in general, enthusiastic about peer support services being developed. There were some concerns expressed (by stakeholders and clinicians) about the general understanding of clinicians of what peer support can offer (and equally importantly what it cannot offer), with a fear that some might regard it as a free/inexpensive catch-all to fill gaps in service provision.

> *"I think people might have trouble differentiating between the different types of support that this is really discussing." (NHS)*

Each team will need to be involved in the development of the PSS in their area to build a collaborative relationship and to work out an operational process to suit their situation. Services are very stretched but also wanting to ensure that their service users are in safe hands: People working in this specialty are acutely aware of the discrimination people living with HIV experience and so they are naturally cautious about suggesting other services, which has been exacerbated in relation to PSS due to the previous service failings.

> *"And I think you know, we wanna work with whoever can deliver that and and we do have to try and let go a little bit of some of these things and accept that it just might not be best delivered by the NHS for all kinds of different reasons. One it might not be best for the people living with HIV because they might see that as too closely associated with the service but two, we wrestle with all kinds of restrictions within the NHS and competing priorities that might mean it just never happens." (NHS)*
>
> *"I think we're happy to relinquish control, but we kind of really have that duty of care feeling, which sounds a very strong thing to say and it's not that we're accusing anybody of not caring or behaving ethically. But you know, if the processes like this can run away with themselves and then we go great, tick that box, got a plan and then really what happens down the line." (NHS)*
>
> *"I think we have a problem in Wales, which is a problem that we used to have in England 20 years ago, which is that there are a lot of clinicians in Wales who would rather refer people to the hospital cleaner than to anybody who doesn't actually already work in the hospital." (PSS)*
>
> *"I think it's kind of partly around clinicians feeling that you know, it's their job to, you know, provide the support and provide the advice and you know to patients … And I think it's probably maybe that's a bit more strongly felt within say, you know by doctors, with you know higher levels or more senior levels of expertise perhaps. But I think there's a bit of sort of maybe there's a bit of territoriality around it, you know professionally." (PSS)*

Consequently, the NGO and the clinical service will need to invest their time and effort to overcome these barriers and build trust in the new service. Whilst there was consensus that the PSS should not be managed or funded by the clinical service, several stakeholders described the potential benefits of the co-ordinator coming into clinic and linked closely with the clinical team.

> *"You would be able to ask the nurse and team, or the clinicians know also this person is interested. Can you tell me a bit of information about them and the doctors or the nurses, whoever they see, will say actually there have been, you know, troubles XY and Z or they're not adhering to their medication or whatever reasons." (NHS)*

One of the key considerations is the divide between peer support and social welfare support e.g., with housing, benefits etc. Some clinical services already have a member of the team providing a broad heath support role in which case the divide between the two roles will need to be clear to avoid duplication or concern about a loss of a valued aspect of the existing role. For services where there is no such role the boundaries between peer support and services provided by other agencies (or gaps in provision) will need to be clearly delineated.

> *"… so, our peer mentors aren't trained to help with welfare benefits or anything like that, but they're trained to signpost and to make referrals." (PSS)*

> *"It also is also a little bit about that compartmentalization of the roles, so if somebody, if a mentor starts being too formal or too much like a support worker, then actually the benefit of the fact that they're a peer starts to disappear."* (PSS)

> *"... if you didn't have a middle person, the clinic would refer somebody for peer support, you would give that to a peer mentor. Peer mentor would make contact and then it will be "I need help with my benefits" that peer mentor was in a very awkward situation there where they've gotta say to them actually it's not what I do." (NHS)*

> *"So, the moment a project like this gets up and running, you were gonna have a huge amount of referrals coming through that are not necessarily peer based that you'll have to shuffle through because they don't have a support net, a system in place. So, they're just gonna be like ohh this person needs help. Please. Just you deal with it." (NHS)*

> *"Because anything that doesn't fall under the criteria of peer has to fall somewhere. And if you don't have that already in place, then that is gonna fall on the clinicians, the nurses, the health advisors that they don't have that time or the resources to take on as well." (NHS)*

This links with a theme connected with the remit of the NGO, whether it should be a "one-stop shop". There is a tendency, primarily driven by the stigma and discrimination experienced by people living with HIV, for the HIV services to try and support people with all their health and social needs.

Priority for service users and providers: With personal and health resources already stretched one of the contextual questions to be addressed was the extent to which the development of a peer support service would be a priority for service users and providers. There was a sense that it was now receiving attention from clinicians and government:

> *"I think I think everybody is very committed to it and it's nice to see that it's a priority for policymakers." (NHS)*

The clinicians mentioned that there was investment in peer support more generally across health conditions in England although not specifically for HIV. This they thought was because "*…they work hard, it's cheap and it works" (NHS)*. Stakeholder's perceptions of government priorities were that greater emphasis, and potential budgetary support, was going to be placed on rapid testing and awareness raising to reduce late diagnosis rather than peer support. In sexual health services in Wales there is a feeling that they have tried a "bottom up" approach to develop PSS for several years but they have been unsuccessful. The size of the drugs budget for HIV dominates discussions and that until antiretroviral therapy is separated from the budget there is virtually no chance for anything else to be prioritised by NHS services.

> *"We've had very little success. We had a big sexual health strategy document that came out a few years ago and we were promised it would end up in an IMTP, a national IMTP, and that it would very likely end up in health board IMTPs. And it didn't appear in either, and it's just died a death. And that's really demoralizing. So, I would hate for that to happen with this." (NHS)*

> *"…we've got our IMTP process, our planning process. So, we can raise our needs within that process. But we're very small fry compared to you know, the bigger needs and the amount of money that gets allocated to the UHB." (NHS)*

However, if the question about prioritisation were not related to funding, ie if peer support were part of a "commissioned costed process" then many clinical teams would definitely be supportive of it. They feel that realistically the only way this will happen is with government impetus: "*try and get that ministerial backing and get that top-down influence" (NHS)*. Also, a recognition that peer support is in the British HIV standards and should be provided as part of good quality routine care. However, it was important to make sure that the support for the development was throughout the organisation not just at a senior level.

> *"At all levels, that's the crucial thing. It would have to be higher up to get people to do it, but then also the danger with that, when that does happen, it comes from high up. People just go, oh yeah, we're doing it. And then like, you know, then it doesn't happen, or they say they're doing it and it doesn't happen sort of on the ground. So, you need sort of all levels of parties locally to actually sort of get it to happen. You'd need that sort of local involvement, engagement*." (NHS)

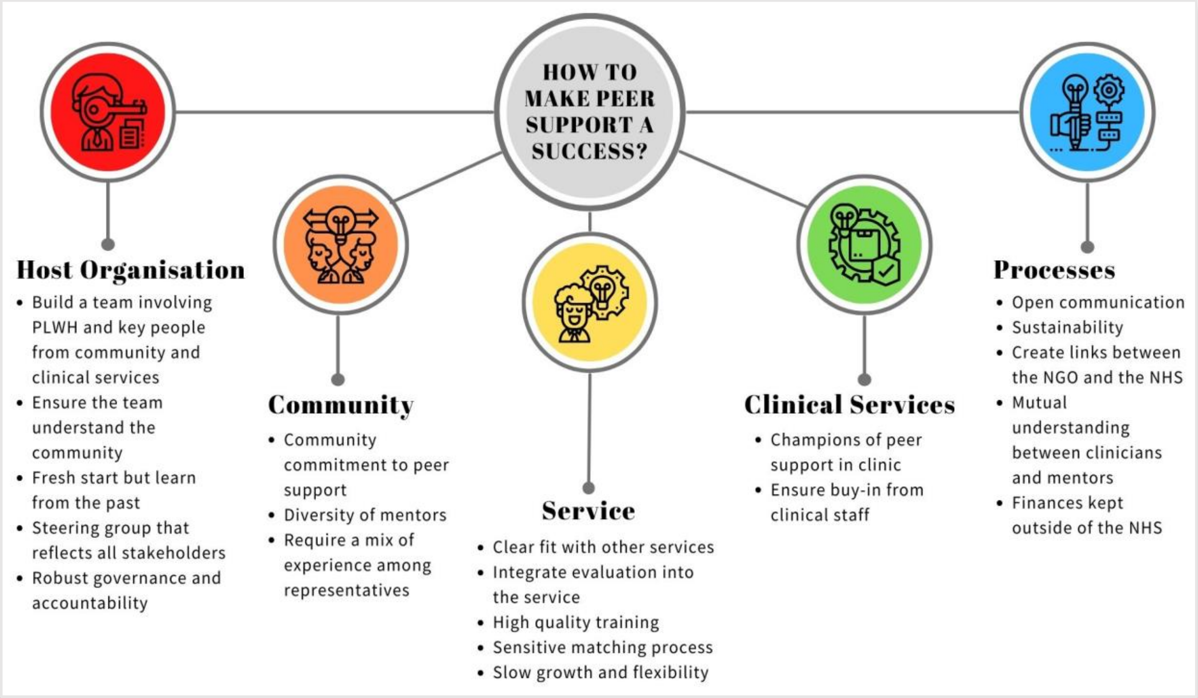
Without having interviewed service users (who are not PSS providers) it is not possible to know from the interviews what people living with HIV would say in response to this question, but the comments made by service providers most reflected the life pressures on people:

> *"I just get an impression at the moment lots of people are struggling financially and as a result of that, there's a knock-on effect on food banks again" (NHS)*
>
> *"In terms of the different type of support that people need, I think at the moment people aren't asking for this type of support." (NHS)*
>
> *"I've had multiple conversations with people about housing and benefits and financial help this morning." (NHS)*

What do we need to make it a success?

The stakeholders were asked what they thought was needed to make a PSS for people living with HIV in Wales a success. The responses have been included in the previous sections in relation to the principles, organisational structure, and the context. Here the main themes are brought together, captured as a potential blueprint for some of the key aspects of the service, in Figure 4. These themes are discussed in relation to the findings from the survey and the systematic review in Chapter 5.

Figure 4. Elements required to make Peer Support as success in Wales.



HOW TO MAKE PEER SUPPORT A SUCCESS?

Host Organisation
- Build a team involving PLWH and key people from community and clinical services
- Ensure the team understand the community
- Fresh start but learn from the past
- Steering group that reflects all stakeholders
- Robust governance and accountability

Community
- Community commitment to peer support
- Diversity of mentors
- Require a mix of experience among representatives

Service
- Clear fit with other services
- Integrate evaluation into the service
- High quality training
- Sensitive matching process
- Slow growth and flexibility

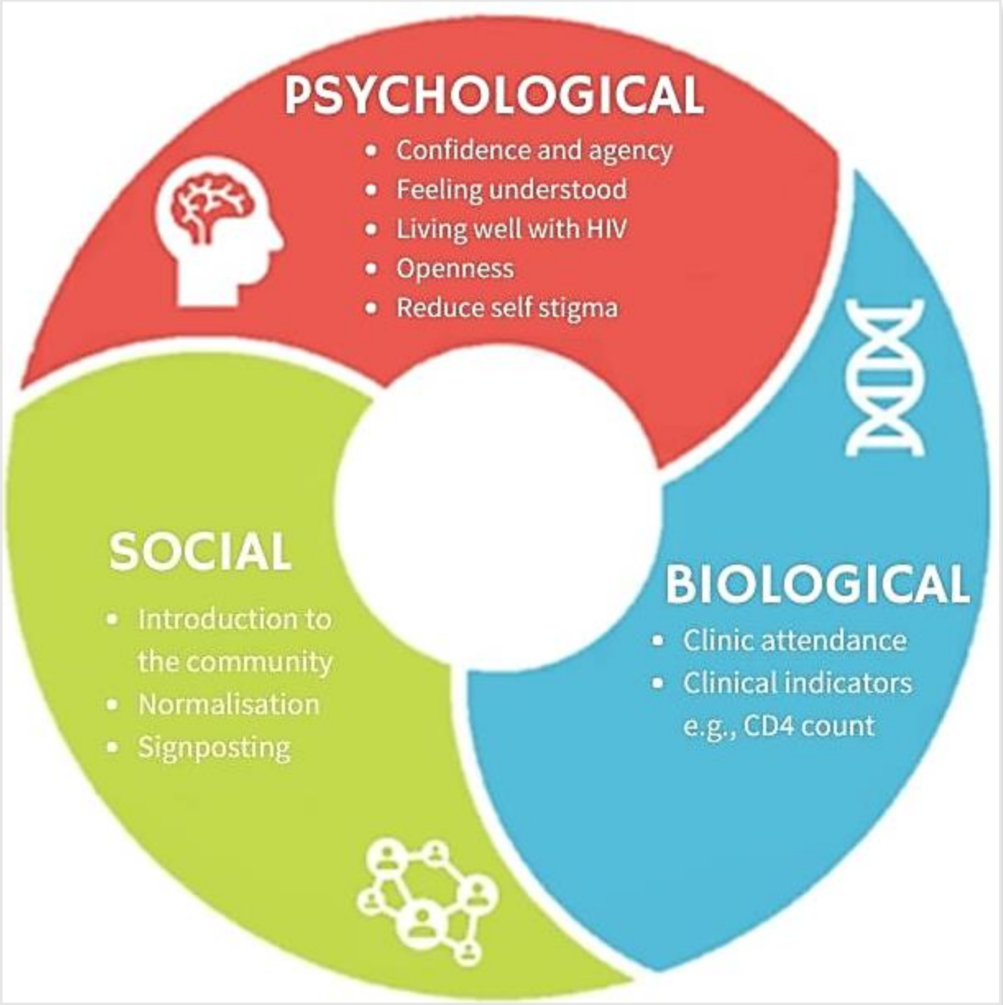
Clinical Services
- Champions of peer support in clinic
- Ensure buy-in from clinical staff

Processes
- Open communication
- Sustainability
- Create links between the NGO and the NHS
- Mutual understanding between clinicians and mentors
- Finances kept outside of the NHS

How do we know if peer support has been a success? What should we measure?

When stakeholders were asked how they would know if a PSS had been a success and was delivering what was needed, most of the responses were related to individual-level outcomes for the person being supported. These suggested outcomes primarily fell into biopsychosocial categories (see Figure 5). In addition to this there were stakeholders who felt that the outcomes should be identified by people living with HIV – what would they define as success? A few stakeholders mentioned the importance of incorporating outcomes for the mentors including career development, as they use their experience as a mentor to move onto other paid roles, either within the NGO or related roles in other organisations. Finally, at a wider system level, some more organisational focussed outcomes should be included, for example the quality of the relationship between the NGO and the NHS, and the accountability of the NGO, for example in relation to resource use, social return on investment or a health economic measure.

Figure 5. Outcomes used to measure the success of a Peer Support Service.



4.4 CONCLUSIONS

The aim of the engagement with stakeholders who work in the HIV sector was to draw on their experiences of peer support services, both in Wales and elsewhere, to help identify potential factors that would impact on the development of a Wales-based peer support service for people living with HIV. From the discussions with clinicians and people involved with providing peer support, the support in principle for a Wales based service was clear. However, with many of the stakeholders having experienced the collapse of previous services in Wales, there were some essential components that would need to be put in place before they would have confidence in such a service. These include some core principles around ethos, sustainability, and governance; a co-design model with service users and other stakeholders; open communication with clinical services from the start and transparent and auditable delivery plans. These key principles have been summarised, added to the service user perspectives identified via the survey and incorporated into the logic model presented in the following chapter.

Chapter 5

A SYNTHESIS OF RESULTS

5.1 OVERVIEW

The aim of this report was to explore the acceptability of a peer support service for people living with HIV in Wales, to identify the essential components of that service from the perspectives of the stakeholders and their perceptions of potential facilitators and barriers to its development. By interviewing professional stakeholders and surveying people living with HIV in Wales we wanted to establish if this would be seen as a positive service development and, if so, to highlight some of the key issues that would need to be addressed if a decision was made to create such a service. As described in the introduction, this work draws on O'Cathain and colleagues' framework for the development of a complex intervention to improve health and healthcare: They describe the key principles of intervention development as being "that it is dynamic, iterative, creative, open to change and forward looking to future evaluation and implementation" (O'Cathain et al 2019a P2). This report is an early part of such an intervention development and as such it raises themes and ideas which can be used in the decision-making and implementation process.

5.2 DISCUSSION

Overall message

The development of a peer support service for people living with HIV in Wales would be broadly welcomed but it needs to be done with significant care and with the long-term in mind. This development will start the process of bringing Wales in line with the British HIV Association standards (BHIVA, 2018) and National Standards for Peer Support in HIV (National Voices, 2017), that everyone living with HIV should have access to PS.

There are some key service ingredients identified where the stakeholder group views are very much in accord. Inevitably at this early stage there are areas with multiple perspectives and so the work done thus far may well pose as many questions as it answers. We have highlighted the areas of difference and where decisions will need to be made and we suggest some frameworks that may be useful in those next steps in the developmental process.

With the current treatment and prevention toolkits (Eisinger et al, 2019) the drive to the target of zero new diagnoses in Wales by 2030 is in theory achievable. However, there are many hurdles between theory and reality, and one of the key barriers is HIV-related stigma. As detailed in the review chapter, stigma, mental health, and quality of life are all inter-related. The findings of the review indicate that PS is associated with decreases in enacted- and self-stigma, depressive symptoms, and anxiety. There were mixed findings on quality of life, potentially owing to the few studies measuring this and varied measures used. Despite the lack of UK-based studies to include in the review, the PS services described mapped reasonably well onto the UK national standards. However, there was a lack of information and evidence of the monitoring, measuring and evaluation processes that would be an ongoing part of the service. This latter point may reflect on the service itself, the context within which it was studied (i.e., a short-term piece of research) or simply the write-up. Based on the Berg et al systematic review (Berg et al 2021) and the additional review work described as part of this project, the overall conclusion is that PS can and should be an important part of the UK approach to decrease HIV-related burden. However more studies are needed to describe the nature of the programmes sufficiently that they can be replicated, to continue evaluating the effectiveness and to consider the relationship between the intervention and the context in which it is delivered.

The systematic review conclusion that PS can play a positive part in HIV services, resonated with the stakeholder's views about the potential value for individuals of a PS service. The survey responses identified the benefits of a shared experience in practical and emotional domains, such as sharing knowledge about services and support and also dealing with stigma and how to tell friends and family. Support for people soon after diagnosis to reduce their sense of isolation and coping alone was highlighted, with PS helping to challenge the stigma and assumptions someone might have about living with HIV. The service providers similarly identified individual level and social outcomes they would hope to see as a result of PS such as reducing stigma, feeling understood, confidence, normalisation and signposting to services and support. In addition, they suggested there could also be some positive impact on more clinic-focussed outcomes, such as attendance and clinical indicators of living well with HIV. The findings of this project map closely onto the National Standards for Peer Support for HIV (referred to as the National Standards from here on) and as such those standards provide a clear set of auditable indicators which should be incorporated into the development of the new service.

There was broad consensus on many of the questions about PSS delivery between people living with HIV in Wales and the professional stakeholders: agreement that an All-Wales PSS for people living with HIV in Wales is needed. It must be predominantly delivered by and for people living with HIV but with a strong link to, and endorsement by the clinical services that people trust. It must be sustainable, and seen to be sustainable, beyond the short-term: this includes having the finance in place for the host organisation to build the service in such a way that people can have confidence that it will last. The complexities of NHS finance are such that there was an unequivocal message from clinicians that the financing of the PSS needs to sit outside of the NHS structure permanently. Perceiving such a service as sustainable goes well beyond finance, it is about the service being designed in such a way that rather than being "parachuted in" it can grow organically over time and respond to local needs and context. PS inherently depends on the involvement and commitment of the community: the engagement of people from across the community, reflecting the diversity of people living with HIV, will be essential.

Key ingredients for a host organisation

In the absence of an obvious host organisation, the service providers have given a clear steer on the key ingredients they would like to see as part of the host organisation, based on their experiences with PSSs in the UK. Governance and a monitoring plan with a steering group comprising representation of all the main stakeholders would be necessary, combined with strong working links with the NHS teams. In determining the nature and functioning of the host organisation, it is important to be mindful of the context of the history of PS for people living with HIV in Wales.

The organisational failures of previous services have left clinical service providers in Wales very wary of PS in HIV; there were also negative experiences described by recipients of the previous services that came through the survey. Moving forward there are distinct lessons to be learned and these underpin many of the suggestions made by stakeholders described earlier about what a service needs to be a success. Most revolve around communication with all stakeholders, leadership teams drawn from within the community being served, a sensitive, needs-led approach to growth and a robust monitoring and evaluation plan, (for example as outlined in the National Standards), to ensure that the service is delivering what was asked for. The format of the connection, and day to day liaison between the new host organisation and the NHS teams, is a crucial component of the PSS design and needs to be determined as part of the relationship building once the host organisation is identified. The National Standards describe this as an agreed pathway which can be tiered depending on resources. For many people living with HIV the NHS team are the most trusted source of support so their endorsement of the organisation and service will be vital.

Whilst a new start is needed with a different host organisation overseeing and leading the PSS, it is also important not to automatically reject existing provisions or believe that we need to start from scratch in designing a service. There were positive experiences from previous services that need to be acknowledged, some people living with HIV described those services as having been helpful and there are pockets of services that continue to thrive. There are excellent PSSs in the UK that Wales can learn from, and there are opportunities to use current UK-wide services (for example the Terrence Higgins Trust chatline service) which people find helpful and which could be included in a menu of provision.

The challenges of stigma

Any service supporting the needs of people living with HIV must be designed with the impact of stigma in mind. The societal stigma surrounding HIV affects the way the individual, their family and friends, their social and work context and their culture, deal with the diagnosis. In relation to PS, it affects how confident people feel about being open about their diagnosis with others, making contact, being part of an HIV-related service etc. The need for confidentiality and sensitivity to this in all aspects of any PSS is paramount, as a service would fail if it did not attend sufficiently to this issue. Both groups of stakeholders flagged confidentiality/anonymity as a major challenge for a PSS, recruiting supporters and enabling people in need of the service to access it. This could be a virtuous circle of influence, that those who feel validated and supported by a PSS could be more willing to identify publicly as living with HIV which will help break down the stigma associated with HIV, allowing more people to come forward. However, breaking into that cycle to get it moving is difficult and a powerful public campaign to create more awareness of the realities of living well with HIV in the 2020s might be necessary as the first step.

Designing a peer support service for Wales

There are many pragmatic decisions that need to be made about the design of the service where there were multiple opinions about what would be part of a service: as indicated at the start, this study raises questions it is not equipped to answer. For example, whether the peer supporter role is paid was a topic on which people had strong opinions, reflecting both sides of the volunteer-paid role divide. There was consensus that an online provision of one to one and group support would be an important early step in the PSS. However, there were different emphases placed by the two different groups of stakeholders on the need for face-to-face, one-to- one support. For the people living with HIV this type of support was seen as essential whilst the practitioners were concerned by difficulties they had experienced with this type of provision (in relation to confidentiality and the nature of that relationship for both parties for example) such that they would not prioritise it in the early development of the service.

The quality of the training and support provided to the peer mentors will be central to the success of the service and to the wellbeing of mentors and people receiving the service alike. There are established training programmes in the UK which Wales could potentially commission, but beyond making sure it was high quality training, there was no particular steer on the type of training that would be preferred. The National Standards provide several auditable indicators to ensure the quality of the training. The process of matching people in any, one-to one model of support was clearly going to be crucial to get right but people had different views on the approach. Similarly, service providers had mixed views about targeting those who were newly diagnosed. The National Standards set an indicator of 90% of people newly diagnosed being offered or signposted to PS at their first clinic appointment. For people living with HIV this was the group who they felt would benefit the most. However, from the open text responses this is a view formed with hindsight rather than reflecting their current status, so it would be important to gauge this with those closer to diagnosis.

These types of design questions are going to be critical in the early days of the service development. Reflecting on the responses in this project in the light of a taxonomy of approaches to intervention development (O'Cathain et al 2019b), the best fit is with a partnership model where the service users participate equally with the providers in the decision-making. If the service is to meet the stakeholders needs articulated in this project, then partnership will underpin the ethos and model of the service. Accordingly, these type of design and delivery questions need to be discussed as part of a co-design process between the host organisation, people living with HIV and people delivering NHS and related services. If these design decisions are made externally or by the organisation without full involvement, then there is a significant risk of history repeating itself and the service failing.

There will be an iterative process between the development of the PSS model, and the implementation, i.e., putting the intervention into practice. The work on the core components of the PSS needs to be planned in advice and agreed: The information from this project that can contribute to this discussion (including questions still to be answered) is presented in logic model form below (figure 6). Often there is a temptation to start delivery before all the processes are agreed, with a view to starting small and seeing what happens. However, this is a complex intervention within a complex system and so deciding and documenting decision-making processes, monitoring plans, potential timescales, programme theory, outcome measurement etc are as important as deciding the design of the service itself.

Using Theoretical Frameworks for the next steps

As with intervention development, there are many frameworks to guide implementation (impsciuw.org). These frameworks are designed to help bridge the gap between theory and practice: As described by Nilsen (2015), some are more focussed on describing how an intervention can be developed into practice (process models) some focus on evaluating implementation and others focus more on understanding and explaining what influences implementation outcomes (e.g., determinant frameworks). All these domains will be of interest at different points of implementation of a PSS and the decision about which models to use will rest with the host organisation and their steering group. Here we outline one example of each of the three different types of frameworks to give a flavour of how they might be used. In general, taking a broader perspective guided by a framework during the developmental phases will facilitate a more reflexive position, enabling the organisational team to adjust and react to the learning as they and the intervention take shape.

Whilst the service is in the early days of its development, the process models offer potentially the most useful framework to help guide those early activities. For example, the Quality Implementation Framework (Meyers et al 2012) identifies 14 steps across four phases:

1. Initial considerations regarding the host setting
2. Creating a structure for implementation

3. Ongoing structure once implementation begins
4. Improving future applications

Each of the 14 steps include questions to ask which could be useful to guide the thinking e.g., in phase 1 there are questions about what problems the innovation addresses and what the organisation's mission and priorities are in terms of fit with the innovation and setting; in phase 2 there are questions about roles and responsibilities etc. A framework such as this can facilitate a planning or steering group for example taking a step back, thinking about their activities through an implementation lens. It can offer questions to explore areas of consensus, similarities and differences in the group and issues that need more development.

Evaluation and monitoring, which would include implementation and outcome measurement, was one of the three UK standards for PS, but from the review of PS this was the standard that was less evident. Embedding evaluation at the start of implementation ensures that the delivery team can gain a better understanding of how their intervention is working and adapt their approach in response to feedback. If evaluation is left until a later date it will feel like a judgemental imposition rather than part of the reflexive cycle of learning and development. One example of an evaluation framework is the RE-AIM framework (Reach, Efficacy, Adoption, Implementation, Maintenance) (Glasgow et al, 2011). RE-AIM has been used extensively to guide implementation in public health interventions. It is designed primarily to be pragmatic, for use in non-research settings rather than as a research-focussed tool.

- Reach refers to the number of people and representatives of the people who participate in the service (a factor that has been identified here as key, to make sure it is appealing across the diversity of the population)
- Effectiveness looks at the impact of the service on important outcomes (e.g., quality of life)
- Adoption looks at the take-up across settings (in Wales this could be across different Health boards)
- Implementation refers to the fidelity of peoples approaches to the service specification, consistency of approach etc (based on the programme theory and model)
- Maintenance refers both to the ongoing nature of the service delivery and, at an individual level, the longer-term effects of receiving the intervention.

The RE-AIM website (https://re-aim.org/) provides tools including a planning checklist of what they describe as "thought-questions" for each of the five dimensions, identifying key issues to be considered when planning an intervention.

Figure 6. Initial logic model for a Peer Support Service in Wales

SITUATION

Currently there is no peer support service provided for PLWH in Wales. Previous attempts to provide peer support in Wales were unsuccessful.

PRIORITIES

- Develop a steering group with representation of all key stakeholder groups (PLWH, clinical services, related NGOs).
- Acquire medium-long term funding outside NHS.

KEY INGREDIENTS

- All Wales service accessible for all PLWH in Wales.
- PLWH working in and with the organisation.
- Decisions through partnership eg co-design model.
- New provider of PSS.
- HIV focussed host organization.
- Salaried coordinator(s).
- Links with clinical services which are transparent.
- PS that spans across the life course of a person.
- Quality assured mentor training.
- Resources: advertising etc.
- PS champion in each clinic.
- Robust governance and monitoring systems agreed at outset.

ACTIVITIES

- Recruit and train supporters.
- Supervise and mentor supporters.
- Provide on-line potentially anonymous PS.
- Group and individual support available.
- Use external resources if appropriate.
- Public facing activities in clinic to advertise service.
- Matching of mentor to person requesting support.
- Signposting to other services.

TO BE DECIDED

- Service emphasis: clinical or psychosocial?
- Paid or volunteer roles?
- Lead with a publicity campaign?
- Mentors spending time in clinic?
- What is the pathway into service?
- What process to make face-to-face support safe?
- Model of training and training provider?
- Role of service with those newly diagnosed?

MECHANISMS OF ACTION

- Reduce self-stigma.
- Increase knowledge of person accessing service.
- Peer modelling of living well with HIV.
- Reduce isolation.
- Increase connectedness to clinic and community.
- Increase engagement with clinic and willingness to speak openly with the clinic team.
- Greater knowledge about HIV within the general population, reducing social stigma.
- Improved adherence to medications.

OUTCOMES

- Improved quality of life.
- Increased confidence and self-esteem.
- Improved mental health.
- Improved clinic attendance.
- Clinical outcomes (TBC).
- Personal development outcomes (eg taking up training or job).

An All-Wales PS model will be delivering a service in very different circumstances with different populations. One of the first tasks of the development of a programme theory and model will be to decide what the "core" offer is to all people living with HIV in Wales, which is likely to be a combination of ethos, approach, and resource. Then they will consider what else might need to be in place in different areas and how Health Boards for example might configure their services differently (e.g., in some health boards it might not be practicable to have a peer supporter in clinic due to numbers and space, but for others it might). These variations may change over time as each area responds to local needs and community response. Given this anticipated variation, it is going to be important to include contextual factors in any implementation framework but also to identify what conditions might influence implementation success. The Consolidated Framework for Implementation Research (CFIR) addresses this with constructs in five domains:

1. Intervention Characteristic
2. Outer Setting
3. Inner Setting
4. Characteristics of Individuals and
5. Process.

As with RE-AIM, there are extensive resources available on the CFIR website that make this framework more accessible (www.cfirguide.org). The CFIR framework was used to help inform the interview schedule in this study to consider the facilitators and barriers to developing PSS in Wales. As described by King et al who looked at the use of RE-AIM and CFIR together 'examining the presence or absence of CFIR constructs can explain "why" implementation was or was not successful, while RE-AIM describes outcomes in terms of "who, what, where, how, and when"' (King et al 2020 P2).

5.3 REFLECTIONS

This project has been a pragmatic, responsive study, bringing together views in a timely way to support the development of the Welsh Government action plan. It has included contributions from across several Health Boards and people with extensive experience of PSSs in Wales and in England. It provides an opportunity to maximise the impact of the academic work reviewing the literature and it has been an opportunity to demonstrate how government, clinicians, professional stakeholders, and academics can work together. Completing this type of work at speed inevitably limits some aspects, and due to the necessary safeguards around contacting people receiving NHS care, we could only contact people living with HIV via social media and other networks. Survey work is limited in the type of information it can glean and the limitations have been discussed. However, the number and quality of responses received was positive and this provides a starting point from which the ongoing service can build. The stakeholder community around HIV in Wales is a close one: having a lead investigator for this work whose expertise was in PS rather than HIV may have been of benefit in terms of looking at the questions to be answered with fresh eyes, from a neutral position. Finding a way to articulate some of the issues that arose from the collapse of the previous service was important to pave the way for change and a fresh start.

We were transparent from the outset that, due to the timescale and resource, this work would not provide an adequate platform for the voices of people living with HIV. However, on reflection this is not necessarily a disadvantage. If developing a PSS was found to be acceptable, as it has been, then the work by the host organisation would need to be based on a partnership model from the start. If we were presenting a much more firmly articulated description of a service, that would in effect start the service off from the wrong point: risking a repeat of the approach of the previous PSS. This may be less polished, and may take more time, but building co-design into the foundations of this service can only be of benefit to the end result. This is the opportunity for Wales to create its own peer support service for the people living with HIV in Wales. Those leading the process need to understand the Wales-wide context; they need to learn from all the work that has gone before and create a quality service, developed by and for the people living with HIV in Wales.

REFERENCES

Akena, D. et al. 2012. The association between aids related stigma and major depressive disorder among HIV-positive individuals in Uganda. PLoS One 7(11), p. e48671. doi: 10.1371/journal.pone.0048671

Armoon, B. et al. 2021. Socio-demographic, clinical and service use determinants associated with HIV related stigma among people living with HIV/AIDS: a systematic review and meta-analysis. BMC Health Services Research 21(1), p. 1004. doi: 10.1186/s12913-021-06980-6

Asrat, B. et al. 2021. Acceptability and feasibility of peer-administered group interpersonal therapy for depression for people living with HIV/AIDS-a pilot study in Northwest Ethiopia. Pilot Feasibility Stud 7(1), p. 147. doi: 10.1186/s40814-021-00889-x

Aung, S. et al. 2021. Evaluation of peer-to-peer HIV counseling in Myanmar: a measure of knowledge, adherence, and barriers. AIDS Care, pp. 1-9. doi: 10.1080/09540121.2021.1902929

Bantjes, J. and Kagee, A. 2018. Common mental disorders and psychological adjustment among individuals seeking HIV testing: a study protocol to explore implications for mental health care systems. Int J Ment Health Syst 12, p. 16. doi: 10.1186/s13033-018-0196-0

Barré-Sinoussi, F. et al. 1983. Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). Science 220(4599), pp. 868-871. doi: 10.1126/science.6189183

Basavaraj, K. H. et al. 2010. Quality of life in HIV/AIDS. Indian journal of sexually transmitted diseases and AIDS 31(2), pp. 75-80. doi: 10.4103/0253-7184.74971

Berg, R. C. et al. 2021. The effectiveness of peer-support for people living with HIV: A systematic review and meta-analysis. PLoS One 16(6), p. e0252623. doi: 10.1371/journal.pone.0252623

Brashers, D. E. et al. 2017. Taking Control: The Efficacy and Durability of a Peer-Led Uncertainty Management Intervention for People Recently Diagnosed With HIV. Health Commun 32(1), pp. 11-21. doi: 10.1080/10410236.2015.1089469

British HIV Association (2018) Standards of Care for people living with HIV. https://www.bhiva.org/standards-of-care-2018 [last accessed 4.8.22]

Brown, G. R. et al. 1992. Prevalence of psychiatric disorders in early stages of HIV infection. Psychosom Med 54(5), pp. 588-601. doi: 10.1097/00006842-199209000-00006

Brown, L. B. et al. 2021. The interplay between HIV and COVID-19: summary of the data and responses to date. Curr Opin HIV AIDS 16(1), pp. 63-73. doi: 10.1097/coh.0000000000000659

Cabral, H. J. et al. 2018. Peer Support and the HIV Continuum of Care: Results from a Multi-Site Randomized Clinical Trial in Three Urban Clinics in the United States. AIDS Behav 22(8), pp. 2627-2639. doi: 10.1007/s10461-017-1999-8

Catalan, J. et al. 2011. HIV infection and mental health: suicidal behaviour--systematic review. Psychol Health Med 16(5), pp. 588-611. doi: 10.1080/13548506.2011.582125

Centers for Disease Control [CDC]. 2001. Morbidity and Mortality Weekly Report. Available at: https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a1.htm#:~:text=Twenty%20years%20ago%2C%20on%20June,homosexuals%22%3B%20two%20had%20died [Accessed: 11 December 2021]

Chambers, L. A. et al. 2015. Stigma, HIV and health: a qualitative synthesis. BMC Public Health 15, p. 848. doi: 10.1186/s12889-015-2197-0

Charles, B. et al. 2012. Association between stigma, depression and quality of life of people living with HIV/AIDS (PLHA) in South India – a community based cross sectional study. BMC Public Health 12(1), p. 463. doi: 10.1186/1471-2458-12-463

Chime, O. H. et al. 2019. Examining the effect of peer-support on self-stigma among persons living with HIV/AIDS. Pan Afr Med J 34, p. 200. doi: 10.11604/pamj.2019.34.200.17652

Department of Health & Social Care. 2011. The mental health strategy for England. Available at: The mental health strategy for England - GOV.UK (www.gov.uk) [Accessed: 10 February 2022]

Department of Health & Social Care. 2016. Care Act Factsheets. Available at: Care Act factsheets - GOV.UK (www.gov.uk) [Accessed: 10 February 2022]

Desai, K. T. et al. 2020. Environment and psychosocial factors are more important than clinical factors in determining quality of life of HIV-positive patients on antiretroviral therapy. Trop Doct 50(3), pp. 180-186. doi: 10.1177/0049475520908180

Domlyn, A. M. et al. 2020. Stigma and psychosocial wellbeing among children affected by parental HIV in China. AIDS Care 32(4), pp. 500-507. doi: 10.1080/09540121.2019.1687834

Earnshaw, V. A. and Chaudoir, S. R. 2009. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. AIDS Behav 13(6), pp. 1160-1177. doi: 10.1007/s10461-009-9593-3

Earnshaw, V. A. et al. 2013. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS Behav 17(5), pp. 1785-1795. doi: 10.1007/s10461-013-0437-9

Eisinger RW, Folkers GK, Fauci AS, Ending the Human Immunodeficiency Virus Pandemic: Optimizing the Prevention and Treatment Toolkits, Clinical Infectious Diseases, Volume 69, Issue 12, 15 December 2019, Pages 2212–2217, https://doi.org/10.1093/cid/ciz998

Eisinger, R. W. et al. 2019. HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable. JAMA 321(5), pp. 451-452. doi: 10.1001/jama.2018.21167

Elliott, S N. & Von Brock Treuting, M. The behaviour intervention rating scale: Development and validation of a pre-treatment acceptability and effectiveness measure, Journal of School Psychology, 1991; 29(1):43-51, https://doi.org/10.1016/0022-4405(91)90014-I.

Fanales-Belasio, E. et al. 2010. HIV virology and pathogenetic mechanisms of infection: a brief overview. Ann Ist Super Sanita 46(1), pp. 5-14. doi: 10.4415/ann_10_01_02

Fast-Track Cities. 2021. London Getting To Zero. Available at: https://fasttrackcities.london/ [Accessed: 09 December 2021]

Geter, A. et al. 2018. HIV-Related Stigma by Healthcare Providers in the United States: A Systematic Review. AIDS Patient Care STDS 32(10), pp. 418-424. doi: 10.1089/apc.2018.0114

Giordano, T. P. et al. 2016. A Randomized Trial to Test a Peer Mentor Intervention to Improve Outcomes in Persons Hospitalized With HIV Infection. Clin Infect Dis 63(5), pp. 678-686. doi: 10.1093/cid/ciw322

Glasgow RE, Vogt TM, and Boles SM, 1999: Evaluating the public health impact of health promotion interventions: the RE-AIM framework.American Journal of Public Health 89, 1322_1327, https://doi.org/10.2105/AJPH.89.9.1322

Glynn, T. R. et al. 2019. High Levels of Syndemics and Their Association with Adherence, Viral Non-suppression, and Biobehavioral Transmission Risk in Miami, a U.S. City with an HIV/AIDS Epidemic. AIDS Behav 23(11), pp. 2956-2965. doi: 10.1007/s10461-019-02619-0

Government of Ireland. 2020. Sharing the Vision: A Mental Health Policy for Everyone. Available at: gov.ie - Sharing the Vision: A Mental Health Policy for Everyone (www.gov.ie) [Accessed: 10 February 2022]

Greenwood, G. L. et al. 2022. HIV-Related Stigma Research as a Priority at the National Institutes of Health. AIDS Behav 26(Suppl 1), pp. 5-26. doi: 10.1007/s10461-021-03260-6

Halkitis, P. N. et al. 2017. Mental Health, Psychosocial Challenges and Resilience in Older Adults Living with HIV. Interdiscip Top Gerontol Geriatr 42, pp. 187-203. doi: 10.1159/000448564

Harris, G. E. and Larsen, D. 2007. HIV peer counseling and the development of hope: perspectives from peer counselors and peer counseling recipients. AIDS Patient Care STDS 21(11), pp. 843-860. doi: 10.1089/apc.2006.0207

Hedge, B. et al. 2021. HIV-related stigma in the UK then and now: to what extent are we on track to eliminate stigma? A qualitative investigation. BMC Public Health 21(1), p. 1022. doi: 10.1186/s12889-021-11000-7

Hemelaar, J. et al. 2020. Global and regional epidemiology of HIV-1 recombinants in 1990-2015: a systematic review and global survey. Lancet HIV 7(11), pp. e772-e781. doi: 10.1016/s2352-3018(20)30252-6

Herron, L.-M. et al. 2022. Enduring stigma and precarity: A review of qualitative research examining the experiences of women living with HIV in high income countries over two decades. Health Care for Women International 43(1-3), pp. 313-344. doi: 10.1080/07399332.2021.1959589

Higgins JPT et. al. 2019. Cochrane Handbook for Systematic Reviews of Interventions. 2nd Edition. Chichester (UK): John Wiley & Sons.

Hoare, J. et al. 2021. Global Systematic Review of Common Mental Health Disorders in Adults Living with HIV. Curr HIV/AIDS Rep 18(6), pp. 569-580. doi: 10.1007/s11904-021-00583-w

Hoffmann, T. C. et al. 2014. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. Bmj 348, p. g1687. doi: 10.1136/bmj.g1687

Holubova, M. et al. 2016. Self-stigma and quality of life in patients with depressive disorder: a cross-sectional study. Neuropsychiatric disease and treatment 12, pp. 2677-2687. doi: 10.2147/NDT.S118593

Hossain, M. M. et al. 2020. Epidemiology of mental health problems in COVID-19: a review. F1000Res 9, p. 636. doi: 10.12688/f1000research.24457.1

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2014. 90-90-90 An ambitious treatment target to help end the AIDS epidemic. Available at: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf [Accessed: 24 November 2021]

Kamen, C. et al. 2016. The Impact of Stigma and Social Support on Development of Post-traumatic Growth Among Persons Living with HIV. J Clin Psychol Med Settings 23(2), pp. 126-134. doi: 10.1007/s10880-015-9447-2

Kellett, N. C. and Gnauck, K. 2016. The intersection of antiretroviral therapy, peer support programmes, and economic empowerment with HIV stigma among HIV-positive women in West Nile Uganda. Afr J AIDS Res 15(4), pp. 341-348. doi: 10.2989/16085906.2016.1241288

Kemp, C. et al. 2016. Mixed-Methods Evaluation of a Novel, Structured, Community-Based Support and Education Intervention for Individuals with HIV/AIDS in KwaZulu-Natal, South Africa. AIDS Behav 20(9), pp. 1937-1950. doi: 10.1007/s10461-016-1386-x

Khademi, N. et al. 2021. Quality of life of HIV-infected individuals: insights from a study of patients in Kermanshah, Iran. BMC Infectious Diseases 21(1), p. 203. doi: 10.1186/s12879-021-05908-z

King DK, Shoup JA, Raebel MA., Anderson CB, Wagner NM., Ritzwoller DP., Bender BG. (2020) Planning for Implementation Success Using RE-AIM and CFIR Frameworks: A Qualitative Study. Frontiers in Public Health vol 8 DOI=10.3389/fpubh.2020.00059

Lesko, C. R. and Bengtson, A. M. 2021. HIV and COVID-19: Intersecting Epidemics With Many Unknowns. Am J Epidemiol 190(1), pp. 10-16. doi: 10.1093/aje/kwaa158

Levy, J. A. et al. 1984. Isolation of lymphocytopathic retroviruses from San Francisco patients with AIDS. Science 225(4664), pp. 840-842. doi: 10.1126/science.6206563

Li, G. et al. 2020. Effects of Depression, Anxiety, Stigma, and Disclosure on Health-Related Quality of Life among Chronic Hepatitis B Patients in Dalian, China. Am J Trop Med Hyg 102(5), pp. 988-994. doi: 10.4269/ajtmh.19-0007

Lifson, A. R. et al. 2015. Implementation of a Peer HIV Community Support Worker Program in Rural Ethiopia to Promote Retention in Care. Journal of the International Association of Providers of AIDS Care (JIAPAC) 16(1), pp. 75-80. doi: 10.1177/2325957415614648

Logie, C. and Gadalla, T. M. 2009. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. AIDS Care 21(6), pp. 742-753. doi: 10.1080/09540120802511877

Luseno, W. K. et al. 2021. Pathways to Depression and Poor Quality of Life Among Adolescents in Western Kenya: Role of Anticipated HIV Stigma, HIV Risk Perception, and Sexual Behaviors. AIDS Behav 25(5), pp. 1423-1437. doi: 10.1007/s10461-020-02980-5

Ma, P. H. X. et al. 2019. Self-Stigma Reduction Interventions for People Living with HIV/AIDS and Their Families: A Systematic Review. AIDS Behav 23(3), pp. 707-741. doi: 10.1007/s10461-018-2304-1

Mahlke, C. I. et al. 2014. Peer support in mental health services. Curr Opin Psychiatry 27(4), pp. 276-281. doi: 10.1097/yco.0000000000000074

Maragh-Bass, A. C. et al. 2021. Examining stigma, social support, and gender differences in unsuppressed HIV viral load among participants in HPTN 065. J Behav Med 44(2), pp. 159-171. doi: 10.1007/s10865-020-00186-7

Masquillier, C. et al. 2015. The impact of community support initiatives on the stigma experienced by people living with HIV/AIDS in South Africa. AIDS Behav 19(2), pp. 214-226. doi: 10.1007/s10461-014-0865-1

Mburu, G. et al. 2013. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. J Int AIDS Soc 16(3 Suppl 2), p. 18636. doi: 10.7448/ias.16.3.18636

Memiah, P. et al. 2021. Mental health symptoms and inflammatory markers among HIV infected patients in Tanzania. BMC Public Health 21(1), p. 1113. doi: 10.1186/s12889-021-11064-5

Meyers DC, Durlak JA, Wandersman A. The quality implementation framework: a synthesis of critical steps in the implementation process. Am J Community Psychol. 2012 Dec;50(3-4):462-80. doi: 10.1007/s10464-012-9522-x. PMID: 22644083

Moher, D. et al. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 6(7), p. e1000097. doi: 10.1371/journal.pmed.1000097

Moir, S. et al. 2011. Pathogenic mechanisms of HIV disease. Annu Rev Pathol 6, pp. 223-248. doi: 10.1146/annurev-pathol-011110-130254

Molassiotis, A. et al. 2002. A pilot study of the effects of cognitive-behavioral group therapy and peer support/counseling in decreasing psychologic distress and improving quality of life in Chinese patients with symptomatic HIV disease. AIDS Patient Care STDS 16(2), pp. 83-96. doi: 10.1089/10872910252806135

Moore, G. et al. 2021. Adapting interventions to new contexts-the ADAPT guidance. Bmj 374, p. n1679. doi: 10.1136/bmj.n1679

Mosack, K. E. et al. 2016. Shared Illness and Social Support Within Two HIV-Affected African American Communities. Qual Health Res 26(11), pp. 1495-1507. doi: 10.1177/1049732315612044

Nakimuli-Mpungu, E. et al. 2021. Mental health interventions for persons living with HIV in low- and middle-income countries: a systematic review. J Int AIDS Soc 24 Suppl 2(Suppl 2), p. e25722. doi: 10.1002/jia2.25722

Namuleme, R. K. 2015. HIV/AIDS-related stigma and information behaviour: an ethnographic study in the UK. Health Info Libr J 32(1), pp. 61-66. doi: 10.1111/hir.12090

National AIDS Trust. 2021. HIV in the UK statistics – Living with HIV. Available at: https://www.nat.org.uk/about-hiv/hiv-statistics [Accessed: 24 November 2021]

National Institute for Health and Care Excellence [NICE]. 1999. National service framework. London: NICE. Available at: National Service Frameworks: Department of Health - Health care (archive.org) [Accessed: 10 February 2022]

National Voices.org.UK (2017) National Standards for HIV peer support. https://www.nationalvoices.org.uk/peer-support-hub/search/national-standards-hiv-peer-support [last accessed 4.8.22]

Nilsen P. Making sense of implementation theories, models, and frameworks. Implement Sci. 2015;10(1):1-13

Niu, L. et al. 2016. The Mental Health of People Living with HIV in China, 1998-2014: A Systematic Review. PLoS One 11(4), p. e0153489. doi: 10.1371/journal.pone.0153489

O'Cathain A, Croot L, Duncan E, et al (2019a) Guidance on how to develop complex interventions to improve health and healthcare. BMJ Open 2019;9:e029954. doi: 10.1136/bmjopen-2019-02995

O'Cathain, A., Croot, L., Sworn, K. et al. (2019b) Taxonomy of approaches to developing interventions to improve health: a systematic methods overview. Pilot Feasibility Stud 5, 41 (2019). https://doi.org/10.1186/s40814-019-0425-6

Pandey, A. and Galvani, A. P. 2019. The global burden of HIV and prospects for control. The Lancet HIV 6(12), pp. e809-e811. doi: 10.1016/S2352-3018(19)30230-9

Patel, V. et al. 2018. The Lancet Commission on global mental health and sustainable development. The Lancet 392(10157), pp. 1553-1598. doi: 10.1016/S0140-6736(18)31612-X

Paudel, V. and Baral, K. P. 2015. Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: a review of literature. Reprod Health 12, p. 53. doi: 10.1186/s12978-015-0032-9

Popovic, M. et al. 1984. Detection, isolation, and continuous production of cytopathic retroviruses (HTLV-III) from patients with AIDS and pre-AIDS. Science 224(4648), pp. 497-500. doi: 10.1126/science.6200935

Positively UK. 2017. National Standards of Peer Support in HIV. Available at: http://hivpeersupport.com/ [Accessed: 12 October 2021]

Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health. 2011; 38(2):65-76. doi: 10.1007/s10488-010-0319-7.

Rao, D. et al. 2012. Social support mediates the relationship between HIV stigma and depression/quality of life among people living with HIV in Beijing, China. International journal of STD & AIDS 23(7), pp. 481-484. doi: 10.1258/ijsa.2009.009428

Remien, R. H. et al. 2021. Integrating mental health into HIV prevention and care: a call to action. J Int AIDS Soc 24 Suppl 2(Suppl 2), p. e25748. doi: 10.1002/jia2.25748

Robertson, D. S. 2016. Origin and activities of human lentivirus particles. Biomed Pharmacother 83, pp. 1311-1314. doi: 10.1016/j.biopha.2016.08.045

Rooks-Peck, C. R. et al. 2018. Mental health and retention in HIV care: A systematic review and meta-analysis. Health Psychol 37(6), pp. 574-585. doi: 10.1037/hea0000606

Rotheram-Borus, M. J. et al. 2014. A cluster randomized controlled trial evaluating the efficacy of peer mentors to support South African women living with HIV and their infants. PLoS One 9(1), p. e84867. doi: 10.1371/journal.pone.0084867

Rueda, S. et al. 2016. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open 6(7), p. e011453. doi: 10.1136/bmjopen-2016-011453

Ruiz, I. et al. 2010. Prospective, randomized, two-arm controlled study to evaluate two interventions to improve adherence to antiretroviral therapy in Spain. Enferm Infecc Microbiol Clin 28(7), pp. 409-415. doi: 10.1016/j.eimc.2009.03.018

Santos, G. M. et al. 2021. Economic, Mental Health, HIV Prevention and HIV Treatment Impacts of COVID-19 and the COVID-19 Response on a Global Sample of Cisgender Gay Men and Other Men Who Have Sex with Men. AIDS Behav 25(2), pp. 311-321. doi: 10.1007/s10461-020-02969-0

Scottish Government. 2017. Mental Health Strategy 2017-2027. Available at: Mental Health Strategy 2017-2027 - gov.scot (www.gov.scot) [Accessed: 10 February 2022]

Senn, T. E. et al. 2021. Global mental health and HIV care: gaps and research priorities. J Int AIDS Soc 24 Suppl 2(Suppl 2), p. e25714. doi: 10.1002/jia2.25714

Shadloo, B. et al. 2018. Psychiatric disorders among people living with HIV/AIDS in IRAN: Prevalence, severity, service utilization and unmet mental health needs. J Psychosom Res 110, pp. 24-31. doi: 10.1016/j.jpsychores.2018.04.012

Shalaby, R. A. H. and Agyapong, V. I. O. 2020. Peer Support in Mental Health: Literature Review. JMIR Ment Health 7(6), p. e15572. doi: 10.2196/15572

Sterne, J. A. C. et al. 2016. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. Bmj 355, p. i4919. doi: 10.1136/bmj.i4919

Sterne, J. A. C. et al. 2019. RoB 2: a revised tool for assessing risk of bias in randomised trials. Bmj 366, p. l4898. doi: 10.1136/bmj.l4898

Stockton, M. A. et al. 2020. The impact of an integrated depression and HIV treatment program on mental health and HIV care outcomes among people newly initiating antiretroviral therapy in Malawi. PLoS One 15(5), p. e0231872. doi: 10.1371/journal.pone.0231872

Turan B, Budhwani H, Fazeli PL, Browning WR, Raper JL, Mugavero MJ, et al. How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. AIDS Behav. 2017;21(1):283-91.

UK Health Security Agency. 2021. HIV testing, new HIV diagnoses, outcomes, and quality of care for people accessing HIV services: 2021 report. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf [Accessed: 1 December 2021]

UKHSA (UK Health Security Agency). Country and region HIV data tables. 2021. Accessed from: https://www.gov.uk/government/statistics/hiv-annual-data-tables

UNAIDS. 2021. Global HIV & AIDS statistics – Fact Sheet. Available at: Glohttps://www.unaids.org/en/resources/fact-sheetbal HIV & AIDS statistics — Fact sheet | UNAIDS [Accessed: 24 November 2021]

Van Brakel, W. H. 2006. Measuring health-related stigma—A literature review. Psychology, Health & Medicine 11(3), pp. 307-334. doi: 10.1080/13548500600595160

Van Tam, V. et al. 2012. Peer support and improved quality of life among persons living with HIV on antiretroviral treatment: a randomised controlled trial from north-eastern Vietnam. Health Qual Life Outcomes 10, p. 53. doi: 10.1186/1477-7525-10-53

Vermund, S. H. and Leigh-Brown, A. J. 2012. The HIV Epidemic: High-Income Countries. Cold Spring Harbor perspectives in medicine 2(5), pp. a007195-a007195. doi: 10.1101/cshperspect.a007195

Vigliotti, V. et al. 2020. Religion, faith, and spirituality influences on HIV prevention activities: A scoping review. PLoS One 15(6), p. e0234720. doi: 10.1371/journal.pone.0234720

Vreeman, R. C. et al. 2017. Mental health challenges among adolescents living with HIV. J Int AIDS Soc 20(Suppl 3), p. 21497. doi: 10.7448/ias.20.4.21497

Waldron, E. M. et al. 2021. Mental Health in Women Living With HIV: The Unique and Unmet Needs. J Int Assoc Provid AIDS Care 20, p. 2325958220985665. doi: 10.1177/2325958220985665

Webel, A. R. 2010. Testing a peer-based symptom management intervention for women living with HIV/AIDS. AIDS Care 22(9), pp. 1029-1040. doi: 10.1080/09540120903214389

Welsh Government. 2012. Together for Mental Health: A strategy for Mental Health and Wellbeing in Wales. Available at: together-for-mental-health-summary.pdf (gov.wales) [Accessed: 10 February 2022]

Wright, K. et al. 2007. Stigma scale revised: reliability and validity of a brief measure of stigma for HIV+ youth. J Adolesc Health 40(1), pp. 96-98. doi: 10.1016/j.jadohealth.2006.08.001

Yellin, H. et al. 2018. Syndemic effect of mental illness and substance use on viral suppression among recently-incarcerated, HIV-infected individuals in the CARE+ Corrections study. AIDS Care 30(10), pp. 1252-1256. doi: 10.1080/09540121.2018.1455961