# Peer support in healthcare services for people living with HIV

## Experiences of peer support in outpatient clinics from the perspective of service users, peer supporters, and healthcare professionals

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the University of Agder 408

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Dissertation for the degree Philosophiae Doctor (PhD)

University of Agder
Faculty of Health and Sport Sciences
2023

Doctoral dissertations at the University of Agder nr. 408
ISSN: 1504-9272
ISBN: 978-82-8427-121-7

Print: 07 Media
Kristiansand

# Acknowledgements

This thesis results from collaboration, and I feel gratitude to all involved in the project. The research project was financed by The Dam Foundation and supported by The Norwegian Federation of Organisations of Disabled People (FFO). Thank you for allowing me to spend time exploring this important topic.

For the realization of the research, the people I am most indebted to are you, who participated in the project. The writings contained in this thesis are my attempt at orchestrating your multiple stories and the impressions that a meeting with you left with me. Nothing would have come of my efforts without you generously sharing your insights, experiences, hopes, and worries with me.

First and foremost, I want to express my gratitude to Kim Fangen. Kim initiated the project, and as a member of the advisory group, he has provided substantial contributions at every step of this project. Kim, you are a star! Also, the advisory group deserves my thanks for sharing valuable knowledge and ideas. I would also like to thank HIV nurse Ingrid Slørdal for being a significant contributor, supportive, and responding to all my e-mails and phone calls. Thank you, Kim and Ingrid, for becoming my friends.

Thank you to all the healthcare professionals at the outpatient clinics for sharing your experience and helping recruit participants for this project. During the time of the COVID-19 pandemic, that was a tremendous task! In addition, your ideological approach to this topic has inspired me in several ways throughout the project. You are role models!

At my side, I have had a stimulating team of PhD supervisors: my primary supervisor, Professor Mariann Fossum, and co-supervisors, Professor Rigmor C Berg and Associate Professor Vegard Skogen. Mariann, your quick and positive response repeatedly kept my head above the surface. Thank you for eminently balancing your role as my supervisor and leader. Rigmor and Vegard, your knowledge of research and experience related to HIV is remarkable and inspiring. Even though you both struggled to find the time spent on other tasks during the COVID-19 pandemic, you managed to find some time for me! Thank you all so much for encouraging me when I believed I had failed! Your support, suggestions, and critique throughout the research process were crucial to whatever kind of accomplishment I can claim the work to have become.

Thank you, Professor Louise Ackers, for inviting me to join you in Uganda through your charity organization Knowledge4Change for two months and another month in Manchester, University of Salford. You opened up a new world to me, and for that, I am grateful! I look forward to future collaboration with you. Thank you, PhD candidate, Claire Horden, for sharing and caring during my stay in Uganda (we all know I needed it). Both of you have helped me improve my everyday English language. Also, thank you to ‘Positively UK’ by project coordinator Garry Brough and ‘George House Trust’ by project coordinator Joshua Wharton for sharing and discussing your peer support experiences.

Thank you to all my PhD peers; I totally adore how supportive you are. You became my meaningful common-concern relationship through this project.

More importantly, you have all made me feel ‘clever’ enough to see this through to the end. We all need peers (like you) in our lives! Thank you also to my very good friends and colleagues at the Department of Health and Nursing Science for offering encouragement and support along the way; you are (of course) the best!

I want to thank all the family and friends (both old and new, whom I appreciate) who have shown interest in my project and cheered along the way, whether it deserved it or not. Thank you for the small celebrations when I reached a milestone (even if I reached them a bit late) and for the childcare and contributions throughout this journey.

Finally, and most crucially, the family that surrounds me in everyday life. My amazingly supportive husband, Ove; my three ‘golden eggs’; Markus, Leah, and Bendik, who I adore above all; and my wonderful twin sister, Monika (and her lovable family). Not only are you all the most important to me, but when coping with the loss of my dad at the beginning of this PhD journey, you were the ones reminding me of what’s most important in life. Also, thank you to my mother and my in-laws for helping us when needed; your help is appreciated!

So, Ove, thank you for giving me this unique opportunity to explore this project all over Norway, Uganda, and England without claiming payback time. The research journey has just started, and I simply just love it!

Anita Øgård-Repål

Grimstad, 2023

# Abstract

**Background:** People living with HIV report a poorer health-related quality of life, which is linked to HIV being one of the most stigmatized diseases worldwide. Many people living with HIV become disconnected from society, impacting the social support they receive. Although peer support has been an intervention for people living with HIV since the beginning of the epidemic, peer support has become a tailored, person-centered outreach for people living with HIV taking an active role in self-management after the introduction of antiretroviral therapy. The outpatient clinics in Norway wanted to make people living with HIV equal partners and increase self-management by involving peer supporters in care. Peer supporters were suggested to provide additional support to people living with HIV.

**Aims:** The overall aim of this thesis was to explore peer support as a service for people living with HIV. This study aimed to describe and get an overview of peer support interventions for people living with HIV worldwide. Furthermore, how peer support was experienced by service users, peer supporters, and healthcare professionals in outpatient clinics was examined.

**Designs, methods, and samples:** This PhD consists of three studies. Study 1 was a scoping review, where descriptive analyses and a simplified manual thematic analysis were performed to summarize the findings across the dataset. In Study 2, in-depth interviews were conducted with 16 service users living with HIV. The collected data were analyzed using directed, qualitative content analysis to organize and report the findings. Study 3 was a qualitative study involving 15 in-depth individual interviews, ten peer supporters, and five healthcare professionals. In addition, two focus group discussions with 4–5 participants were conducted. An inductive approach was followed when patterns in the empirical data were identified, analyzed, and reported following a reflexive and collaborative thematic analysis.

**Main results:** The thesis shows that peer support is an increasingly preferred intervention for people living with HIV in various settings worldwide, and there is extensive research on the topic. However, there is a dearth of studies regarding the experiences of receivers and peer support providers, and few studies describe the peer support interventions integrated into clinics. In addition, only a few studies were conducted in Europe, with none in the Nordic countries.

The thesis strongly suggests that a meeting between peers contributes to social support through social connectedness for people living with HIV. The service users and peer supporters developed a common-concern relationship through sharing emotions and daily living with HIV. Furthermore, the cooperation and exchange of knowledge between peer supporters and healthcare professionals at outpatient clinics indicate the potential for increased awareness for both parties. In addition, the peer support contributed to framing a dialogue between peers about different understandings of HIV and the management of a chronic lifelong condition in daily life.

Implementing and situating peer support at the outpatient clinics increased the opportunity to provide flexible, person-centered support and could be seen as a response to people living with HIV’s need for confidentiality. The results indicated that locating the peer support services at the outpatient clinics offers more accessibility to general services as the peer supporters and healthcare professionals cooperate in providing the services. However, facilitating peer support at outpatient clinics requires considering other critical aspects to be successful, such as the competence of the peer supporters to ensure quality care and how the peer supporters balance their roles as both service providers and service users.

**Conclusions:** This thesis provides knowledge of peer support as a low threshold intervention to meet the need for social support to enhance the quality of life for people living with HIV. The project provides increased knowledge of a peer supporter's contribution to the existing outpatient clinics to respond to the multiple challenges faced by people living with HIV. The increased recognition of peer support worldwide and the supporting literature demonstrate the flexibility of peer support, adjusted to the needs of the service users. These findings indicate that peer support contributes to a more person-centered approach in outpatient clinics. Improved understanding of the providers' experiences found in this study calls for the greater availability of peer support and the development of peer support programs as a part of usual care in outpatient clinics in Norway. An increased formalization of the peer supporter role will benefit service users, peer supporters, and healthcare professionals by informing expectations. Furthermore, it seems crucial to consider the increased exchange of knowledge at outpatient clinics when incorporating people living with HIV into the development and distribution of services.

# Sammendrag

**Bakgrunn:** Mennesker som lever med HIV rapporterer dårligere livskvalitet, og kan ses i sammenheng med at HIV er en av de mest stigmatiserende sykdommene i verden. Mange mennesker med HIV isolerer seg, noe som påvirker den sosiale støtten de får fra sine omgivelser. Selv om likepersonsarbeid har vært benyttet siden HIV-epidemiens begynnelse, har introduksjonen av antiretroviral behandling ført til at likepersonsarbeid i økende grad har blitt et systematisk rettet, personsentrert tilbud for mennesker med HIV for å bidra til at de inntar en mer aktiv rolle i egen mestring. Poliklinikker i Norge ønsket å bidra til at mennesker med HIV ble likeverdige partnere og øke deres egenmestring gjennom å involvere likepersoner i tjenestetilbudet. Likepersoner ble lansert for å kunne tilby ytterligere støtte til mennesker som lever med HIV.

**Formål:** Det overordnede formålet var å utforske likepersonsarbeid som et tilbud til mennesker som lever med HIV. Avhandlingen har som mål å beskrive og gi en oversikt over likepersonstilbud for mennesker som lever med HIV på verdensbasis. Videre å få økt forståelse for hvordan likepersonsarbeid erfares av tjenestebrukere, likepersoner og helsepersonell som en tjeneste ved HIV poliklinikken.

**Designs, metode og utvalg:** Denne avhandlingen består av tre studier. Studie 1 var en kunnskapsoppsummering hvor vi utførte beskrivende analyser og tematisk analyse for å oppsummere funnene på tvers av datasettet. I studie 2 har vi dybdeintervjuet 16 tjenestebrukere som lever med HIV. De innsamlede dataene ble analysert ved hjelp av en direkte, kvalitativ innholdsanalyse for å organisere og rapportere funnene. Studie 3 var en kvalitativ studie hvor det ble gjennomført 15 dybdeintervjuer, 10 likepersoner og 5 helsepersonell. I tillegg ble det gjennomført 2 fokusgruppe diskusjoner, med 4-5 deltakere. For å analysere dataene ble det brukt en refleksiv tematisk analyse. Vi hadde en induktiv tilnærming når vi identifiserte, analyserte og rapporterte de empiriske data.

**Hovedresultat:** Likepersonsarbeid er i økende grad en foretrukket intervensjon for mennesker som lever med HIV i ulike situasjoner på verdensbasis, og det er omfattende forskning på området. Derimot er det få studier relatert til erfaringer sett fra perspektivet til tjenestemottakere og likepersoner, og studier hvor likepersoner er integrert i helsetjenestetilbudet. I tillegg var få studier gjennomført i Europa, og ingen i Norden.

Resultatene i dette prosjektet indikerer at et møte mellom mennesker som lever med HIV bidrar til sosial støtte gjennom gjensidig tilhørighet. Tjenestebrukere og likepersonene opplevde en felles følelse av tilhørighet gjennom å dele følelser, erfaringer og bekymringer knyttet til det å leve med HIV. Dessuten viser samarbeidet og utvekslingen av kunnskap mellom likepersoner og helsepersonell ved poliklinikkene et potensiale for økt kunnskap og bevissthet for begge parter. I tillegg bidro integrering av likepersoner i

poliklinikken med å tilrettelegge for dialog mellom ulike kulturelle forståelser av HIV, samt håndtering av en kronisk lidelse i dagliglivet.

Å implementere og lokalisere likepersoner ved poliklinikkene økte muligheten for å fremme fleksibel, personsentrert støtte til mennesker som lever med HIV, og kan sees på som et svar på deres uttrykte behov for konfidensialitet. Resultatene indikerte at lokalisering av likepersoner ved poliklinikkene i spesialisthelsetjenesten gir økt tilgjengelighet til generelle tjenester da likepersoner og helsepersonell samarbeider om å tilby tjenestene. Å legge til rette for tilbud om å møte en likeperson ved poliklinikk krever imidlertid at man vurderer andre kritiske aspekter, f.eks. kvalitetskriterier på omsorgen gitt av likepersonene, og hvordan likepersonene balanserer rollen ved å være både tjenesteleverandører og tjenestebrukere.

**Konklusjon:** Denne avhandlingen bidrar til verdifull kunnskap om hvordan likepersoner gjennom økt sosial støtte, som et lavterskeltilbud for å møte de daglige, emosjonelle behov, kan bidra til å øke livskvaliteten for mennesker med HIV. Avhandlingen bidrar til økt bevissthet knyttet til likepersoners bidrag til eksisterende helsetjenester for å svare på de mange utfordringene mennesker som lever med HIV står overfor. Den økte anerkjennelsen av likepersoner på verdensbasis demonstrerer en fleksibilitet tilpasset behovene til de ulike tjenestebrukere. Resultatene i denne avhandlingen foreslår at likepersoner kan bidra til en mer personsentrert tilnærming i spesialisthelsetjenesten. Forbedret forståelse av likepersoners erfaringer knyttet til styrker og utfordringer funnet i denne avhandlingen krever større tilgjengelighet av likepersoner som en del av den ordinære tjenesten for mennesker som lever med HIV i Norge. En økt formalisering av likepersoner vil komme tjenestebrukere, likepersoner og helsepersonell til gode ved å tydeliggjøre forventninger. Videre er det avgjørende å ta i betraktning den økten kunnskapen som blir tilført spesialisthelsetjenesten ved å inkludere mennesker som lever med HIV i utviklingen og distribusjonen av tjenester.

## Contents

## List of papers

This thesis is based on the following original research papers. The papers are referred to in the text accordingly:

### Paper I

Øgård-Repål, A., Berg, R.C., & Fossum, M. (2021). Peer support for people living with HIV: A Scoping Review. *Health promotion practice.* https://doi.org/10.1177/15248399211049824

### Paper II

Øgård-Repål, A., Berg, R.C., & Fossum, M. (2021). A Scoping Review of the Empirical Literature on Peer Support for People Living with HIV. *Journal of the international association of providers of AIDS care*, *20.* https://doi.org/10.1177/23259582211066401

### Paper III

Øgård-Repål, A., Berg, R.C., Skogen, V., & Fossum, M. (2022). Peer support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users' experiences. *BMC health services research*, *22*(1), 549. https://doi.org/10.1186/s12913-022-07958-8

### Paper IV

Øgård-Repål, A., Berg, R.C., Skogen, V., & Fossum, M. (2022). "They make a difference": A qualitative study of providers' experiences of peer support in outpatient clinics for people living with HIV. *BMC health services research.* 22, 1380. https://doi.org/10.1186/s12913-022-08810-9

## List of abbreviations

| | |
|---|---|
| AIDS | Acquired Immunodeficiency Syndrome |
| ART | Antiretroviral Therapy |
| CLLC | Chronic Lifelong Conditions |
| COVID-19 | Coronavirus disease 2019 |
| FGD | Focus Group Discussion |
| HIV | Human Immunodeficiency Virus |
| NCD | Non-communicable disease |
| NGO | Non-governmental Organisation |
| OPC | Outpatient Clinic |
| PrEP | Pre-Exposure Prophylaxis |

# 1 Introduction

Today, an estimated 38.4 million people are living with the human immunodeficiency virus (HIV) worldwide (WHO, 2022). HIV untreated can lead to acquired immunodeficiency syndrome (AIDS), making people more vulnerable to other infections and diseases (WHO, 2022). However, global and national actions have reversed the rate of AIDS and thereby the morbidity and mortality of people living with HIV. The reduction of AIDS incidents is mainly related to the introduction of highly active antiretroviral therapy (ART) in 1996 and its further development. For the 25 million people living with HIV receiving ART, life expectancy has reached that of the general population and HIV has become a chronic lifelong condition (CLLC) (Lohse & Obel, 2016; Trickey et al., 2017; WHO, 2019a, 2022).

The increased life expectancy of people living with HIV involves a burden of non-communicable diseases (NCDs) and mental health issues (Brandt, 2009; Parcesepe et al., 2018; WHO, 2016b). In addition, people living with HIV also report poorer health-related quality of life (Bristowe et al., 2019; Engelhard et al., 2018), which is linked to HIV being one of the most stigmatized diseases worldwide (Chaudoir & Fisher, 2018; Pantelic et al., 2019; Relf, Holzemer, et al., 2021). Furthermore, societal prejudice and stigma affect people living with HIV's emotional well-being, and consequently, report psychological anxiety and uneasiness related to the diagnosis (Liamputtong, 2013; Major & Schmader, 2018). Consequently, many people living with HIV become disconnected from society, which negatively impacts their social support (Hatzenbuehler et al., 2013; Relf, Holzemer, et al., 2021).

Interventions have been designed to improve retention in care, ART initiation and adherence, improve mental health and reduce the stigma of people living with HIV. Several studies have reviewed the effectiveness of such interventions and found that interventions involving peer support were the preferred approach to complement healthcare services in several settings, with promising albeit mixed results (Berg et al., 2021; Boucher et al., 2020; Kanters et al., 2016; Spaan et al., 2020). Moreover, since the introduction of ART, peer support has been rising as a tailored, person-centered outreach complementing or as a substitute for ordinary healthcare services for people living with HIV. Peer support has encouraged people with HIV, to actively manage their daily life, despite living with a CLLC (Positively, 2016; WHO, 2016b).

Although various reviews have studied the effectiveness of peer support interventions, a recent review found that few studies explore the varied experiences of peer support (Roland et al., 2020). Furthermore, a recent systematic review and meta-analysis of the effects of peer support suggests that more information on the adoption of interventions, experiences, and setting-related aspects of peer support is required (Berg et al., 2021).

The Norwegian healthcare services aim to meet the healthcare needs of people living with HIV as a part of their quality care. Therefore, they have encouraged people to be involved in healthcare to fit the services to different conditions (Bakke et al., 2016; Berg et al., 2015; The Norwegian Directorate of

Health, 2018). The outpatient clinics (OPCs) have expanded and developed their services by incorporating the contributions of ‘lived experiences’. OPCs throughout Norway have designed peer support in response to changing needs to individualize and improve the quality of treatment and care for people living with HIV. Furthermore, they wanted to make people living with HIV equal partners in HIV care to increase self-management and empowerment (Bakke et al., 2016; Venter et al., 2017).

In addition, former research suggests that peer supporters should provide social support for people living with HIV (Dennis, 2003; Krulic et al., 2022; Simoni, Franks, et al., 2011). As shown by the Stigma Index Study (UK) (Chinouya et al., 2017), stigma negatively impacts the social support for people living with HIV, both at an individual and a structural level, thereby creating barriers to HIV-related care and support. Knowing that social support is a resource that helps people face distressing and even harmful situations, referring to interpersonal interactions involving help to enhance well-being, it is essential to address social support as a part of the services for people living with HIV (Dulin et al., 2018; Earnshaw et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017, Shumaker & Brownell,1984).

Peer support was a service offered at several HIV OPCs in Norway. This thesis will explore peer support as a service for people living with HIV and examine how peer support in the context of HIV OPCs is experienced by service users, peer supporters, and healthcare professionals.

## 2 Aim and research questions

This thesis aimed to examine peer support for people living with HIV as a specific aspect of healthcare services and peer support integrated into the HIV OPCs throughout Norway. We examined how peer support was experienced by service users living with HIV, peer supporters, and healthcare professionals. This thesis consists of three studies reported in four journal papers. The aims of the studies and research questions were as follows:

**Study 1, Papers I & II**

The scoping review aimed to describe the characteristics of studies investigating peer support for people living with HIV, including a brief overview of what was studied. It also summarized key findings from each identified study category to identify knowledge gaps and offer suggestions for further research.

**Study 2, Paper III**

The study aimed to explore the lived experiences of service users' meetings with a peer supporter in the context of an OPC.

**Study 3, Paper IV**

The study explored how peer supporters experienced providing support, contributing, and working as peer supporters in OPCs, as well as healthcare professionals' perceptions of working with peer supporters in OPCs.

# 3 Background

This chapter presents an overview of the relevant literature and the rationale for this thesis. First, the chapter briefly summarizes HIV-related incidents and existing challenges. Then, it elaborates on the concepts of peer support, stigma, and social support related to HIV as these concepts are found essential in previous research relevant to this project. The concepts of stigma and social support are further explored in chapter 4.

## 3.1 HIV today

HIV manages to infect cells of the immune system and destroys or impairs the function of the cells by reducing the body's CD4 cells. This virus starts a deterioration of the immune system, potentially leading to an incomplete immune system. A poor immune system cannot fulfill the role of fighting infections and other diseases. HIV is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or medicine to prevent or treat HIV) or through sharing injection drug equipment. Although there is no cure for HIV, since the introduction of ART, the treatment has reduced the virus to undetectable viral loads, enabling people living with HIV to reach the life expectancy of the general population (UNAIDS, 2020; WHO, 2022).

Significant inequities still persist for many people living with HIV worldwide. Some countries and regions are left behind as ART provisions in highly endemic settings are challenged due to shortages of universal health coverage (UNAIDS, 2020; WHO, 2022). In addition, there is a difference in the ART provision provided for specific groups of populations. For example, people from the 'key population', i.e., those at elevated risk of acquiring HIV infections, tend to have less access to ART and ordinary healthcare services (Sokol & Fisher, 2016).

An increasing burden for people living with HIV is co-infections such as hepatitis, tuberculosis, and other co-morbidities (WHO, 2016b), with NCDs and mental health disorders being some of the most prevalent (Jespersen et al., 2021; Parcesepe et al., 2018; WHO, 2016b). In addition, although the life expectancy for people with an HIV diagnosis has increased dramatically, they continue to face a range of challenges, such as discrimination and stigma, negatively affecting their health and well-being (Grønningsæter & Hansen, 2018; Pantelic et al., 2019; WHO, 2016b).

The Global Health Sector Strategy on HIV 2016–2021 (WHO, 2016b) outlined fast-track actions to be implemented as an HIV response to the 2030 Agenda for Sustainable Development (United Nations, 2015). The effort aimed to address challenges related to countries' different healthcare systems and variable healthcare coverage. A multisectoral response was outlined as a strategy that highlighted the importance of involving the community, particularly people living with HIV, to deliver healthcare services effectively (WHO, 2016b).

### 3.1.1 HIV in Norway

Norway has a low prevalence of people living with HIV, with 6,778 people diagnosed with HIV by the end of 2020 (4585 men and 2193 women) and approximately 130–200 people in Norway diagnosed with HIV each year (Caugant et al., 2021; Whittaker et al., 2020). Of the newly diagnosed people living with HIV in 2020, about 66 (48%) were heterosexual, and 63 (46%) were men who had sex with men. Respectively, 44 (70%) and 43 (68%) of these were migrant men who have sex with men who had acquired HIV before migration, primarily from central and eastern Africa and Southeast Asia. According to our findings, few people in Norway get HIV from injecting drugs (Caugant et al., 2021; Whittaker et al., 2020).

There has been a decrease in reported cases of HIV in Norway over the last decade, which is related to several strategies. One of the intervention strategies is ‘Test-and-Treat’, where the population at risk is screened for HIV infection, and people diagnosed with HIV receive early treatment. Another intervention strategy is ‘Treatment as Prevention (TasP)’, which involves taking HIV medication to prevent sexual transmission of HIV. Lastly, access to prophylactic treatment Pre-Exposure Prophylaxis (PrEP), an antiretroviral medication used by HIV-negative people, has contributed to reducing the risk of acquiring HIV infection (Caugant et al., 2021; Whittaker et al., 2020). In 2013, the United Nations Programme on HIV/AIDS 90-90-90 developed the following treatment targets. By 2020, 90% of all people living with HIV should know their status, 90% should receive sustained ART, and 90% of people receiving ART should have viral suppression (UNAIDS, 2014). Norway seems to have achieved the 90-90-90 target (Whittaker et al., 2020).

Despite the improved treatment and access to high-quality healthcare services, people living with HIV in Norway experience an increased risk of co-morbidities, mental distress, and fatigue compared to the general population. Furthermore, they report loneliness related to living with HIV (Caugant et al., 2021; Grønningsæter & Hansen, 2018; Langseth et al., 2021). Research has shown that people living with HIV often experience specialized physicians focusing more on their disease's biomedical aspects than on their psychosocial needs because of the excellent available medical treatment. Therefore, people living with HIV express a desire for healthcare services to acknowledge them as whole individuals and actively discuss their lives and experiences of health and life with HIV as a CLLC. The service users request individualized support, recognizing their unique needs. For example, they strongly suggest that healthcare services increase their knowledge of ART medication and treatment when aging with HIV (Grønningsæter & Hansen, 2018).

## 3.2 HIV-related stigma

HIV-related stigma could be experienced when people living with HIV experience that someone views them negatively and/or have negative beliefs about them based on their HIV status, and thereby regarded as imperfect by social standards (PLHIV Stigma Index, 2022). Since the epidemic's beginning, HIV infection has been associated with social stigma and prejudice. The HIV-related stigma might be due to HIV transmission mainly happening through behaviors considered a social taboo, such as sexual intercourse and injection drug use (Chaudoir & Fisher, 2018). The knowledge about HIV-related stigma is supported by results from The People Living with HIV Stigma Index (The Stigma Index Library, 2022, Friedland, Gottert, Hows et.al, 2020, UNAIDS, 2014), an important study of stigma and discrimination presented in country reports, which stresses that stigma and discrimination still exist in several countries.

The introduction of ART, the increased public awareness of HIV and other advancements have, to some extent, decreased the ambient stigma during the past decades. However, as Pantelic et al. (2019) and Relf et al. (2021) have noted, prejudice against HIV has been slow to reduce and seems resistant to change. As a result, HIV remains one of the most stigmatized diseases in almost every culture worldwide and could be understood as a fundamental cause of health inequalities as people living with HIV face social and legal barriers to accessing treatment compared to the general population in several countries (Relf, L Holzemer, et al., 2021; WHO, 2016a, 2016b).

Societal prejudice directed towards people living with HIV can be severe, causing harm in numerous ways, perhaps most detrimentally through increased mental health issues (Berg & Ross, 2014; Chaudoir & Fisher, 2018; Relf, L Holzemer, et al., 2021). Consequently, many people living with HIV are using social isolation as a mechanism to avoid stigma and by that disconnected from society (Hatzenbuehler et al., 2013; Relf, L Holzemer, et al., 2021). In addition, people living with HIV are often already members of socially marginalized groups, such as gay men and other men who have sex with men, sex workers, people having non-binary gender, people who use drugs, and experience intersectional stigmas (Chinouya et al., 2017; Relf, Holzemer, et al., 2021). According to Major and Schmader (2018), intersectional stigma can occur when different types of stigmas are compounded due to belonging to more than one socially marginalized group. This can increase anticipated stigma, as the affected individuals may fear stigmatization based on several characteristics. Recent research suggests that HIV-related and key population-related stigma could increase barriers to HIV-testing and engagement in care (Chinouya et al., 2017; Friedland, Gottert, Hows et.al, 2020)

Therefore, HIV-related-stigma may result in severe consequences for people's health. Stigma influences affective, cognitive, and mental health outcomes as well as healthcare behaviors. Healthcare behaviors affect physical health outcomes as a potential global threat because they keep people living with HIV from accessing healthcare services and treatment (Chambers et al., 2015; Friedland, Gottert, Hows et.al, 2020; Pantelic et al., 2019).

Recommendations to overcome stigma consists of multi-level approaches, where fostering networks focused on support through socialization with peers is a relevant means at the individual level (Chinouya et al., 2017; Relf, Holzemer, et al., 2021). Following this argument, knowing that social support involves helpful relations to enhance wellbeing, social support to overcome barriers related to healthcare services and treatment is a relevant means to improve the quality of care for people living with HIV experiencing HIV-related stigma (Dulin et al., 2018; Earnshaw et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017, Shumaker & Browne,1984).

## 3.3 HIV and social support

The correlation between social support and health has been observed in research for several years (Berkman et al., 2000; Cohen et al., 2001; Earnshaw et al., 2015). As pointed out in the classical work of Cohen, social support is historically recognized as being associated with well-being and is mainly linked to stressful events (Cohen, 1988; Cohen & Wills, 1985). Recent studies show that decreased anxiety and depression and higher resilience are associated with social support (Dulin et al., 2018). In addition, research by Subramanian et al. (2021) emphasizes the correlation between social support and health outcomes, concluding that social support impacts both the quality of life and clinical endpoints for people living with HIV.

Awareness of the interrelationship between social support and health (Hatzenbuehler et al., 2013) can cause social support to become a potential resource when experiencing stress in response to HIV-related stigma (Dulin et al., 2018; Earnshaw et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017). Research indicates that an individual’s social support network is essential for helping people living with HIV maintain good physical and mental health. However, Li et al. (2021) found that the social support experienced by people living with HIV was lower than the domestic norm. In addition, other studies suggest that disclosing one’s HIV status allows access to the necessary social support for living with HIV (Smith et al., 2008). Despite this knowledge, people living with HIV experience decreased social support following the diagnosis. Reduced social support seems to be related to people’s multidimensional concerns and their need for confidentiality (Chambers et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017; Smith et al., 2008). These findings correlate with a study conducted in Norway, suggesting that people experience loneliness and a lack of a supportive environment while living with an HIV diagnosis (Grønningsæter & Hansen, 2018), which is relevant when facilitating a meeting between peers in the peer support program at the OPCs.

Furthermore, several studies support an interrelationship between social support and resilience factors (Earnshaw et al., 2013; Garrido-Hernansaiz & Alonso-Tapia, 2017; Wen et al., 2021). However, former resilience literature often defined resilience as a component at the individual level (Richardson, 2002). The resilience literature has disregarded the social context and systems’ influence on resilience, as Dulin et al. (2018) point out in their review. Following the argument of Dulin et al. (2018), resilience resources can be defined as:

> '(…) positive psychological, behavioral, and/or social adaptation in the face of stressors and adversities that draws upon "an individual's capacity, combined with families' and communities' resources to overcome serious threats to development and health' (Dulin et al., 2018, p. 7)

The recent study by Wen et al. (2021) tested the mediating mechanism of resilience to social support as the environmental context and adaptive outcomes such as depression and ART adherence. This study found that social support was a direct and indirect predictor of depression. In addition, the study highlighted how a supportive and accepting environmental context increases resilience and thereby reduces the adverse effects of HIV-related stress, concluding that social support should be taken into account when planning interventions for resilience and depression (Wen et al., 2021). The provision of social support to enhance health is a common peer supporter role that falls within the lay caregiver tradition (Simoni, Franks, et al., 2011), and will be further elaborated in chapter 3.5. The research described above should be considered when looking further into the experiences of peer support interventions in this thesis.

## 3.4 Patient involvement

For several years, patient and public involvement has been a political goal in Norway and is enshrined in law (Larsen, 2021; The Norwegian Directorate of Health, 2013, 2018). Traditionally, citizens could influence decision-making in Nordic countries through local and regional democracy. However, when it came to patients' participation in decisions related to healthcare, they historically could only influence these decisions indirectly through patient organizations' decision-making (Larsen, 2021). Therefore, healthcare professionals have hugely influenced healthcare services, although the voice of service users has been repeatedly raised.

In the past two decades, patients' experiences have been increasingly recognized as an essential voice when developing healthcare services in Norway. As a result, there have been several reforms, and patient involvement has become more widely acknowledged in national policies and healthcare services. Consequently, the traditional medical hierarchy has been challenged, and it has been recognized that knowledge production takes place both inside and outside healthcare services. This recognition explicitly focuses on the patients' expertise regarding CLLC (Larsen, 2021; Torjesen et al., 2017).

Taking a person-centered approach by being responsive to the service users' values in healthcare services is recognized by WHO (2015) as particularly important for people living with a CLLC. WHO (2015) defines person-centered care as follows:

> 'Care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health' (WHO, 2015, p. 48)

As highlighted by Bristowe et al. (2019), to address the multidimensional concerns of people living with HIV, a person-centered approach is required to consider each individual's needs when planning services. Also relevant to the mentioned challenges, health literacy is an essential factor in healthcare utilization for people living with HIV (Mgbako et al., 2022). Health literacy is defined as a person's skills, knowledge, and confidence to acquire, communicate and manage basic health information and services to make informed health decisions (Mgbako et al., 2022; Reynolds et al., 2019; World Health, 1998). Peer support is a recognized means to meet service users' healthcare needs in several ways and involves service users in strengthening supportive resources in healthcare services and increasing self-management through, for example, health education and linking people to share knowledge and following person-centered principles (Fisher, 2014; Fisher et al., 2018; WHO, 2016a).

## 3.5 Peer support

Support between lay community members, often referred to as support between peers (herein referred to as *peer supporters*), has been provided throughout history. The role of peer supporters relies on the closeness, understanding, and experience shared between nonprofessional peers and their community to enable effective communication, education, advocacy, and social support (Dennis, 2003; Simoni, Franks, et al., 2011). Thereby, a peer supporter can be defined as someone sharing common characteristics with the supported individual and who can relate to and empathize with them (Doull et al., 2017). Additionally, as raised by several (Fisher et al., 2018; Simoni et al., 2011), the benefit from peer support derives mainly from their peerness through sharing key characteristics. Further, the peer supporter lacks professional status relevant for this context, and the peer support function is according to a specific protocol, and not naturally occurring circumstances. Thus, peer supporters in healthcare services are usually recruited from the same client pool as the individuals they support, sharing some similar experiences or characteristics, and having a specific role according to the context. These mentioned conceptualizations are relevant to be able to distinguish between what constitutes a peer supporter compared to a professional (Simoni et al., 2011).

Even so, the concept of peer support raises questions. The requirements and expected qualifications for being a peer supporter, beyond the sharing of similar characteristics, are often unclear, and the function of the peer supporter depends on the dialogue between the peer supporter and service user. More often than not, in addition to having the motivation for providing peer support, there are no prescriptions for being a peer supporter, except the requirement of sharing specific characteristics with the service users, relevant to the context where the peer support is provided. In that sense, there is a risk of over-professionalizing life when turning lay people into professional helpers (Borkman, 1999).

The function of the peer supporters is often characterized by increasing the service user's self-management and ongoing support as part of the settings of their daily lives rather than decontextualized in clinical settings. However, even though peer support often is connected to healthcare services, linking service users to clinical care seems to be a part of several peer support programs.
A systematic review of peer support indicated that peer support might be an effective and preferred way to reach and link people who do not use ordinary healthcare services to clinical care (Sokol & Fisher, 2016). WHO's (2019b) definition of individualized peer support is:

> ‘One-to-one support provided by a peer who has personal experiences of issues and challenges similar to those of another peer who would like to benefit from this experience and support’ (WHO, 2019b, p. 1).

Similarly, Dennis (2003) defined the concept of peer support as:

> ‘(…) the giving of assistance and encouragement by an individual considered equal’ (Dennis, 2003, p. 323).

Some clarify the concept of peer support further (Fisher et al., 2018; Simoni, Franks, et al., 2011; Solomon, 2004). For example, Fisher et al. and the Peers for Progress program draw out four key functions for peer support: 1) daily management assistance, 2) social and emotional support, 3) linkage to clinical care and community resources and 4) ongoing support related to chronic disease, that is, flexible, accessible support that is available to patients when the need arises (Fisher, 2014; Fisher et al., 2018). In addition, as a complement or even a substitute to general healthcare services, there is increased recognition that peer support contributes to meeting consumers’ healthcare needs at the individual level during their lifespan with a CLLC (Fisher, 2014; Fisher et al., 2018; WHO, 2016a). This aligns with the key functions of peer support, which outlines directives for functions, not content, thus supporting interventions to be adjusted according to specific settings and needs (Fisher et al., 2018; Krulic et al., 2022).

In addition to studying the effects of peer support from the receiver's perspective, literature exploring perspectives of being a peer supporter shows the benefits and challenges of the role. The equalizing of the provider-client power differential seems to be the core of peer support’s effectiveness and puts the peer supporter in a unique situation by sharing personal experiences. This literature further supports the beneficial effects of being a peer supporter, suggesting a transition from social marginalization to active participation through the role of peer supporter (MacLellan et al., 2015).

Peer support has been implemented through multiple forms of interaction, such as self-help groups, one-on-one meetings, drop-ins, and computer-mediated groups. These implementations have been carried out in diverse settings (Fisher, 2014; Fisher et al., 2018; Krulic et al., 2022). In addition, peer support has been structured in different ways, including by management, other staff members, or service users. (Fisher, 2014; Krulic et al., 2022). Furthermore, both voluntary and paid peer support approaches have been used, and as a consequence, a peer supporter has become a formal occupation alongside other healthcare professionals in several sectors.

In all its forms, peer support is characterized by being flexible and responsive to the needs of the supported. Therefore, peer supporters offer support and encouragement to others and range from informal visits and sharing experiences to formal appointments focused on practical information. Thus, peer support models are diverse and applied across health contexts (Fisher, 2014; Fisher et al., 2018; Krulic et al., 2022; MacLellan et al., 2015).

## 3.6 HIV and peer support

Peer support for people living with HIV has existed since the beginning of the HIV/AIDS epidemic and grew out of the 1980s activism to combat stigma and discrimination and advocate for better treatment and care (Positively, 2016). Peer support was first organized into small groups, with people living with HIV supporting each other and sharing knowledge (Positively, 2016). After introducing ART, peer support has become a tailored, person-centered outreach to provide linkage and adherence to HIV medical care and to support people living with HIV in taking an active role in the self-management of their CLLC (Positively, 2016; Simoni, Nelson, et al., 2011; WHO, 2016b). Nevertheless, people living with HIV still form communities for people who fear exposure and ostracization (Positively, 2016).

As described, HIV-related stigma is highly relevant, and a multi-level approach is recommended to overcome stigma (Chinouya et al., 2017). At the individual level, socialization through peer support is a suitable means (Relf, Holzemer, et al., 2021), supported by results from the Stigma Index Study (UK) (Chinouya et al., 2017), suggesting mentoring opportunities. Furthermore, providing social support through peers allows for creating helpful relations and overcoming barriers related to healthcare services and treatment for people living with HIV experiencing HIV-related stigma (Dulin et al., 2018; Earnshaw et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017).

As noted in chapter 3.5, the similarity between the peer supporters and those they support is often the only requirement of being a peer supporter, thereby suggesting similarity by the diagnosis as relevant for peer support for people living with HIV (Fisher et al., 2018). However, several aspects should be considered when looking into peer support for people living with HIV. Shared characteristics between key populations of people living with HIV, for example, being a migrant, pose other stigmas intersecting with HIV-related stigma and thereby raises a need for flexible and individualized peer support. As demonstrated by the results from the Stigma Index Study (UK) (Chinouya et al., 2017), migrant people living with HIV experience intersecting stigma. This indicates the need for increased mentoring opportunities among migrants living with HIV to fight stigma ‘from within’.

To ensure individualized and tailored peer support for every person living with HIV, non-governmental organizations (NGOs) in the UK (Positively, 2016) and Australia (National Association of People With HIV Australia, 2020) have published peer support standards, which acknowledge peer support as a preferred intervention. Peer support related to people living with HIV has been widely used; however, there is still unclear evidence of its effect. A systematic review, which included nine studies of peer interventions as linkage, retention, and/or adherence tools for ART, stated that the impact of peer support varies (Genberg et al., 2016). However, according to the systematic review of Berg et al. (2021), peer support improves ART adherence, viral suppression, and long-term retention in care.

Importantly, research findings indicate peer support is flexible and responsive to the population’s needs (Berg et al., 2021; Genberg et al., 2016). In addition, two recent reviews (Berg et al., 2021; Dave et al., 2019) encourage and recommend exploring innovative interventions such as peer support for people living with HIV. However, the reviews found few studies conducted in Europe and none in the Nordic countries (Berg et al., 2021; Dave et al., 2019).

### 3.6.1 Peer support and healthcare services

Peer support is mainly related to the provisions of ART and is aimed to provide linkage, adherence, and retention in clinical care for people living with HIV. In addition, a volunteer often provides peer support from a community-based NGO as an outreach to complement community-based care (Boucher et al., 2020; Kanters et al., 2016; Spaan et al., 2020).

Community-based care stretches from patient homes and communities to modern healthcare centers and hospitals. The increased recognition of community-based peer support follows WHO guidelines, making decentralized care the norm for HIV care delivery when scaling up ART (WHO, 2016b; WHO, 2019a). Therefore, several interventions are conducted in a partnership between an NGO and healthcare services, as shown in the studies of Eaton et al. (2021) and Karwa et al. (2017) on the transition between inpatient and outpatient care.

Peer supporters also exist on-site in HIV clinics. For example, most HIV clinics in London, U.K., provide one-to-one support in cooperation with the NGO Positively UK (2016). Peer support in clinics provides every person living with HIV connected to the clinic access to peer support. However, to our knowledge, few studies explore the experiences of peer supporters' contributions and the perspectives of peer supporters and healthcare professionals working together in HIV clinics. Born et al. (2012), for example, evaluated perceptions regarding whether a peer educator program could relieve the professionals' workload and deliver services of acceptable quality. Although the results of the task shift were viewed as mixed, they still positively confirmed the involvement of peer educators. We also found examples of other interventions incorporating peer support in clinics to help patients take control; providing information about living with HIV and providing social support (Brashers et al., 2017; Cabral et al., 2018; Derose et al., 2015).

Although this study specifically focused on a peer support program as a part of the OPCs, peer support offers services beyond the traditional medical model of care. Several researchers, as described above, clarify the concept of peer support in line with its varied contributions, including inspiring people to live a full life with HIV (Fisher, 2014; Fisher et al., 2018; Simoni, Franks, et al., 2011). Furthermore, as a complement to general healthcare services, there is a recognition that peer support contributes to meeting needs at the individual level, covering several dimensions of well-being (Swarbrick, 2006).

# 4 Conceptual frameworks

This chapter aims to clarify conceptual definitions of the key variables, stigma and social support, that form the thesis. The concepts were discovered and found to be essential during and as a result of Study 1, which influenced the two subsequent studies (Studies 2 and 3).

## 4.1 The social construction of stigma

Stigma is a recognized concept in HIV research that was highly relevant from the beginning of HIV and is still relevant in many people's lives. In Study 1, although stigma was not the main focus or primary measured outcome in the studies included in the scoping review, they all somehow voiced the concept of stigma.

Stigma can be understood through social constructivism; thus, our society categorizes people into several groups where members are expected to have common attributes, which vary according to different social circumstances. According to Berger and Luckmann (1984), we ‘typify’ others in various ways. A categorization by characteristics helps prepare individuals for what might be expected in relation to others without giving it much attention (Berger & Luckmann, 1984; Goffman, 1968). For example, based on our first impression of interacting with strangers, we anticipate strangers’ attitudes and belongingness to a group. This allows us to predict the stranger’s social identity (Goffman, 1968*)*.

Goffman’s (1968) theory contributes to our understanding of stigma. First, he differentiated between *virtual* and *actual social identity*. *Virtual social identity* is the expectation or demand others have on an individual based on their social identity. However, according to this virtual social identity, the categorizations by attributes followed by expectations may neither be correct nor accurate. The category and attributes that the individual is proven to possess are thus their *actual social identity*. For example, an individual might have an undesirable attribute that does not fulfill the category's expectations to which the individual seemingly belongs. This attribute can be called a *stigma*. Goffman’s (1968) theory aligns with Major and Schmader’s (2018) extended definition of stigma. However, Major and Schmader (2018) emphasize the labeled persons' experience of status loss and discrimination, leading to unequal outcomes and power relations in society. Major and Schmader (2018) defined stigma as follows:

> ‘Social devaluation of an individual or group of individuals based on an attribute or social identity with which they are perceived to be associated. These stigmatized attributes or social identities are associated with negative evaluations and stereotypes that are often widely shared and well known within a culture’ (Major & Schmader, 2018, p. 1).

According to Goffman (1968), the non-stigmatized constructs a cognitive stigma theory to help justify the prejudice or discriminatory behavior directed towards the stigmatized individual. This is to help them explain the stigmatized person’s inferiority by indicating the potential dangers represented by the stigmatized. Furthermore, when the negative association of the stigma is shared knowledge within a society, the negative status of the stigmatized is known by everyone. Both the stigmatized and the non-stigmatized are aware of the power differential in their relationship (Goffman, 1968; Major & Schmader, 2018).

Goffman's (1968) differentiation between the *discredited* and the *discreditable* is helpful in the context of HIV. The *discredited* stigma is known to others, and the *discreditable* are individuals who have a secret they fear will result in stigmatization if disclosed. HIV is a concealable stigma, and thereby people living with HIV can be both *discreditable* and *discredited,* depending on their level of openness about their diagnosis. Criminalization laws throughout the world have supported the societal stigma and non-disclosure behavior of HIV. Therefore, a repeal of criminalization laws may affect HIV stigma (Pantelic et al., 2019; Relf, Holzemer, et al., 2021).

It is worth noting that several types of HIV-related stigma have been identified in the literature. People living with HIV might experience i) perceived stigma, when people fear that disclosure of HIV will lead to stigmatization; ii) enacted stigma, when people are discriminated against based on their serostatus; iii) internalized stigma, where people blame and depreciate themselves because of HIV. Internalized stigma, which Goffman calls 'spoiled identities' or 'self-stigma' (Goffman, 1968), occurs when people who belong to a socially *discredited* group (e.g., people living with HIV, people who use illicit drugs) internalize a feeling of shame and worthlessness due to a socially devalued characteristic. Livingston and Boyd (2010) define self-stigma (herein called internalized stigma) as:

> '(…) a subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reactions on the basis of their [socially devalued identity or] illness' (Livingston & Boyd, 2010, p. 2152).

Even though internalized stigma is experienced at the level of individuals, it is influenced by structural and relational conditions in their lives that act as contextual barriers, such as discrimination, social exclusion, and poverty (Pantelic et al., 2019).

## 4.2. Social support

Different conceptualizations of social support are found within social support theory. Therefore, this chapter will clarify the concept of 'social support' relevant to this thesis. It should be noted that, even though some of the concepts described below seem to differ, they all encompass aspects of interpersonal relatedness. Therefore, they are relevant to exploring peer support in this thesis.

This study focuses on specific aspects of social support and differentiates between social support and social network, acknowledging that not all interactions in a network are supportive (Langford et al., 1997). In this study, the definition of social support offered by Shumaker and Brownell (1984) was followed because of its relevance in the context of face-to-face peer support:

> ‘(…) an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well’ (Shumaker & Brownell,1984, p. 11).

Langford et al. (1997) found four defining attributes in their conceptual analysis of social support. These attributes are emotional, instrumental, informational, and appraisal support. The four core functions of peer support defined by the Peers for Progress program (Fisher, 2014) described above in chapter 3.4 can be interpreted as an operationalization and a development of the social support attributes mentioned by Langford et al. (1997).

Relevant to the concept of social support, the following chapters explore the classical work of Baumeister and Leary (1995) related to the need to belong as a human motivation and the sense of belonging as a concept deliberated by Hagerty et al. (1992). These concepts were highly relevant when analyzing the empirical data in Studies 2 and 3 and the overall thesis. The studies support the former knowledge that people living with HIV, in a Norwegian context, experience a sense of loneliness due to their diagnosis and thereby self-isolate (Grønningsæter & Hansen, 2018).

In this thesis, social support is defined as a resource that helps people living with HIV face distressing and even harmful situations related to their diagnosis. Social support thus refers to interpersonal interactions involving help to enhance their well-being in their everyday life living with HIV (Shumaker & Browne,1984). Consequently, when exploring peer support from the receiver's point of view, as shown in Study 2, it was helpful to look further into *what kind of* support the receivers experienced from the peer supporters. Therefore, the relevance of the different provisions of social relations described by Weiss (1974) will be presented in chapter 4.2.2.

### 4.2.1 To belong

‘To belong’ has been described as an interpersonal process affecting health in several ways (Hagerty et al., 1996; Hagerty et al., 1992). Through a literature review, Hagerty et al. (1992) identified the sense of belonging as a process related to others and defined two attributes describing the sense of belonging. These attributes included being valued, needed and essential to others and, additionally, the experience of being congruent with other people (Hagerty et al., 1996; Hagerty et al., 1992). They developed a theoretical model proposing it to be essential for people's social well-being and mental health. Importantly, they highlighted how a sense of belonging could comprise social support processes as one element among many. Furthermore, they found that a lower sense of belonging was associated with poorer psychological functioning.

In the same decade, to understand interpersonal attachment and the motivation for establishing and maintaining social bonds, Baumeister and Leary (1995), through a literature review, described the need to belong as a fundamental human motivation. This motivation supported a belief that individuals are socially embedded, where social relations constitute an individual’s identity. Their results suggested that people desire to form relationships and get attached to others, mainly through shared experiences. The review explicitly focused on interpersonal connections and their contribution to everyday lives, particularly as a buffer when stressful events occur. Baumeister and Leary (1995) also suggested that individuals resist loosely established attachments and bonds, even if the attachments are problematic. In the review, it is noticeable, especially in HIV research, that even potential threats to social relationships create unpleasant emotions, indicating that several emotional problems are a reaction to a perceived or anticipated threat to their social relations or an unmet need to belong.

As shown, the theories of Hagerty et al. (1992) and Baumeister and Leary (1995) both emphasize the importance of people’s need to belong and highlight the importance of being connected to and congruent with someone who has similar experiences, which is supported by the findings in Study 1 and found essential in the empirical data in Studies 2 and 3.

### 4.2.2 The provisions of social relations

Social support has different functions for both the receiver and the provider, often according to the providers' relationship with the receiver. Interestingly, in this study related to peer support, several aspects of the relationship between the provider and the receiver were recognized, as described by Weiss (1974).

Weiss (1974) provided theoretical formulations for different purposes in social relations, such as the Social Provision Scale by Cutrona and Russel (1987). Weiss’s model has its origin in the context of loneliness. Nonetheless, it captures several elements of importance when conceptualizing social support. He identified six different social functions or ‘provisions’ needed to feel supported and avoid loneliness. The provisions, as described below, reflect what the participants receive from relationships with others.

The first provisions Weiss (1974) mentioned are *guidance* and a *reliable alliance.* These provisions are the most relevant functions to direct problem-solving in a situation of experienced stress. Second, the provision of *reassurance of worth* is related to recognizing one’s competence, skills, and value. Third, an *opportunity for nurturance* points to an essential aspect of the interpersonal relationship: the need to feel needed by others. This provision is not strictly considered to provide social support. However, giving and receiving in an interpersonal relationship may be health-promoting. Earlier research even reveals that a turning point could be a mutual helping relationship (Riessman, 1965). This value is also recognized by Borkman (1999), a leading researcher on the mutual support dynamic, as an essential component of peer support, which supports including this function in Weiss’ provisions of social relations. The final provisions, *attachment* and *social integration,* are regarding affectional ties. Affectional ties concern an emotional closeness to others that contributes to a sense of security, while social integration concerns the feeling of belonging to a group that shares the same interests, concerns, and activities (Cutrona & Russell, 1987; Weiss, 1974).

Importantly, Weiss (1974) demonstrated how features like age, life stage, and specific individual circumstances require different relational provisions. Therefore, Weiss's theory (1974) suggests that social integration should be provided by a network of relationships in which a person shares common interests and concerns. On the contrary, the absence of social integration could result in social isolation.

# 5 Methodology

This thesis is based on three related studies, communicated in four papers, conducted from 2019 to 2021. This section will first introduce the philosophical considerations of the thesis and overall design.

The settings for Studies 2 and 3, where the data were constructed, as well as the peer support program and peer supporter in this context, will be described. This chapter will then present how the scoping review was conducted. Finally, how Studies 2 and 3 were carried out in terms of the recruitment strategy, data construction and data analysis will be explained.

## 5.1 Philosophical considerations

Study 1 consists of both quantitative and qualitative data, indicating that the thesis could employ a combination of positivistic and interpretative approaches. However, the scoping review helped this project sensitize with the literature in the field and aimed to give increased insight into the phenomenon of study (Booth et al., 2022). Thereby, Study 1 was crucial in informing the two subsequent studies and contributing to the overall understanding. However, most of the data to address the aim of this thesis are qualitative (Studies 2 and 3), as an interpretative approach inspired the philosophical foundation. This approach is characterized by the ontological viewpoint of plentiful realities and meanings grounded in experiences (Alvesson & Sköldberg, 2018; Clark et al. 2021; Denzin & Lincoln, 2018; Johnsen, 2016).

In this thesis, these experiences are represented by the participants in the related studies and an advisory group. In an interpretative approach, reality is complex, holistic, and context-dependent. This epistemological assumption aims to increase our understanding of reality (Alvesson & Sköldberg, 2018; Denzin & Lincoln, 2018; Johnsen, 2016). Thus, the thesis argues for the aim of the study, understanding and revealing people living with HIV's experiences of peer support and explaining how to get insight and knowledge into their perspective of meaning in the context of peer support organized by the OPCs.

Even though a clear, mind-independent biological entity is related to the HIV diagnosis, researchers consider the meaning and experience of living with HIV constructed by socially and culturally negotiated perceptions. When planning and conducting this study, this societal construction of meanings is a part of the preunderstanding. Therefore, a social constructivist understanding of knowledge-creation contributed to framing this study, meaning that knowledge is created in specific settings in social relations (Alvesson & Sköldberg, 2018; Gergen, 2015). Thus, this research argues for a constructivist-interpretivist approach (Denzin & Lincoln, 2018).

Following these arguments, the thesis strived for a reflexive interpretation. In Studies 2 and 3, knowledge is gained through dialogue between the participants, where different perspectives and traditions are met (Alvesson & Sköldberg, 2018; Berger, 2015). In Study 1, the aim was to contextualize the findings by interpreting the results in the discussion of this thesis, which was also inspired by a dialogue with the advisory group. Finally, a collaborative research design is chosen to increase reflexivity by cooperating with an advisory group in the research process. See chapter 5.7.3 for more information regarding researchers' position and reflexivity.

## 5.2 Collaborative interpretive research design

The design is collaborative and interpretive as it strives to explore the depth of the phenomena of peer support for people living with HIV in collaboration with an advisory group. This study follows the epistemological democratic argument for collaborative interpretive research. This acknowledges the unique knowledge about the context of research received as a result of being a part of the world to be explored.

A democratic and critical dialogue between several perspectives in research provides the opportunity to construct new knowledge (Borg et al., 2012). To combine the experienced and professional knowledge from the healthcare service, the 'insider' perspective, either as a service user or as a healthcare professional, with an academic 'outsider' perspective can contribute to knowledge construction that can improve the healthcare service. A democratic argument also highlights that the researcher is ethically responsible for listening to the people affected by the research. The development of involving service users in knowledge construction made it possible to:

> 'Advance the evidence base for the social understandings of service users and the issues they experience which they themselves have developed, rather than being tied solely to other people's interpretations and understandings of them' (Beresford, 2019, p. 6).

In this sense, the researchers have the most significant responsibility of including the participants of a research project, in this context represented by an advisory group. However, in their review, Malterud and Elvebakken (2019) concluded that there are several substantial challenges with patient-involving strategies in research. It is also worth noting that there is a risk of tokenism, meaning having participants without actually giving them real influence (Glover, 2009), as further elaborated in the following chapter and chapter 8.1.

### 5.2.2 The collaboration with the advisory group

To aim for a democratic approach to knowledge production and avoid tokenism, the researcher worked closely with an advisory group to identify and prioritize unanswered questions about the topic of interest. The user perspective was strived for by working with the advisory group at several levels throughout the research process. Five people were invited to form an advisory group because it was essential to include lay community experts' perspectives and feedback during the research process. To optimize diversity, the advisory group consisted of two service users (people living with HIV), one being a peer supporter and the other representing service users. The man and the woman living with HIV included one immigrant and one member of a sexual minority group. To represent the healthcare professionals, one nurse and one medical doctor who have been working at two different HIV OPCs for several years were also members of the advisory group. In addition, one representative of an NGO was a member of the advisory group.

Although there was a continuous dialogue between the researcher and the advisory group, the frequency of contact between the project and the advisory group varied. The project group initiated a meeting point before each planned research phase. Twice a year, the advisory group was invited to a three-hour meeting to discuss the progress of the related studies. The first meeting was physical; however, the subsequent sessions were digital because of the coronavirus disease (COVID-19). The successive communication between the advisory and project groups was done through e-mail correspondence. The communication was related to the project's progress, the recruitment of participants in Studies 2 and 3, and the data analysis. Some of the advisory group members gave immediate responses, either by e-mail or phone. In contrast, other advisory group members responded after being sent reminders.

The project strived for continuous awareness of how to involve the advisory group to minimize the risk of tokenism. Participation at every step in the study was not feasible due to the time limit. Even so, it was essential to raise the end-users’ voice by involving service users, peer supporters, and healthcare professionals in the research process. Furthermore, to decrease the risk of potential cooptation of peer support values in the meetings related to power dynamics between the advisory group members, separate, independent meetings were conducted with the representatives living with HIV.

Most significantly, the advisory group contributed to understanding terms, provided increased insight into enabling patient involvement, explored research questions, and gave input on the analytical process as described in the analysis of Studies 2 and 3. To a great extent, they helped interpret the revealed data to reflect and confirm the participants’ experiences from different perspectives. This collaborative interpretation was a way to establish a relationship between the direct and subjective experience of the individual participants and the advisory group to validate their claims (Gergen, 2015). In addition, the collaboration with the advisory group helped include a critical view of potential conflicting ideologies and power relations reflected in the data.

### 5.2.3 A descriptive and explorative methodological approach

The interpretative paradigm guided the methodology. A descriptive, exploratory design was chosen to search for meaning within the experiences of individuals to understand their perspective of their world. The researcher also wanted to voice their unique experiences collaborating with the advisory group through this thesis. Hence, a combination of methods was chosen (Denzin & Lincoln, 2018; Polit & Beck, 2018).

Qualitative methods strive to study a phenomenon in its natural setting (Alvesson & Sköldberg, 2018; Clark et al., 2021; Denzin & Lincoln, 2018). The data construction in Studies 2 and 3 was conducted in the OPCs, where peer support was undertaken. Therefore, the OPCs are considered a ‘natural context’ for peer support by all participants and the follow-up they get from healthcare services when living with HIV. In this respect, an outsider's perspective of not being familiar with the OPCs in everyday life was represented by the researcher.

In Study 1, a scoping review was conducted to describe the empirical literature on peer support for people living with HIV (for further description, see chapter 5.4). Hence, there is an argument for abduction as the methodological approach used in the research process. Abduction involves interpreting singular cases from a hypothesized overarching pattern that might explain what is found. Abduction commonly shares elements of induction and deduction, adding a level of understanding and could be understood as a pragmatic approach to research to develop new insights (Alvesson & Sköldberg, 2018; Clark et al. 2021; Eriksson et al., 1997). There are arguments for claiming abductional reasoning related to this project, as the scoping of empirical research in Study 1, in addition to the advisory groups’ and the researchers’ prior understanding of relevant, existing concepts, contributed to discovering patterns of key concepts. These concepts further informed and brought understanding to the two subsequent studies. In addition, Study 1 informed the reinterpretation of the data in Studies 2 and 3. The methods in Studies 2 and 3 explore the people living with HIV’s qualitative, lived experiences of peer support meetings from the service users’, peer supporters’, and healthcare professionals’ perspectives. A further description of the design and methods of each study is given in the chapters below.

Table 1. Overview of study design, participants, data construction, and methods of analysis for the three studies

| | Design | Data construction | Participants | Inclusion criteria | Methods of analysis |
|---|---|---|---|---|---|
| **Study 1** | Descriptive | Scoping review | 24 932 | Quantitative and/or qualitative research methods, age ≥18, peer supporter living with HIV, Peer support including > 60 minutes of face-to-face interaction | Descriptive analysis<br>Thematic analysis |
| **Study 2** | Exploratory | Individual, semi-structured interviews | 16 service users living with HIV | Living with HIV, enrolled in HIV clinical care at one of the OPCs, age ≥18, signed written informed consent, attended peer support meeting at least once, healthcare professional-initiated peer support meetings | Directed qualitative content analysis |
| **Study 3** | Exploratory | Individual, semi-structured interviews and focus group discussions | 10 peer supporters<br>Five healthcare professionals | Peer supporters: living with HIV, engaged as a peer supporter at least two times, enrolled in HIV care at one of the OPCs, peer meeting initiated by a healthcare professional.<br>Healthcare professional: worked at OPC with peer supporters, initiated peer support | Reflexive, qualitative thematic analysis |

## 5.3 Study setting

Norway has organized healthcare services according to the Nordic healthcare model, founded on solidarity, equity, and public participation. This tax-funded compulsory social security system and health insurance scheme give universal access to comprehensive and high-quality care based on individual needs regardless of the social and economic situation (Adnan, 2021; Torjesen et al., 2017). Consequently, the role of the NGOs is primarily complementary to the existing services. The Ministry of Health and Care has overall responsibility for the quality of health services, the determination of capacity in all regions, and health policies for all hospitals in Norway, as the state owns the public hospitals. The hospitals are organized into four regional health authorities. These regional health authorities consist of 20 hospital establishments located geographically around Norway, whereas six are University Hospitals (Adnan, 2021; OECD, 2019).

The HIV OPCs in Norwegian hospitals are part of the specialist healthcare system and meet every person newly diagnosed with HIV at least once a year. As a national standard, the HIV OPCs provide free-of-charge medical follow-up and treatment for people living in Norway who have been diagnosed with HIV (Medical Association, 2021; Whittaker et al., 2020). The OPCs consist of infectious disease specialists and healthcare professionals, often registered nurses. When people are diagnosed with HIV, they meet an infectious disease specialist during their first consultation at the OPC. Furthermore, the OPCs provide regular follow-ups once to twice a year. Supplementary follow-ups are performed in collaboration with primary healthcare and other parts of the specialist healthcare system depending on the patients' needs; for example, mental and somatic comorbidity (The Norwegian Medical Association, 2021).

The setting for the peer program was five public OPCs situated in local hospitals in three regional health authorities in Norway, two of which were university hospitals. The five OPCs provide the routine follow-up as described above, but differ in the number of service users connected to the OPCs. The university hospital of St. Olav has approximately 250 service users at the OPC and has thereby the most considerable number of service users. The University Hospital of Northern Norway has about 177, and The Hospital of Southern Norway has 160 service users. The two last OPCs, Østfold Hospital and Nordland Hospital, have 150 and 60 service users with HIV, respectively.

### 5.3.1 Description of the peer support program

The peer support program at the OPCs is user-initiated and started as a part of the services at one user-driven OPC that serves people living with HIV. In 2011, based on the service users' experiences and needs, a user board consisting of people living with HIV developed targets for the services. These targets involved making the changes required for the OPC to become user-driven. Thus, this clinic is an example of service users becoming involved and contributing to an organizational redesign in partnership with clinic management. One of the user-driven OPC’s aims was to establish peer support as a part of the services organized by healthcare professionals. Until now, peer support has mostly been offered to people living with HIV through NGOs. The NGOs are situated in larger cities in Norway and are therefore only available for one of the OPCs included in this study.

As a result of the patient involvement at this specific clinic, four other OPCs incorporated a peer support program as a part of their services during 2019 and 2020. The peer program's implementation and the training were conducted together, and a dialogue between peer supporters and healthcare professionals at the different clinics ensured that the values of peer support were understood and implemented. Therefore, the peer supporters and the healthcare professionals in the OPCs cooperate when providing the overall services.

The peer support program at the OPCs aimed to offer service users with HIV an opportunity to meet peer supporters by following the description of a peer supporter below. Consequently, healthcare professionals at the five OPCs offered peer support to every person with HIV enrolled at the OPCs as a part of their services.

### 5.3.2 Description of a peer supporter

A peer supporter in this study is a person living with HIV receiving treatment and care at one of the included OPCs. The peer supporter is formally trained following a training program. The training and the peer program implementation in the OPCs are inspired by the non-peer-reviewed literature of Bloomsbury Patient Network (2019), Positively U.K.’s national training program for peer mentors, *Project 100* and National Standards for HIV Peer Support (2020). Through this training, the peer supporters gained and developed knowledge to provide support on a variety of issues faced by people living with HIV. A peer supporter was suggested to offer assistance grounded on values of equality and thus provide an opportunity to focus the support on the immediate, here-and-now needs the service users presented (Berg et al., 2015).

Some of the peer supporters knew how the clinic functioned, and what services it provided and were familiar with the healthcare professionals at the OPCs. The newly recruited peer supporters knew how the clinic functioned and received additional information from healthcare professionals at the OPCs where they were volunteers if and when needed. Even though the peer supporters were volunteers, in this project they work as independent consultants and receive a payment (72 USD per consultation funded by the OPCs) as compensation for their contribution and coverage of travel expenses. The healthcare professionals provide the peer supporters with regular supervision. In addition, the peer supporters regularly meet for peer discussions and assessments.

## 5.4 Study 1: A scoping review

Given that existing research examining peer support programs in several healthcare service areas and among different groups found mixed and conflicting evidence of the benefits of these programs, as exemplified in chapter 3.3 (Genberg et al., 2016), there was a need for further research related to this topic.

Additionally, most of the reviews related to peer support for people living with HIV were about the interventions' effectiveness. In contrast, fewer research reviews were found on other aspects of peer support, such as experiences from the providers' and receivers' perspectives.

The purpose of the scoping review was to provide an overview of relevant empirical research, identify knowledge and research gaps and suggest implications for further research. Therefore, this study aimed to identify and describe the characteristics and results of empirical research on peer support for people living with HIV. Due to the high number of included studies and the volume of data, it was necessary to disseminate the review results into two reports (papers I and II).

The scoping review followed the guidance document for scoping reviews formed by the Joanna Briggs Institute (Peters et al., 2020), which is based on the work by Arksey and O'Malley (Arksey & O'Malley, 2005) and Levac et al. (Levac et al., 2010). Study 1 was reported in accordance with the PRISMA extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018).

### 5.4.2 Inclusion criteria

The main criterion for the scoping review was that the study used empirical quantitative and/or qualitative research methods to address peer support for people living with HIV. In addition, the study population had to be adults (18 years or older). The chosen definition of peer support was proposed by Dennis (2003) as described in chapter 3.4, wherein the peer supporter should be a person living with HIV using their own experiences to support others living with HIV.

The peer support intervention in the included studies had to include a minimum of 60 minutes of face-to-face interaction. Studies were considered ineligible if 1) the participants were children and youth, 2) prevention of HIV, 3) mother-to-child transmission was the primary focus or 4) support groups. However, studies in which the population or peer support programs were mixed (e.g., had both adults and youth in the study population) were included. Studies where at least half of the population or program met the inclusion criteria or if the results were reported separately for our population and program of interest were also included. The review enforced no settings or publication format limits but included only publications in English or Scandinavian languages (Norwegian, Swedish or Danish). Since 1981 was the first year when studies on HIV/AIDS were published, there was a natural selection of studies published after 1981.

### 5.4.3 Search strategy

A preliminary search was conducted by the researcher (first author paper I & II) to identify relevant keywords and search for existing scoping reviews in the JBI Database of Systematic Reviews and Implementation Reports and PROSPERO. An abbreviated PCC (population, concept, and context) format was used as a framework since the research question implies that the context is not predefined (Booth et al., 2016).

The search was first conducted in January 2019, and then an updated search was conducted in May 2021. The following eight electronic databases were searched: MEDLINE (OVID), MEDLINE In-Process (OVID), EMBASE (OVID), CINAHL (EBSCOhost), PsycINFO (OVID), SocINDEX (EBSCOhost), Social Work Abstracts (EBSCOhost) and BASE (Bielefeld Academic Search Engine). A strategy incorporating prespecified subject headings (e.g., MeSH terms in MEDLINE) was adopted. Also, text words in the titles and abstracts adapted for each database were used to conduct the searches. The search was completed together with a librarian who was an information search specialist. The search strategy is shown in papers I and II, additional file 1. Additionally, a search in the grey literature was conducted through Google Scholar, the U.K. government website, and CORE (which aggregates all open-access research outputs from repositories and journals worldwide and makes them available to the public) to supplement the database searches. Furthermore, hand searches were performed in the reference lists of all the included studies, relevant literature reviews, and forward citation searches through Web of Science (June 2021).

### 5.4.4 Selection of literature

We used the Endnote database X9 (Thomas Reuters, New York) to store the retrieved references. Duplicate entries were deleted, and the remaining references were imported to Rayyan (Ouzzani et al., 2016). Using Rayyan, a web-based software platform that organizes all references and secures the integrity of the selection process (Ouzzani et al., 2016), two reviewers screened all titles and abstracts independently according to the inclusion and exclusion criteria. Based on the inclusion criteria, selection criteria (questions) were developed and used that could be answered using yes/no. For example, one selection criterion was ‘Is the intervention in-person peer-support?’ These selection criteria ensured the consistent selection of studies and adherence to the inclusion criteria. All relevant titles and abstracts were promoted to full-text independent screening by the two reviewers. The researchers resolved any differences in opinion during each stage of the screening process through a re-examination of the study and subsequent discussion. When necessary, a third reviewer was consulted. Please refer to the PRISMA Flow Diagram of Literature Reviewing Process, figure 1 in papers I and II for a further description.

### 5.4.5 Data extraction and synthesis

Given this review’s aim and scoping reviews in general, methodological quality assessment is not a prerequisite. Therefore, the researcher did not appraise the included studies (Peters et al., 2020).

The researcher (the first author) performed the data extraction, and two other reviewers checked the completeness and accuracy of the data. A data extraction form was predesigned and piloted by the researchers to ensure standardization and consistency (Peters et al., 2020). In addition, during the data extraction process, new data were added if found relevant. Data were extracted regarding the author, year, study characteristics (e.g., country, study design, sample size), population characteristics (e.g., gender, sexual identity) peer support characteristics (e.g., terminology, duration, content, settings), and main findings. By keywording each study by such variables and compiling the data into a single spreadsheet, the studies could be grouped according to their main characteristics (Clapton et al., 2009). Descriptive analyses were performed using frequencies and cross-tabulations. The grouping followed a data-driven approach and included sorting the studies into clusters according to how they were seen to be related to each other (Clapton et al., 2009; Levac et al., 2010). Similarly, the main findings of the qualitative studies were copied into a word document, restricted to instances across the data with relevance to peer support. Finally, a simplified manual thematic analysis was performed to summarise the findings across the dataset (Harden & Thomas, 2008).

## 5.5 Study 2: Peer support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users' experiences

Study 2 (paper III) had an exploratory research design, including in-depth, semi-structured qualitative interviews. The interviews explored the lived experiences of service users' meetings with a peer supporter in the context of an OPC. In addition, other aspects related to the dialogue found relevant to the experiences of the peer meeting were examined as a follow-up during the conversation (Alvesson & Sköldberg, 2018; Kvale et al., 2015; Malterud, 2017).

### 5.5.1 Participants

The individuals were considered eligible for interviews following the inclusion criteria described in Table 1. The individuals could participate regardless of literacy, but they had to understand Norwegian or English. Service users with a severe mental disorder or cognitive impairment that would make them incapable of answering the questions were not recruited. Individuals enrolled in an OPC were eligible whether they were on ART or not.

### 5.5.2 Recruitment strategy

The healthcare professionals at the OPCs were helpful in this sampling strategy, as they followed the inclusion criteria and invited people living with HIV to participate. A purposeful sampling of people living with HIV was used to get as many experiences as possible, defined as centrally essential, to get an in-depth understanding of the meetings between service users and peer supporters. To capture the core experience of receiving peer support, the study aimed for maximum variation sampling (Patton, 2002). The healthcare professionals invited eligible people living with HIV to participate in individual interviews or focus group discussions (FGDs). The healthcare professionals were given information about purposeful sampling, which implied in-depth interviews with individuals they perceived could provide rich information about their experiences (Patton, 2002; Ryen, 2017).

The healthcare professionals at the OPCs gave the potential participants initial information about the study, both orally and in writing. A further description is given in chapter 5.7.

### 5.5.3 Data construction

The qualitative data were constructed in 11 months through in-depth, semi-structured interviews. All the participants in Study 2 preferred an individual interview rather than FGD due to confidentiality. The interviews were conducted at the participants' local OPC according to their convenience. Participants did not receive any compensation other than covering their travel expenses; however, refreshments were provided for the interviews. The interviews lasted from 30 to 60 minutes, with an average of 47 minutes and they were audiotaped and transcribed verbatim. Memos containing the researchers' overall impressions and subjective reflections were written immediately after each interview.

The number of participants was considered while reading the transcripts and preliminarily coding the three initial interviews. The number of participants was decided through an iterative, context-dependent process to ensure a comprehensive picture of the topic. Considering the narrow study aim and the quality of the empirical data, 16 interviews were found to provide sufficient information. In addition, the participants were asked if they wanted to read the transcripts. However, all participants declined the offer to read and discuss the transcripts after the interview.

The interview guide included 21 open-ended questions to help increase insight into the participants' experiences, their perspectives on meeting a peer supporter and their own words about their life with HIV (Additional file 1, paper III). Study 1 informed the first draft of the interview guide related to social support and stigma. In addition, the interview guide was discussed with the other researchers and the advisory group.

During the interviews, the participants and the researcher explored the content of the peer meeting and how peer support was organized and conducted. The participants were invited to share their narratives with detailed descriptions of their experiences. As follow-up questions, experiences with HIV status disclosure and their concerns and perceptions of social stigma were explored. The participants and the researcher also investigated their personal experiences with social support in general and related to their HIV diagnoses. Their own experiences included insight into vulnerable situations as well as positive experiences of social support.

### 5.5.4 Data analysis

A directed, qualitative content analysis was chosen to prepare, organize and report the findings according to Assarroudi et al. (2018) and Hsieh & Shannon (2005). Please refer to Study 2, Paper III, for further description of the data analysis process. Directed content analysis is based on existing theories about a phenomenon (Hsieh & Shannon, 2005; Polit & Beck, 2018).

The chosen theoretical approach in the analytical phase was based on the six social functions Weiss (1974) identified needed for individuals to feel supported and avoid loneliness. Weiss' social provisions is a recognized theory related to social support studies. As the immediate impression of the results demonstrated that peer support was experienced as a positive contribution in the service users' lives, the choice of analysis is based on the need to know more about what kind of support the service users felt they received.  This was scrutinized to determine the main concepts set as six pre-determined categories: attachment, social integration, the opportunity of nurturance, reassurance of worth, reliable alliance, and guidance (Cutrona & Russell, 1987; Cutrona & Russell, 1990; Weiss, 1974). A further description of Weiss' (1974) six identified social functions is given in chapter 4.2.2.

The initial phase involved familiarisation with the textual data; two researchers (the first and last authors of paper III) read through the transcripts to get a sense of the content. In the second stage, the data were de-identified before being imported into the Nvivo12 software program for qualitative analysis (2018). Next, Nvivo12 helped structure the coding of the data. The pre-determined categories were applied to the textual data, and a researcher (the first author) searched for meaning units found to be correlated with each of the pre-determined categories. Data found relevant but not fitting into one of the pre-determined categories inductively formed a new category. Next, the researchers (first and the last author) coded the interviews according to the categorization matrix defined by coding rules exemplified with sample quotes (Assarroudi et al., 2018). After having the meaning units transferred from NVivo12 to M.S. Word, the meaning units relating to each pre-determined category were inductively condensed by the researcher. Finally, two researchers (the first and the last author) discussed condensation. In stage four, the researcher coded the condensed meaning units and discussed the codes with the other researchers and the advisory group separately. The involvement of the advisory group was significant at this point to make sure the meaning units were recognizable to them and to adjust the researcher's understanding of the coded material. The coding included that the text was reanalyzed to provide an opportunity for identifying texts missing from the pre-determined categories (Assarroudi et al., 2018). Next, all researchers examined the codes for differences and similarities and then abstracted the codes into sub-categories in a back-and-forth process. At this point, the advisory group was invited to give feedback on the codes, and two of the group members contributed at every step of the analysis.

At last, the sub-categories were abstracted into their representative pre-determined categories. Members of the research team reviewed the sub-categories before proceeding to the reporting phase. There were a few contradictions in the empirical data and in the discussions with the advisory group. The disagreements were discussed until a consensus was reached. When finalizing the results with the advisory group, they read the report and provided feedback before submission to a scientific journal. The feedback was mainly found to be a confirmation of how the results in the report correspond with their own experiences. Please refer to the third additional file, Paper III, for a further definition of categories, operationalization, and the meaning of each category relevant in the context of peer support.

## 5.6 Study 3: ‘They make a difference’: A qualitative study of providers’ experiences of peer support in outpatient clinics for people living with HIV

Study 3 (paper IV) had an exploratory research design where qualitative methods were used, involving in-depth, semi-structured individual interviews and FGDs. The interviews explored the qualitative, lived experience of being a peer supporter and the healthcare professionals' experience of working with peer supporters. The FGDs in Study 3 aimed to examine the experiences of the peer support program, where they can be reflected through interaction between the participants (Smith, 2015).

### 5.6.1 Participants

The individuals were considered eligible for interviews if they were peer supporters or healthcare professionals at the OPCs, following the inclusion criteria described in table 1.

### 5.6.2 Recruitment strategy

To get an in depth-knowledge of the phenomenon, and to capture the core experience of the different perspectives of a peer support program, there was a need for maximum variation sampling, which presupposed asking for key informants (Patton, 2002). Through this, the study aimed to explore both the possible similarities and diversities of the lessons learned (Patton, 2002; Ryen, 2017).

The healthcare professionals invited people living with HIV who were engaged as peer supporters to participate in this study. The healthcare professionals were informed about purposeful sampling, which implied interviews and FGDs with individuals they perceived could provide rich information about their experiences as peer supporters (Miles & Huberman, 1994; Patton, 2002; Ryen, 2017). The healthcare professionals helped this sampling strategy by engaging a variety of people living with HIV as peer supporters. In addition, healthcare professionals involved in the intervention at the OPCs were invited to participate in individual interviews and FGDs. Thus, peer supporters’ perspectives and healthcare professionals’ experiences of working together were crucial to understanding the peer program experiences.

The healthcare professionals at the OPCs gave the peer supporters initial information about the study both orally and in writing. A further description is given in chapter 5.7.

### 5.6.3 Data construction

The in-depth semi-structured interviews and FGDs were conducted face-to-face during the spring and autumn of 2020. According to participants’ convenience, most of the interviews and FGDs were conducted at the OPCs. However, three individual interviews with peer supporters were conducted elsewhere. Two of them were conducted at a café at the peer supporters’ request, and one was conducted digitally because of the pandemic situation related to Coronavirus Disease 2019. One FGD included four peer supporters and one healthcare professional, whereas the other FGD consisted of two peer supporters and two healthcare professionals.

The participants aimed to cover the OPCs involved and the diversity of the peer supporters. The sample size was a result of a continuous process during the interviews. After each individual interview and FGD, the comprehensiveness of the empirical data was aimed at providing sufficient data to get an in-depth understanding of the phenomenon.

The researcher audited the interviews, transcribed them verbatim, and made field notes immediately after the interviews and the FGDs to remember the reflections. The nine interviews with peer supporters lasted 23–102 minutes, with an average of 60 minutes. The duration of the five interviews with healthcare professionals was 32–52 minutes, with an average time of 39 minutes. The two FGDs lasted 60–99 minutes, with an average of 80 minutes. Light refreshments were provided during the interviews and FGDs.

An interview guide developed for the study helped structure the interview and discuss the relevant topic of interest (appendix 8). The researchers and the advisory group formulated the interview guide. The interview guide was developed and informed by Study 1. However, it was not pilot-tested. The interview guide related to individual interviews with peer supporters and healthcare professionals included sixteen and thirteen open-ended questions, respectively. The interview guide related to FGD had fourteen open-ended questions. The questions helped increase insight into the participants' experiences and perspectives as peer supporters and healthcare professionals at the OPCs. For example, the initiation of the peer support meetings and the topics discussed during peer support meetings were explored, as were the peer supporters' narratives with detailed descriptions. As follow-up questions to the peer supporters' responses, the participants and the researcher explored HIV status disclosure experiences and their concerns and perceptions of social stigma, and how they relate to their work as peer supporters. Furthermore, the peer supporters and the researcher explored their personal experiences with social support in general and according to their HIV diagnoses.

### 5.6.4 Data analysis

A reflexive, collaborative thematic analysis was conducted using an inductive approach when identifying, analyzing, and reporting the patterns in the empirical data. The process followed Braun and Clarke's analysis phases (Braun & Clarke, 2006, 2013, 2019; Braun et al., 2018). Please refer to Table 1, Paper IV, for further description of the coding procedures.

In the first phase, all four researchers in Study 3 read the transcribed data to become familiar with the empirical data. In the second phase, the NVivo software program for qualitative data analysis helped structure the coding of the data (QSR International Pty Ltd, 2018) when developing the codes. Two researchers conducted this phase and chose to follow Tjora's stepwise-deductive inductive approach (Tjora, 2018). This approach, empirically close coding, was chosen in this specific phase to reduce the potential influence of the researcher's presumptions and theories. In addition, it reduces the volume of empirical material while working close to the empirical data when ideas are developed in the next phase. Most importantly, the empirical close codes could be shared with the advisory group without risking the participants' confidentiality (Tjora, 2018), making the reflexibility of the analysis possible.

In the next phase, themes were generated. The codes were sorted into potentially larger groups according to the shared meanings. Furthermore, the researcher actively created subthemes and overarching themes representing several codes. Contradictory data were almost non-existent, therefore not expanding the themes identified in our study. In addition, and importantly, the third phase was completed with the advisory group, which provided a more nuanced understanding of the data as they contributed with an insider's perspective when interpreting the data (Braun & Clarke, 2019).

The fourth phase was a process of reviewing and refining the themes. The researchers repeatedly checked the data and the coding structure to determine whether the overarching themes covered the data's content or missing links in the analysis.

The final process of defining and naming the themes was conducted to capture each theme's essence (Braun & Clarke, 2006, 2013). The last step was to write the report. The report concluded the analytical work by including representative and illustrative quotes from the participants to illustrate the themes. Repeated words and word fillers were deleted from the quotes to increase readability. However, the quotes are verbatim as presented in the results chapter in paper IV.

## 5.7 Ethical consideration

This thesis contends that overall, ethically strategic decisions regarding ethical reflexivity were made. In addition, the researcher performed continuous systematic and ethical reflexivity along with the project's different phases as needed (Finlay, 2012).

This PhD project was financially supported by the Dam Foundation and the Northern Norway Regional Health Authority, underlining the need for comprehensive research on this specific topic. However, the funders were not involved in the study's design, collection, analysis, and interpretation of the data or the writing of this manuscript.

### 5.7.1 Formal ethics

In accordance with the norms for conducting social research, approval was sought before recruiting and interviewing participants in Studies 2 and 3. The Regional Ethics Committee for Medical Research (REK) and the Norwegian Social Science Data Services (NSD) considered the PhD project. NSD considered and approved the studies (NSD; reference number 184248, appendix 1). However, REK considered the PhD project not to be within the scope of the Norwegian Health Research Act, and approval was deemed unnecessary (REK; reference number 28944, appendix 2). In addition, the Ethical Committee at the Faculty for Health and Sports Sciences, University of Agder, approved the project (FEK; reference number 19/07709, appendix 3). Before commencing

Studies 2 and 3, approval for the five hospitals' where the OPCs are situated (appendix 4) was applied for and received.

Information about the studies was communicated both orally and in writing before the participants chose to participate. Informed consent was obtained from all participants before the data collection started. It included information about their opportunity to withdraw without negative consequences regarding their relationship with healthcare professionals at the OPCs. Furthermore, they were informed that all data were unidentified, and that confidentiality was safeguarded. Finally, they were informed that the data were stored following appropriate rules and guidelines for storing research material.

### 5.7.2 Ethical considerations in the selection of research field

There are ethical considerations related to researching people in potentially vulnerable situations. Wigginton and Setchell (2016) argue that the researcher, as an ‘outsider’, have a responsibility to reduce the effect of stigma. Helping reduce stigma is especially crucial if the researcher, as an outsider, is a part of the group that creates or perpetuates the stigma. It is essential to acknowledge this ethical responsibility of being an ‘outsider’ in the research since an outsider may have more social influence or power than the people being potentially stigmatized.

To recruit people living with HIV who had met a peer supporter to interview their experiences, the researcher required the help of healthcare professionals (often nurses) at the OPCs. They contributed to getting access to valuable participants and not disclosing the service users without their consent. For some participants, the healthcare professionals were the only people who knew about the service users’ HIV-serostatus, indicating that people living with HIV had a relationship with the healthcare professional’s dependence on trust. Trust is important when participants risk being exposed by participating (Wigginton & Setchell, 2016).

Consequently, the healthcare professionals were particularly mindful of the situation and emphasized voluntary participation due to this relationship. The healthcare professionals informed the potential participants about the research, both orally and in writing, and requested permission to give the researcher their contact information. The researcher repeated the information when making an appointment to ensure voluntary participation and just before conducting the interview. This repetitive information emphasized the importance of voluntary participation in the study. It seemed especially important since some participants do not have Norwegian as their native language because of their migrant background.

The healthcare professionals asked service users with HIV who had an appointment at one of the OPCs to participate in the study. However, constraints influenced this recruitment, considering that the participants had to understand Norwegian or English. As a potential consequence of this selection, the voices of newly arrived people living with HIV with a migrant background who do not understand Norwegian or English will not be captured. Considering the researchers’ social responsibility to the various people living with HIV, leaving newly arrived people living with HIV with a migrant background out of the research could be ethically challenging. One question will be whether the results will do them justice.

### 5.7.3 Researcher's position and reflexivity

Qualitative research literature appears to reflect a consensus about the need for reflexivity during the research process. Reflexivity in this context means a continuous dialogue and self-evaluation of the researcher's positionality, in the meaning reflecting upon myself and my experiences. Acting reflexive is a recognition that research cannot be value-free (Clark et al., 2021). Additionally, it recognizes that the researcher's position may affect the research process and outcomes (Berger, 2015; Clark et al., 2021; Finefter-Rosenbluh, 2017; Finlay, 2012).

When being reflexive in this project I, as a researcher, tried to question values, assumptions, power relations, and even the theoretical positions related to the research project (Clark et al., 2021; Wigginton & Setchell, 2016). I chose to disclose the lack of personal and professional experience with HIV when meeting the participants in studies 2 and 3. This disclosure was an attempt to establish trust between the participants and me and to facilitate openness in the context. By this, I positioned myself as an 'outsider'. My approach to being ethically responsible, not to mislead the participants, was to acknowledge the lack of experience. At the same time, I was open about being a nurse with a specialty in health promotion, though emphasized that in this situation, I was a researcher (Clark et al., 2021; Wigginton & Setchell, 2016).

I could be categorized as an 'outsider' at several levels in this research project, and a disclosure of my outsider-ness required an in-depth understanding of my own social positioning. First, I am not living with HIV. Additionally, I do not share several of the other characteristics of the participants found relevant for the research topic, e.g. being homosexual or having a migrant background. On the contrary, my position, being a white heterophile woman coming from a conventional, working-class family, share characteristics with people who perpetuate the often experienced stigma of people living with HIV. What this demonstrates is how impressionable and vulnerable we are when facing other, unfamiliar stories, the stories with which we do not identify. Thus, the degree of my personal familiarity with the topic in this thesis needed consideration.

Being an outsider adds an important perspective to the topic of research. Acknowledging that research cannot be value-free, I strived to approach the field of research with an openness trying to understand and even listen to the potential unexpected when framing a dialogue with the participants when conducting interviews in studies 2 and 3 (Clark et al., 2021). Still, recognizing that I was more an 'outsider' than an 'insider' when conducting the qualitative interviews, there was a need to know how this could affect my situatedness in the project and even the outcomes (Berger, 2015; Finefter-Rosenbluh, 2017; Finlay, 2012). Consequently, I needed to talk to people with HIV in advance of starting the data construction, to involve myself in the topic and get to know as much as possible about HIV from the perspective of the people who have immediate experiences. My, I assumed, generalized perception about people living with HIV needed to be explored. Therefore, involving myself in the topic required both to know more about the medical aspects of living with HIV as well as the emotional. Simultaneously, I had a period of diving into my own preconceptions related to the people who get affected by HIV. I questioned what did my personal history add to the context when I met people with HIV, and what my preconceptions were. To learn more about HIV and at the same time get to know my preconceptions, I spent three days at an NGO in Norway which provides support to people with HIV. I engaged myself with people living with HIV, listened to their stories of disclosure/non-disclosure, and learned about how HIV affects their lives and other aspects they found relevant. I found myself looking at the stories from the outside. When they told their stories, I am embarrassed to admit that I struggled with several questions in my own mind, e.g., how the people I met got HIV, if they were gay, or if they used drugs. Out of nowhere, my preconceptions were out in the open. At that moment, as my ‘out-of-the-blue’ preconceptions demonstrated, I knew my research process required awareness at every step. Increasing my own awareness included sharing the preconceptions and assumptions with some of the members of the advisory group.

The involvement of an advisory group was an important step to ensure that the ‘insider’ perspectives were included in the research process. The advisory group’s involvement was a recognition that my biases, assumptions, and personality may affect the research in several ways.

In every project phase, the researcher required this ‘insider’ perspective to ensure congruence between the issues of interest and their views. The advisory group members provided ‘insider’ perspectives on the project's planning, execution, and analysis (Wigginton & Setchell, 2016). To understand how the researcher’s social position shaped the research process, there was a need to ensure that the advisory group recognized the topics in the interview guides. This involvement of an advisory group was also important when the analysis was conducted, and this ensured that the analysis was a trustworthy representation of the themes in the narratives. Constantly consulting the advisory group was important when considering the accuracy of the analysis. As a result, it is more likely that the other researchers and I did not misinterpret data or misunderstood experiences. Therefore, our ‘insider’ consultant was the advisory group, helping the researcher increase awareness of pre-assumptions, values, and preferences. In addition, as a researcher, one must remember that the priorities of people with conditions and those who treat and care for them may differ. Interestingly, through the cooperation with the advisory group, the researcher became aware that some of my preconceptions and assumptions were shared with the members of the group who were living with HIV. Later, through the data construction, I learned that several of the participants also had shared my preconceptions before they got HIV themselves. Thereby, the idea of intersectionality is found relevant, as we all occupy positions within different social categories which cannot be understood in isolation and thus can affect our experiences and interpretations (Clark et al., 2021). From this one could learn, that prior to conducting a study, every research project could profit from questioning values, assumptions, and power relations, either as an ‘insider’ or ‘outsider’ researcher (Finefter-Rosenbluh, 2017; Wigginton & Setchell, 2016).

### 5.7.4 Situated ethics

In the situated meetings with the participants, several considerations are to be taken as researchers (Guillemin & Gillam, 2004; Mathiassen, 2011). First, the sessions were framed to be safe and ensure the participants’ anonymity. To create a safe environment, the participants could decide where to meet, which led to most of the interviews being held at the OPCs at the participants’ request. Despite this, some participants in Study 2 felt insecure and needed more information to be confident in the situation. In addition, several of the participants were considering the potential consequences and costs of disclosing the diagnosis to a researcher. Therefore, I aimed to decrease the emotional agony of the participants. At the same time, attempts were made to avoid being paternalistic in taking all responsibility for the meeting and acknowledged the participant’s ability to regulate their needs (Wigginton & Setchell, 2016).

Recognizing that power is a part of every relationship, my openness was an attempt of equalizing the power between the participants and me. I made sure to highlight that the participants’ experiences and knowledge were essential to this project. Throughout the interviews, I tried to foreground participants’ voices and control. The intention was to allow the interview process to be more collaborative between the participants and me in terms of topics they found important and relevant.

Still, the researcher was responsible for framing the conversation related to the main topic of interest, and the aim of the interview was made clear in the invitation to participate. However, despite framing the questions, the participants shared personal and emotional stories related to their own experiences of living with HIV beyond what was expected in the situation. This sharing of stories seemed to be driven by the participants’ wish to share what they felt was essential to talk about in relation to the primary aim of the conversation. Sharing of stories could be understood as the researcher’s tool to minimize the power between me as the interviewer, and give the participants more control. At the same time, this openness required a continuous assessment of the situation, finding a balance between being a respectful and empathic researcher and avoiding turning the conversation into a therapeutic relationship (Mathiassen, 2011). In addition, it required the contextual and ethical awareness of both the participants’ and my motivation to continue talking about specific topics (Guillemin & Gillam, 2004).

To capture any potential challenges the participants may have after the conversation, they could speak to a healthcare professional at the OPC or contact me if they needed to talk. This opportunity was a way to prevent unnecessary emotional agony.

# 6 Summary of findings

The three studies of this thesis each represent significant parts. Therefore, this chapter briefly presents the findings, while the original papers I–IV offer further elaboration.

## 6.1 Study 1: A scoping review

Øgård-Repål, A., Berg, R.C., & Fossum, M. (2021). Peer support for people living with HIV: A Scoping Review. Health Promotion Practice. https://doi.org/10.1177/15248399211049824

Øgård-Repål, A., Berg, R.C., & Fossum, M. (2021). A Scoping Review of the Empirical Literature on Peer Support for People Living with HIV. Journal of the International Association of Providers of AIDS Care, 20. https://doi.org/10.1177/23259582211066401

This scoping review identified eighty-seven studies using predefined inclusion criteria specified in the protocol. Due to the somewhat surprisingly high number of included studies and the volume of data, it was necessary to separate the review results into two reports (papers I and II). Of the included studies in the scoping review, papers I and II reported 53 and 34 studies, respectively. However, in this chapter, the results are written in summary. For a further description of the results, please refer to papers I and II.

### 6.1.1 Characteristics

Although peer support interventions are conducted worldwide, few studies have been conducted in Europe (n=3), indicating a research gap. However, the geographical aspect of interventions showed that a large proportion of the included studies were conducted in low-resource settings and other settings heavily affected by the HIV epidemic, indicating that peer support attempts to respond to the needs of people living with HIV in priority settings.

There was a total of 24,932 participants in the included studies. The scoping review demonstrated heterogeneity in populations, interventions, characteristics, study outcomes, and settings. Although the study populations varied, most of the interventions were aimed at populations in vulnerable settings.

The studies were categorized by objective. When a study fit into more than one category, it was placed in the category that most closely matched the overall objective of the paper. Five categories were identified for studies. The categories of '*Effectiveness*' and *'Evaluation'* were included in paper I. Furthermore, '*Studies about experiences', 'Studies presenting program descriptions'*, and *'Studies on the training of peer supporters' were* reported in paper II.

The analysis helped us become aware of the different roles and key functions of peer support provided in the various peer support programs, as suggested in peer support recommendations (Fisher, 2014). Therefore, we categorized peer support's key functions, demonstrating how interventions combine several functions that align with HIV being a CLLC.

### 6.1.2 The key functions of peer support

The analysis found that linkage to clinical care and community resources were the most common key functions of peer support. The findings report that assistance in the daily management of living with HIV and social and emotional support appear in several included studies. However, only one of the included studies focused explicitly on ongoing support related to chronic disease, which might not be surprising as they often are a supplement to general healthcare services. Nonetheless, numerous peer support interventions combine the described functions and seem to meet the participants' request for continuing support, although not explicitly reported in the studies.

### 6.1.3 Terms and labels

There was little uniformity in terms of peer support terminology and practice. For example, 19 different labels for peer supporters were identified in the included studies. The terms 'peer', 'peer counselor/advocate/supporter/mentor/health worker', and 'health advocate' were used from 2000 to 2009. In addition, new labels appeared between 2010 and 2021. The most frequently used labels in the included studies were 'peer' (n = 20), followed by 'peer counselor' (n = 10), 'peer mentor' (n = 10), 'peer supporter' (n= 9) and 'peer educator' (n = 8).

### 6.1.4 Categories of studies

In the category '*Effectiveness'*, most of the interventions included female and male participants from settings where they experienced barriers to accessing good HIV healthcare services. The most frequently measured outcomes in the effect studies were biological markers and adherence to ART—only five studies measured stigma as the primary outcome. Although, if they reported the results related to stigma, they found that peer support decreased negative feelings and enacted/internalized stigma. Also, seven studies measured how peer support affects mental health and quality of life as primary outcomes. It is important to note that the interventions varied with respect to populations, the content of peer support, comparisons, and length of follow-up.

The studies related to *'Evaluation'* reported on either the implementation, process, feasibility, or cost. The implementation studies described barriers, challenges and strategies conducted related to the implementation of peer support. For example, one intervention linked people living with HIV to care and found it most relevant for newly diagnosed people (Addison et al., 2019). Two other studies addressed how the specific settings affected the implementation and offered considerations on the quality of peer support and the support of peers as an integrated part of healthcare services (Hallum-Montes et al., 2013; Ryerson Espino et al., 2015). In addition, the process evaluations sought to understand the underlying mechanisms of the intervention results, whereas the feasibility studies investigated whether the participants were motivated and accepted the interventions. Finally, the cost study analyzed and compared the costs of a peer health worker intervention and a phone peer support intervention, indicating results for the peer health worker intervention (Chang et al., 2013).

When it comes to *'Studies about experiences'*, some studies focused on experiences with either providing peer support, receiving peer support, or both providing and receiving peer support.

Most of the studies related to experiences of being a peer supporter (Table 1, paper II) mainly focused on the role of peer supporters when meeting people living with HIV. In addition, they investigated the challenges of being a peer supporter, their experience with the delivery of support, and their experiences with implementing peer support. Several studies suggest that peer supporters provide practical, informational, emotional and social support, which is supported by the results related to experiences from the perspective of the receivers of peer support. Other studies, from both the receivers' and the providers' perspectives, found that the peer supporters model healthy behavior. In addition, studies support that peer supporters feel empowered in their own lives. They learn skills, share knowledge, gain self-awareness, and even feel they are becoming more visible in the community. Three studies supported that they were a positive supplement to healthcare services (Alamo et al., 2012; Harris & Alderson, 2007; Lee et al., 2015). The receivers supported this as they experienced being referred to other NGOs and helped to connect to the community. However, the peer supporters reported work-related stress and a need for training and emotional support.

Furthermore, in the category '*Studies presenting program descriptions',* all studies described different interventions and priority groups. The program descriptions mainly focused on the linkage to clinical care and community resources, diagnosis, retention in care, daily management assistance, and social and emotional support.

A variety of peer training methods were found in the category *'Studies on the training of peer supporters*. For example, motivational interviewing was a part of the training in two studies (Allicock et al., 2017; Wolfe et al., 2013). One tested a standardized training program for mentors (MAPPS) (Cully et al., 2012), and another developed a simulation-based training program for learning how to take care of terminally ill people living with HIV (Kim & Shin, 2015). Finally, a study described a program that trained health educators and program directors (Tobias et al., 2012). All of the included studies supported the need for quality training of peer supporters to ensure performance standards (Table 1, paper II).

## 6.2 Study 2: The service users' experiences

Øgård-Repål, A., Berg, R.C., Skogen, V., & Fossum, M. (2022). Peer support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users' experiences. *BMC health services research, 22*(1), 549. https://doi.org/10.1186/s12913-022-07958-8

Through 16 individual interviews with service users, this study explored how they experienced the support provided by a peer and integration of peer support as a part of the OPCs' services. The participating service users included six women and ten men, ranging between 30 and 58 years of age (mean age: 44 years), including six with a migrant background from Asian (n=2) or African (n=4) countries, representing characteristics of people living with HIV in Norway. Unfortunately, other socio-demographic characteristics were not presented to protect the anonymity of the participants (due to the small number of people living with HIV in Norway).

In this study, the analytical findings according to the pre-determined categories were reported to describe the provision of peer support, further elaborated in chapter 5.5.4. The pre-determined categories follow Weiss' defined social relations provisions (Weiss, 1974) and constitute attachment, social integration, an opportunity for nurturance, reassurance of worth, reliable alliance, and guidance. Reliable alliance is, in this context, operationalized as 'serving as a liaison between patients and clinical care, motivating patients to communicate and assert themselves to obtain regular and quality care, helping to identify local resources when needed'. However, no meaningful units concerning the peer supporters' providing support were found to align with the 'reliable alliance' provision, although healthcare professionals offered this to our participants. The results suggest that the service users did not express a need for peer support to be motivated for regular care or to identify requested resources. This might be the case because the service users are already connected to the OPCs, and the peer support services thereby shoulder the already existing services. Therefore, this provision was excluded from the results section. In addition, one category was created inductively through the analysis. The identified sub-categories within the categories are described accordingly (Table 1). For quotes illustrating the sub-categories, see the result chapter of paper III.

Table 2. Overview of the pre-determined categories and sub-categories

| **Support provided by peer supporters to people living with HIV** | | | | | |
|---|---|---|---|---|---|
| Pre-determined categories | | | | | |
| Attachment | Social integration | Opportunity for nurturance | Reassurance of worth | Guidance | OPCs as the setting for peer support |
| Sub-categories | | | | | |
| Gained emotional support | Non-disclosure promoted the need to meet a peer with similar concerns | Activated an opportunity for mutual support | Means to re-establish belief in one's own worth | Perceived a positive affirmation of disease management | A safe place |
| Disclosure behaviour allowed garnering of emotional support | Experienced a sense of belonging | | | Facilitated dialogue about disease management | A setting for flexible, individualized support |

### 6.2.1 Attachment

The results show that the participants drew emotional support from their peer supporters, notably when they lacked other close emotional relationships. On the contrary, the participants who had experienced support when disclosing their diagnosis did not perceive a need for emotional support from peers. The sub-categories related to this category were *'gained emotional support'* and *'disclosure behaviour allowed garnering of emotional support'*.

The sub-category '*gained emotional support'* strongly indicated that the peer supporters offered emotional support when the service users did not disclose their diagnosis or the reaction after revealing it was a lack of approval or even rejection from friends and family. This was particularly prominent among the participants with a migrant background. They had a former, pre-existing cultural understanding of HIV, which hindered them from disclosing their diagnosis because of an expected rejection. Whereas the sub-category '*disclosure behaviour allowed garnering of emotional support'* showed that many participants did not get as emotionally attached to their peer supporters if they had disclosed their diagnosis to friends and family followed by support. These participants were mainly Norwegian-born, most of them gay men. When revealing their diagnosis was followed by support, they did not need the same emotional content of support from peers. The most important aspect was to have someone to rely on when they needed support.

### 6.2.3 Social integration

As our results in Study 2 demonstrate, peer supporters provided a sense of belonging to a group where one could share experiences. The sub-categories *'non-disclosure promoted the need to meet a peer with similar concerns'* and *'experienced a sense of belonging'* were developed in this category.

The results in the sub-category '*non-disclosure promoted the need to meet a peer with similar concerns'* support that participants who did not disclose their diagnosis to friends and family needed to meet people with similar experiences to address their concerns regarding living with HIV. Some participants deliberately chose not to reveal their diagnosis and actively avoided adverse reactions. In addition, the sub-category *'experienced a sense of belonging'* supports that most of the participants experience a sense of belonging when meeting peer supporters, just by their presence. In addition, the participants recognized experiences and emotions through mutual disclosure. Thus, this sharing of experiences promoted supportive surroundings by validating the participants' experiences.

### 6.2.4 Opportunity of nurturance

The findings suggest that the participants experienced a peer support meeting to be mutually supportive by sharing experiences. The sub-category *'activated an opportunity for mutual support'* was developed in this category.

The sub-category *'activated an opportunity for mutual support'* indicates that the meeting between peer supporters and service users allows for the rendering of support related to recognisable experiences and emotions. The results support that, emotionally honest conversations create a mutually supportive atmosphere and stimulate learning between peers.

### 6.2.5 Reassurance of worth

As this category suggests, the peer supporters helped the participants feel normal and strengthened their self-worth through the peer support meetings. Therefore, the sub-category *'mean to re-establish belief in one's own worth'* was developed.

The sub-category *'mean to re-establish belief in ones' own worth'* indicates that several participants expressed how getting HIV affected their self-worth negatively. The peer supporters validated their emotions and normalised their experiences. Therefore, they contributed to strengthening the participants' self-worth and acceptance.

### 6.2.6 Guidance

The second study also found that peer supporters could provide helpful advice on disease management and positively affirm the participants' way of living with HIV. Therefore, the sub-categories *'perceived a positive affirmation of disease management'* and *'facilitated dialogue about disease management'* were developed during the analysis.

In the sub-category *'perceived a positive affirmation of disease management',* the results show that the peer supporters listened to the participants, shared information and confirmed the participants' experiences. The peer supporters provided the information through their sharing of how they managed their lives and thereby confirmed the information given by the healthcare professionals as credible.

In the second sub-category, *'facilitated dialogue about disease management',* the result indicated that participants valued the opportunity to discuss disease management. In the peer support meeting, the participants expressed they could ask personal questions about HIV-related health issues. The peer supporters gave specific advice concerning how to achieve a healthy lifestyle while living with HIV.

### 6.2.7 OPCs as the setting for peer support

Finally, related to organising peer support at the OPCs, the participants evaluated the context of peer support as positive. The participants viewed the OPCs as safe and suitable places to offer flexible, individualized peer support. Therefore, I developed the sub-categories '*a safe place'* and *'a setting for flexible, individualized support'* in this category.

The results presented in the sub-category *'a safe place'* show that OPCs represent the only setting to meet other people living with HIV without fear of being exposed. At the OPCs, they knew that their confidentiality was assured, and the participants experienced that the OPCs could offer a neutral, non-judgmental environment suitable for peer support meetings.

In the sub-category *'a setting for flexible, individualized support',* the participants found that OPCs' services were positively affected by offering a peer support meeting due to the experienced flexibility of the peer support. However, the participants expressed that peer support needed to be modified to the preferences of the individuals supported according to content, time and place.

## 6.3 Study 3: The providers' experiences

Øgård-Repål, A., Berg, R.C., Skogen, V., & Fossum, M. (2022). "They make a difference": A qualitative study of providers' experiences of peer support in outpatient clinics for people living with HIV. *BMC health services research.* 22, 1380. https://doi.org/10.1186/s12913-022-08810-9

Through fifteen individual interviews and two FGDs, the objective was to explore how peer supporters experienced being peer supporter at the OPCs. Furthermore, it aimed to investigate the peer supporter's perspective of the peer meeting and explore how healthcare professionals experienced working side by side with the peer supporters in the OPCs.

Ten peer supporters and five healthcare professionals were interviewed. Nine participants were women, and six were men, aged 37–65 years (mean, 49 years). Four of the peer supporters had a migrant background.

The qualitative analysis is presented in three overarching themes. Each theme includes aspects described in sub-themes as displayed below (Table 2). For quotes illustrating the themes, see the result chapter of paper IV.

Table 3. Themes and Sub-themes

| **Emotionally honest conversations promote mutual support** | **Negotiation of preconceptions create reframed understandings of HIV** | **Critical components for facilitating peer support** |
|---|---|---|
| • Recognisable experiences and emotions<br>• Reciprocal backing between the peer supporter and the service user | • Credible lived experiences<br>• Replicating positive experiences | • Integration of peer support into usual care<br>• Skill standards<br>• Occupying the middle ground |

### 6.3.1 Emotionally honest conversations promote mutual support

The results indicate that peer supporters experience mutual support through emotional and genuine interactions. This theme includes two sub-themes: *‘recognisable experiences and emotions’* and *‘reciprocal backing between the peer supporter and the service user’.*

The sub-theme ‘*recognisable experiences and emotions’* shows that the peer supporters recognized most of the life stories described by the service users and recalled their fears, self-quarantine behaviors and the loneliness related to living with HIV. In addition, the healthcare professionals recognized the fear and uncertainty the service users described as an expected outcome for people living with HIV and promoted meeting a peer supporter to share experiences. Conversely, if the peer supporters only shared positive experiences instead of confirming the service users’ experiences, the peer support was not considered valuable.

The other sub-theme, *‘reciprocal backing between the peer supporter and the service user’,* strongly indicates that the peer supporters’ meeting a service user contributed to personal development in their own lives. In addition to getting the feeling of being helpful to others, the emotional closeness to the service users affected them. This reciprocal backing seemed to contribute to a sense of mutual belongingness between peers living with HIV in meeting challenges. For example, several peer supporters mentioned the Coronavirus Disease 2019 pandemic as a situation they needed to talk about to a peer, which supports that the need to meet peer supporters can arise throughout life when living with a CLLC.

### 6.3.2 Negotiation of preconceptions creates reframed understandings of HIV

The peer supporters also found it essential to negotiate with the service users about their preconceptions of HIV, confront their views through dialogue and replicate positive experiences by being credible role models. This theme consists of the sub-themes '*credible lived experiences'* and *'replicating positive experiences.*

The first sub-theme, '*credible lived experiences',* suggests that the peer supporters needed to be aligned with their messages both in appearance and behaviour when living with HIV. This way the information provided by peer supporters was often the same as that offered by healthcare professionals but perceived as more credible. The credibility increased when visualising a good life with HIV, and thereby the peer supporters contributed to a reconstruction of the service users' unique understanding of HIV.

The second sub-theme, *'replicating positive experiences',* demonstrated how the peer supporters replicated their own experiences meeting a peer supporter. They reported that meeting a peer supporter with an alternative understanding of HIV helped them decrease their internalised stigma, negative attitudes, and shame due to their preconceptions of HIV. In addition, replicating their positive experiences made them respectably confront and challenge the service users' opinions and fears. The healthcare professionals support the results, underscoring the need for newly diagnosed service users to meet a peer supporter. Both peer supporters and healthcare professionals anticipated that the peer supporters could negotiate with and adjust the service users' preconceptions of HIV.

### 6.3.3 Critical components for facilitating peer support

The participants expressed that integrating peer support into the OPCs' usual care processes increases the prospect of equitable services. The quality of peer support and role clarity were identified as critical components. The sub-themes '*integration of peer support into usual care', 'skill standards'* and *'occupying the middle ground'* were developed in this theme.

In the sub-theme '*integration of peer support into usual care',* the results revealed that the healthcare professionals at the OPCs recognized that people living with HIV needed a place to meet peers and wanted to ensure equal opportunities by integrating peer support into usual care. Furthermore, the findings show that the service users preferred to meet a peer supporter connected to the OPCs. Some service users even want the healthcare professionals to attend the first meeting with a peer supporter. Both peer supporters and healthcare professionals stated that this indicated trust in the services at the OPCs. In addition, the implementation of peer supporters at the OPCs broadens the perspectives. Therefore, the peer supporters contributed to the knowledge production at the OPCs, improving the quality of the services.

The second sub-theme, '*skill standards',* demonstrates that peer support training was essential to ensure specific standards. Since the healthcare professionals offered peer support as a part of the OPC's services, they wanted to be informed about what to expect from the peer supporters. Furthermore, the peer supporters expressed loyalty toward healthcare professionals' work and even tried to persuade the service users to follow the advice provided by the healthcare professionals. However, the narratives of the healthcare professionals indicated that they recruited peer supporters according to what they believed were valuable skills for being a peer supporter.

In the last sub-theme, *'occupying the middle ground',* the results suggest that the peer supporters are in an in-between position, wanting both to be a part of the formal healthcare system as professionals and have the liberty to be flexible and connect like 'friends. The findings support that the peer supporters wanted to personalise the support to the service users' needs and conditions and therefore preferred being flexible about time and place. Most of the peer supporters believed that the emotional component of the meeting required a more informal context than the OPCs could provide. On the contrary, healthcare professionals believed that service users were sceptical about meeting an unknown peer supporter outside the OPCs due to confidentiality. Meeting more informally was experienced as more challenging when trying to balance the role and expectations of the formal system and the service user. The peer supporters seemed to be seeking some form of behavioural consensus.

# 7 Discussion of main results

> 'As a fundamental motivation, the need to belong should stimulate goal-directed activity designed to satisfy it. People should show tendencies to seek out interpersonal contacts and cultivate possible relationships, at least until they have reached a minimum level of social contact and relatedness. Meanwhile, social bonds should form easily, readily, and without requiring highly particular or conducive settings' (Baumeister & Leary, 1995, p. 500).

The objective of this thesis was to gain an in-depth understanding of several aspects of peer support. The researcher found that increasing knowledge of HIV as a physical diagnosis and the HIV care provided was essential to exploring peer support for people living with HIV. The researcher found it necessary to improve insight into how the social construction of HIV is embedded within the environment where individuals are situated. I have emphasized on interpreting the results from my subjective understanding and the participants' and advisory groups' situatedness, as deliberated in chapter 5.7.3. Positioning oneself is due to an overall commitment to the participants, the OPCs involved and the advisory group. Consequently, the discussion results from multiple voices contributing throughout the research process.

This thesis comprises three studies presented in four papers. The first study gave an overview of the empirical research conducted until 2021 about peer support services for people living with HIV worldwide. The two subsequent studies explored service users', peer supporters' and healthcare professionals' experiences with peer support for people living with HIV as an integrated part of the services in five OPCs in Norway. The thesis aims to present a nuanced, interpretive description of experiences with peer support for people living with HIV, specifically in the OPCs in a high-income, low-HIV-prevalence Nordic country.

Overall, it seems relevant to look further into whether and how people living with HIV in Norway need the peer support service provided at the OPCs. Although the thesis aims are to explore experiences from different perspectives, it is relevant to give implications for practise as a follow-up. Therefore, the researcher deliberated on the results in the four chapters, discussing how the findings in the three studies link the thesis' overall aim. These findings are related to former knowledge of peer support for people living with HIV, giving implications for practice and further research presented in chapter 9. Chapter 7.1 discusses experiences of the peer support meeting from the service users' and peer supporters' perspectives. The next chapter looks further into how new understandings of HIV can be constructed through dialogue. The two subsequent chapters provide an overall discussion on the experiences with peer support as an integrated part of the OPC's services, with the last chapter raising more critical reflections.

## 7.1 Reciprocal social connectedness

Study 1 shows how several peer support interventions aim to provide social and emotional support and how both the service users and peer supporters benefit from the peer meeting. A critical finding in Studies 2 and 3 is how the service users and peer supporters developed a relationship through sharing emotions and concerns relating to the persisting socio-cultural understanding of HIV. All three studies suggest that a meeting between peers contributes to reciprocal social support for people living with HIV in Norway.

HIV is still a diagnosis that causes people to face severe challenges related to stigma. Having a discreditable stigma (Goffman, 1968) gives people living with HIV a choice to disclose the diagnosis or not, and either way, they must manage their disclosure. However, research suggests that concealing a diagnosis with the knowledge that it could be revealed creates additional stress, for example, feeling inauthentic in social interactions (Pantelic et al., 2019; Relf, Holzemer, et al., 2021). Baumeister and Leary (1995) support this, emphasizing how people resist losing relationships. The theories of Goffman (1968) and Baumeister and Leary (1995) propose that people living with HIV might conceal their diagnosis to maintain their relationships with others. The results in Studies 2 and 3 mirror these findings, suggesting stigma relevant to decisions regarding disclosing HIV status, specifically for the participants with a migrant background. The results are also reflected by Bristowe et al. (2019), describing anxiety especially related to negative experiences regarding disclosure and stigma, sadness and shame associated with contracting HIV. However, Study 1 demonstrates that few peer support interventions measure stigma as a primary outcome (Been et al., 2020; Katz et al., 2021; Lifson et al., 2017).

Given the experienced necessity to conceal the diagnosis, the participants in Study 2 seemed to have a need to get emotionally attached to their peer supporters, which corresponds with the findings in Studies 1 and 3. When facing a peer supporter, the participants in Study 2 identified an individual with several similar experiences and concerns related to HIV without fear of rejection, which they could not find elsewhere. Hagerty et al. (1992;1996) highlight the importance of being valued by and congruent with others as essential for achieving a sense of belonging and relatedness. Hence, being congruent with others' experiences and concerns was important to the experience of service users receiving peer support, as recognizable in Weiss' (1974) description of 'common-concern relationships.' However, it seems like 'the sense of belonging' described by our participants is based on sharing common concerns related to HIV, and is most relevant for those with lack of support elsewhere. The theoretical model of Hagerty et al. (1992) shows how peer support could be seen as clinically relevant, complementing the OPCs in assisting people living with HIV to develop their capacity to augment a common-concern relationship. Even though the participants may not share other characteristics with their peers, living with HIV was experienced as a dominating characteristic in most of the participants' lives. Therefore, it was essential to feel socially connected in the meetings despite other differences.

The correlation between social support and health is recognized and even suggests social support as a resilience resource when stressful events arise (Dulin et al., 2018; Earnshaw et al., 2015; Garrido-Hernansaiz & Alonso-Tapia, 2017). Weiss (1974) noted that specific circumstances require additional support. It could be suggested that the theory of Weiss (1974) implies that people with potential complex needs when living with a CLLC like HIV require substantial backing. Furthermore, given that several participants conceal their HIV diagnosis, a meeting with a peer supporter sharing recognizable experiences and concerns contributes to the emotional closeness described by Weiss (1974). This emotional closeness is supported by Study 1, suggesting that the receivers of peer support experience being emotionally and socially supported.

In contrast, the absence of a common-concern relationship creates the potential for social isolation, which is relevant in the context of several people living with HIV in Norway (Grønningsæter & Hansen, 2018). Supported by the literature (Fisher et al., 2018), it was found that the presence of others with common concerns has a substantial value for the participants, although not necessarily equal in other respects than living with HIV. This ‘sense of belonging’ through sharing emotions, experiences, and concerns seemed to alleviate the internalized stigma associated with the HIV diagnosis.

The results from Studies 2 and 3 suggest that a meeting between peers provided an opportunity for nurturance for both the service user and the peer supporter through a reciprocal supportive relationship. This indicates that one can receive social support by giving, as supported by studies included in Study 1. Although nurturance is well described by Weiss (1974), Riessman (1965) raises nurturance as a turning point between the giver and receiver in a relationship. Other researchers demonstrate the supportive interpersonal relationship between peers (Borkman, 1999; Harris & Alderson, 2007). Harris and Alderson (2007) illustrate this in their research:

> 'Experiences in one role cannot help but to inform the others, making it neither possible nor desirable to fully separate the experience of these separate roles' (Harris & Alderson, 2007, p. 847).

Harris and Alderson (2007) point out that service users and peer supporters influence one another as the roles overlap. These results correspond with the three studies in this thesis, suggesting that the service user and peer supporter benefit from the peer meeting. For example, the chronicity of living with HIV is coupled with lifetime challenges, currently exemplified by the COVID-2019, suggesting that both parties' recognisable experiences when meeting a peer were followed by reciprocal backing. Studies 2 and 3 suggest that a meeting between peers contributes to increased support through mutual relatedness. One could therefore argue that peer support and social support interventions have the potential to enhance the participants' resilience against adversities related to HIV, as described in other studies (Dulin et al., 2018; Wen et al., 2021), specifically relevant for individuals concealing the diagnosis. However, the studies have not explored the concept of resilience further.

Speaking from the position of participants, some experienced supportive surroundings from family and friends when disclosing. Consequently, their narratives suggested a sense of acceptance and increased resilience after revealing their diagnosis. However, being related to others through sharing HIV-related concerns seemed crucial to all participants, despite the support from friends and family, supporting Baumeister and Leary's (1995) need to belong as a human motivation for relationships. The healthcare professionals emphasized this, as they found that most of their service users benefited from talking to other peers regardless of their coping with daily life with HIV. The findings in Studies 2 and 3, and several of the included studies in Study 1, suggest that a meeting between peers increases the well-being of both the receiver and the provider, following Shumaker and Brownell's (1984) definition of social support.

## 7.2 Dialogue to frame new understandings

This thesis proposes that implementing peer support in the OPCs in Norway can facilitate dialogue between the service users, peer supporters, and healthcare professionals. Therefore, one could suggest that the integration of the peer supporters in the OPCs created a knowledge conduit for all involved.

Studies 2 and 3 suggest that the exchange of knowledge between peer supporters and healthcare professionals at the OPCs provided the peer supporters with updated knowledge about the latest information related to HIV medicine and care. The exchange of knowledge was also evident when healthcare professionals contributed to the training of peer supporters. The healthcare professionals also gained insight into living with HIV by listening to and cooperating closely with the different voices of peer supporters, which is supported by studies included in Study 1, describing peer supporters as a positive contribution and supplement to the healthcare services.

The knowledge exchange between peer supporters and healthcare professionals demonstrated increased awareness for both parties, which seemed necessary when facilitating dialogue about preconceptions with the service users. As supported by our findings, the Peers for Progress program (Fisher, 2014) highlights how peer supporters can contribute to building the cultural competence of healthcare professionals. This is supported by the results from the Stigma Index Study (UK) (Chinouya et al., 2017), reporting that migrant people living with HIV experience intersecting stigma. It underscores the importance of the involvement of people living with HIV through a collaborative partnership with healthcare services. One could argue that peer supporters improve the two-way communication between service users and healthcare professionals by having peer supporters on-site.

The frequent interaction between peer supporters and healthcare professionals presented in Study 3 enriched the healthcare professionals' perspectives, which is supported in other studies as an essential and critical element of peer support services (MacLellan et al., 2015).

Health education through connecting people is an acknowledged contribution of peer support (Fisher, 2014). It could seemingly be related to relevant health literacy when people get a chronic diagnosis followed by an increased risk of NCDs (Jespersen et al., 2021; WHO, 2016b). It is worth recognizing that the societal narratives of HIV form health literacy. These narratives are cultural constructions situated in history and reflect the diversity of the participants, emphasizing that the individual understanding of the narrative is negotiable (Alvesson & Sköldberg, 2018; Chinouya et al., 2017; Gergen, 2015). Intersectional stigma experienced by many people living with HIV creates an increased need for discussions related to the cultural understandings of HIV, reflecting different countries relevant in the context of people living with HIV in Norway.

There is a difference between the challenges raised by participants with a migrant background and the Norwegian-born participants living with HIV in Studies 2 and 3. The challenges seemed to result from the migrants' contextual barriers in their former countries. Contextual barriers worth mentioning are structural and relational conditions like discrimination, social exclusion, and even poverty (Pantelic et al., 2019). A recent review of migrants in Europe (Ward et al., 2019) emphasizes the need for health systems to improve the quality of healthcare delivery as a response to the identified gap in health literacy and different cultural-religious values among African migrants to reduce ethnic disparities (Mgbako et al., 2022), which is supported by the results from the Stigma Index Study (UK) (Chinouya et al., 2017). The peer supporters and healthcare professionals in Study 3 found that having peer supporters representing migrant backgrounds was important to get insight into the contextual barriers and narratives of several service users.

The participating peer supporters and healthcare professionals in Study 3 suggested that peer supporters created reframed understandings of HIV for people diagnosed with HIV by negotiating preconceptions in peer support meetings. Several of the service users come from countries with social and legal barriers to accessing treatment, for example, the illegality of homosexuality, compared to the Norwegian-born population (WHO, 2016a, 2016b). The suggested negotiating preconceptions were supported by participants' experiences in Study 2 and several studies included in Study 1, indicating that they got information and knowledge about daily life management by talking to peer supporters living in a Norwegian context. Both the peer supporters and healthcare professionals were able to decrease the service users’ internalization of others’ negative views, helping them to avoid absorbing the cultural narratives of HIV. These findings resonate with studies emphasizing the role of social support in helping individuals undergo cognitive restructuring after negative experiences like discrimination (Cohen, 1988; Earnshaw et al., 2013).

Peer supporters underlined how they valued meeting a peer when getting the HIV diagnosis themselves and getting input on managing daily life with HIV. The peer supporters wanted to replicate their positive experiences by being role models when providing support to the service users. The peer supporters could additionally present a positive affirmation of credible lived experiences with positive coping as they wanted to create a dialogue connected to normalizing living with HIV. The peer supporters suggested this could contribute to the reassurance of worth, which the healthcare professionals strongly supported and found to be necessary for the literature on social support (Cohen & Wills, 1985). It could be argued that peer supporters embodied the experiences of living with HIV and thereby contradicted preconceptions just by their presence, which is supported by the healthcare professionals in Study 3 and several studies included in Study 1. Consequently, following WHO's definition of health literacy (1998), the researcher suggests that the created dialogue between service users and peer supporters has the potential to increase the participants' health literacy. Although the project did not explore health literacy specifically, it is relevant to raise whether increased awareness and knowledge affected their health literacy.

Raising the voices of service users, peer supporters and healthcare professionals contributed to mutually adjusting the understanding and preconceptions of living with HIV. When facilitating dialogue between service users and peer supporters, numerous realities meet up, with the potential to create new understandings. This is eminently expressed by Gergen (2015):

> 'As we speak together, listen to new voices, raise questions, ponder alternatives, and play at the edges of common sense, we cross the threshold into new worlds of meaning' (Gergen, 2015, p. 6).

Constructing a new understanding of HIV among people living with HIV is challenged by the often-experienced intersectional stigma (Major & Schmader, 2018; Relf, Holzemer, et al., 2021). The participants with a migrant background in Studies 2 and 3 signaled how their former socio-cultural understanding of HIV affected their internalized stigma, as Livingston and Boyd (2010) explain is often the case. However, we should be cautious in implicitly considering migrant people to have an understanding of HIV that needs adjustments, rather than an experience colored by their former social and cultural context. The diverse backgrounds of the peer supporters, several having a migrant background themselves, contributed to increasing the healthcare professionals’ competence related to how socio-cultural context impacts the service user’s perception when getting their HIV diagnosis.

The results from Studies 2 and 3 indicate the potential for increased knowledge and awareness through the cooperation between the peer supporters and the healthcare professionals and the framing of a dialogue between peers about different understandings of HIV and the management of a CLLC in daily life.

## 7.3 Peer support to promote integrated, person-centered HIV care

The Global Health Sector Strategy on HIV 2016–2020 (2016b) raised the need for person-centered chronic care, acknowledging the multiple challenges people living with HIV face. Simultaneously, Lazarus et al. (2016) proposed adding a 'fourth 90', good health-related quality of life, to the '90-90-90' target of UNAIDS (2014). People living with HIV, even when viral suppression is achieved, must often contend with other multidimensional concerns. The suggestion of Lazarus et al. (2016) is to pay more attention to the overall HIV care provided to people living with HIV, in addition to viral suppression through medical treatment.

In Norway, people living with HIV have access to ART free of charge, and PrEP has been available since January 2017 (Whittaker et al., 2020). However, as a low-prevalence country that seems to have reached the UNAIDS 90-90-90 target in the general population with HIV (UNAIDS, 2014; Whittaker et al., 2020), Norway still emphasizes increased services for people living with HIV as a CLLC.

The Global Health Sector Strategy on HIV 2016–2020 (WHO, 2016b) emphasizes the value of HIV services adjusted for various populations and locations. Peer support is, according to research, recognized as being flexible to the different needs of the supported and claims to be person-centered (Fisher, 2014; Fisher et al., 2014; Fisher et al., 2018). NGOs provide peer support in the bigger cities in Norway. Therefore, it is essential to look further into why and if peer support should be an integrated part of the OPCs when offered otherwise. Therefore, part of the PhD project was to explore experiences of peer support situated at HIV OPCs. Integrating peer supporters at the OPCs involves setting the stage for these encounters. Hoffman et al. (2017) defined relevant concepts to decide whether an intervention or activity is evidence-based related to its feasibility, appropriateness, meaningfulness, and effectiveness. As the effectiveness of peer support interventions is measured in several studies, as shown in Study 1 and the review of Berg et al. (2021), the participants in Studies 2 and 3 were explicitly asked about their experiences with peer support situated at the OPCs. The findings in this project suggest several aspects for consideration.

Study 1 supports the flexibility of peer support for people living with HIV related to different needs across settings and priority groups. Notably, several of these interventions' objectives in Study 1 are linkage, adherence, and retention to care, which are not found relevant in a Norwegian context (Whittaker et al., 2020). Furthermore, the findings support that due to the low incidence of HIV in Norway, peer supporters situated at the OPCs allow enhanced equal access to peers. According to Studies 2 and 3, locating peer support at the OPCs increased the opportunity to provide flexible, person-centered support to people living with HIV despite geographical differences in accessing peer support through NGOs. It could also be seen as a response to the barriers related to people living with HIV's fear of their diagnosis being revealed (Pantelic et al., 2019; Relf, Holzemer, et al., 2021). This is supported by results from the Stigma Index Study (UK) (Chinouya et al., 2017), indicating that e.g. people living with HIV with a migrant background experience barriers to healthcare services. Mobilization through a collaboration between people living with HIV and the healthcare services is suggested as a means to decrease barriers to HIV-related care (Chinouya et al., 2017). Thus, it could be argued that incorporating peer supporters into usual care is a way of being responsive to the different needs of people living with HIV in Norway.

Hoffman et al. (2017) emphasize clinical feasibility according to whether an intervention is physically, culturally, or financially practical within a given context. As described in chapter 5.3, every individual with HIV has universal access to high-quality follow-up from the OPCs. Therefore, physically locating peer support at the OPCs seems to correspond with being culturally sensitive, given Norway's geographical distances and low HIV prevalence. Furthermore, listening to the potentially vulnerable situations of people living with HIV with non-disclosure behavior supports integrating peer support into the OPCs as an attempt to expand the person-centered services of HIV care. The participants in Study 2 experienced the OPCs providing a safe environment where confidentiality was guaranteed. Corresponding with the results of Bristowe et al. (2019), service users, peer supporters, and healthcare professionals emphasized how the non-disclosure behavior underlined the importance of framing an environment of safety due to confidentiality when organizing support for people living with HIV.

As mentioned in chapter 4.2, Langford et al. (1997) found four attributes when analyzing social support, which partly mirrors the functions of peer support described by the Peers for Progress program (Fisher, 2014). Our findings in Study 1 support both the attributes defined by Langford et al. (1997) and the core functions by Peers for Progress (Fisher, 2014), analyzing peer support interventions worldwide. In contrast, instrumental support defined by Langford et al. (1997) and the linkage to clinical care and community resources described by the Peers for Progress program (Fisher, 2014) is not explicitly mentioned as provided by the peer supporters in Studies 2 and 3. On the contrary, our results indicated that locating peer support at the OPCs offers more accessibility to general services at the OPCs as the peer supporters and healthcare professionals cooperate in providing the services. The different key functions of the peer supporters in the studies included in the scoping review (Study 1) and the two other studies conducted in a Norwegian setting (Studies 2 and 3) may reflect a difference in the healthcare systems. For example, a large number of the peer support interventions in Study 1 were conducted in the U.S. or an African country, where healthcare services are a part of a mixed economy, and the roles of the NGOs are different. In several of these studies, the peer supporters seem to fill a gap related to a shortage of healthcare services, therefore linking people in vulnerable situations to care; whereas in a Norwegian context, the peer supporters seem to complement an already high-quality service for people living with HIV.

Clinical appropriateness and meaningfulness are suitable concepts when considering the feasibility of integrating peer support at the OPCs, as Hoffman et al. (2017) demonstrated. Furthermore, the cooperation between the peer supporters and healthcare professionals seemed to sharpen the delivery of the services, adding continuous perspectives and knowledge (Norwegian Ministry of Health and Care services, 2016; Torjesen et al., 2017) and thereby increasing the opportunity for person-centered delivery of care.

## 7.3 Divergent expectations

As suggested in Study 1, there is a need to pay attention to work-related stress, training, and emotional support when implementing peer supporters in healthcare services. Experiences concerning integrating peer supporters at the OPCs were described in Study 3 as positive but also demanding for both the peer supporters and the healthcare professionals. Facilitating peer support requires considering other aspects to be successful, such as the competence of the peer supporters to ensure quality care and how the peer supporters balance the role when being both service user and service provider.

The findings reveal that we must be careful when focusing on peer supporters who only demonstrate successful living with HIV. Peer supporters are expected to share vulnerability and coping strategies and promote new behaviors that others can identify, which is also evident in peer support literature (Fisher et al., 2018). Studies 2 and 3 report that emotional, honest conversations, through self-disclosure, are a crucial component in peer meetings. The increased recognition of modest self-disclosure among professionals contributes to an increased acceptance of using oneself in delivering services (Patrick et al., 2013; Unhjem et al., 2018), as noticeable in Study 3, where healthcare professionals approved the peer supporters' approach. Consequently, the OPCs as the setting for peer support increased the need for the peer supporters' role clarity to decrease potential boundary issues (Reamer & Reamer, 2020). The important thing is how that applies to person-centered care in this context, as suggested in chapter 7.2. Several peer supporters want to meet informally and be available when the service user requires it. On the contrary, most healthcare professionals prefer the meetings to be on-site with a framed meeting according to time and content. Several peer supporters in Study 3 questioned whether meeting a peer supporter at the OPCs approved the idea of concealing the diagnosis, thus undermining people living with HIV's effort to disclose to their family and friends. The findings in Studies 2 and 3 support a combination of formal and informal meetings, being responsive to the different needs of the service users, which could be more complex to organize in an OPC, but might fit a person-centered response.

The informal interactions between peers seem to provide authentic, reciprocal support. This genuine interaction through emotional, honest self-disclosure of shared concerns seemed essential to the process. Several peer supporters questioned whether organizing the peer meetings in more informal settings would support the interaction's emotional component. The flexibility several peer supporters suggested in the delivery of peer support can be understood both as a prerequisite and a contrast to the peer support program and raises a need for role clarity for the peer supporters. This can also be seen as a contrast to the traditional provider-client boundaries that originated in the medical clinical care model, where emotional attachment and informal delivery of services could be understood as professional misconduct. A growing awareness of a deconstruction of power connections was discovered between peer support and healthcare professionals, in which the use of self is encouraged (Patrick et al., 2013; Unhjem et al., 2018).

Healthcare professionals required specific skill standards from the peer supporters when facilitating peer support at the OPCs, which was suggested as a critical component both by the peer supporters and the healthcare professionals. The question is the content of the standards required. For example, one could ask if representing 'lived experiences' should be sufficient for a peer supporter. When interpreting the findings in Study 3, it seems relevant that the attempt to professionalize the peer supporters' personal experience raises the questions of how to define the quality of peer support related to content and how to deliver it. Findings in Study 1 demonstrated the need for quality training of peer supporters to ensure performance standards.

The results in Study 3 demonstrate that the peer supporters find themselves in a unique but complex position, moving between service user and service provider roles. The peer supporters, also being service users at the OPCs, recognized the needs of the service users. In addition to meeting the service users at the OPCs, the peer supporters' request to organize informal peer meetings underlines the 'friend' aspect of being peers. The findings support this, as some peer supporters experienced sharing the service users' narratives with the healthcare professionals as breaking the confidentiality. Studies included in Study 1 support these findings, suggesting a need to consider work-related stress, peer training, and emotional support for the peer supporters (Alamo et al., 2012; Harris & Alderson, 2007; Lee et al., 2015). As suggested above, a question of relevance raised in Study 3 was how to acknowledge peer support without adjusting the support to the medical model and losing the core element of peer support.

However, it is found to be important to assure the quality of care requested by the healthcare professionals when situating the peer support at the OPCs. As demonstrated by the findings, when integrating peer support into the OPCs, the healthcare professionals expressed significant responsibility for the quality of the services. The peer supporters and the healthcare professionals agreed that they benefit from being aligned in their understanding of living with HIV and the required HIV care when meeting the individualized needs of the service users. For further development of the peer support program, it was suggested that an increased formalization of the peer supporter role would benefit the service users, peer supporters, and healthcare professionals by informing expectations related to role clarity. The training of the peer supporters implies further development related both to content and delivery. Due to years of experience in delivering peer support, national standards for peer support were published in the U.K. to ensure that peer support is provided to and by people living with HIV and that peer support is tailored to their needs (Positively, 2016). A similar standard was recently published by the National Association of People with HIV Australia (2020), which, together with the findings in this thesis, suggests a need for increased focus on the peer supporter role when provided for people living with HIV in Norway.

# 8 Methodological reflections

This chapter will reflect on methodological choices and procedures related to the collaborative design, delimitation, data construction, and analysis of the different studies, thereby pointing to this project's limitations and possibilities.

## 8.1 Study design

A scoping review (Study 1) and two qualitative methods (Studies 2 and 3) were used to answer the overall aims, taking advantage of several methodological techniques and different perspectives. The combination of methods contributed to an in-depth understanding of the topic in question (Denzin & Lincoln, 2018; Patton, 2002; Polit & Beck, 2018).

The scoping review resulted from the need to learn more about various peer support interventions, as suggested in chapter 5.4. The choice of methodological approach in Studies 2 and 3 was based on our knowledge that qualitative studies can explore experiences from several perspectives (Denzin & Lincoln, 2018; Hoffmann et al., 2017; Polit & Beck, 2018). Qualitative research can increase our knowledge about experiences, the context of healthcare, and why we experience things in specific ways. This helps us better understand how people living with HIV manage their health and make decisions on healthcare service usage based on these experiences. As suggested by a systematic review by Cassidy et al. (2021a), there is a need for more qualitative studies to understand what works, for whom, and in what context when planning implementation strategies for practice guidelines in healthcare settings.

Qualitative research increases our understanding of the culture of implementing changes, how patients experience living with a CLLC, and the associated healthcare service. Finally, according to Hoffmann et al. (2017), qualitative research can inform us when making clinical decisions related to a specific activity's feasibility, appropriateness, and meaningfulness, which is applicable to Studies 2 and 3, as described in chapter 7. The researcher examined the different experiences of peer support as a part of the services at the OPCs. Qualitative research can therefore increase our understanding of the usefulness of peer support from these perspectives.

However, as Denzin and Lincoln emphasize (2018), we must acknowledge that no single method alone can grasp the great variety of human experiences. Alternative research approaches are numerous, also when it comes to qualitative research designs, such as ethnography and participant observation. Ethnography and participant observation are widely used across health and social sciences and require extensive engagement for an extended period (Clark et al., 2021). Although ethnography and participatory observation could have provided a unique insight into the phenomenon of peer support, the advisory group members underlined that the peer meetings often consisted of the service user, peer supporter, and the healthcare professionals due to the service user's confidentiality issues. Considering that the peer meetings could be understood as a ‘closed setting’ in the OPCs, my presence, as a researcher, could have affected how the service users experienced the meetings. Therefore, they did not recommend this approach due to confidentiality. Additionally, doing ethnography and participant observation often requires the researcher to immerse in a social group for an extended period, and also experienced research skills (Clark et al., 2021), which could challenge the duration of a PhD-project.

The research looked further into peer support as a part of the services. Further exploration of the comprehensive services that people living with HIV receive at the OPCs might have nuanced our understanding. Hoffman et al. (2017) emphasize evaluating the effectiveness of an intervention or activity. This project did not assess the effectiveness of the peer support program because of the lack of adequate numbers of service users and peer supporters at the point of data construction. Although, measuring the effect of peer support could have complemented the findings of Studies 2 and 3. Even though Study 1 found the worldwide existence of effect studies related to peer support, it would be relevant to measure the effect of peer support in a Norwegian context. As study 1 demonstrated, few randomized controlled trials (RCT) measuring HIV-related stigma as the primary outcome of peer support, the impact of peer support related to social support and stigma would benefit future peer support interventions. Study 1 also revealed a need for more research in Europe, which would suggest that effect studies conducted in high-income European countries might be relevant. As opposed to a positivist worldview, the interpretive paradigm followed in this thesis strives to ‘understand’ rather than ‘explain’ (Delanty & Strydom, 2003; Lincoln & Guba, 1985).

However, considering that Norway has a relatively low prevalence of people living with HIV (Caugant et al., 2021; Whittaker et al., 2020), there are some methodological challenges when planning an RCT. People living with HIV in Norway represent a diverse population with several characteristics influencing their experience and need for peer support. However, as raised by the PLHIV Stigma Index (2022), there is a need for more research that considers the different key populations within the population living with HIV. This would recognize that the experience of living with HIV differs as it intersects with other characteristics, such as being a migrant or being homosexual (Clark et al., 2021).

That being said, a mixed method study, balancing explorative research, as was the aim of studies 2 and 3, with quantitative research, could have provided another essential and nuanced perspective in this project. A systematic review by Minary et al. (2019), who considered different designs to evaluate complex interventions, demonstrated that several methods could be used when evaluating complex interventions, e.g., RCTs, but it concluded that no method is ‘ideal’. Contrarily, the review suggests that a range of methods can be used successively or combined to address various issues. An RCT often requires a follow-up of professionals, which in the included OPCs could be demanding due to the small number of people working at the OPCs. However, as the peer support program in this project was integrated into the OPCs' general services, a pragmatic RCT might have been a preferred way to measure the effect of peer support when aiming for a controlled design in a complex context as the OPCs described in this project. Still, as the context and services at the five OPCs differ and, as study 2 demonstrated, the experienced received support varied due to several intersecting characteristics of the service users, even a pragmatic RCT would be challenging.

For the objective of this thesis, the scoping review gave an opportunity to get an overview of what former research has found in the context of peer support for people living with HIV, whereas the qualitative approach allowed exchanging and exploring the experiences as requested.

### 8.1.2 The collaborative design

Citizen participation has been acknowledged, and patient and public involvement is valued as a fundamental requirement for doing research (Malterud & Elvbakken, 2019; Rose, 2014). There are several ways to involve service users in research, and as described by Rose (2014), there is an ethical dimension to involving the individuals affected by the research. In addition, collaborative research approaches throughout the research process increase the use of research in practice and policy (Cassidy et al., 2021b). Thus, patient and public involvement highlight the notion of co-creation of knowledge.

Therefore, as this was a user-initiated project, it was important to raise the voices of the service users through participation. The representatives were invited to be involved in an advisory group for several reasons, as described in chapter 5.2. First, the advisory group was established to represent different perspectives and experiences relevant to the project. This diverse representation was meant to contribute to a broader perspective. One could argue that asymmetric power relations between the service users and healthcare professionals could affect knowledge production, and thereby suggest a stronger involvement of participants in research. The peer supporters and the healthcare professionals working closely together in the OPCs contributed to a more open dialogue. However, there are some critical aspects involving an advisory group. For example, the advisory group did not consist of the voices of newly migrated people living with HIV in Norway. In addition, although the advisory group needed to represent different perspectives and experiences, they needed to speak and understand Norwegian or English to understand the project and be actively involved.

Unfortunately, despite an effort to involve the advisory group, several group members did not participate as expected in terms of their response and contribution in the different phases of the project. Furthermore, the advisory group members did not receive compensation for participating as the PhD project did not have any extra funding provided for co-researchers. Therefore, the advisory group did not attend as co-researchers but were as active as they preferred during the process. As a result, the researcher learned that she could have been more precise about her expectations related to the group members' contributions. A stronger involvement of people living with HIV in the research project might have, to a higher degree, liberated the involvement of their voices. Future engagement of participants in research might request stronger institutional support to identify strategies for authentic collaboration and co-creation of knowledge (Cassidy et al., 2021b).

One alternative approach could have been participatory action research as it, in addition to enabling action, pays attention to power relationships and is context-driven (Baum, MacDougall & Smith, 2006). Participatory research is exemplified by The People Living with HIV Stigma Index (The Stigma Index Library, 2022), where people from HIV-positive communities have asked others who are living with HIV about their experiences living with HIV. Retrospectively, as the results in studies 2 and 3 suggest that the peer program would have benefitted from improvements, participatory action research could have enabled these changes. The participatory action research approach calls for constant work and adjustments through reflections and discussions, and although a combination of methods within a participatory action approach is suggested to broaden perspectives beyond the scope of any single research methodology (Sendall et al., 2018), the time-limited nature of the project poses challenges.

However, as described in chapter 5.3.1, one must keep in mind that the user board initiated the peer support program. The user board, which includes representatives of the service users, could thereby be seen as the key stakeholders of this project’s aim and content, and the inter-subjective dialogue between the researcher and the various members of the advisory group was found important to align the different voices relevant when conducting research in the healthcare services. Thus, some of the advisory group members in this project contributed beyond expectations. The members of the advisory group were encouraged throughout the process to express their opinions and ideas and make suggestions on changes and improvements. The feedback gave valuable information about people living with HIV and the services at the OPCs. Therefore, the involvement of the advisory group was a significant strength of this study.

## 8.2 Study participants and sample size

The study participants in the included studies in the scoping review (Study 1) reflect the diversity of people living with HIV worldwide, with a varied priority population living in low-resource settings heavily affected by the HIV epidemic. However, few studies present peer interventions addressing the needs of people living with HIV living in Europe, pointing out a need for more research.

The sample size of Studies 2 and 3 aims to reflect and meet the aims of the two studies. Studies 2 and 3 aimed for maximum variation sampling and to explore the possible similarities and diversities of the lessons learned. Therefore, participants who could give valuable insight into the phenomenon of research were recruited (Patton, 2002; Ryen, 2017).

Consequently, the purposeful sampling benefited the studies, with participants providing different perspectives. For example, the participating service users (Study 2) and the peer supporters (Study 3) varied in gender, age, sexual orientation, and country of residence during HIV transmission. In addition, they differed in when they were diagnosed with HIV, as some of the peer supporters got HIV at the early start of ART. The participants' varied perspectives provided rich, insightful data. The participating healthcare professionals were chosen because of their engagement and involvement in the OPC peer support program.

As the OPCs represented in this project are small clinics with few healthcare professionals, selection of participating healthcare professionals in Study 3 was evident. All healthcare professionals directly involved in the peer support program were invited. This could be a limitation of the study. The healthcare professionals invited were engaged in organizing the peer support and helped recruit the participating service users and peer supporters in Studies 2 and 3. It could be argued that the healthcare professionals invited service users who were favorable to peer support, as the healthcare professionals had organized the services. However, the peer support program was initiated by people living with HIV. Therefore, healthcare professionals do not necessarily need to be sympathetic to peer support.

One could argue that the sample size of five healthcare professionals in Study 3 was too small. With only five OPCs involved, few healthcare professionals were available. Malterud et al. (2016) emphasize that several factors should affect the sample size, and they criticize saturation as a possible tool for sample size in qualitative research. Saturation was discussed in Study 3 to guide the sample size, but as described above, the participating healthcare professionals depended on the available healthcare professionals while constructing the data. The participating peer supporters in Study 3 could be argued as if saturation was evident. This is because the number of participants was not planned before the interviews and FGDs. However, the project group estimated a sample size due to the limited time available to spend on the project. The researcher continuously evaluated the sample size and would have been willing to continue the interviewing phase. However, the latest interviews did not develop new perspectives or experiences, and the comprehensive empirical data was considered sufficient to get an in-depth understanding. Even so, this will not guarantee that subsequent interviews, if conducted, will not offer new perspectives.

In qualitative research, the range and quality of empirical data are considered equally as important as the sample size (Denzin & Lincoln, 2018), and the concept of data saturation can therefore be questioned (Braun & Clarke, 2021). Malterud et al. (2016) argue that the sample size should be determined by the information power. Following this argument, the narrow aim of Studies 2 and 3 indicates a smaller number of participants to get sufficient information related to the topic. The aim was not to cover the full range of experiences but to get a deeper insight into the research phenomena. However, a certain number of participants were required to conduct meaningful interpretation when planning cross-case analysis. The experiences the study explored are specific to the context of the OPCs, and thereby fewer participants were eligible. Thus, based on the experiences of the included healthcare professionals working at the OPCs with people living with HIV for several years, they were considered to provide insight into peer support from healthcare professionals' perspectives. Moreover, the specific characteristics of the included peer supporters and service users argue for a robust information power. In addition, purposeful sampling made it possible to have participants with various relevant characteristics.

The aim of the thesis might have limited our knowledge of peer support at the OPCs in general. Talking to service users who did not want or feel they needed a peer supporter could have broadened our knowledge regarding peer support as an integrated part of the OPC services. However, this perspective would not have contributed to increased insight in the peer support meetings, as was the aim in Study 2.

## 8.3 Methods for data construction

The thesis incorporated different methods of data construction. This approach follows the overall aim.

### 8.3.1 Scoping review

The scoping review conducted in Study 1 was to get familiar with the number of studies and the aspects of studies in peer support for people living with HIV. In searching for relevant studies due to the scope of research, a surprisingly high number of studies were found. However, the considerable number of studies challenged the key-wording and the analyzing processes of the data, and therefore it was decided to divide the results into two separate reports. Consequently, one could argue that the scope was too broad when defining the inclusion criteria. In addition, several unknown terms related to peer support were found when starting the literature search, which could indicate that studies were left out. However, the literature search found several studies using other words for peer supporters. The significant number of included studies gave an enormous overview of the topic of peer support research, which informed our subsequent studies in advance and was particularly useful when planning the analysis in Studies 2 and 3.

### 8.3.2 Individual interviews

The in-depth, semi-structured interviews contributed to gaining insight and knowledge about the varied experiences of peer support, exploring the views of service users, peer supporters and healthcare professionals related to Studies 2 and 3. The interviews were chosen to be semi-structured to be open to the potential knowledge production between the participants and researcher. Furthermore, a semi-structured interview allowed the participants and researcher to select the angle essential to the topic. According to Brinkmann (2018), this helps the participants be more visible in knowledge production. Although there was a conscious effort to make the participants and researcher equal in the dialogue, there was the possibility of asymmetrical power. As Brinkmann (2018) highlights, the interviewer initiated the interview and defined the topic of interest in the conversations.

Further, the interviewer is the one who is competent in doing research and situates the discussion. Therefore, the researcher tried to redress the dominance by letting the participants decide where to conduct the interview. In addition, the choice of semi-structured was an attempt to let the participants' voices be heard and avoid the discussion from ending up as a one-way dialogue. However, there was a risk of getting more information than the participants wanted to share. The participants could experience the topic of the conversation as emotionally demanding, and some of the participants were seemingly in a vulnerable situation, affected by the content they shared. Therefore, the empathic approach of the researcher could be misleading (Guillemin & Gillam, 2004). When conducting the individual interviews, the researcher experienced a difference when meeting the participants in Studies 2 and 3. In Study 2, the interviews were shown to be more unstructured despite the semi-structured interview guide. The unstructured interviews are probably related to the emotional content of the conversations in Study 2. In Study 3, to a higher degree, the participants followed the structure of the interview guide as they seemingly already had processed their experiences.

### 8.3.3 Focus group discussions

The FGDs performed in Study 3 complemented the individual semi-structured interviews to strengthen the methodological approach in this study. An FGD allows hearing, discussing, and even commenting on each other's responses to enhance the quality of the data (Patton, 2002). Prior to the FGDs, there was a debate about whether to have peer supporters and healthcare professionals participate together. After consideration, since the healthcare professionals organizing the peer support at the OPCs and the peer supporters conducting the peer support had limited opportunities to meet up and discuss, the researcher thought the FGDs could create a venue for them to meet and confer. This would contribute to broadening their perspectives through sharing experiences and, in addition, strengthening Study 3. Therefore, the FGDs were conducted, among others, to let the different participants’ voices emerge, particularly the peer supporters, and thereby draw attention to possible differences in perspectives and experiences (Kamberelis et al., 2018).

## 8.4 Choice of data analysis

This thesis approached the analysis differently in every study. Study 1 was mainly descriptive, although a simplified thematic analysis was conducted (Harden & Thomas, 2008). In Study 2, the researcher chose to run a directed, qualitative content analysis according to Assarroudi et al. (2018) and Hsieh & Shannon (2005) based on existing theory (Hsieh & Shannon, 2005; Polit & Beck, 2018). Finally, in Study 3, a reflexive and collaborative thematic analysis was conducted with an inductive approach following Braun and Clarke's analysis phases (Braun & Clarke, 2006, 2013, 2019; Braun et al., 2018).

The scoping review was a mixed-study review that included studies with different research designs (Booth et al., 2016). Consequently, the various research designs challenged the data analysis given the number of heterogeneous studies. In addition, the scoping review gave an overview of research on peer support globally, which is relevant to peer support for people living with HIV in general. Even though the participants living with HIV in Studies 2 and 3 live in Norway, they come from different parts of the world. Therefore, their experiences cannot be separated as exclusively Norwegian-context experiences.

Consequently, it is believed that including various studies in the scoping review represents the global diversity of peer support. The scoping review also identified research gaps and relevant concepts and theories to inform the subsequent studies. Additionally, the simplified thematic analysis of the qualitative data of the included studies in Study 1 allowed informing Studies 2 and 3 by contextualizing the empirical data.

In Study 2, the directed, qualitative analysis was chosen based on the theory of the phenomenon of social relations (Weiss, 1974). However, the research could be biased when one approaches the empirical data with an already-existing theory (Hsieh & Shannon, 2005). Study 1 informed Study 2 about the lack of research regarding the experiences of peer support from the receiver's perspective. In addition, when planning the overall project, the researcher came across several studies where social support was described as an essential aspect affected when living with HIV. Therefore, the researcher found it necessary to look further into how the service users experience the contribution of peer support. Several crucial elements of the provisions of social relations supported in peer support literature (Fisher, 2014) were recognized in Weiss' (1974) theory. Therefore, the researcher aimed to capture the essence of the experiences by supporting the analysis with a theoretical framework. However, two of the researchers independently analyzed the data and reflected on it through all stages to keep an open-minded approach to minimize bias. Also, the involvement of the advisory group made the analysis more transparent as both the researchers and the advisory group had to discuss the analysis.

The reflexive, collaborative thematic analysis in Study 3 attempted to see if cross-case themes were found despite different perspectives involving peer supporters and healthcare professionals. The study also aimed to look further into peer support as an integrated part of the OPCs. Exploring this topic inductively when analyzing the empirical material increased our insight. Braun and Clarke's analysis phases were followed (Braun & Clarke, 2006, 2013, 2019; Braun et al., 2018). However, Tjora's (2018) stepwise-deductive inductive approach was added in the second phase for several reasons. First, this step helped the researchers to be semantically oriented when coding the data. In addition, this approach reduced the volume of the empirical material, which was helpful when involving the advisory group. In addition, since few people live with HIV in Norway, sharing all the empirical data with the advisory group would have been a risk. Thereby, this approach allowed us to share the data after eliminating confidential information. Furthermore, the researchers both generated themes and explored subthemes and overarching themes together with the advisory group members, strengthening the study and contributing to a more nuanced exploration of the material when raising several voices. This could be seen as a creative and reflective process (Braun & Clarke, 2016). In addition, engaging all the researchers in the back-and-forward process during the coding was appropriate to understand better and grasp what we believed was the theme's essence (Braun & Clarke, 2006, 2013).

## 8.5 Trustworthiness of the project

Trustworthiness is usually considered an aspect to view throughout the study as a whole, as a reflective approach to the entire research process (Polit & Beck, 2018). For this purpose, Lincoln and Guba (Lincoln & Guba, 1985) referred to credibility, dependability, and transferability. These concepts reflect similar terms such as validity and reliability in quantitative research (Denzin & Lincoln, 2018; Polit & Beck, 2018). They further suggest that the trustworthiness of qualitative studies can be assessed along with these three interconnected concepts. In the next paragraphs, these three concepts will be utilized to discuss the trustworthiness of the research and the transferability of the findings.

Establishing credibility refers to having confidence in the 'truth' of the findings, whereas transferability refers to showing that the results have applicability in other contexts (Denzin & Lincoln, 2018; Lincoln & Guba, 1985; Polit & Beck, 2018). In Studies 2 and 3, member checking of the qualitative data was attempted to allow them to correct what they had said during the interview and add information if needed. However, none of the participants wanted to read the transcripts of the discussions. A member check could have helped increase the amount of data and even the credibility (Morse, 2018).

On the contrary, the advisory group members contributed to every phase to improve the credibility of the results. Their contribution included interpreting the empirical data and re-reading the results to see if they were recognizable and understandable. The 'insider' perspective from the advisory group and the researcher's 'outsider' perspective enabled a dialogue that contributed to richness and depth and a greater understanding. The advisory group's perspective is crucial in contextualizing the data and making the results more credible. By including both service users and healthcare professionals in the analysis, the dialogue's knowledge contains a width and richness that the researcher alone cannot achieve. This closeness to the OPCs increases the transferability of the result to other similar settings, as several voices were heard (Rose, 2014). Variation, sample size, and context are essential parameters influencing transferability (Malterud et al., 2016). Due to the sample characteristics of the participants in Studies 2 and 3 and reflections related to sample size shown in chapter 8.2, several of the findings are not meant to be generalized. This is supported by research suggesting that people living with HIV differ due to having other intersecting characteristics affecting their experiences of living with HIV, e.g. gay men and other men who have sex with men, sex workers, people having non-binary gender, and people who use drugs (Chinouya et al., 2017; Relf, Holzemer, et al., 2021). However, the results could still be transferable to other contexts and potentially marginalized groups living with a CLLC.

The term dependability shows that the findings are consistent and could be repeated (Denzin & Lincoln, 2018; Lincoln & Guba, 1985; Polit & Beck, 2018). In Study 1, the process aimed to be transparent according to inclusion criteria, search strategy, and selection of studies, demonstrating how one could repeat the scoping review and check for its dependability. The consistency of Study 1 is also assured by including all the researchers in every step of the process. In Studies 2 and 3, the consistency is related to how the data in the two studies correspond. The quotations were also provided in the result chapters to strengthen the credibility of Studies 2 and 3.

In addition, due to the variety of characteristics of service users and peer supporters despite a limited number of eligible participants, the described reflections related to sample strategy, methods of data construction, and analysis above are believed to increase the trustworthiness and even the transferability of the data. Moreover, it is necessary to acknowledge that different study designs, data construction, and analysis methods would have given appropriate, although additional, insight into the phenomena of peer support for people living with HIV.

# 9 Concluding remarks

This thesis is, to our knowledge, the first to report on the experiences of a cross-national multi-center peer support program for people living with HIV in Norway. Overall, the three studies contributed to knowledge related to peer support for people living with HIV. The thesis enhanced our understanding of the experiences of peer support for people living with HIV from multiple viewpoints as it explored the perspectives of the service users, peer supporters, and healthcare professionals. As a result, the thesis gained increased insights into the contribution of peer support organized by and situated at an OPC. Five main concluding remarks can be drawn from this thesis:

- Peer support is an increasingly preferred intervention for people living with HIV in various settings worldwide. However, there were few studies on the experiences from the perspective of the receivers and providers, as well as a few studies on peer support in clinics. Furthermore, few of the included studies have been conducted in Europe and none in the Nordic countries.
- The reciprocal backing between peers living with HIV supports the human drive to be connected to others through sharing similar concerns and experiences, which is also relevant in several theoretical models.
- Peer support at the OPCs indicates a potential for increased knowledge and awareness through the cooperation between peer supporters and healthcare professionals. The OPCs facilitated a dialogue with the service users about different understandings of HIV and the management of a CLLC in daily life.
- The project found that peer support is a recognized intervention for people living with HIV, adapted to varied settings worldwide. Moreover, it is flexible and aims to adjust the support to the receivers' different needs, indicating that peer support promotes a person-centered approach.
- The thesis found that peer supporters and healthcare professionals have divergent expectations of peer support delivery and content. Facilitating peer support at the OPCs requires continuous consideration of the competence of the peer supporters to ensure quality care. Furthermore, it requires role clarity when examining how peer supporters balance their role as both service providers and service users.

## 9.1 Implications for practice and further research

When discussing the main results, the question of whether people living with HIV in Norway need peer support services at the OPCs was raised. Relevant to the concluding remarks, this project contributes to existing research in the field of peer support. The theoretical models presented in this project (Baumeister & Leary, 1995; Hagerty et al., 1992; Weiss, 1974) provide deeper insight into how peer support is experienced by both the receiver and the provider. This thesis gives implications for practice related to the integration of peer supporters in usual care, represented by the OPCs.

Most importantly, to enhance the quality of life for people living with HIV, the studies in this thesis provide valuable knowledge of peer support as a low-threshold intervention to meet the need for early access to social support. The thesis contributes to increased awareness of a peer supporter's additional assistance in supporting the existing healthcare services to respond to the multiple challenges facing people living with HIV. The increased recognition of peer support worldwide and the supporting literature demonstrate the flexibility of peer support, adjusted to the needs of the service users in varied settings. These findings indicate that peer support contributes to a more person-centered approach to healthcare services.

Improved understanding of the providers' experiences of benefits and challenges found in this study calls for the greater availability of peer support and the development of peer support programs as a part of usual care. An increased formalization of the peer supporter role will benefit service users, peer supporters, and healthcare professionals by informing expectations. Furthermore, it seems crucial to consider the increased knowledge of the healthcare professionals working at the OPCs by incorporating people living with HIV into the development and distribution of services. Finally, integrating peer support into the OPCs' usual care increases equalized availability as it frames supportive surroundings for facilitating peer support, ensuring confidentiality.

Further studies of peer support in professional settings should be carried out, focusing on how healthcare professionals' experiences develop perspectives and care by working with peer supporters. Future research exploring whether peer support affects the service users' perceptions of living with HIV, specifically whether peer support impacts HIV-related stigma, would also be valuable. Following the Centers for Disease Control and Prevention, US (2022), it would be of interest to explore whether the OPCs have a 'whole person approach' when providing services for people living with HIV, keeping in mind that the result of this thesis suggests peer support for improving the services to become more person-centered. The next step could be a participatory action research approach where the researcher and participants enable future changes in the OPCs.

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# Appendices 1–8

Paper I‒IV

1. Approvals from the Norwegian Centre for Research Data (NSD)
2. Approval from the Regional Ethics Committee for Medical Research (REK)
3. Approval from the Ethical Committee at the Faculty for Health and Sports Sciences, University of Agder (FEK)
4. Approval from the included HIV outpatient clinics
5. Information about Study 2 and informed consent
6. Interview guide, Study 2
7. Information about Study 3 and informed consent
8. Interview guides, Study 3

# Paper I

Peer Support for People Living With HIV: A Scoping Review

# *Peer Support for People Living With HIV: A Scoping Review*

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*Peer support for people living with HIV has gained increasing traction and is considered a way to take an active role in self-management. The existing research examining peer support interventions has reported promising evidence of the benefits of peer support. The purpose of our scoping review was to describe research on peer support for people living with HIV. We included 53 studies and sorted them into analytic categories and conducted descriptive analyses. The studies that were published between November/December 2000 and May 2021, had a range of study designs and heterogeneous priority groups, and included 20,657 participants from 16 countries. We identified 43 evaluations of the effect of peer support and 10 evaluations of implementation, process, feasibility, cost of peer support. We also categorized peer support by key functions, finding that the most common key functions were linkage to clinical care and community resources and assistance in daily management, with only one study directly related to chronic care. There is growing research interest in peer support for people living with HIV, particularly in high-income countries and related to the evaluation of effects. The revealed gaps of prioritized functions of peer support have implications for further research. Further focus on interventions addressing secondary prevention related to noncommunicable diseases as part of a care package is recommended to meet people's needs and preferences and increase self-management related to a chronic lifelong condition.*

**Keywords:** *people living with HIV; chronic disease; peer support; medication adherence; antiretroviral therapy*

**Health Promotion Practice**
Month XXXX Vol. XX, No. (X) 1–19
DOI: 10.1177/15248399211049824
Article reuse guidelines: sagepub.com/journals-permissions

At the end of 2020, there were an estimated 37.6 million people living with human immunodeficiency virus (PLHIV) worldwide, with approximately 25.4 million undergoing antiretroviral therapy (ART; World Health Organization [WHO], 2021). Although global and national actions have halted and reversed the acquired immunodeficiency syndrome (AIDS) epidemic and reduced HIV incidence overall, HIV infections are on the rise in some countries and regions (WHO, 2021). Furthermore, ART provisions in highly endemic settings, such as sub-Saharan Africa, are challenged due to shortages linked to universal health coverage (UNAIDS, 2020). Thus, HIV remains a public health concern worldwide. The Global Health Sector Strategy on HIV, 2016–2021 (WHO, 2016b), outlines fast-track actions to be implemented as an HIV response to the 2030 Agenda for Sustainable Development (United Nations). These actions must address challenges related to different health care systems and varying health care coverage (such as inconsistent price of medications) across countries. A multisectoral response is outlined as a strategy highlighting the importance of involving the community, particularly PLHIV, for effective delivery of health services (WHO, 2016b).

People from key populations, that is, those at elevated risk of acquiring HIV infection (including sex workers,

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people who inject drugs, prisoners, transgender people, and men who have sex with men) tend to have less access to ART and health care services (Liamputtong, 2007; Sokol & Fisher, 2016). However, for PLHIV and receiving ART, HIV has become a chronic lifelong condition (CLLC; WHO, 2021). An increasing burden for PLHIV is coinfections such as hepatitis, tuberculosis, and other comorbidities (WHO, 2016b), the most prevalent being noncommunicable diseases and mental health disorders (Brandt, 2009; Parcesepe et al., 2018; WHO, 2016b).

Although the life expectancy for PLHIV has increased dramatically, they continue to face other challenges, such as discrimination, stigma, and self-stigma (Grønningsæter & Hansen, 2018; Pantelic et al., 2019; WHO, 2016b). Since the beginning of the epidemic, HIV infection has been associated with social stigma and prejudice, and it remains one of the most stigmatized diseases in almost every culture, worldwide (Pantelic et al., 2019; Relf et al., 2021). Furthermore, apart from utilizing health care services for HIV medical care, many PLHIV disconnect from society owing to stigma and discrimination (Berg & Ross, 2014; Chaudoir & Fisher, 2018; Relf et al., 2021). The societal prejudice can harm those living with the virus in numerous ways, perhaps most detrimentally, through mental health issues (Chaudoir & Fisher, 2018; Relf et al., 2021).

The range of health challenges indicates the importance of continued strengthening of self-management and involvement of PLHIV in their own health care services. This may contribute to empowerment and a more tailored health care service (Venter et al., 2017). Peer support from the larger HIV community can be important in this regard (Positively UK, 2016) and has been found to reduce stigma (Dunbar et al., 2020). Dennis (2003) defined the concept of peer support as "the giving of assistance and encouragement by an individual considered equal" (p. 323).

Peer support for PLHIV grew out of the 1980s activists' reaction to combat stigma and discrimination, advocating for better treatment and care. Peer support still forms communities for people experiencing stigma or fear of exposure and ostracization (Positively UK, 2016). After the introduction of ART, peer support has become a tailored, person-centered method to provide linkage and adherence to HIV medical care, as well as support for PLHIV in taking an active role in self-management of their CLLC (Fisher, 2014; WHO, 2016a). Thus, the provision of peer support is one way of involving patients to strengthen supportive resources in health care services and increase self-management (Fisher, 2014). There is increased recognition that peer support complements general health care services and contributes to meeting consumers' health care needs (Fisher, 2014; Fisher et al., 2018; WHO, 2016a). The Peers for Progress program draws out four key functions of peer support: (1) assistance in daily management, (2) social and emotional support, (3) linkage to clinical care and community resources, and (4) ongoing support related to chronic disease, that is, flexible, accessible support available to patients when the need arises (Fisher, 2014; Fisher et al., 2018).

A systematic review of peer support among "hardly reached individuals," indicates that peer support may be an effective and preferred way to reach people who do not use ordinary health care services (Sokol & Fisher, 2016). Conversely, a systematic review of nine studies on peer interventions, reported the varying effect of peer support (Genberg et al., 2016). The findings of Genberg et al. (2016) are supported in a recent review on effects of peer-led self-management interventions on ART adherence and patient-reported outcomes, which showed unclear but promising effects (Boucher et al., 2020). Additionally, findings indicate that peer support is flexible enough to be applied to people with different health problems in various settings (Genberg et al., 2016; Simoni et al., 2011; Sokol & Fisher, 2016) and has positive effects, especially in lower middle- and low-income countries (Dave et al., 2019).

Given that existing research examining peer support interventions in several health service areas and among different groups has reported inconsistent evidence of the benefits of peer support (Genberg et al., 2016), there is a need for further research. To date, no review has consolidated existing research or described the scope of the empirical work undertaken on peer support for PLHIV. Therefore, this scoping review aims to document the current status of empirical research on peer support for PLHIV, to describe the characteristics of previous studies through a brief overview, and to summarize key findings from each study category to identify knowledge gaps and offer suggestions for further research.

## METHOD

### Design

To identify the range of available evidence on the topic, a scoping review was conducted following methodological framework of scoping reviews (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2017) and is in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) extension for scoping reviews (Tricco et al., 2018). Unlike a systematic review on effects of intervention, diagnostic test accuracy or another narrow question, a scoping review has a broader scope, examining the extent, range, and nature of research activity on a specific topic (Peters et al., 2020). The methods, objectives, and inclusion criteria of this scoping review, were specified in advance and documented in a published protocol (CRISTIN ID = 635403).

### Search Strategy for Identification of Studies

Our preliminary searches in the JBI (Joanna Briggs Institute) Database of Systematic Reviews and Implementation Reports and PROSPERO identified relevant reviews and key words. We used population, concept, and context as our search framework because the aim of the scoping reviews implies that the context is not predefined (Booth et al., 2016). Articles published between 1981 and 2021 were searched on eight electronic databases—MEDLINE (OVID), MEDLINE In-Process (OVID), Embase (OVID), CINAHL (EBSCOhost), PsycINFO (OVID), SocINDEX (EBSCOhost), Social Work Abstracts (EBSCOhost), and BASE (Bielefeld Academic Search Engine). Articles published after 1981 were included, as this was the first year when studies on HIV/AIDS were published. The search was conducted in May 2021. Our search strategy incorporated prespecified subject headings and text words in the titles and abstracts, adapted for each database. One of the reviewers (AØR) conducted the search together with an information search specialist/librarian, who was also consulted regarding the search strategy. The search strategy is shown in the Supplemental Material. In collaboration with the information search specialist/librarian, we supplemented the database searches with searches in Google Scholar, the U.K. government website, and CORE (a website that aggregates all open access research outputs from repositories and journals worldwide and makes them available to the public). Additionally, we performed hand searches in the reference lists of the included studies and relevant reviews and forward citation searches through the Web of Science (conducted June 2021).

### Eligibility Criteria

Considering the aim of the review, the main inclusion criterion was that a study used empirical quantitative and/or qualitative research methods to address the topic of peer support among PLHIV. Moreover, both, those receiving and those providing peer support needed to be PLHIV aged 18 years and older. We followed the definition of peer support interventions/programs proposed by Dennis (2003), whereby the provision of assistance and encouragement is from an individual considered equal. Specifically, PLHIV had to use their own experiences to support other PLHIV, through face-to-face interaction. Furthermore, we considered studies ineligible if they included children and youth, focused on primary prevention of HIV or mother-to-child transmission, or described PLHIV support groups. However, when populations or interventions were mixed (e.g., included both adults and youth), a study was included if at least half of the population or intervention met the inclusion criteria or if the results were reported separately for our population and intervention of interest. We enforced no limits regarding settings or publication format but included only publications in English or Scandinavian languages (Norwegian, Swedish, Danish).

### Selection of Literature

We stored retrieved references in an Endnote database, X9 (Thomas Reuters, New York, NY), deleted duplicate entries, and imported references to the web-based software platform, Rayyan (Ouzzani et al., 2016). Using Rayyan, two blinded reviewers independently screened all titles and abstracts according to the inclusion/exclusion criteria. We promoted all relevant publications to full-text, and the two blinded reviewers independently screened the full texts. They attempted to retrieve full texts of any studies that were not available in the public domain, by contacting the main author. Throughout the screening process, we resolved differences in opinions through reexamination of the studies and subsequent discussion. If necessary, a third reviewer decided.

### Data Extraction and Synthesis (Charting Data)

Methodological quality assessment is not a prerequisite for scoping reviews. Therefore, we did not appraise the included studies (Peters et al., 2020). One reviewer (AØR) performed data extraction. Two other reviewers checked for completeness and accuracy of the extracted data. A predesigned and piloted data extraction form was used to ensure standardization and consistency (Peters et al., 2020). We extracted data regarding author, year, study characteristics (e.g., country, study design, sample size), population characteristics (e.g., gender, sexual identity), peer support characteristics (e.g., term for peer support, duration, content, and settings), and main findings/results. We also categorized the interventions based on four key functions of peer support described by Fisher et al. and the Peers for Progress program (Fisher, 2014). Studies with unclear or minimally described intervention characteristics were excluded. We key worded (Clapton et al., 2009) each study using these variables and compiled the data in a single spreadsheet. We grouped them according to their main characteristics and conducted descriptive analyses using frequencies and cross-tabulations. The grouping included sorting the studies into clusters based on how they were observed to be related to each other (Arksey & O'Malley, 2005; Clapton et al., 2009). Similarly, we copied the main findings of the qualitative studies relevant to peer support, in a Microsoft Word document. The findings are summarized in the data set.

## RESULTS

The searches resulted in 6922 individual records, of which 230 were considered potentially relevant (Figure 1). Eighty-seven studies met the inclusion criteria. The high number of included studies and the volume of data made it necessary to separate the results from the two reports. This review addresses all studies that examined the effects of peer support and evaluated implementation, process, feasibility, and cost.

Thus, in this study, we included 53 studies (Table 1).

### *Characteristics of the Included Studies*

The main characteristics of the 53 included studies are presented in Tables 1 and 2. For ease of reporting, each study was given a number. All studies were published in English. The number of publications on the topic of peer support for PLHIV has grown rapidly—from no publications prior to 2000 to only a few publications between 2000 and 2009 ($n = 9$) to 44 publications between 2010 and 2021. The study designs varied, but most were RCTs ($n = 18$) or mixed-method studies ($n = 12$). The study settings varied, but most studies took place in the United States ($n = 24$), while the fewest studies took place in Europe ($n = 2$). The total number of participants in the included studies was 20,657, with most of the studies including both males and females ($n = 37$), but five studies prioritized only males and six prioritized only females. Only four studies included nonbinary gender as the priority population. However, nine studies reported nonbinary gender among participants.

### *The Key Functions of Peer Support*

Our analysis demonstrates the different roles and key functions (Fisher, 2014) of peer support delivered, in the included studies. The most common key functions of the interventions were linkage to clinical care and community resources ($n = 41$, Studies 1–4, 7–13, 15–20, 22–23, 26–28, 30–35, 37–45, 48–50, 53), followed by assistance in daily management ($n = 32$, Studies 5–6, 9–13, 18–23, 27–28, 35–40, 42–44, 46–48, 50–53) and social and emotional support ($n = 28$, studies 1–9, 11, 15, 19–20, 22–23, 27–28, 33, 35, 37–44, 50). Several peer support interventions have a combination of the described functions. Notably, only one study (44) explicitly focused on ongoing support related to chronic disease. In two studies, the intervention could not be categorized by key functions.

### *Terms and Labels*

We identified 13 different labels/names for peer supporters. Between 2000 and 2009, the terms "peer," "peer counselor/advocate/supporter/mentor/health worker," and "health advocate" were used. Between 2010 and 2021, in addition to the prior labels, a range of new labels appeared: "peer educator/navigator/worker/facilitator/case manager/caregiver/adherence supporter/interventionist," "community health worker," "support worker," and "community care coordinator." All terms represent PLHIV serving as peers. The most frequently used labels across all included studies were "peer" ($n = 10$), "peer counselor" ($n = 7$), and "peer navigator" ($n = 6$).

### *Categories of Studies*

We categorized studies by objective/aim (see Figure 1). When a study fit into more than one category, we placed it in the category that most closely matched the overall objective of the article. This review included two study categories: studies evaluating effects of peer support interventions ($n = 43$) and studies evaluating their implementation, process, feasibility, and cost ($n = 10$). We note that six larger projects on peer support had two or more related publications that examined the intervention: all six projects had at least one publication on the effects of peer support; four projects conducted a process evaluation, and two projects included a program description.

*Studies About Effectiveness of Peer Support.* Of the 43 studies with a main focus on the effectiveness of a peer support intervention (Studies 3–7, 9–13, 15–23, 25–27, 29, 31–38, 41–49, 51–53), most were published within the past 10 years (81%), were set in the United States (44%) and Uganda (12%), and were RCTs (42%) and used mixed methods (19%; Table 3). Only two studies were conducted in Europe (Netherlands and Spain: Studies 4 and 45). In total, 18,833 participants were included in the experimental studies at baseline. Of the 30 effectiveness studies that had a comparison group, 21 of these groups received ordinary health care services.

Although, the priority population of the effectiveness studies was diverse, the studies mainly included female and male participants living in settings associated with

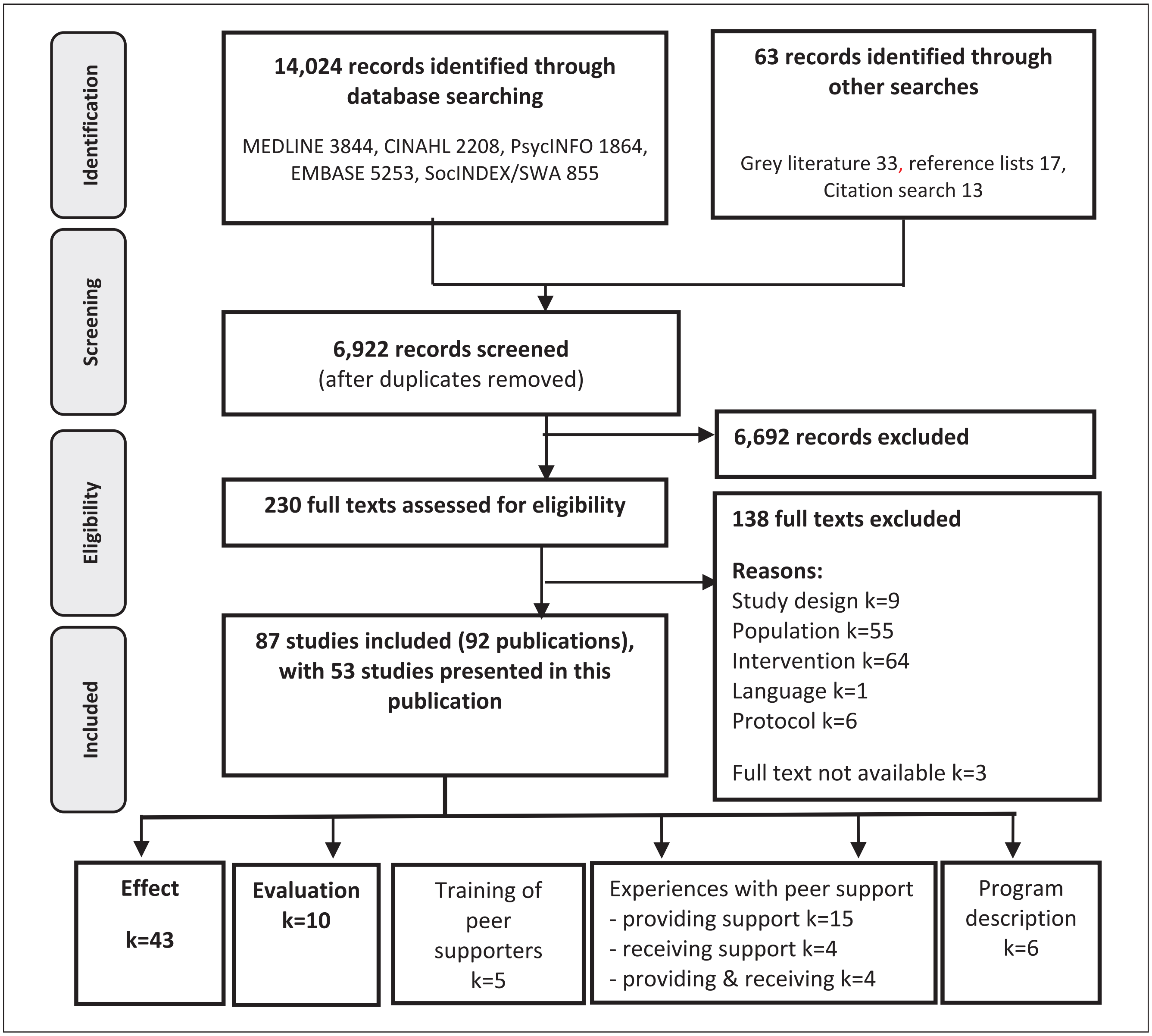

**FIGURE 1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Diagram of Literature Reviewing Process**

social factors that created barriers to accessing effective and affordable HIV health care services. Five studies included only women (Studies 5, 20, 25, 34, 51), four included people who inject drugs (Studies 5, 7, 20, 43), four recruited men who have sex with men (Studies 27, 36, 38, 46), and two U.S. studies specifically recruited people of color (Studies 9, 29).

About the chosen theoretical framework, the interventions differed. Most interventions were based on diverse frameworks, such as social cognitive theory (Studies 17, 19, 23, 29), several social support frameworks (Studies 9, 7, 42, 43), stress, and coping models (Study 5). Several interventions were based on the information, motivation, and behavioral skills model ($n$ = 7; Studies 15, 21, 26, 27, 36, 41, 46). Eighteen studies did not report a theoretical framework.

ART initiation and/or adherence (19 studies), viral load (16 studies), and cluster of differentiation 4 counts (CD4; 8 studies) were the most frequently measured outcomes in the included studies related to effectiveness.

**TABLE 1**
**Characteristics of the Included Studies (Listed in Alphabetical Order; $N$ = 53)**

| *Study no.* | *Author, year* | n | *Country* | *Study design* | *Study focus* |
|---|---|---|---|---|---|
| 1 | Addison et al., 2019 | 233 | USA | Mixed method | Evaluation (implementation) |
| 2 | Arem et al., 2011 | Ns | Uganda | Mixed method | Evaluation (process) |
| 3 | Aung et al., 2021 | 1,022 | Myanmar | Cross-sectional | Effect |
| 4 | Been et al., 2020 | 352 | Netherland | Controlled before-after study | Effect |
| 5 | Boyd et al., 2005 | 13 | USA | Mixed method | Effect |
| 6 | Brashers et al., 2017 | 98 | USA | Mixed method | Effect |
| 7 | Broadhead et al., 2012 | 78 | USA | RCT | Effect |
| 8 | Broadhead et al., 2002 | 14 | USA | Mixed method | Evaluation (feasibility) |
| 9 | Cabral et al., 2018 | 348 | USA | RCT | Effect |
| 10 | Campbell, 2008 | 1,639 | USA | Retrospective cohort | Effect |
| 11 | Chang et al., 2009 | 360 | Uganda | Retrospective cohort | Effect |
| 12 | Chang et al., 2011 | 970 | Uganda | Mixed method | Effect |
| 13 | Chang et al., 2010 | 1,336 | Uganda | RCT | Effect |
| 14 | Chang et al., 2013 | 1,416 | Uganda | Economic evaluation | Evaluation (economic) |
| 15 | Chang et al., 2015 | 442 | Uganda | RCT | Effect |
| 16 | Coker et al., 2015 | 600 | Nigeria | RCT | Effect |
| 17 | Cunningham et al., 2018 | 356 | USA | RCT | Effect |
| 18 | Cuong et al. 2016[a] | 640 | Vietnam | RCT | Effect |
| 19 | Dawson-Rose et al., 2020 | 574 | Mozambique | One group posttest only | Effect |
| 20 | Deering et al. 2009 | 20 | USA | One-group pre–post evaluation | Effect |
| 21 | Derose et al., 2015 | 482 | Honduras | Mixed method | Effect |
| 22 | Enriquez et al., 2019 | 30 | USA | Mixed method | Effect |
| 23 | Enriquez et al., 2015 | 20 | USA | RCT | Effect |
| 24 | Ryerson Espino et al., 2015 | Ns | USA | Qualitative | Evaluation (implementation) |
| 25 | Fogarty et al., 2001 | 1,611 | USA | Mixed method | Effect |
| 26 | Giordano et al., 2016 | 460 | USA | RCT | Effect |
| 27 | Graham et al., 2020 | 60 | Kenya | RCT | Effect |
| 28 | Graham et al., 2015 | 40 | Kenya | Mixed method | Evaluation (safety, feasibility, and acceptability) |
| 29 | Gwadz et al., 2011 | 342 | USA | RCT | Effect |
| 30 | Hallum-Montes et al., 2013 | 30 | USA | Qualitative | Evaluation (implementation) |
| 31 | Hatcher et al., 2012 | 483 | Kenya | Prospective cohort | Effect |
| 32 | Hussein et al., 2020 | 355 | Ethiopia | Pre–post intervention study | Effect |
| 33 | Katz et al., 2021 | 84 | South Africa | RCT | Effect |

(continued)

**TABLE 1 (CONTINUED)**

| *Study no.* | *Author, year* | n | *Country* | *Study design* | *Study focus* |
|---|---|---|---|---|---|
| 34 | Kiweewa et al., 2013 | 85 | Uganda | RCT | Effect |
| 35 | Lifson et al., 2017 | 142 | Ethiopia | Mixed method | Effect |
| 36 | Liu et al., 2018 | 367 | China | RCT | Effect |
| 37 | MacKellar et al., 2021 | 1,234 | Eswatini | One group before and after study | Effect |
| 38 | McKirnan et al., 2010 | 313 | USA | RCT | Effect |
| 39 | Minick et al., 2018 | 25 | USA | Qualitative | Evaluation (process) |
| 40 | Monroe et al., 2017 | 41 | Uganda | Qualitative | Evaluation (process) |
| 41 | Pearson et al., 2007 | 350 | Mozambique | RCT | Effect |
| 42 | Pokhrel et al., 2018 | 682 | Nepal | Controlled before and after study | Effect |
| 43 | Purcell et al., 2007 | 966 | USA | RCT | Effect |
| 44 | Reback et al., 2019 | 139 | USA | One group before and after study | Effect |
| 45 | Ruiz et al., 2010 | 240 | Spain | RCT | Effect |
| 46 | Safren et al., 2011 | 176 | USA | Mixed method | Effect |
| 47 | Scarcella et al., 2011 | 106 | Mozambique | Retrospective cohort | Effect |
| 48 | Selke et al., 2010 | 208 | Kenya | RCT | Effect |
| 49 | Shacham et al., 2018 | 322 | USA | One-group pre/post | Effect |
| 50 | Steward et al., 2018 | 25 | South Africa | Qualitative | Evaluation (process) |
| 51 | Thomas & Holland, 2018 | 129 | USA | Retrospective chart audit/review | Effect |
| 52 | Wewers et al., 2000 | 15 | USA | RCT | Effect |
| 53 | Wouters et al., 2014[b] | 340 | South Africa | RCT | Effect |

*Note*. RCT = randomized controlled trial.

[a] This study was reported in multiple publications: see also Cuong et al. 2012 and Van Tam et al. 2012. [b] This study was reported in multiple publications: see also Masquillier et al. 2014 and Masquillier et al. 2015.

TABLE 2
**Summary Characteristics of the Included Studies (*N* = 53)**

| *Characteristics* | *All studies (*N = *53)* | *Effect (*n = *43)* | *Evaluation (*n = *10)* |
|---|---|---|---|
| Year of publication | | | |
| 2016–2021 | 23 (43) | 19 (44) | 4 (40) |
| 2010–2015 | 21 (40) | 16 (37) | 5 (50) |
| 2005–2009 | 6 (11) | 6 (14) | |
| 2000–2004 | 3 (6) | 2 (5) | 1 (10) |
| Country/setting | | | |
| Ethiopia | 2 (4) | 2 (5) | |
| Kenya | 4 (7) | 3 (7) | 1 (10) |
| Mozambique | 3 (6) | 3 (7) | |
| South Africa | 3 (6) | 2 (5) | 1 (10) |
| Uganda | 8 (15) | 5 (12) | 3 (30) |
| USA | 24 (45) | 19 (44) | 5 (50) |
| Other | 9 (17) | 9 (20) | |
| Study design | | | |
| RCT | 18 (34) | 18 (42) | |
| Mixed method | 12 (23) | 8 (19) | 4 (40) |
| Other | 23 (43) | 17 (39) | 6 (60) |
| Gender of participants | | | |
| Male | 5 (9) | 4 (9) | 1 (10) |
| Female | 6 (11) | 5 (11) | 1 (10) |
| Male and female | 37 (70) | 30 (70) | 7 (70) |
| Male, female, and trans | 4 (8) | 4 (9) | |
| Not stated | 1 (2) | | 1 (10) |

*Note.* The “other” countries were China, Eswatini, Ethiopia, Honduras, Myanmar, Nepal, Netherland, Nigeria, Spain, and Vietnam. RCT = randomized controlled trial.

Other measured outcomes were retention in care, adherence to medical care, mental health, sexual behaviors among PLHIV, quality of life, and stigma. With respect to findings, most studies measuring ART initiation and/or adherence found a positive effect, but not all. One study measured HIV stigma and three others assessed internalized stigma. However, only two studies reported their results, which found decreased negative feelings and enacted/internalized stigma. Similarly, the results for the other outcomes varied. It is important to bear in mind that the populations, content of peer support, comparisons, and length of follow-up varied.

*Evaluation Studies.* The other evaluation studies focused on implementation (Studies 1, 24, 30), process (Studies 2, 39, 40, 50), feasibility (Studies 8, 28), and cost (Study 14; Table 1). They included 1824 male and female participants from the United States (*n* = 5), Uganda (*n* = 3), Kenya (*n* = 1), and South Africa (*n* = 1).

*Implementation.* The three studies on implementation were qualitative (n = 2) and mixed methods (n = 1) design. They described barriers, challenges, and strategies related to the implementation of peer support interventions as a link to care for PLHIV. One study concluded that the intervention was best suited to newly diagnosed patients (Study 1), while the other two reasoned that the specific settings affected the implementation of peer-based programs and offered considerations on the quality of the training and support of peers and their integration in the delivery of health services (Studies 24, 30).

*Process.* There were four process evaluations of qualitative (*n* = 3) and mixed-methods (n = 1) design. All sought to understand the underlying mechanisms of the intervention results: gain insight into lack of effect (Study 2), clarify positive effects (Study 50), examine how to improve the intervention (Study 39),

## TABLE 3
## Characteristics of Effect studies Related to PICO (Population, Intervention, Comparison, and Outcome) in Alphabetic Order ($N = 43$)

| *Study (country)* | *Population* | *Intervention* | *Comparison* | *Outcome domains* |
|---|---|---|---|---|
| Aung et al., 2021 (Myanmar) | *N* = 1,022, female and male | A counselor met with the patient over 1–3 pre-ART sessions. Based on counselor availability, the patient may or may not have retained the same counselor through all sessions. Once PC or SC counselling was complete, patients initiated ART. | Usual care | HIV knowledge<br>Enacted and internalized stigma<br>ART-nonadherence<br>Barriers to care<br>Social support<br>Attitudes regarding counselling |
| Been et al., 2020 (Netherland) | *N* = 352, Migrants living with HIV | *RO*tterdam *AD*herence (ROAD) project. Four existing interventions that could potentially improve treatment adherence in MLWH. The fourth of these interventions was peer support by MLWH, whereby individuals have increased access to emotional support, informational support, and appraisal support. | No comparison group | Social support<br>Internalized stigma<br>Adherence<br>Anxiety and depression |
| Boyd et al., 2005 (USA) | *N* = 13, Women, substance use | Provide emotional and informational support to change their substance abuse patterns and problem-focused coping strategies.<br>Motivation enhancement therapy (MET).<br>The intervention was implemented over an 8- to 12-week period. | No stated | Substance use |
| Brashers et al., 2017 (USA) | *N* = 98, female and male, newly diagnosed | "Living with HIV/AIDS: Taking Control". Educate people newly infected with HIV about the disease, treatments and resources available. The group had one session per week for 6 weeks. | Usual care | Illness uncertainty<br>Social support<br>Level of depression symptoms<br>Self-advocacy |
| Broadhead et al., 2012 (USA) | *N* =78, female and male, IDUs | Intervention (PDI) model rewards drug users who recruit their own peers. Participants play two roles: promoters of adherence and recipients of an advocate's efforts. | Usual care | Enrollment in and utilization of primary care services for HIV<br>Drug- and sex-related risk behavior<br>Adherence skills |
| Cabral et al., 2018 (USA) | *N* = 348, female and male, people of color | Intervention based on the social support framework. The peer addressed four domains: (1) informational support, (2) instrumental support, (3) emotional support, and (4) affiliation support. | Usual care | Retention in care<br>Viral suppression |
| Campbell, 2008 (USA) | *N* = 1,639, female and male | The Peer Mentor Program to establish and develop an effective mentor system to assist HIV-positive patients as they access care and services in this urban HIV-specific clinic for the first time. | Usual care | Retention in HIV care<br>Viral load<br>CD4 counts |
| Chang et al., 2009 (Uganda) | *N* = 360, female and male, low socioeconomic status | The Reach Out care model: A patient-led, holistic approach to AIDS care with the provision of comprehensive health and social services. | No stated | ART adherence<br>Viral load<br>CD4 counts<br>Immunologic |
| Chang et al., 2011 (Uganda) | *N* = 970, female and male | Peer health workers (PHWs) randomized to the mHealth Arm send a text message reporting adherence and clinical data back to a centralized database after home visit. PHWs in the mHealth Arm were encouraged to call a RHSP mobile phone or toll-free warmline with questions or concerns. Clinic staff receiving PHW texts and calls could opt to provide care instructions to PHWs, send a higher level care provider to the patient, or arrange transport to health care facilities. | The comparison group consisted of PHWs who did not receive the mHealth intervention. | ART adherence<br>Viral load<br>Lost to follow-up<br>Mortality |
| Chang et al., 2010 (Uganda) | *N* = 1,336, female and male, on ART | Task shifting with PHW. ART provided through a mobile clinic program. A PHW intervention delivers additional support. | Usual care | ART adherence<br>Viral load |
| Chang et al., 2015 (Uganda) | *N* = 442, female and male | Peer support structured home visits to promote clinic attendance and preventive care intervention use or standard of care. Peers visited each participant monthly. | Usual care | ART initiation<br>Retention in care<br>BCP preventive care use<br>Risky sexual behaviors |
| Coker et al., 2015 (Nigeria) | *N* = 600, female and male | Participants were randomized into one of three intervention arms: a standard-of-care arm; a second arm included daily reminders via alarm, follow-up calls from peer educators, and adherence support by a home-based treatment partner; and a third arm included second-arm activities plus home visits by peer educators | Usual care | ART adherence<br>Viral load<br>CD4 counts |

*(continued)*

## TABLE 3 (CONTINUED)

| *Study (country)* | *Population* | *Intervention* | *Comparison* | *Outcome domains* |
|---|---|---|---|---|
| Cunningham et al., 2018 (USA) | *N* = 356, men or transgender women released from a large municipal jail system | LINK LA. A peer navigation intervention. The intervention group participated in a 24-week peer navigation intervention. Trained peer navigators counselled participants on goal setting and problem solving. | Usual care | ART use and adherence<br>Viral load<br>Linkage to care<br>Retention in HIV care<br>Retention/adherence knowledge<br>Physical and mental health |
| Cuong et al., 2016 (Vietnam) | *N* = 640, female and male, treatment-naïve | Peer supporters visited their homes twice a week during the first 2 months, followed by once a week afterward. The peer supporters asked the patients about their general well-being, social–psychological problems, OI symptoms, adverse drug reactions, and adherence and conducted a pill count. They also performed some home care and referred patients to hospitals. | Usual care | ART initiation<br>Viral load<br>CD4 count<br>Mortality rate<br>Causes of death and risk factors |
| Dawson-Rose et al. 2020 (Mozambique) | *N* = 574, female and male | Peer educators helped clients to explore ways to disclose to partners. They provided emotional support. They provided information on the four identified and UNAIDS-approved steps of disclosure to HIV positive clients. | No comparison group | HIV disclosure |
| Deering et al., 2009 (USA) | *N* = 20, female sex workers who use illicit substances | The PDI intervention consisted of four key elements: weekly peer support meetings, capacity training for women to become health advocates (“buddies”) to one another, a peer outreach service, and drop-in onsite nursing service. | No comparison group | ART adherence<br>Viral load |
| Derose et al., 2015 (Honduras) | *N* = 482, female and male, on ART | A simplified version of visual aids and a reference technical manual based on a nutrition education curriculum were developed for peer counselors, supported by educational materials. | No comparison group | Food insecurity<br>Nutritional knowledge/dietary intake<br>Nutritional status |
| Enriquez et al., 2019 (USA) | *N* = 30, female and male, nonadherence to ART medications | The Peers Keep It Real intervention program consisted of seven individual sessions facilitated by a peer interventionist. It occurred at the health care setting where the participant would obtain his or her HIV care and were scheduled on the same day as appointments with HIV medical care providers. | Usual care | ART adherence<br>Viral load |
| Enriquez et al.,2015 (USA) | *N* = 20, female and male, nonadherence to ART medications | “READY”. The peer support is based on the readiness stage of the wellness motivation theory and framed in understanding the process of initiating and maintaining healthful behavior change. Tailored to enhance its cultural relevance for a target population living day-to-day in a culture of HIV. | A graduate health psychology student facilitated education | ART adherence<br>Viral load |
| Fogarty et al., 2001 (USA) | *N* = 1,611, women and at-risk women | The intervention included support groups and one-on-one contact with peer advocates tailored to client needs. The strategies included group support, peer advocacy, multiple sessions, tailored educational messages and theory. | Usual care | Demographic and risk data<br>Behavioral outcomes<br>Self-efficacy<br>Perceived advantages |
| Giordano et al., 2016 (USA) | *N* = 460, female and male, hospitalized HIV-infected patients who had never been in outpatient HIV care, had been poorly retained in care, or had detectable HIV viral load | The intervention MAPPS. The intervention is delivered during 2 in-person sessions in the hospital, followed by 5 telephone calls after discharge over the next 10 weeks. The intervention focused on mentors serving as role models for successfully managing HIV infection and for encouraging active self-management. | The control intervention was delivered as the MAPPS intervention but with a different goal and approach. | Retention in care<br>Viral load |
| Graham et al., 2020 (Kenya) | *N* = 60, MSM | The Shikamana intervention. The intervention combines modified Next-Step Counseling by trained providers, support from a trained peer navigator, and tailored use of SMS messaging, phone calls, and discrete pill carriers. | Usual care and an invitation to attend a monthly support group | ART adherence<br>Viral load |
| Gwadz et al., 2011 (USA) | *N* = 342, female and male, people of color | The intervention’s mechanisms of action were grounded in the theory of normative regulation, as well as motivational interviewing and social–cognitive theory. The intervention included 6 hours of structured, facilitated sessions plus the opportunity to educate up to 3 peers about AIDS clinical trials. | A time- and attention-matched health education intervention. | Participation in screening for AIDS clinical trials |
| Hatcher et al., 2012 (Kenya) | *N* = 483, female and male, not previously enrolled in HIV care or treatment | HIV counseling and testing (HCT) was offered in accordance with the Kenyan national guidelines. Newly diagnosed clients were invited to receive a follow-up home visit by a trained PLWHA navigator. Following the campaign, PLWHA navigators attempted to conduct home visits with all persons providing locator information to offer support for enrolling into HIV care. | No comparison group | Linkage to care |

*(continued)*

## TABLE 3 (CONTINUED)

| *Study (country)* | *Population* | *Intervention* | *Comparison* | *Outcome domains* |
|---|---|---|---|---|
| Hussein et al., 2020 (Ethiopia) | $N$ = 355, female and male | Peer education not specified. | No comparison group | ART adherence |
| Katz et al., 2021 (South Africa) | $N$ = 84, female and male who delay or discontinue ART | The theory of triadic influence (TTI) designed to address individual-, social-, and structural-level barriers to ART initiation: (1) individual-level factors by building the knowledge base and trust of treatment, while promoting self-efficacy and effective coping strategies; (2) social-level factors through social interactive processes that address HIV-related stigma and the need for disclosure; and (3) structural-level factors through facilitating engagement with clinic providers. | Usual care | General health perceptions<br>Depression, anxiety, and somatic complaints<br>Social support<br>Stigma and disclosure concerns<br>Barriers to ART |
| Kiweewa et al., 2013 (Uganda) | $N$ = 85, female on ART | The model evaluated the effect of a task-shifting model in which ART nurses managed most follow-up visits at longer intervals between visits, and patients were supported by peer counselors and home visits, if indicated. | Usual care | Initiated ART<br>Viral load<br>CD4 count |
| Lifson et al., 2017 (Ethiopia) | $N$ = 142, female and male, newly enrolled in HIV clinical care | The CHSWs provided HIV and health education and counseling/social support, as well as facilitated communication with the HIV clinics. The CHSWs visited clients 1 to 4 times/month to provide the following: (1) education on HIV treatment, nutrition, and other health-promoting behaviors; (2) counseling and social support; (3) facilitated communication with the nurse from the HIV clinic; and (4) referrals as needed to community organizations | No comparison group | Retention in care<br>HIV knowledge, physical and mental quality of life<br>Internalized stigma<br>Perceived social support |
| Liu et al., 2018 (China) | $N$ = 367, newly diagnosed, MSM | The peer counseling manual was based on an adapted information–motivation–behavioral skills (IMB) model. The peer counseling session involved a 60-minute one-on-one discussion focusing on topics regarding specific high-risk behavior modification | Usual care | High-risk behavior change<br>Quality of life<br>HIV stigma<br>Self-efficacy<br>Hospital anxiety and depression |
| MacKellar et al., 2021 (Eswatini) | $N$ = 1,234, female and male | Community-based HIV testing, mobile HIV care, and peer delivered, linkage case management program (CommLink). The CommLink package of linkage services included, for example, peer-delivered counseling, at least two additional (three total) face-to-face HIV counseling and psychosocial-support sessions. | No comparison group | Barriers to HIV care |
| McKirnan et al., 2010 (USA) | $N$ = 313, MSM | The Treatment Advocacy Program (TAP). The intervention consisted of four 60- to 90-minute individual counseling sessions, 3-month "check-in" telephone calls, and 6- and 12-month coping follow-up counseling sessions. | Usual care | Sexual risk behavior |
| Pearson et al., 2007 (Mozambique) | $N$ = 350, female and male, initiating HAART | Participants received 6 weeks (Monday through Friday; 30 daily visits) of peer-delivered modified directly observed therapy (mDOT). Peers provided education about treatment and adherence and sought to identify and mitigate adherence barriers. | Usual care | Adherence to HAART<br>CD4 counts |
| Pokhrel et al., 2018 (Nepal) | $N$ = 682, female and male, on ART | The intervention encompassed home-based psychosocial support and peer counseling, adherence support, basic health care, and referral services. The support team comprised a community health worker, a trained HIV-positive person, and a social worker. | Usual care | ART adherence<br>Depressive symptoms<br>Anxiety<br>Stress<br>Substance use |
| Purcell et al., 2007 (USA) | $N$ = 966, female, male and transgender, IDUs | The INSPIRE project. The peer-mentoring intervention (PMI, the intervention condition) was developed based on a combination of theories and concepts. INSPIRE integrated key concepts of empowerment theory into an HIV prevention intervention. | The control condition: eight small-group video-and-discussion sessions on topics relevant to participants' lives. | Substance use<br>Sexual risk behavior<br>Retention<br>Adherence |
| Reback et al., 2019 (USA) | $N$ = 139, transgender women | The Alexis Project was a combined peer health navigation (PHN) and contingency management (CM) intervention that targeted HIV milestones associated with advancement along the HIV care continuum. | No comparison group | Linkage to care<br>Retention<br>CD4 counts<br>HIV medication pick-up |
| Ruiz et al., 2010 (Spain) | $N$ = 240, female and male, on ART | The intervention group was treated by a "peer." Patients in both groups received a psychoeducational intervention to increase their adherence to ART. In addition to the baseline visit, patients were seen at Weeks 8, 16, and 24. The intervention visits were scheduled to coincide with routine hospital visits to facilitate attendance by the patients (adherence to the intervention). | Group A was treated by a health professional (physician or pharmacist with extensive knowledge about HIV) | ART adherence<br>Viral load<br>Psychological distress |

*(continued)*

## TABLE 3 (CONTINUED)

| *Study (country)* | *Population* | *Intervention* | *Comparison* | *Outcome domains* |
|---|---|---|---|---|
| Safren et al., 2011 (USA) | *N* = 176, MSM | A peer-driven IMB. The intervention included five visits with an HIV-infected MSM peer interventionist over the course of approximately 3 months, which included one “intake” visit, and four “intervention” visits. These were followed by four follow-up “booster” visits at 3, 6, 9, and 12 months postintervention. The intervention was delivered in the clinic setting. | Medical social workers as interventionists who had specific HIV-risk inclusion/exclusion criteria<br>and intensive study procedures | The feasibility of delivering an HIV sexual risk reduction counseling program in the context of primary HIV care<br>Acceptability of the intervention<br>Transmission risk behavior |
| Scarcella et al., 2011 (Mozambique) | *N* = 106, female and male, BMI< 18.5, presence of the wasting syndrome, TB coinfection, insufficient access to food, CD4 count < 200 | The DREAM program. The program is characterized by provision of HAART, clinical and laboratory monitoring, peer-to-peer health and nutritional education, and food supplementation. The activists become peer-to-peer health and nutrition educators, and they are particularly involved in supporting adherence to the therapy and promoting food hygiene and a balanced diet. | No comparison group | BMI<br>Hemoglobin<br>Viral load<br>CD4 count<br>Dietary intake |
| Selke et al., 2010 (Kenya) | *N* = 208, female and male, on ART | The intervention group received monthly personal digital assistant-supported home assessments by PLHWA at clinic appointments every 3 months. | Usual care | Viral load<br>CD4 count<br>Stability of ART regimen<br>Opportunistic infections<br>Pregnancies<br>Number of clinic visits |
| Shacham et al., 2018 (USA) | N=322, female, male and transgender | The Barrier Elimination and Care Navigation (BEACON) Project Evaluation. Participants enrolled in a community- and clinic-based intervention that included intensive case management, access to a community nurse and peer navigator, and emergency stabilization funds. | No comparison group | Quality of life<br>Biomedical markers of HIV<br>Retention in care |
| Thomas and Holland, 2018 (USA) | *N* = 129, female | The intervention consisted of peer mentors providing information about cervical cancer screening and assisted with scheduling a gynecological visit. Peer mentors educate, support, and provide linkage to health care services to persons living with HIV. | Usual care | Cervical cancer screening uptake |
| Wewers et al., 2000 (USA) | *N* = 15, female and male, self-reported smoking | Smoking cessation intervention. The intervention was based on the Agency for Health Care Policy and Research Smoking Cessation Clinical Practice Guideline and was delivered by an ex-smoker who was HIV positive. The intervention was delivered primarily by a peer. | They were mailed the same written materials as the intervention group including a strong message to quit smoking. | Abstinence rates |
| Wouters et al., 2014 (South Africa) | *N* = 340, female and male, on ART | The peer intervention was developed based on the family functioning framework. It focused on family dynamics in community-based peer adherence support. Peer adherence support comprised biweekly visits by a trained community-based peer. he peers performed a wide range of adherence counseling tasks. | Usual care | CD4 counts<br>ART adherence |

*Note*. ART = antiretroviral therapy; PC = peer counselor; SC = standard counselor; MLWH = migrants living with HIV; IDU = injection drug user; PDI = peer-driven intervention; RHSP = Rakai Health Sciences Program; BCP = basic care package; OI = opportunistic infection; UNAIDS = Joint United Nations Programme on HIV/AIDS; MAPPS = Mentor Approach for Promoting Patients’ Self-Care; MSM = men who have sex with men; SMS = short message service; PLWHA = people living with HIV/AIDS; CHSW = community health support worker; HAART = highly active antiretroviral therapy; INSPIRE = Interventions for Seropositive Injectors-Research and Evaluation; BMI = body mass index; TB = tuberculosis; DREAM = Drug Resources Enhancement against AIDS and Malnutrition.

and investigate why and how peer supporters improved client engagement in care (Study 40).

*Feasibility.* Both studies on feasibility had a mixed methods design. One was related to the willingness and ability of persons who inject drugs to help each other. Findings indicated a high level of willingness and that the peer support intervention increased their adherence to care (Study 8). Another study, which examined the engagement of Kenyan men who have sex with men, concluded that the peer support intervention was feasible and acceptable to the participants (28).

*Cost.* The economic evaluation analyzed and compared the costs of a peer health worker intervention and a phone peer support intervention (Study 14). While both interventions were evaluated as potentially cost-effective, the threshold analysis suggested that the peer health worker intervention was potentially most cost-effective if it was able to avert 1.5 patients every year from switching to second-line ART.

## DISCUSSION

Our scoping review, aimed to describe the characteristics and results of evaluation research on peer support for PLHIV, identified 53 studies, all published since 2000. Research on peer support for PLHIV has grown rapidly over the past decade. This may reflect the increased life expectancy of PLHIV following the introduction of ART and, hence, peer support becoming a more integrated part of health care services.

### *Different Populations and Intervention Characteristics*

The 53 studies demonstrated heterogeneity of populations, intervention characteristics, outcomes, and settings investigated in peer support programs. Most studies had both females and males as the priority population for peer support. Other priority groups included people who inject drugs, men who have sex with men, people of color, and individuals with little disposable income, which uncovered a varied priority population. Consistent with the aim of health promotion strategies and the Global Health Sector Strategy on HIV 2016–2021 (WHO, 1986, 2016b), it seems these investigations represent a diversity of needs of PLHIV. However, it is also worth mentioning the low number of studies that included nonbinary genders. This was true despite these individuals being at increased risk of acquiring HIV infection compared with the general population (UNAIDS, 2020). The geographical aspect is noteworthy. A large proportion of the included studies were conducted in low-resource settings and in the U.S. regions heavily affected by the HIV epidemic, while only two were conducted in Europe. This suggests that there is limited interest in this intervention among researchers in Europe.

Furthermore, the most common key intervention function, used in 41 of the interventions, was linked to care and community resources, which is important to strengthen the health care workforce related to HIV. From this perspective, peer support attempts to respond to the needs of PLHIV in priority settings. The key functions "assistance in daily management" and "linkage to care and community resources" have the flexibility to engage those living with HIV in the process of planning peer support. This involvement ensures that peer support fits the priority population. A setting-specific approach acknowledges that low-resource and high-resource settings have different needs, which is evident in the context of studies.

### *A Reflection on Measured Outcomes*

Biological markers, such as viral load, CD4 counts, and adherence to ART, were the most frequently measured outcomes in the included studies. A recent systematic review detailed findings on these outcomes (Berg et al., 2021). Only four of our studies measured stigma as the primary outcome. This is despite stigma being a known barrier to HIV treatment and care (Relf et al., 2021), with studies showing that it affects the degree of disclosure, followed by decreased social support and health-seeking behavior (Smith et al., 2008).

It is important to measure the effect of peer support on perceived stigma. Research shows that interventions that increased linkages to care and community resources, as well as social and emotional support, were able to facilitate improvements in mental health status and had the potential to enable those living with HIV to overcome the effects of anticipated and internalized stigma (Garrido-Hernansaiz & Alonso-Tapia, 2017). Thus, social support from peers may be a resource when people experience stress in response to stigma (Dulin et al., 2018; Dunbar et al., 2020; Earnshaw et al., 2015).

We also found a need to clarify the support needed by PLHIV as individuals living with a CLLC. Although anticipated and/or experienced stigma might affect their general efforts to seek support, the included studies indicate that meeting a peer supporter may contribute to social support. However, few studies have measured whether and how peer support affects aspects of mental health and quality of life as primary outcomes, despite the high rates of documented mental health disorders among PLHIV (Brandt, 2009; Parcesepe et al., 2018). This could be related to the scant amount of peer support related to chronic diseases as a key function, according to the definition of ongoing chronic support by the Peers for Progress program (Fisher, 2014; Fisher et al., 2018). Despite the large number of studies that support self-management, social and emotional support, and linkage to HIV care, few studies have reported peer support as a long term, flexible outreach program.

### *What Defines Peers?*

We found little uniformity in terms of both the terminology and practice of peer support. We identified 13 different labels/names for peer supporters, with the most frequently used label being "peer'. This is somewhat surprising considering our narrow inclusion criteria. In their review of "Peer Interventions to Promote Health: Conceptual Considerations," Simoni et al. (2011) proposed the term "peer" as standard terminology with an extended definition consisting of four elements: (1) peers share key personal characteristics, circumstances or experiences with the priority group; (2) the benefits of a peer intervention derive largely from their status as peers; (3) peers do not need professional training; and (4) peers function according to a specific role. The first element coincides with a definition proposed by Dennis (2003). Still, Simoni et al. (2011) used a clearer conceptualization to distinguish peer work interventions from work by others involved in services. In this terminology, the definition of Dennis (2003) might have a wider reach than Simoni's, although Simoni's definition is more focused on peer roles. The variation of labels discovered across the included studies in this review may suggest that different labels fit different interventions. We categorized the key functions of peer support and found that three key functions were part of most interventions—only one focused on ongoing support related to chronic disease and two studies lacked information on key functions. It is necessary to understand the characteristics and primary key functions of peer supporters. When the intervention characteristics are insufficiently described or poorly reported, and the intervention subsequently appears to exist in many variants under different labels, it becomes harder to understand what is meant when "peer support" and similar terms are used.

### *Agreements and Disagreements With Other Studies or Reviews*

Several reviews on peer support interventions for PLHIV have been conducted. While focusing on separate aspects, these largely mirror our findings. First, Simoni et al. (2011) conducted a systematic review to investigate the efficacy of different types of peer support in HIV/AIDS patients. The review resolved some effects of peer interventions, but heterogeneity in populations and outcomes affected the ability to draw conclusions. These authors and authors of a review published a decade later (Berg et al., 2021) state that additional, carefully designed studies are required to investigate the effectiveness of peers and the conditions that need to be present to ensure successful interventions. This reflects our finding that various intervention characteristics, settings, and outcomes challenge the ability to compare interventions. Genberg et al. (2016) conducted a systematic review of peer interventions to improve engagement in care, indicating that peers had a mixed impact on ART adherence, viral suppression, and mortality. Although peer interventions had a positive effect on linkage to and retention in care, a limited number of studies have measured these outcomes. Decroo et al. (2012) published a review that examined whether expert patients were an untapped resource of ART provision in sub-Saharan Africa. Findings indicated that PLHIV can serve as a resource in the provision of ART in this region, which is promising in this high-epidemic area. Notably, we have identified no reviews on the implementation of peer support, process evaluation, or cost analysis.

### *Implications*

The increased number of publications on peer support for PLHIV over the last decade has shown a growing interest in this topic. Despite this, we recognize the need for more studies in Europe and sub-Saharan Africa. Only two studies were from Europe, and less than 40% of the included studies were conducted in sub-Saharan Africa, which is a high-epidemic area of HIV, identified by the WHO as a priority population (WHO, 2016b). There have been no studies from Russia, which is one of the few countries with growing HIV incidence rates. Areas such as sub-Saharan Africa and Russia are in need of fast-track action (WHO, 2016b), and research evidence from other areas with comparable populations can be transferred to these. However, there will be a lack of setting-specific knowledge. A handful of forthcoming studies on peer support for PLHIV are registered at ClincalTrials.gov. They mostly relate to the prevention of HIV, which is promising; however, few prioritize the population in sub-Saharan Africa.

Our results show that the most common key characteristics of peer support are linkage to care and community resources, assistance in daily management, and social and emotional support. These are appropriate for the priority population and the settings of the existing interventions and can, arguably, have an impact on stigma, mental health, and quality of life. Our results suggest a broader scope when the effects and experiences of peer support are measured in relation to living with HIV, knowing that new needs arise throughout life when living with a CLLC (Fisher, 2014; Fisher et al., 2018). As noted, our results align with existing global strategies and guidelines, and have relevance for policy makers and health care providers. As indicated by other reviews (Berg et al., 2021), the results support that peer support can help shoulder existing services. The Global Health Sector Strategy on HIV 2016–2020 recommends an integrated care package designed to meet people's needs and preferences and increase self-management related to CLLC. Hence, peer support is a type of care package that can meet the various needs of PLHIV. Further focus on interventions addressing secondary prevention related to noncommunicable diseases as part of this package is recommended.

Because of its broad aim and inclusion of studies, this review is summative in nature and provides an opportunity for detailed analysis of effect studies in particular. Our results further demonstrate the scarcity of studies on the implementation, process, and cost analyses. These are important perspectives for researchers and health care entities in consideration of improvement of peer support services.

### *Strengths and Limitations*

The systematic approach regarding searches, selection, and data extraction is the main strength of our scoping review, although a limitation of the review is the absence of studies in languages other than Scandinavian and English. Our framework helped us to be consistent in the approach, and the data analyses made it possible to identify and maintain consistency for all categories. The broad scope of this review, along with the large number of included studies with diverse findings, limited the opportunity to draw firm conclusions. This review provides a comprehensive overview of the research field on the evaluation of peer support for PLHIV. A main limitation was that the included studies had several labels for peer supporters that were previously unknown to the reviewers. It is possible that this could have affected the search strategy, and we might have missed some relevant studies.

## CONCLUSIONS

This scoping review documented an increased research interest in peer support for PLHIV, although it revealed gaps in *where* the research was conducted, *outcomes* measured, and prioritized function of peer support related to chronic care. With about 25.4 million people accessing ART, the need for support related to retention in care and chronic care is increasing. The gaps in the prioritized functions of peer support have implications for further research. The flexibility of the peer support role related to settings, health outcomes, and populations appears to complement health care services with regard to the different needs of PLHIV.

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## Supplemental Material

Supplemental material for this article is available online at https://journals.sagepub.com/home/hpp.

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# Search strategy

## MEDLINE, EMBASE and APA PsycInfo (Ovid)

Database: Embase <1980 to 2021 Week 20>, Ovid MEDLINE(R) ALL <1946 to May 21, 2021>, APA PsycInfo <1806 to May Week 3 2021>. Search Strategy: link results based on search date: 23.05.2021

--------------------------------------------------------------------------------

1 ((hiv or aids) adj6 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)).ti,ab. (470967)

2 (peer or peers).hw. (134476)

3 peer*.ti,ab. (332044)

4 (lay adj3 (people* or patient* or client*)).ti,ab. (5993)

5 (patient* adj2 expert*).ti,ab. (7232)

6 2 or 3 or 4 or 5 (392228)

7 1 and 6 (8403)

8 exp HIV Infections/ or exp Human immunodeficiency virus infection/ or hiv/ (794523)

9 exp Anti-Retroviral Agents/ or acquired immune deficiency syndrome/ or Acquired Immunodeficiency Syndrome/ or aids/ (482469)

10 8 or 9 (917056)

11 (peer* adj6 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)).ti,ab. (81375)

12 2 or 11 (184850)

13 10 and 12 (6210)

14 7 or 13 (10836)

15 ((hiv* or aids) and peer*).ti. (1417)

16 14 or 15 (10968)

17 limit 16 to yr="1981 -Current" (10961)

18 limit 17 to yr="1981 - 2013" (5477)

19 remove duplicates from 18 (3222)

20 limit 17 to yr="2014 -Current" (5484)

21 remove duplicates from 20 (3222)

22 21 or 19 (6444)

**Notes on search syntax**

- Adj6 = N5 (EBSCOhost), adjacency. . The ADJ3 operator finds terms in any order with two words (or fewer) between them. The ADJ4 operator finds terms in any order and with three words (or fewer) between them, and so on
- Field codes used
    - ti,ab = words from title, abstract (text words)
    - .hw = single word from a subject heading word/or part of a subject heading phrase like “peer tutoring”
    - / exact subject headings- search 8 and 9 – subject headings used in the three databases
    - Exp / exact subject headings including narrowing terms – search 8 and 9 subject headings used in the three databases

| **Notes on the searches** | | Search string | Results |
|---|---|---|---|
| Population HIV/AIDS<br>Word from title or abstract | 1 | ((hiv or aids) adj6 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)).ti,ab. | 470967 |
| Peer(s), words from subject headings, single word or words from a subject phrase that includes peer(s) | 2 | (peer or peers).hw. | 134476 |
| Words from title or abstract, peer | 3 | peer*.ti,ab. | 332044 |
| Synonyms/related terms for peers | 4 | (lay adj3 (people* or patient* or client*)).ti,ab. | 5993 |
| Synonyms/related terms for peers | 5 | (patient* adj2 expert*).ti,ab. | 7232 |
| **Peers total with synonyms/related** | **6** | **2 or 3 or 4 or 5** | **392228** |
| ***HIV/AIDS and peers*** | ***7*** | ***1 and 6*** | ***8403*** |
| HIV – or AIDS, subject headings | 8 | exp HIV Infections/ or exp Human immunodeficiency virus infection/ or hiv/ | 794523 |
| | 9 | exp Anti-Retroviral Agents/ or acquired immune deficiency syndrome/ or Acquired Immunodeficiency Syndrome/ or aids/ | 482469 |
| **HIV OR AIDS subject headings** | **10** | **8 or 9** | **917056** |
| Peers – words from title/abstract | 11 | (peer* adj6 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)).ti,ab. | 81375 |
| Peers – words form title or abstract or subject headings | 12 | 2 or 11 | 184850 |
| **HIV/AIDS subject headings AND peers (subject/title/abstracts words)** | **13** | **10 and 12** | **6210** |
| **HIV and peers, words from title/abstract or subject headings** | **14** | **7 or 13** | **10836** |
| **Words from title HIV/aids AND peer*** | **15** | **((hiv* or aids) and peer*).ti.** | **1417** |
| **Combined; HIV/AIDS AND peers** | **16** | **14 or 15** | **10968** |
| **Limit year** | **17** | **limit 16 to yr="1981 -Current"** | **10961** |
| | 18 | limit 17 to yr="1981 - 2013" | 5477 |
| | *19* | *remove duplicates from 18* | *3222* |
| | 20 | limit 17 to yr="2014 -Current" | 5484 |
| | *21* | *remove duplicates from 20* | *3222* |
| **Remove duplicates** | **22** | **21 or 19** | **6444** |

Exporting to EndNote 2000 at a time, link to segments. **Result total 23.05.2021 (search line 16)**: EMBASE: 5253, MEDLINE: 3844, APA PsycInfo: 1864: 10961

**CINAHL;Social Work Abstracts;SocINDEX (EBSCOhost), Advanced search, Boolean/Phrase search mode. 23.05.20021**

**Notes:**

- If no field codes, the search is executed in the standard fields, includes words from title, abstract, subject headings
- N# - Near Operator (N) - ex N5 finds the words if they are within five words of one another regardless of the order in which they appear. For example, type tax N5 reform to find results that would match tax reform as well as reform of income tax. N5 = adj6 in Ovid search syntax
- SU = words form subject headings, a single word, or a single word from a subject heading phrase
- TI = words form title
- AB = words from abstract
- MH = exact subject headings used in CINAHL, + includes narrowing terms

| | # | Query | Limiters/Expanders | Results |
|---|---|---|---|---|
| People with HIV/AIDS Words from title or abstract | S1 | TI ((hiv or aids) N5 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)) OR AB ((hiv or aids) N5 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)) | | 81,647 |
| Peer* words from title, abstract or subject headings | S2 | TI peer* OR AB peer* OR SU peer* | | 102,895 |
| Synonyms – related peer | S3 | TI (lay N2 (people* or patient* or client*)) OR AB (lay N1 (people* or patient* or client*)) | | 1,335 |
| Synonyms – related peer | S4 | TI (patient* N1 expert*) OR AB (patient* N1 expert*) | | 1,443 |
| peers | S5 | S2 OR S3 OR S4 | | 105,572 |
| *HIV/AIDS and PEERS* | *S6* | *S1 AND S5* | | *2,221* |
| HIV/AIDS Words from subject headings | S7 | (MH "Acquired Immunodeficiency Syndrome") OR SU aids OR SU hiv OR (MH "Anti-Retroviral Agents+") | | 149,337 |
| Peer words from subject headings | S8 | SU peer* | | 31,719 |
| Peers, words from title, abstract, restricted by narrowing words | S9 | TI (peer* N5 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)) OR AB (peer* N5 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)) | | 25,470 |
| Peers, subject headings, or title abstract (restricted by narrowing terms) | S10 | S8 OR S9 | | 49,600 |
| *HIV/aids AND peers (subject) or title/abstract restricted with nearby words* | *S11* | *S7 AND S10* | | *1,774* |
| *HIV/AIDS AND peers – words from title* | *S12* | *TI (HIV or AIDS) AND TI peer** | | *527* |
| **Combined HIV/AIDS – and peers** | **S13** | **S6 OR S11 OR S12** | | **3,065** |
| ***Limit year*** | ***S14*** | ***S6 OR S11 OR S12*** | ***Limiters - Published Date: 19810101-*** | ***3,063***<br>***link*** |

**Total: 3063;** CINAHL (2,208)**,** SocINDEX (796)**,** Social Work Abstracts (59)

# Paper II

A Scoping Review of the Empirical Literature on Peer Support for People Living With HIV

Journal of the International
Association of Providers of AIDS Care
Volume 20: 1-10

DOI: 10.1177/23259582211066401
journals.sagepub.com/home/jia
SAGE

# A Scoping Review of the Empirical Literature on Peer Support for People Living with HIV

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## Abstract

People living with HIV receiving antiretroviral therapy need support related to linkage to care and self-management in everyday life. Peer support has been found to provide varied support according to the unique needs of the group. This scoping review aims to provide an overview of research on peer support provided to people living with HIV. A search was conducted in eight databases until May 2021, and two reviewers independently screened all identified studies. We sorted the included studies into categories and conducted descriptive analyses. For this communication, we included 34 studies representing three study categories: the experiences of peer support (n = 23), program descriptions (n = 6), and training of peer supporters (n = 5). The studies were published between 2000 and 2021 and included 4275 participants from 10 countries. The flexibility of peer support complements healthcare services, but there is a need to clarify and adjust the ongoing support when living with HIV.

## Keywords

HIV, chronic disease, peer support, experiences, scoping review

Date received: 19 November 2021; revised: 21 September 2021; accepted: 25 November 2021.

## Background

With 37.6 million people living with human immunodeficiency virus (HIV) infection at the end of 2020, HIV remains a worldwide public health concern. Although global and national actions have halted and reversed the acquired immunodeficiency syndrome (AIDS) epidemic and reduced the overall incidence of HIV, the prevalence of HIV infection is still increasing in some countries and regions.[1] Furthermore, antiretroviral therapy (ART) provision in highly endemic settings, such as sub-Saharan Africa, are challenged due to shortages linked to universal health coverage (Joint United Nations Programme on HIV/AIDS [UNAIDS].[2] The Global Health Sector Strategy on HIV 2016-20213 outlines a multisectoral response as a strategy that highlights the importance of involving the community, particularly people living with HIV [PLHIV], to effectively deliver health services.[3]

People from key populations, that is, those at elevated risk of acquiring HIV infection (including sex workers, people who inject drugs, prisoners, transgender people, and men who have sex with men) tend to have less access to ART and ordinary healthcare services.[4,5] However, for PLHIV receiving ART, HIV has become a manageable chronic lifelong condition (CLLC).1 Unfortunately, since the beginning of the epidemic, HIV infection has been associated with social stigma and prejudice, and it remains one of the most stigmatized diseases in almost every culture worldwide.[6,7] In addition, co-infections such as hepatitis, tuberculosis, and other comorbidities constitute an increasing burden among PLHIV,3 with noncommunicable diseases (NCDs) and mental health disorders as some of the most prevalent comorbidities.[3,8,9]

To manage the differentiated needs of PLHIV as described above, there is a need to prioritize specific populations and settings while providing HIV services.10 Peer support

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interventions have been highlighted as a flexible and promising approach to provide linkage to and adherence to ART among PLHIV.[10,11] Peer support for PLHIV has a long history and grew out of the reactions of activists in the 1980s to combat stigma and discrimination. PLHIV still constitute communities of people experiencing stigma or fear of exposure and ostracization.[12] The World Health Organisation (WHO) defines individualized peer support as "one-to-one support provided by a peer who has personal experiences of issues and challenges similar to those of another peer who would like to benefit from this experience and support."[13] (p.1). Dennis et al.similarly defined the concept of peer support as "the giving of assistance and encouragement by an individual considered equal.".[14]

Peer support is one way of involving patients to strengthen supportive resources in healthcare services and increase self-management,[11] and diverse peer support models have been applied across various health contexts.[11,15,16] Peer support from the larger HIV community is essential[12] and has been found to reduce stigma.[17] Peer supporters offer support and encouragement to their counterparts through meetings ranging from informal visits and shared experiences to formal appointments focused on practical information sharing. National standards for peer support in HIV were published in the UK to ensure that peer support is provided to PLHIV by PLHIV, and that peer support is tailored to the needs of PLHIV.[12] A similar standard was recently published by the National Association of People With HIV Australia.[18]

More than a dozen systematic reviews of the effectiveness of peer support for PLHIV suggest that peer support is flexible enough to be applied across healthcare contexts and diverse populations,[5,19–21] positively affect communities,[22] and is a feasible and practical approach for linking and retaining PLHIV in HIV care.[23] Unlike the numerous reviews investigating the effectiveness of peer support for PLHIV, few reviews exist on other aspects of this topic, such as the experiences of peers with peer support or the needs of peer supporters. Further, despite the conceptual analysis of peer interventions put forth by Simoni et al.[24] and two reviews on providers' perspectives of peer support,[15,25] the scope of empirical research undertaken on peer support for PLHIV remains unclear and there is a need to map the rapidly expanding field of research on this topic. To this end, to better understand the scope of the current state of research and identify research gaps, this scoping review aimed to identify the characteristics of studies investigating peer support for PLHIV and the key results thereof.

## Methods

### Design

The present scoping review was conducted following the guidelines for scoping reviews.[26–28] We report the results in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews (PRISMA-ScR).[29] The methods used in this scoping review, including its objectives and inclusion criteria, were specified in advance and documented in a published protocol (CRISTIN ID = X).

### Search Strategy for the Identification of Studies

Our preliminary searches in the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports and PROSPERO identified relevant reviews and keywords. We used population, concept, and context as our search framework because the research question implies that the context is not predefined.[30] We searched in an online Medical literature Analysis and Retrieval System (MEDLINE) (OVID), MEDLINE In-Process (OVID), Embase (OVID), CINAHL (EBSCOhost), PsycINFO (OVID), SocINDEX (EBSCOhost), Social Work Abstracts (EBSCOhost), and BASE (Bielefeld Academic Search Engine) for the period 1981 to May 2021. Only papers published after 1981 were included, as this was the year in which studies on HIV/AIDS were first published. Our search strategy incorporated pre-specified subject headings and text words in the titles and abstracts adapted for each database. One reviewer (XX) conducted the search with an information search specialist, who was also consulted regarding the search strategy. The search strategy is presented in the supplemental material (Online Supp 1). In collaboration with the information search specialist, we searched for gray literature on Google Scholar, the UK government website, and COnnecting REpositories (CORE), a website that aggregates all open access research outputs from repositories and journals worldwide and makes them publicly available. In addition, we manually searched the reference lists of the included studies and relevant reviews and forward citation searches through the Web of Science (May 2021).

### Eligibility Criteria

Considering the aim of the review, the main inclusion criterion was studies that used empirical quantitative and/or qualitative research methods to address peer support among PLHIV. Both those who were receiving and providing peer support needed to be PLHIV aged 18 years and older. We followed the definition of peer support interventions/programs proposed by Dennis,[14] whereby assistance and encouragement were obtained from an individual considered equal. Specifically, PLHIV had to use their own experiences of living with HIV to support other PLHIV through face-to-face interactions. Further, we considered studies ineligible if they were on children or youth, focused on primary prevention of HIV or mother-to-child transmission, or described PLHIV support groups. However, studies on mixed populations or interventions (eg, those including both adults and youth) were included if at least half of the population or intervention met the inclusion criteria or if the results were reported separately for our population and intervention of interest. We enforced no settings or publication format limits but included only publications in English or Scandinavian languages (Norwegian, Swedish, and Danish).

## *Selection of Literature*

We stored retrieved references in an Endnote X9 database (Thomas Reuters, New York, NY), deleted duplicate entries, and imported the references to the web-based software platform Rayyan.[31] Using Rayyan, two reviewers independently screened all titles and abstracts according to the inclusion/exclusion criteria (XX, XX/XX). We promoted all relevant publications to full-text screening, which was independently performed by three reviewers. We attempted to retrieve the full texts of any studies that were unavailable in the public domain by contacting the main author. We resolved differences in opinion during the screening process at each stage through a re-examination of the study and subsequent discussion. Arbitration was achieved through discussion in consultation with a third reviewer.

## *Data Extraction and Synthesis (Charting data)*

Considering the aim of this review and the scope of scoping reviews in general, whereby methodological quality assessment is not a prerequisite, we did not appraise the included studies.[32] One reviewer (XX) performed data extraction. Two other reviewers checked the completeness and accuracy of the data extracted from all studies and corrected the data when necessary. A predesigned and piloted data extraction form was used to ensure standardization and consistency.[32] The data were extracted regarding author, year, study characteristics (eg, country, study design, and sample size), population characteristics (eg, gender, sexual identity), peer support characteristics (eg, term of peer support, duration, content, and settings), and main findings/results. We also categorized the interventions based on the four key functions of peer support described by Fisher et al. and the Peers for Progress program.[11] Studies with unclear or minimally described intervention characteristics were not included. By keywording[33] each study by such variables and compiling the data in a single spreadsheet, we could group them according to their main characteristics and conduct descriptive analyses using frequencies and cross-tabulations. The grouping included sorting the studies into clusters according to their relations to each other.[27,33] Similarly, we copied the main findings of qualitative studies in a Word document, restricted to instances across the data with relevance to peer support, and looked for patterns. The results were summarized in the dataset.

## Results

The searches resulted in 6922 individual records, of which 230 were considered potentially relevant (Figure 1).

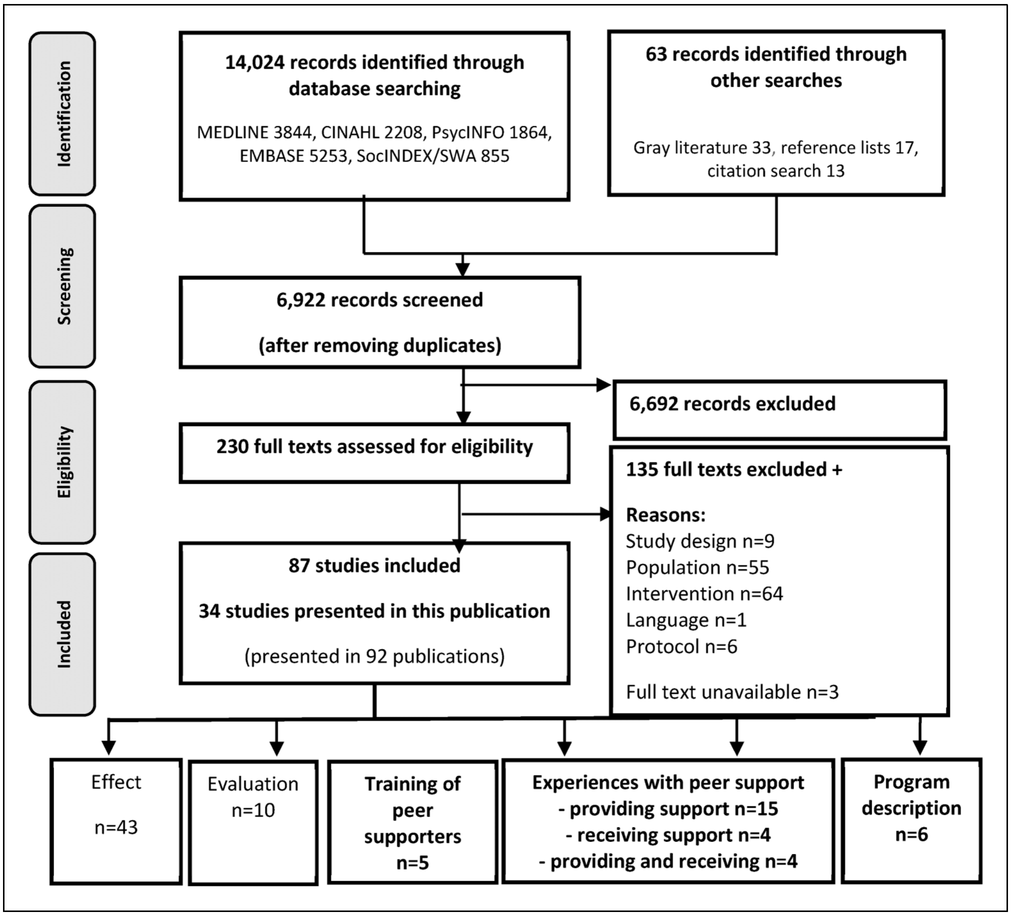

**Figure 1.** PRISMA flow diagram of the literature review process.

Eighty-seven studies met the inclusion criteria. Due to the high number of included studies and the volume of data, it was necessary to separate the results into two reports. Our categorization of studies by objective/aim produced five categories of studies, which we used to separate the results into two reports. A description of the 53 studies that examined the effects of peer support and evaluations (implementation, process, feasibility, and cost) are available elsewhere.[34] The present study addressed 34 studies that examined experiences with peer support (experiences providing and/or receiving peer support) (n = 23), program descriptions (n = 6), and descriptions of the training of peer supporters (n = 5) (Tables 1 and 2). Studies that fit more than one category were placed in the category that most closely matched the overall objective of the paper.

**Table 1.** Characteristics of the Included Studies (n = 34).

| Study no. | Author, year | n | Country | Study design | Term/ label | Key function |
|---|---|---|---|---|---|---|
| **Experiences with peer support (n = 23)** | | | | | | |
| 1 | Akinde et al. 2019 | 15 | USA | Qualitative | Peer mentor | Assistance; Linkage |
| 2 | Alamo et al. 2012 | 347 | Uganda | Mixed method | Community health worker | Assistance; Linkage |
| 3 | Born et al. 2012 | 230 | Zambia | Mixed method | Peer educator | Assistance; Support; Linkage |
| 4 | Cane, 2018 | 6 | England | Qualitative | Support worker | Ns |
| 5 | de Souza, 2014 | 31 | India | Qualitative | Peer worker | Ns |
| 6 | Driskell et al. 2010 | 41 | USA | Qualitative | Peer counselor | Assistance |
| 7 | Dutcher et al. 2011 | 23 | USA | Qualitative | Peer educator | Ns |
| 8 | Enriquez et al. 2013 | 15 | USA | Qualitative | Peer | Ns |
| 9 | Greene et al. 2015 | 121 | Canada | Qualitative | Peer case manager | Assistance; Support; Linkage |
| 10 | Gusdal et al. 2011 | 118 | Uganda and Ethiopia | Qualitative | Peer counselor | Ns |
| 11 | Harris and Alderson, 2007 | 12 | Canada | Qualitative | Peer supporter | Ns |
| 12 | Harris and Larsen, 2007 | 12 | Canada | Qualitative | Peer supporter | Ns |
| 13 | Houston et al. 2015 | 11 | USA | Qualitative | Peer facilitator | Support |
| 14 | Kyakuwa, 2010 | Ns | Uganda | Qualitative | Expert client | Assistance; Support; Linkage |
| 15 | Lee et al. 2015 | 12 | South Korea | Qualitative | Peer supporter | Assistance; Support; Linkage |
| 16 | Li et al. 2015 | 27 | Canada | Qualitative | Peer supporter | Ns |
| 17 | Mackenzie et al. 2012 | 68 | USA | Qualitative | Peer mentor | Assistance |
| 18 | Marino et al. 2007 | 9 | USA | Qualitative | Peer | Assistance; Support; Linkage |
| 19 | Messias et al. 2006[1] | 6 | USA | Qualitative | Peer counselor | Ns |
| 20 | Moyer et al. 2014 | 10 | Kenya | Qualitative | Peer mentor | Assistance; Support; Linkage |
| 21 | Sunguti et al. 2019 | 230 | Kenya | Descriptive | Peer educator | Assistance; Support; Linkage |
| 22 | Tan, 2012 | 21 | USA | Mixed method | Peer | Ns |
| 23 | Tobias et al. 2010 | 186 | USA | Cross-sectional | Peer | Ns |
| **Program descriptions (n = 6)** | | | | | | |
| 24 | Karwa et al. 2017 | 1357 | Kenya | Mixed method | Peer | Support; Linkage |
| 25 | Leonard et al. 2013 | Ns | USA | Mixed method | Peer | Assistance; Support |
| 26 | Purcell et al. 2004 | 966 | USA | RCT | Peer mentor | Assistance; Support; Linkage |
| 27 | Raja et al. 2007 | 122 | USA | Mixed method | Peer | Assistance; Linkage |
| 28 | Tenthani et al. 2012 | 114 | Malawi | Mixed method | Expert client | Linkage |
| 29 | Thomas et al. 2008 | 25 | USA | Qualitative | Peer supporter | Ns |
| **Training of peer supporters (n = 5)** | | | | | | |
| 30 | Allicock et al. 2017 | 6 | USA | Mixed method | Peer | Assistance; Linkage |
| 31 | Cully et al. 2012 | 7 | USA | Mixed method | Peer mentor | Ns |
| 32 | Kim and Shin, 2015 | 32 | South Korea | Qualitative | Peer caregivers | Ns |
| 33 | Tobias et al. 2012 | 91 | USA | Mixed method | Peer | Ns |
| 34 | Wolfe et al. 2013 | 4 | USA | Mixed method | Peer | Linkage |

[1] This study was reported in multiple publications: see also Messias et al. 2009. Ns: not stated, PS: Peer support, RCT: Randomized controlled trial, Assistance: Assistance in daily management, Linkage: Linkage to clinical care and community resources, Support: Social and emotional support.

**Table 2.** Summary Characteristics of the Included Studies (n = 34).

| Characteristics | All studies (n = 34) | Experiences (n = 23) | Training (n = 5) | Program description (n = 6) |
|---|---|---|---|---|
| Year of publication | | | | |
| **2015** to 2021 | 10 (29) | 7 (30) | 2 (40) | 1 (17) |
| **2010** to 2014 | 17 (50) | 12 (53) | 3 (60) | 2 (33) |
| **2005** to 2009 | 6 (18) | 4 (17) | | 2 (33) |
| **2000** to 2004 | 1 (3) | | | 1 (17) |
| **Country/setting** | | | | |
| Canada | 4 (12) | 4 (17) | | |
| Kenya | 3 (9) | 2 (9) | | 1 (17) |
| South Korea | 2 (6) | 1 (4) | 1 (20) | |
| Uganda[1] | 3 (9) | 3 (13) | | |
| **USA** | 18 (53) | 10 (44) | 4 (80) | 4 (67) |
| Other | 4 (12) | 3 (13) | | 1 (17) |
| **Study design** | | | | |
| **RCT** | 1 (3) | | | 1 (17) |
| Qualitative | 20 (59) | 18 (78) | 1 (20) | 1 (17) |
| Mixed method | 9 (26) | 3 (13) | 2 (40) | 4 (66) |
| Other | 4 (12) | 2 (9) | 2 (40) | |
| **Gender of participants** | | | | |
| Male | 4 (12) | 3 (13) | 1 (20) | |
| Female | 3 (9) | 3 (13) | | |
| Male and female | 19 (56) | 14 (61) | 3 (60) | 2 (33) |
| Male, female, and transgender | 2 (6) | | 1 (20) | 1 (17) |
| Not stated | 6 (18) | 3 (13) | | 3 (50) |

Legend: The ‘other’ countries were England, India, Malawi, Zambia.
[1] One study was conducted in both Uganda and Ethiopia.
RCT: randomized controlled trial.

## *Characteristics of the Included Studies*

The main characteristics of the included studies are presented in Table 2. All studies were published in English. The number of publications on the topic of peer support for PLHIV has increased rapidly, from no publications prior to 2000 to only a few publications between 2000 to 2009 and 27 publications from 2010 to 2021. The study designs varied, but most were qualitative (n = 20) or mixed-method studies (n = 9). In addition, the study settings varied, but most studies were conducted in the United States (U.S.) (n = 18), while the fewest studies were conducted in Europe (n = 1). The total number of participants in the included studies was 4,275, with a majority of the studies including both men and women (n = 19); however, four studies included only males and three included only females as priority groups. Only two studies included non-binary-gender participants.

## *Key Functions of Peer Support*

Our results of the key functions of peer support[11] demonstrated the different roles and key functions of peer support delivered across the studies (Table 1). The commonest key function of the intervention was linkage to clinical care and community resources (n = 15) and assistance in daily management (n = 15), followed by social and emotional support (n = 11). Several peer support interventions have a combination of the described functions. Notably, none of the included studies focused explicitly on ongoing support related to chronic diseases. In 15 (44%) studies, the description was too limited to categorize peer support interventions by key functions.

## *Terms and Labels*

In this set of 34 studies, we identified 12 different labels/names for peer supporters (Table 1). In the period 2000 to 2009, the terms “peer, peer counselor/supporter/mentor” were used. In the years 2010 to 2021, in addition to the labels used in prior years, a range of new labels appeared: “peer educator/worker/facilitator/case manager/caregiver”, “community health worker”, “support worker”, and “expert client”. The most frequently used label across the 34 included studies was “peer” (n = 10), followed by “peer supporter” (n = 5), “peer mentor” (n = 5), and “peer counselor” (n = 3).

## *Categories of Studies and their Results*

*Studies about experiences.* Of the 23 studies about experiences with peer support, 15 concerned experiences with *providing* peer support (Table 1; studies 2, 4, 5, 7-9, 15-23),[35–49] four addressed experiences with *receiving* peer support (Table 1, studies 1, 6, 11, 13),[50–53] and four explored PLHIV’s views on both providing and receiving peer support (Table 1, studies 3, 10, 12, 14).[54–57] Most studies (n = 20, 59%) utilized a qualitative design (Table 2). The four studies that covered experiences both with providing and receiving peer support included 360 participants in Uganda, Ethiopia, Zambia, and Canada. The results of these studies are combined with those of studies on experiences with providing and receiving peer support (below).

*Experiences with providing peer support.* Overall, the 15 studies on experiences with providing peer support comprised 1112 male and female participants from nine countries and 11 studies utilized a qualitative design. These studies on experience covered various peer support interventions. The studies varied in their main focus on experiences with providing peer support. A majority of the studies focused mainly on the role of peer supporters when meeting PLHIV. Other main interests were the challenges of being a peer supporter, their experience with the delivery of support, experiences with implementing peer support, and preferences concerning personal contact versus telephone support.

With respect to the results, nine studies reported that peer supporters provided practical, informational, emotional, and/or social support (studies 4, 5, 7, 9, 10, 12, 14, 17, 23)[36–38,40,43,49,55–57] and modeled healthy behavior (studies 8, 9, 17).[39,40,43] Studies have shown that peer supporters feel empowered in their own lives, have different motivations (such as being a role model and helping others), learn new skills and share knowledge, gain self-awareness, and become more visible in the community.[44,55–57] Three studies described peer supporters as positive supplements to healthcare services. However, they noted the need to pay attention to issues such as work-related stress, training, and emotional suppor.t[35,41,51]

*Experiences with receiving peer support.* All four qualitative studies that explored experiences with receiving various types of peer support included 79 participants from the U.S. and Canada (studies 1, 6, 11, 13).[50–53] The results indicated multiple benefits of meeting a peer supporter: a role model for living with HIV; social, informational, emotional, and instrumental support; and referrals to other care organizations that helped them connect with their community.

*Studies presenting program descriptions.* Six studies that included a total of 2584 participants used various data to describe a peer support program.[58–63] (Table 1) Four of the studies were conducted in the U.S. (studies 25-27, 29),[59–61,63] and three of these studies prioritized people of color (studies 25, 27, 29).[59,61,63] Each of the six studies described a different program: an inpatient HIV peer navigator program which aimed to improve diagnosis and linkage to and retention in care (study 24),[58] AIDS clinical trials (ACT) (study 25),[59] Interventions for Seropositive Injectors Research and Evaluation (INSPIRE) (study 26),[60] the Treatment Advocacy Program–Sinai for African Americans (study 27),[61] an expert patient program in Malawi (study 28),[62] and the Caribbean HIV Evaluation Support demonstration program (study 29).[63] These focused equally on linkage to clinical care and community resources, assistance in daily management, and social and emotional support.

*Studies on the training of peer supporters.* The third and last category of studies covered five studies on the training of peer supporters (Table 1).[64–68] All except one of these studies were conducted in the U.S. (study 32).66 Overall, there were 140 male and female participants in the five studies, of which one utilized a qualitative design and four used mixed methods. The peers varied in training. Two studies trained peer supporters in motivational interviews in peer support programs (studies 30, 34).[64,68] One study tested a standardized training program for mentors in MAPPS (study 31),65 another developed a simulation-based training program for peer supporters who would care for terminally ill PLHIV (study 32),66 and the last study described a trainer program, which trained health educators and program directors (study 33).67 All five studies supported the value of and the need for quality training of peer supporters to ensure that peer supporters met performance standards.

## Discussion

Our scoping review, which aimed to provide an overview of the characteristics and results of empirical research on peer support for PLHIV, identified 34 studies published since 2000 on first-hand experiences with peer support, program descriptions, and depictions of the training of peer supporters.

Similar to the results of the 53 studies on the effects of peer support and evaluations, which we present elsewhere,34 we found that there has been an exponential growth in research on the topic of peer support, from no publications prior to 2000 to a steady stream of studies since 2010. Similarly, across both sets of studies, a geographical aspect was evident, with most studies being conducted in the U.S., the fewest taking place in Europe, and a large number of studies being conducted in low-resource settings. A setting-specific approach acknowledges that low-resource and high-resource settings have different needs, which is evident in the context of studies. With respect to the participant characteristics, an approximately equal number of men and women were included, and other priority groups were people who inject drugs, men who have sex with men, people of color, and individuals with little disposable income. Although this suggests a varied priority population, the low number of studies that included non-binary genders is noteworthy. This was true despite the increased risk of acquiring HIV infection among these individuals compared to the general population.[2]

Taken together, our two reports of empirical research on peer support for PLHIV, despite our relatively narrow inclusion criteria, show that 17 different labels are being applied, with “peer” and “peer counsellors” being the most frequently used. In combination with other terms related to the specific role of “peer” support, peers may be the most flexible label, suitable for various interventions and functions, and corresponds to the key functions described by Fisher et al.[16] and the Peers for Progress program. Similarly, the versatility in the practice of peer support found in our scoping review confirms peer support as a flexible approach to outreach that can be adapted to different settings. Still, there seem to be benefits in ensuring an understanding of both the characteristics and key functions of peer supporters. Our analysis of the key functions of peer support in the included studies demonstrates that most of the interventions combine several key functions that align with HIV as a CLLC. Although none of the included studies explicitly focused on ongoing support related to a CLLC as a key function, the many-faceted interventions indicated otherwise.

In contrast to the plentiful examinations of the effects of peer support,34 few studies have examined experiences with peer support for PLHIV from the providers' perspective and still fewer from the receivers' perspective. A similar observation was recently made in a related review.25 The experiences described in the included studies substantiate the idea that peer supporters contribute as role models among PLHIV. Related studies examining the receivers' perspective show that meeting a peer supporter builds various types of support and connections to the wider community. Thus, social support from peers may be a resource when people experience stress in response to stigma.[17,19,20] Notably, the experiences described from the perspective of the receivers of peer support are only described in four studies that reflect participants from the U.S. and Canada.

Despite the existence of only a handful of studies covering program descriptions and training of peer supporters, we found that the development of the role of peer supporters was deliberated in several settings. According to both the Australian and the UK HIV Peer Support Standards, peer support should be provided *to* PLHIV *by* PLHIV, and the peer support description and function should be tailored to the needs of specific populations.[12,18] Our results indicate a positive awareness of the peer supporter role, quality, and function supported in this review.

The increased number of publications on peer support for PLHIV over the last decade has shown a growing interest in this topic. Despite this, we recognize the need for more studies in Europe, sub-Saharan Africa, and Russia. Few of the included studies were conducted in sub-Saharan Africa, a region with a high prevalence of HIV that has been identified by the WHO as having a vulnerable and at-risk population,3 and we identified no studies from Russia, which is one of only a few countries with increasing HIV incidence rates.3

Our results argue for a broader scope when the experiences of peer support are examined from the perspectives of providers and receivers regarding living with HIV as a CLLC.[11,16] The Global Health Sector Strategy on HIV 2016 to 2020 recommends an integrated care package designed to meet people's needs and preferences and increase self-management related to CLLC. There is a need to clarify the support needed by PLHIV as individuals living with CLLC. Our results highlight the fact that peer support can provide practical, informational, emotional, and social support, and specifically help shoulder existing services, which is supported by other reviews.[22,23] Despite the feeling of being empowered and gaining self-awareness, it is worth noticing the work-related stress peer supporters are addressing. The results demonstrated a scarcity of studies that include experiences from peer supporters and recipients, which is a perspective that healthcare entities should consider when improving their services. Therefore, our results are relevant for policymakers and healthcare providers to continue developing peer support programs and training of peer supporters to the specific needs of PLHIV. Further, the included studies highlight the need for quality peer support training followed by increased role clarity when integrating peer support into healthcare services.

### Strength and limitations

The systematic approach regarding searches, selection, and data extraction is the main strength of our scoping review. However, a limitation is the absence of studies in languages other than English. Nevertheless, the charting and analyses of the data made it possible to identify and maintain consistency for all categories. Another limitation was that the included studies had several labels for peer supporters previously unknown to the researchers. This could have affected the search strategy, and we might have missed some relevant studies.

## Conclusions

Research on peer support for PLHIV has increased in the last decade. This is not surprising given the increased life expectancy of PLHIV following the introduction of ART; hence, peer support has become a more integrated part of healthcare services. However, this scoping review revealed gaps in the evidence emanating from research. There is also a need for more studies related to the *experiences* of receiving peer support, *training* of peer supporters, and *program descriptions,* particularly in Europe, sub-Saharan Africa, and Russia. With about 25.4 million people accessing ART,1 there is an increasing need for support related to retention in care and chronic care. The increased need for setting specific peer support programs and role clarity has implications for further research. The flexibility of the peer support role related to settings and populations appears to complement healthcare services concerning the different needs of PLHIV.

### Acknowledgments

We would like to thank librarian Ellen Sejersted for her excellent support and recommendations during the search process, and Editage (www.editage.com) for English language editing.

### Funding

The PhD project is supported by the Dam Foundation.

### Declaration of Conflicting Interests

The authors have no relevant financial or non-financial interests to disclose. The authors have no conflicts of interest to declare that are relevant to the content of this article.

## Ethical Statement

Our study did not require an ethical board approval because it did not contain human or animal trials.

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## Supplemental Material

Supplemental material for this article is available online.

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## Search strategy

### MEDLINE, EMBASE and APA PsycInfo (Ovid)

Database: Embase <1980 to 2021 Week 20>, Ovid MEDLINE(R) ALL <1946 to May 21, 2021>, APA PsycInfo <1806 to May Week 3 2021>. Search Strategy: link results based on search date: 23.05.2021

--------------------------------------------------------------------------------

1 ((hiv or aids) adj6 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)).ti,ab. (470967)

2 (peer or peers).hw. (134476)

3 peer*.ti,ab. (332044)

4 (lay adj3 (people* or patient* or client*)).ti,ab. (5993)

5 (patient* adj2 expert*).ti,ab. (7232)

6 2 or 3 or 4 or 5 (392228)

7 1 and 6 (8403)

8 exp HIV Infections/ or exp Human immunodeficiency virus infection/ or hiv/ (794523)

9 exp Anti-Retroviral Agents/ or acquired immune deficiency syndrome/ or Acquired Immunodeficiency Syndrome/ or aids/ (482469)

10 8 or 9 (917056)

11 (peer* adj6 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)).ti,ab. (81375)

12 2 or 11 (184850)

13 10 and 12 (6210)

14 7 or 13 (10836)

15 ((hiv* or aids) and peer*).ti. (1417)

16 14 or 15 (10968)

17 limit 16 to yr="1981 -Current" (10961)

18 limit 17 to yr="1981 - 2013" (5477)

19 remove duplicates from 18 (3222)

20 limit 17 to yr="2014 -Current" (5484)

21 remove duplicates from 20 (3222)

22 21 or 19 (6444)

**Notes on search syntax**

- Adj6 = N5 (EBSCOhost), adjacency. . The ADJ3 operator finds terms in any order with two words (or fewer) between them. The ADJ4 operator finds terms in any order and with three words (or fewer) between them, and so on
- Field codes used
    - ti,ab = words from title, abstract (text words)
    - .hw = single word from a subject heading word/or part of a subject heading phrase like “peer tutoring”
    - / exact subject headings- search 8 and 9 – subject headings used in the three databases
    - Exp / exact subject headings including narrowing terms – search 8 and 9 subject headings used in the three databases

| **Notes on the searches** | | Search string | Results |
|---|---|---|---|
| Population HIV/AIDS<br>Word from title or abstract | 1 | ((hiv or aids) adj6 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)).ti,ab. | 470967 |
| Peer(s), words from subject headings, single word or words from a subject phrase that includes peer(s) | 2 | (peer or peers).hw. | 134476 |
| Words from title or abstract, peer | 3 | peer*.ti,ab. | 332044 |
| Synonyms/related terms for peers | 4 | (lay adj3 (people* or patient* or client*)).ti,ab. | 5993 |
| Synonyms/related terms for peers | 5 | (patient* adj2 expert*).ti,ab. | 7232 |
| **Peers total with synonyms/related** | **6** | **2 or 3 or 4 or 5** | **392228** |
| ***HIV/AIDS and peers*** | ***7*** | ***1 and 6*** | ***8403*** |
| HIV – or AIDS, subject headings | 8 | exp HIV Infections/ or exp Human immunodeficiency virus infection/ or hiv/ | 794523 |
| | 9 | exp Anti-Retroviral Agents/ or acquired immune deficiency syndrome/ or Acquired Immunodeficiency Syndrome/ or aids/ | 482469 |
| **HIV OR AIDS subject headings** | **10** | **8 or 9** | **917056** |
| Peers – words from title/abstract | 11 | (peer* adj6 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)).ti,ab. | 81375 |
| Peers – words form title or abstract or subject headings | 12 | 2 or 11 | 184850 |
| **HIV/AIDS subject headings AND peers (subject/title/abstracts words)** | **13** | **10 and 12** | **6210** |
| **HIV and peers, words from title/abstract or subject headings** | **14** | **7 or 13** | **10836** |
| **Words from title HIV/aids AND peer*** | **15** | **((hiv* or aids) and peer*).ti.** | **1417** |
| **Combined; HIV/AIDS AND peers** | **16** | **14 or 15** | **10968** |
| **Limit year** | **17** | **limit 16 to yr="1981 -Current"** | **10961** |
| | 18 | limit 17 to yr="1981 - 2013" | 5477 |
| | *19* | *remove duplicates from 18* | *3222* |
| | 20 | limit 17 to yr="2014 -Current" | 5484 |
| | *21* | *remove duplicates from 20* | *3222* |
| **Remove duplicates** | **22** | **21 or 19** | **6444** |

Exporting to EndNote 2000 at a time, link to segments. **Result total 23.05.2021 (search line 16)**: EMBASE: 5253, MEDLINE: 3844, APA PsycInfo: 1864: 10961

**CINAHL;Social Work Abstracts;SocINDEX (EBSCOhost), Advanced search, Boolean/Phrase search mode. 23.05.20021**

**Notes:**

- If no field codes, the search is executed in the standard fields, includes words from title, abstract, subject headings
- N# - Near Operator (N) - ex N5 finds the words if they are within five words of one another regardless of the order in which they appear. For example, type tax N5 reform to find results that would match tax reform as well as reform of income tax. N5 = adj6 in Ovid search syntax
- SU = words form subject headings, a single word, or a single word from a subject heading phrase
- TI = words form title
- AB = words from abstract
- MH = exact subject headings used in CINAHL, + includes narrowing terms

| | # | Query | Limiters/Expanders | Results |
|---|---|---|---|---|
| People with HIV/AIDS Words from title or abstract | S1 | TI ((hiv or aids) N5 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)) OR AB ((hiv or aids) N5 (patient* or people* or person* or client* or living or men or women or woman or female* or adult* or service* or support* or positiv* or care or caring or affect*)) | | 81,647 |
| Peer* words from title, abstract or subject headings | S2 | TI peer* OR AB peer* OR SU peer* | | 102,895 |
| Synonyms – related peer | S3 | TI (lay N2 (people* or patient* or client*)) OR AB (lay N1 (people* or patient* or client*)) | | 1,335 |
| Synonyms – related peer | S4 | TI (patient* N1 expert*) OR AB (patient* N1 expert*) | | 1,443 |
| peers | S5 | S2 OR S3 OR S4 | | 105,572 |
| *HIV/AIDS and PEERS* | *S6* | *S1 AND S5* | | *2,221* |
| HIV/AIDS Words from subject headings | S7 | (MH "Acquired Immunodeficiency Syndrome") OR SU aids OR SU hiv OR (MH "Anti-Retroviral Agents+") | | 149,337 |
| Peer words from subject headings | S8 | SU peer* | | 31,719 |
| Peers, words from title, abstract, restricted by narrowing words | S9 | TI (peer* N5 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)) OR AB (peer* N5 (group* or support* or couns* or service* or provide* or care* or mentor* or tutor* or educat* or led)) | | 25,470 |
| Peers, subject headings, or title abstract (restricted by narrowing terms) | S10 | S8 OR S9 | | 49,600 |
| *HIV/aids AND peers (subject) or title/abstract restricted with nearby words* | *S11* | *S7 AND S10* | | *1,774* |
| *HIV/AIDS AND peers – words from title* | *S12* | *TI (HIV or AIDS) AND TI peer** | | *527* |
| **Combined HIV/AIDS – and peers** | **S13** | **S6 OR S11 OR S12** | | **3,065** |
| ***Limit year*** | ***S14*** | ***S6 OR S11 OR S12*** | ***Limiters - Published Date: 19810101-*** | ***3,063***<br>**link** |

**Total: 3063;** CINAHL (2,208)**,** SocINDEX (796)**,** Social Work Abstracts (59)

# Paper III

Peer Support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users' experiences

Øgård-Repål *et al.*
*BMC Health Services Research (2022) 22:549*
https://doi.org/10.1186/s12913-022-07958-8

BMC Health Services Research

RESEARCH

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# Peer support in an outpatient clinic for people living with human immunodeficiency virus: a qualitative study of service users' experiences

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## Abstract

**Background:** Although human immunodeficiency virus (HIV) has become a manageable condition with increasing life expectancy, people living with HIV (PLHIV) are still often isolated from society due to stigma and discrimination. Peer support provides one avenue for increased social support. Given the limited research on peer support from the perspective of PLHIV, this study explored their experiences of peer support organised by healthcare professionals in an outpatient clinical setting.

**Methods:** The study used a qualitative, descriptive research design for an in-depth understanding of peer support provided to PLHIV in the context of outpatient clinics. Healthcare professionals contributed to the recruitment of 16 participants. We conducted in-depth interviews about participants' experiences of peer support, and performed a directed content analysis of the data. Further, we sorted the data into pre-determined categories.

**Results:** The pre-determined categories constituted attachment, social integration, an opportunity for nurturance, reassurance of worth, reliable alliance, and guidance. The identified themes were: *gained emotional support*, *disclosure behaviour allowed garnering of emotional support*, *non-disclosure promoted the need to meet a peer*, *experienced a sense of belonging*, *activated an opportunity for mutual support*, *means to re-establish belief in one's own worth*, *perceived a positive affirmation of disease management*, *facilitated dialogue about disease management*, the outpatient clinic as *a safe place*, *and a setting for flexible, individualised support*.

**Conclusions:** This study highlights the peer support experiences of PLHIV in the context of outpatient clinics. The participants' experiences align with previous findings, showing that peer support contributes to mutual emotional support between peers. This is particularly important in cultures of non-disclosure where PLHIV experience intersectional stigma. Additionally, our results show outpatient clinics to be supportive surroundings for facilitating peer support, ensuring confidentiality in peer support outreach. Therefore, peer support contributes positively to individualising outpatient clinic services to meet the changing needs of PLHIV.

**Keywords:** HIV, Peer support, Outpatient clinics, Social support, In-depth interviews, Directed content analysis

## Background

For over 25 million people living with human immunodeficiency virus (PLHIV) with access to antiretroviral therapy (ART), their life expectancy is approaching that of the general population [1, 2]. However, human

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immunodeficiency virus (HIV) is a chronic lifelong condition (CLLC) [3], involving complex needs with an increased burden of non-communicable diseases and mental health disorders [4–6]. In addition, PLHIV report poorer health-related quality of life than the general population [7, 8]. This may stem from negative societal reactions towards PLHIV, defining HIV as one of the most stigmatised diseases in almost every culture worldwide [9–12]. Being subjected to societal prejudice and stigma negatively affects emotional well-being of PLHIV. PLHIV often constitute members of marginalised groups, such as sexual minorities and people who use intravenous drugs; thus, many experience intersectional stigma [13, 14].

As a result of many PLHIV becoming disconnected from society [9, 15], with their multidimensional concerns being followed by a need for confidentiality, their ability to reach out for help is negatively affected. Consequently, the degree of social support is impacted [16, 17]. This is unfortunate given the recognised relationship between social support and health [15]. Nevertheless, social support can be a potential source of resilience when PLHIV experience stress, for example, in response to the stigma connected to HIV [18–20]. Specifically, peer support for PLHIV seems to be a crucial resource, as it has been found to increase social support and reduce HIV-related stigma [21, 22].

Peer support, which refers to the support provided by a peer who has had similar personal experiences, has increasingly become a recognised outreach for PLHIV. It strengthens supportive resources in healthcare services, increases self-management, and supports PLHIV in taking an active role in self-management of a CLLC in daily life [23–25]. Notably, the involvement of users in their healthcare services may contribute to increased empowerment and promote a person-centred service that is sensitive and responsive to emotional well-being [3, 26, 27]. Therefore, peer support aligns with the World Health Organization's (WHO) strategy that calls for a person-centred chronic care for PLHIV [27, 28]. WHO defines individualised peer support as 'one-to-one support provided by a peer who has personal experiences of issues and challenges like those of another peer who would like to benefit from this experience and support' [29, p.1]. Different peer support models have been applied across various healthcare contexts. These range from informal visits and sharing experiences to formal appointments focused on practical information sharing [23, 30, 31].

The effectiveness of a range of peer support interventions for PLHIV has recently been reviewed. According to Berg et al.'s systematic review [25], peer support improves ART adherence, reduces the risk of virologic failure, improves viral suppression, and increases long-term retention in care. In addition, other research findings indicate that peer support provides an opportunity for individuals to be an active part of their recovery process, is flexible enough to be applied to varied settings, and is responsive to people's varied needs [24, 25, 32].

Although the effectiveness of a range of peer support interventions has been studied, a recent review [33] demonstrated a scarcity of studies that explored experiences with peer support from the receiver's perspective. The results of the review indicated multiple benefits of meeting a peer supporter, necessitating a clarification of the peer support provided to PLHIV as a CLLC. In addition, although we are aware that different contexts can affect the contribution of peer support, there is limited knowledge about the incorporation of peer supporters as an integral part of healthcare services in outpatient clinics (OPCs) [25]. Therefore, the objective of this study was to explore how PLHIV experience the support provided by peers in OPCs.

### Theoretical frameworks

Although this study specifically focused on a peer support program as a part of healthcare services, peer support offers services beyond the traditional medical model of care. Several researchers clarify the concept of peer support in line with its varied contributions, including providing inspiration toward living a full life [23, 24, 31]. As a complement to general healthcare services, there is a recognition that peer support contributes to meeting needs at the individual level covering several dimensions of well-being [34]. The correlation between health and social support has been recognised in recent years [18]. Disclosure of their HIV status allows PLHIV to garner the social support they need [17]. Social support is associated with decreased anxiety and depression, and higher resilience, particularly pertaining to HIV-related stigma [18–20]. However, PLHIV often experience decreased social support following diagnosis [20].

Social support can serve several functions; Weiss [35] provides theoretical formulations for several purposes of social support. Although Weiss's model originates from the context of loneliness, it captures important elements when conceptualising social support. He identifies six different social functions or 'provisions' needed to feel supported, thereby avoiding loneliness. The themes reflect what the participants gain from relationships with others.

First, guidance and reliable alliance are the most relevant functions to direct problem-solving in stressful situations. Second, the provision of reassurance of worth is related to others recognising one's competence, skills, and values. Third, an opportunity for nurturance points to an essential aspect of feeling needed by others in interpersonal relationships. While this provision is not strictly considered social support, it indicates that giving and receiving in an interpersonal relationship may enhance health. This value is also recognised by Borkman [36], a leading researcher on the mutual support dynamic, as an essential component of peer support. The last functions described by Weiss are attachment and social integration. These functions regard the presence of affectional ties. Affectional ties concern emotional closeness to others that contribute to a sense of security. In contrast, social integration involves the feeling of belonging to a group that shares the same interests, concerns, and activities [35, 37].

## Methods

### Study design

This study used a qualitative, descriptive research design involving directed content analysis, which explores a phenomenon guided by existing theory [38, 39]. In-depth interviews were conducted to explore the qualitative, lived experience of meeting a peer supporter [40, 41]. We also examined several aspects related to living with HIV. Using a qualitative method, this study provided comprehensive data on the phenomenon, as it allowed an assessment of both similar and different components of peer meetings [42].

### The advisory group

Two user representatives of PLHIV, one non-governmental organisation representative, one nurse, and one medical doctor, were invited to form an advisory group. The purpose of the advisory group was to secure lay community experts' perspectives and feedback throughout the research process, and thus improve the quality of the research. The nurse and the medical doctor worked at separate HIV OPCs. Among the user representatives were men, women, an immigrant, and a member of a sexual minority group. The advisory group clarified terms, explored research questions, developed the interview guides with the research team, and was actively involved in the data analysis. To decrease the risk of potential cooptation of peer support values in the meetings related to power dynamics between the members of the adivsory group, we conducted separate, independent meetings with the PLHIV representatives.

### Study setting

The HIV OPCs in Norwegian hospitals are funded by the government and part of the specialist healthcare services, and meet every person newly diagnosed with HIV at least once. As a national Norwegian standard, OPCs located in hospitals provide free medical follow-up and treatment of people infected with HIV [43]. When people are diagnosed with HIV, during their first consultation at the OPC, they meet an infectious disease specialist. Further, the OPCs provide regular follow-ups in general once to twice a year. Supplementary follow-ups are performed in collaboration with the primary healthcare and other parts of the specialist healthcare system depending on the patients' needs, for example, mental and somatic comorbidity [43]. At the end of 2020, Norway had a low prevalence of 6,778 people diagnosed with HIV (4585 men and 2193 women) [42], and has achieved the United Nations Programme on HIV/AIDS 90–90-90 treatment targets developed in 2013. The 90–90-90 targets aim for 90% of all people with HIV knowing their status, 90% receiving sustained antiretroviral therapy, and 90% of people with HIV receiving ART having viral suppression [44, 45].

The setting for the peer program (described below) was five public OPCs situated in local hospitals in the four regional health authorities in Norway, two of which were university hospitals. The five OPCs provide the routine follow-up as described above. Until now, per support has only been offered to PLHIV through non-governmental organisations. The non-governmental organisations are situated in the larger cities in Norway, and thereby only available for one of the OPCs included in this study.

#### *The peer support program*

A user-initiated peer support program for PLHIV started nearly ten years ago as part of the healthcare services at one user-driven OPC serving PLHIV. A committee of PLHIV developed goals for healthcare services based on their needs and experiences. One goal was to establish peer support. This was because a peer supporter could offer assistance, grounded on values of equality, and thus an opportunity to focus the support on the direct, here-and-now needs with which the service users presented [46, 47]. As a result of the user-involvement process, five OPCs incorporated the peer support program as part of their healthcare services for PLHIV during 2019 and 2020. Healthcare professionals (HPs) at the five OPCs aim to provide peer support to the PLHIV enrolled at the respective OPC through a peer support program. HPs organise meetings between peers. Peer supporters work as independent consultants, and receive a payment (72 USD per consultation funded by the OPCs) as compensation for their contribution and coverage of travel expenses. The HPs provide the peer supporters with regular supervision. In addition, the peer supporters regularly meet for peer discussions and assessments.

Peer supporters are PLHIV, receiving treatment and care at one of the included OPCs, and formally trained to be peer supporters through a training program jointly developed by the HPs and supporters. The non-peer-reviewed literature of Bloomsbury Patient Network, the

UK's National Training Program of Peer Mentors, *Project 100*, and National Standards for HIV Peer Support [21] inspired the training program and its implementation in OPCs. Inspired by the peer support training conducted in the UK [21], the peer support program's implementation and training were conducted in a dialogue between peer supporters and healthcare professionals at the different clinics to ensure that the values of peer support were understood and implemented.

### Recruitment strategy and eligibility criteria

We aimed to explore diverse levels of involvement, thoughts, and perceptions, to gain a thorough, in-depth understanding of the peer support experiences of PLHIV [43]. The HPs at the OPCs therefore purposively recruited PLHIV enrolled in the clinics who they believed could share valuable and rich experiences [42, 48].

The following eligibility criteria were used for PLHIV: 1) living with HIV, 2) enrolled in HIV clinical care at one of the OPCs, 3) aged 18 or older, 4) willing to sign written informed consent for study participation, and 5) having attended at least one peer support meeting. The participants could participate regardless of literacy, but they had to understand Norwegian or English. Individuals enrolled in an OPC were eligible irrespective of whether they were receiving ART.

The number of participants to be interviewed was considered after reading through three initial interview transcripts and initiating preliminary coding. We aimed for an iterative, context-dependent decision regarding sample size to reach data saturation. Through the analytical process with predefined categories, the 16 interviews provided us with an increasingly comprehensive picture of the predefined categories as well as an ability to develop sub-categories. Following Malterud's guidance of sample size [49], and considering the narrow study aim, quality of the interview data and the HPs' involvement in participant recruitment, we found 16 interviews to have yielded sufficient information.

All 16 invited individuals agreed to participate. We covered the participants' travel expenses and provided light refreshments during the interviews.

#### *Data construction*

The first author conducted face-to-face, in-depth, semi-structured interviews at participants' convenience during spring and autumn of 2020. The interviews were conducted in office at the respective OPCs. The first author, who had not met any of the participants before, informed them that she was a registered nurse with prior interviewing experience. The first author made field notes immediately after each of the 16 interviews, which lasted between 30 and 60 min, with an average of 47 min. The interviews were audiotaped and transcribed verbatim. The participants were asked if they wanted to read the transcripts, but all of them declined the offer.

The current study formed part of a larger PhD study where a scoping review of the empirical literature on peer support for PLHIV was conducted. The results and patterns in the scoping review informed the interview guide of the current study. In addition, the interview guide was not pilot tested, but developed jointly by the authors and the advisory group. The advisory group contributed to the clarification of concepts based on relevance. It included 21 open-ended questions (Additional File 1).

### Analysis

In accordance with the description by Assarroudi et al. [36] and Hsieh and Shannon [37], we conducted a directed, qualitative content analysis to prepare, organise, and report the findings (see Additional File 2). Our directed content analysis was based on existing theory of the phenomenon [39, 42], namely social support.

First, the first and last author deductively applied Weiss' six identified provisions of social relations as predetermined categories: attachment, social integration, the opportunity for nurturance, reassurance of worth, reliable alliance, and guidance [35, 37, 50]. Then, the first and last author used an inductive process to develop specific codes within each pre-determined category [39].

The initial phase involved familiarisation with the textual data; the first and last author read through the transcripts to get a sense of the entire collected information. In the second stage, the data were de-identified and imported into the NVivo 12 software program to assist in coding and analysing the qualitative data. Next, we applied the pre-determined categories to the textual data, and the first author searched for meaningful units related to each of the pre-determined categories. Data found to be relevant, but not fitting into one of the pre-determined categories, inductively formed a new category. Finally, the first and last author coded the interviews according to the categorisation matrix defined by the coding rules, exemplified through sample quotes (see Additional File 3) [38].

In the next stage, meaningful units relating to each pre-determined category were inductively condensed by the first author. The first and last authors discussed the condensation. In stage four, the first author coded the condensed meaningful units and discussed the codes with the authors and the advisory group. The coding included reverting to the text and reanalysing to identify texts missing from the pre-determined categories [38]. Next, all authors examined the codes for differences and similarities and abstracted them into sub-categories in a back-and-forth process (see Table 1).

Finally, the sub-categories were abstracted into their representative pre-determined categories. The sub-themes were reviewed by members of the research team (AØ-R, RB, VS, and MF) before proceeding to the reporting phase. Any disagreements were discussed until a consensus was reached.

### Ethical considerations

The Norwegian Social Science Data Service approved of this study (NSD; reference number 184248). Information about the study was communicated both orally and in writing before the participants chose to participate. Informed consent was obtained from all participants before data collection started. Informed consent included information about participants' opportunity to withdraw from the study at any time without negative consequences regarding their relationship with HPs at the OPCs. The manuscript preparation adhered to the Criteria for Reporting Qualitative Research (COREQ) checklist [51].

## Results

We interviewed six women and ten men, with ages ranging between 30 and 58 years (mean age: 44 years), representing characteristics for PLHIV in Norway. The findings concerning how the participants experienced peer support organised and undertaken by the OPCs were reported according to the pre-determined categories from the primary sources of provisions of social relationships. These constitute attachment, social integration, an opportunity for nurturance, reassurance of worth, reliable alliance, and guidance [35, 37]. Reliable alliance is, in this context, operationalised as 'serving as a liaison between patients and clinical care, motivating patients to communicate and assert themselves to obtain regular and quality care, helping to identify local resources when needed' (see Additional file 3). However, we found no meaningful units concerning the peer supporters providing support aligned with the 'reliable alliance' provision, although HPs offered this to our participants. Therefore, this provision was excluded from the results section. In addition, the category 'OPCs as the setting for peer support' was developed inductively (see categories in Table 2).

### Attachment

The participants expressed that they gained emotional support from peer supporters when they were short of other emotionally close relationships, or when their former close relationships were negatively affected or destroyed due to their HIV diagnosis. Conversely, participants who had disclosed their diagnosis to others, followed by a supportive response, did not get emotionally attached to the peer supporters.

#### *Gained emotional support*

Non-disclosure behaviour seemed to prevent participants from garnering emotional support from friends and family. They even recognised that they could not expect support when they did not disclose their HIV diagnosis:

**Table 1** Examples of the directed content analysis

| *Meaningful units* | *Condensations* | *Codes* | *Sub-categories* | *Pre-determined categories* |
|---|---|---|---|---|
| 'I got support here at the hospital, and this is like my 'health family', talking to the nurse and the peer supporters. That is important'. (Cries when saying this) (P1) | Talking to nurses and peer supporters when needing support related to HIV | The hospital as a supportive family | Gaining emotional support | Attachment |
| 'It was good. I am not alone. I knew I was not alone, but I knew no one else'. (P3) | Meeting peer supporters provided a feeling of not being alone | Meeting peers promotes the feeling of not being alone | Experiencing a sense of belonging | Social integration |
| 'You have to be discreet all the time. I survive by being so quiet about this. I am happy that we had this peer talk here at the hospital. It is a typical problem that you really have to talk to someone about, but you cannot talk about it because people probably cannot relate, and they might be discriminating.' (P4) | Need of discretion when afraid of being stigmatised; the hospital is the only place to meet peers | Non-disclosure of PLHIV prevents them from meeting other peers outside of the hospital | A safe place | OPCs as the setting for peer support |

**Table 2** Overview of the pre-determined categories and sub-categories

| Support provided by peer supporters to PLHIV | | | | | |
|---|---|---|---|---|---|
| Pre-determined categories | | | | | |
| Attachment | Social integration | Opportunity for nurturance | Reassurance of worth | Guidance | OPCs as the setting for peer support |
| Sub-categories | | | | | |
| Gained emotional support | Non-disclosure promoted the need to meet a peer with similar concerns | Activated an opportunity for mutual support | Means to re-establish belief in one's own worth | Perceived positive affirmation of disease management | A safe place |
| Disclosure behaviour allowed garnering of emotional support | Experienced a sense of belonging | | | Facilitated dialogue about disease management | A setting for flexible, individualised support |

> *'I have no one to talk to. So, you go all by yourself. I have not said anything about my HIV to my friends, so I do not know whether they would support me or not'. (P11)*

Some of the participants, who were immigrants and had experienced stigma related to HIV in their home country, said that when they disclosed their HIV diagnosis to their families, it was followed by rejection:

> *'He [my father] told me I am a whore. My family had this perception irrespective of the amount of education they received. This is due to their culture and society. Mom said the same thing. It was such a bomb, such an electric current in my brain, so uncomfortable. Therefore, I just cut the phone. They disapproved of me'. (P10)*

These participants described experiences of either non-disclosure behaviour or rejection when disclosing their diagnosis, which promoted a need to garner emotional support from other sources as a 'substitute' for the help generally received from friends and family. Thereby, some participants expressed that people connected to the OPCs were a 'supportive family'. In addition, some of the participants had not disclosed their diagnosis to anyone outside of the hospital, in the sense that only the HPs and peer supporters knew about their HIV status.

#### *Disclosure behaviour allowed garnering of emotional support*

Some of the participants, mainly gay men with a Norwegian background who had chosen to disclose their HIV diagnosis to their family and/or friends, expressed emotional support from their close relations as a response:

> *'I chose to share the diagnosis right away. I received no negative reactions. There may have been some worries at home, but that is how it will be. Thus, it has been the reaction I expected. I never thought there was going to be a problem at home or with close family and friends at all'. (P13)*

It seems like the need for emotional support from peers living with HIV was reduced when participants disclosed their HIV diagnosis; the most important thing for them was to have someone to rely on when the need arose:

> *'When it comes to friends, there are not so many questions... They ask if everything is okay, but there is no such thing as feeling sorry for me, which is the most important thing. This is not what I want. I have someone to talk to who can listen. This is often what you need... to get things off your chest, and I get that support'. (P13)*

If a shortage of knowledge characterised the support they received from friends and family, the participants found their concerns and lack of rejection as an expression of support:

> *'They are as supportive as you might expect them to be. HIV is no issue. When HIV is the pertinent topic, they are as supportive as one might expect them to be, considering the naivety of heterosexual adults, because they have very little knowledge'. (P12)*

### Social integration

When non-disclosure increased the feeling of being alone, the participants found that peer supporters could provide them with a sense of belonging to a group with similar concerns.

#### *Non-disclosure promoted the need to meet a peer*

The participants described several reasons for their non-disclosure behaviour, followed by a need for support from peer supporters. They expressed a combination of protecting the family from being worried and protecting themselves. Some of the participants feared social and family exclusion if they were to share their HIV diagnosis:

> *'I do not want to share my illness with them. We have a great relationship as a family. I do not want them to be afraid of me.' (P1)*

Further, some participants explained their non-disclosure behaviour as a personal protection and response to experienced societal prejudices:

> *'When it comes to HIV, it is like their reaction is that of disgust and fear. It is not an inspiration for disclosure, I must say. Thus, I am glad I am not open about having HIV.' (P12)*

The participants' non-disclosure behaviour promoted the need to meet other people with similar experiences and concerns:

> *'When I need to talk, I call. I will call, and then I will come and talk if I need to.' (P1)*

Some participants actively chose not to disclose their diagnosis to family and friends, preferring to avoid potential adverse reactions:

> *'So, I do not know if I should be stigmatised. But I am afraid I will. For now, those who know have not reacted like that… But of course, I decide whom I disclose my diagnosis to.' (P6)*

Thereby, participants asked for peer supporters to have someone to talk to about their HIV status. This seemed to be a way to address their HIV-related concerns.

#### *Experienced a sense of belonging*

The participants found that peer support left them with a sense of belonging to a group just by being present, as an immediate embodied feeling of togetherness, indicating that they affected the participants' well-being:

> *'It was good. I am not alone. I knew I was not alone, but I knew no one else. So really, meeting someone was...'(P3)*

The results also indicated that the sharing of recognisable experiences and emotions created a supportive environment. The mutual disclosure between peers embraced the sharing of reflections, wonder, and engagement. The mutuality revealed itself as felt, lived, and true to the individuals involved.

> *'We sat there and talked about our experiences, and then it coincided. We live in the same cultural context. And it was a bit like coming home.' (P12)*

A meeting between peers became a place to openly share their worries, knowing that they would receive support for their emotions related to living with HIV. Peer supporters validated the participants' experiences:

> *'It gave me an understanding in a completely different way, and it made it less scary. It became easier to grasp. When you hear that they recognise what you feel... they tell you that it is completely normal to feel like this. You then understand why you feel it.' (P16)*

Receiving peer support helped participants feel that they belonged to a group; they were not alone. This helped them fight the feeling of being an outsider. Acceptance and belonging were important for participants and seemed to offer them a sense of hope.

### Opportunity for nurturance

Meeting a peer supporter allowed the participants to be mutually supportive by sharing their experiences and concerns.

#### *Activated an opportunity for mutual support*

The participants expressed that meeting a peer supporter offered an opportunity to receive support and, at the same time, render support through the sharing of recognisable experiences and emotions. This supports the notion that conversations at the emotional level promote mutual support, as they have overlapping roles with mutual influence:

> *'It is good to have someone to relate to who has some of the same struggles. The help often goes both ways. Our conversation probably also helps peer supporters. Thus, I think it is important to be able to have someone to talk to and someone to share it with, so you do not sit in this dark pit alone. Because it is a scary place to be in.' (P16)*

The participants believed that sharing their personal stories and coping strategies stimulated mutual learning. Despite the peer supporter being in an explicit helper position, the peer meeting provided an opportunity for mutual support:

> *'You know, we are learning from each other.' (P8)*

Further, peer support activated a wish to support others and replicate the positive experience of meeting a peer supporter.

> *'When I have the time, I go and meet them. I want to meet them and talk to them. There are probably some who have the same questions as me when meeting a peer supporter for the first time. I can imagine that someone newly diagnosed with HIV*

> *will need the same help. Therefore, I think it is wise to be together. Support each other.' (P10)*

### Reassurance of worth

Several participants expressed how the peer supporters made them feel normal, strengthening their belief that their personal worth remained unchanged even after their HIV diagnosis.

#### *Means to re-establish belief in one's own worth*

Some participants expressed ambiguity regarding their worth upon getting HIV, and how living with HIV affected their self-evaluation. Peer supporters seemed to provide an opportunity to discuss their emotions related to self-worth and acceptance:

> *'There are many times I feel I do not deserve to be as healthy as I am now. However, at the same time, you need to talk to the people who understand you. It is hard to accept. I have accepted a lot in my life. I have a diagnosis. I have some bad days, and then, it is good to be able to talk about everything, right; it is not just about the HIV diagnosis, but about everything.' (P6)*

Meeting a peer supporter who normalised their experiences helped the participants feel valued and less atypical. In addition, being treated as 'any other person' strengthened their self-worth:

> *'It is important that I am part of society. I need to be part of a network in Norway. To have a normal life without people pointing out that I have HIV and should thus not come near me. Therefore, I choose not to tell people outside the hospital. When I come here, I feel normal; it is like therapy. That is important to me. I want people to treat me as normal and not be afraid.' (P1)*

### Guidance

Peer supporters provided positive affirmation and advice to participants on managing their daily lives with HIV.

#### *Perceived a positive affirmation of disease management*

From the participants' perspective, peer supporters provided support by sharing their own and confirming participants' experiences, thereby contributing to improved disease management. In addition, perceiving positive affirmations from peer supporters for managing their lives with HIV was crucial for the participants:

> *'They tell me stuff I probably want to know if I knew what to ask. We might have different causes, but at least we know. We are still the same in taking medications. We have common experiences and questions. So, that is what I needed, because I do not want to search for my questions online.' (P4)*

Obtaining information from experience was highlighted as necessary for the participants, although all of them confirmed receiving the same information from HPs. The same information became more credible when confirmed by peer supporters. They described this as life-affirming:

> *'They say you can live a good life with HIV; you just have to take medication. Life is not over. The doctor has told me several times that you do not have to believe that you will die right away. However, this is not understood inside here (pointing to the head and heart). I believed the doctor came to my house and gave me a death certificate. I had a very nice doctor, but I believed nothing of what he said. However, when I got to talk to someone living with HIV, I realised that it worked. Then, I remembered all the information I got from the healthcare professionals after meeting others with HIV.' (P8)*

#### *Facilitating dialogue about disease management*

The participants received advice from the peer supporters about having a healthy lifestyle, specifically important for PLHIV to prevent non-communicable diseases:

> *'We also talked about the importance of diet. You are especially vulnerable. Learning about what you can do in everyday life is related to exercise and diet, like regular life habits. The importance of taking medicine regularly is an important topic.' (P7)*

Peer supporters facilitated dialogue related to disease management. Mutual experiences gave rise to questions and led to conversations:

> *'It was nice because you have so many questions. At first, when I got the diagnosis, I thought, oh, I have to move to Berlin, because it is probably only at the sex clubs that I can get sex. You are terrified, but then you get to talk to others with HIV who have a girlfriend, for example, saying that you cannot infect others when you are taking your medication. For me, it probably helped the most to just talk to someone who has HIV.' (P9)*

Some participants found it easier to direct personal questions to peer supporters than to the HPs. Thus, peer support created an opportunity to discuss health issues:

> *'I need to discuss about how they cope with depression and what are their plans of disclosure; do they have to tell everyone or do they have to be open*

> *about it, or not, because you know... me coming out that I have HIV... I ask myself whether I need to. I have survived being quiet for eight years.' (P4)*

### OPCs as the setting for peer support

The participants explained that they appreciated the peer support being organised at the OPCs, mainly because they experienced the latter as a safe place. In addition, they valued OPCs as a natural starting point for flexible, individualised peer support.

#### *A safe place*

The participants' non-disclosure behaviour hindered them from meeting other PLHIV outside the OPCs; they had no one to talk to about HIV. When participants expressed a need to talk about HIV, the HPs became their peer support facilitators:

> *'Yes, in the beginning, I felt I had to talk about HIV and meet others. It was perfect. I met with peer supporters three weeks later. It was great.' (P9)*

Although some concerns were expressed regarding the personal acceptance of having HIV and not being ready to meet a peer supporter, the HPs helped them overcome these concerns:

> *'I was not sure if I wanted to meet others because I struggled to accept that I had HIV. I did not want to have it; I just wanted to keep it secret. But now, I do not care. I have HIV, and there are several others living with HIV too.' (P10)*

Most of the participants claimed to be afraid of disclosure if the meeting with a peer supporter happened informally, outside the OPCs. Therefore, the hospital was the only place where they wanted to meet someone in relation to their HIV status, in order to ensure that their confidentiality was maintained.

> *'Like I told the nurse, you have to be discreet all the time. I survive by being quiet about this. However, although it was a time when I needed someone to talk to, I am happy that we had this peer talk here at the hospital. It is a typical problem that you really have to talk to someone, but you cannot talk about it because they probably cannot relate, and they might be stigmatising; they might be feeling weird that I have this kind of illness.' (P4)*

The participants' non-disclosure behaviour contributed to the OPCs being the only safe place in the sense that they offered a neutral, non-judgmental environment, where they knew their HIV diagnosis would be treated confidentially.

> *'The hospital is experienced as a safe environment for all involved because it is a place. I think that this is important. You get to talk in peace. If you meet at a cafe, you cannot be as open or honest. Sitting in a closed room makes it much easier to share feelings. Therefore, offering an HIV-infected person to meet a peer can be valuable because you can avoid ending up in the dark as I did all alone, without anyone to talk to.' (P16)*

#### *A setting for flexible, individualised support*

Small communities and geographical distances were expressed as factors that decrease the chance of getting the support participants needed outside the OPCs. The limited opportunity to meet peers was also related to the participants' non-disclosure behaviour and the need for confidentiality. Hence, OPCs were the only places where they could be introduced to a peer supporter:

> *'Of course, it is a challenge to gather PLHIV. It is a small town; it is too small.' (P3)*

Consequently, the participants suggested that the experienced flexibility in content, time, and place for peer support positively contributed to OPC services. However, they found it crucial to adjust peer support according to individual preferences when providing support:

> *'It depends on how secretive each individual is. The HPs and peer supporters ask if you want to meet someone at the hospital or if you want to meet in the city. I think it should be a flexible service based on each individual. To begin with, I think it is important that you meet a peer supporter together with the healthcare professionals. Further, everyone has been asked what they prefer.' (P5)*

## Discussion

This study aimed to explore how PLHIV experienced meeting peer supporters in an OPC. To our knowledge, this is the first study investigating experiences of PLHIV with peer support in OPCs in a Scandinavian, low-prevalence, high-income country.

This study demonstrates that, in terms of peer support, each of Weiss' six provisions of social relationships [35] is affirmed through our findings, except for the provision of a reliable alliance. Our results suggest that the participating service users do not express to need a peer supporter to be motivated for regular care or to identify local resources. This might be the case because the service users are already connected to the OPCs, and the peer support services thereby shoulder the already existing services. Therefore, based on our results, we could argue that peer support complementary with the OPCs' existing services, provides a diversity of individualised support responsive to the receivers' personal needs and preferences [23, 26]. Furthermore, this individualised support is in accordance with the WHO's strategy regarding integrated and person-centred chronic care to promote well-being for PLHIV [6, 27, 28].

The study revealed differences among the participants regarding how they experienced the content of the peer support. In the present study, several participants lacked emotionally close relationships in their everyday lives, or had their former close relationships negatively affected upon getting diagnosed with HIV. In fact, previous studies show that social isolation is often related to HIV, which diminishes support [52]. This is despite our knowledge that expressing personal emotions through social support can increase people's resilience to stigma [20, 53, 54]. PLHIV with non-disclosure behaviour and few or no close relations have been found to become emotionally attached to peer supporters. Many PLHIV are immigrants who have not disclosed their diagnosis due to a fear of stigma [13, 52], suggesting potential inequalities in health within the population of PLHIV in Norway. Our results, which are in line with other studies [17, 53], demonstrate that until stigma connected to HIV is reduced globally, both disclosure behaviour and social support for PLHIV in Norway can be compromised. Thus, the results suggest the need for equitable, individualised peer support, as a complement to existing healthcare services, to increase the emotional well-being of PLHIV [3, 26, 28].

Peer support provided participants in this study with a sense of belonging to a group with similar experiences and concerns, without any fear of rejection, which was not found elsewhere, following Weiss' [35] description of common-concern relationships. Baumeister and Leary [55] described the anxiety arising from imagined or expected social rejection, which could be seen in the non-disclosure behaviours of PLHIV mentioned by our participants. Similar to previous findings [56], several participants' non-disclosure of HIV increased their feeling of loneliness. Past literature supports the contribution of peer supporters in terms of just 'being there', to be of substantial value for the participants [31], as corroborated in our study. This sense of belonging strengthened their belief in their worth, alleviating the internalised stigma associated with HIV [52].

Our results align with previous findings that mutual support between peers increases participants' sense of belonging [30, 55]. As affirmed by our study, human beings are driven to form and maintain positive interpersonal relationships in which mutual care is perceived [55]. Further, the dialogue between peers concerning mutual experiences was perceived as positive affirmation and advice on living positively with HIV, consistent with one of the known key functions of peer support described in *Peers in Progress* [23, 31].

Norway is a low-prevalence country [57] and has achieved the UNAIDS 90–90-90 target [65,44]. Yet, perhaps partially because of this situation, PLHIV in Norway experience loneliness, which seems to be linked to the lack of spaces where living with HIV is regarded as 'natural and unproblematic'. This is doubly problematic, as informal peer support is challenging in Norway, given the significant geographical distances and the anticipated intersectional stigma among PLHIV [5, 13]3. Even though telehealth is expected to play a greater role in future global healthcare services, peer support is not yet available for PLHIV in Norway as a part of the telehealth services. Overall, this affects their quality of life and well-being [56]. A person-centred approach highlights the importance of contextual factors, which is evident in our research. The participants appreciated that peer support was organised and located at the OPCs because they provided a safe environment where confidentiality was guaranteed. In addition, peer supporters, as a part of the OPC services, allowed for enhanced equal access to peers. Therefore, incorporating peer supporters as a part of OPC services might increase the opportunity to provide flexible, individualised support to every individual living with HIV. These findings complement the Global Health Sector Strategy on HIV 2016–2020 [6], emphasising the value of HIV services that are adjusted for various populations and locations.

### Relevance to clinical practice

Addressing the evolving needs of PLHIV is vital to achieving and maintaining good health-related quality of life; peer support acts as a contribution to the same. Thus, this study adds to our knowledge and understanding of the complex needs of PLHIV, calling for a holistic approach to ensure well-being [28]. In today's HIV treatment landscape, the continuum of care goes far beyond virologic suppression, with innovations such as digital technologies becoming important facilitators of health for responding to the growing needs of PLHIV [56]. However, this study also highlights the importance of face-to-face peer support as part of a continuing, flexible, and individualised support to strengthen the well-being of PLHIV. In addition, studies indicate that personalised peer support with routine medical care is superior to a routine clinic follow-up in improving the health outcomes of PLHIV [25]. Concerning implications, to enhance the quality of life of PLHIV, this study provides valuable knowledge of peer support as a lower-threshold intervention to meet daily emotional needs. Furthermore, it contributes to an increased awareness of the additional assistance a peer supporter provides in shouldering the existing healthcare services, as supported by other reviews [25, 58] in response to the intersecting challenges facing PLHIV [59]. The study also highlights the necessity of embedding peer support in OPCs to equalise peer support opportunities for PLHIV, overcoming barriers in contacting non-governmental organisations in a culture of non-disclosure. Furthermore, most non-governmental organisations are connected to religious organisations. Therefore, from the service users' point of view, most non-governmental organisations represent values not aligned with being a Muslim or a gay man. The OPCs also represent the only place all people diagnosed with HIV have follow-up care, whilst non-governmental organisations are only present in larger cities. Expanded telehealth services might provide PLHIV with peer support offered by either the OPCs or the non-governmental organisations, suggesting a more individualised approach to decrease peer support barriers for future practice [60].

### Strength and limitations of the study

This study was based on 16 participants who spent various amounts of time with their peer supporters. In addition, some of the interviews were conducted in English when the participants requested it, based on their limited competence in the Norwegian spoken language. Although there was diversity among both peer supporters and participants in the current study in terms of age, sexual orientation, time since diagnosis, and country of origin, we did not have the resources to interview PLHIV who could not communicate in Norwegian or English. Overall, this may have affected the participants' shared experiences and reflections. Nonetheless, the results highlighted multiple experiences of PLHIV with the provision of peer support.

Additionally, the participants were recruited by HPs. This could have affected their decision to participate, although the HPs already had an established relationship with the participants. The participants were informed that their decision would not negatively impact the HIV care they received. Every step in the analysis was discussed with all the authors and the advisory group to ensure credibility.

## Conclusions

This study highlighted the content of peer support from the receiver's perspective in the context of OPCs. The participants' experiences aligned with previous findings, with peer support contributing to mutual emotional support between peers. This is particularly important in cultures of non-disclosure where PLHIV experience intersectional stigma. Additionally, the results of this study emphasised the OPCs as supportive surroundings for facilitating peer support, ensuring confidentiality in peer support outreach. Thereby, peer support was found to positively contribute to individualising OPC services to meet the changing needs of PLHIV.

### Abbreviations

HIV: Human immunodeficiency virus; PLHIV: People living with HIV; ART: Antiretroviral therapy; CLLC: Chronic lifelong condition; OPCs: Outpatient clinics; HPs: Healthcare professionals; WHO: World Health Organization; UNAIDS: United Nations Programme on HIV and AIDS.

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-022-07958-8.

**Additional file 1.**

**Additional file 2.**

**Additional file 3.**

### Acknowledgements

The authors would like to thank the study participants who kindly shared their experiences with us. We would also like to thank the healthcare professionals who helped us recruit the participants and organise the interviews.

### Authors' contributions

AØ-R: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Writing- Original draft preparation RB and VS: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Supervision, Writing-Reviewing and Editing. MF: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Supervision, Validation, Writing- Reviewing and Editing. All authors critically read and provided input on the manuscript, and approved the final manuscript.

### Funding

This work was financially supported by the Dam Foundation and Northern Norway Regional Health Authority. The funders were not involved in the study's design, collection, analysis, and interpretation of the data and writing of this manuscript.

### Availability of data and materials

The datasets used in this study are presented in this article. Approval from the NSD and the participants were only linked to this study. Further information is available from the corresponding author upon request.

## Declarations

### Ethics approval and consent to participate

The study was approved by the Norwegian Centre for Research Data (NSD; reference number 184248). The study was approved by the Registered Norwegian Regional Ethics Committee for Medical and Health Research (REK; reference number 28944). We confirm that all methods were performed in accordance with the relevant guidelines and regulations.

All participants in the study were given oral and written information about the project, and they provided written informed consent. In addition, the participants were informed of the possibility of withdrawal from the study.

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

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Received: 10 December 2021 Accepted: 18 April 2022

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## Publisher’s Note

# Interview guide

The purpose of this interview is to tell me as much as possible about your experiences of peer support to gain expanded knowledge. I also want to talk to you about how you were informed about peer support and how the meetings were organised. In addition, I would like to hear more about your experiences of living with HIV.

## Introduction

- ✓ Presentation of the project (theme and the contribution needed from participants)
- ✓ Practical aspects of the interview (use of time, the opportunity for flexibility if something interesting arose during the conversation)
- ✓ Research ethics related to the interviews and the bigger project. Particular focus on my duty of confidentiality and confidential treatment of the data (emphasis on openness and honesty; there are no correct answers and that the participants themselves decide what they want to share along the way.

*Names, surnames, and contact information are obtained and coded with respondents 1-4.*

To prevent the disclosure of personal information about third parties, we will discuss privacy with the informant prior to the interview. However, we want to be aware of how we ask the questions and let them know that they must use other names / refrain from using names when referring to people, omitting any characteristics related to them.

## Background information

1. Age
2. Gender
3. How long have you been living with HIV?
4. In what country were you born?
5. Sexual orientation

## Themes

### About meeting a peer supporter

1. Tell me about your experiences with meeting a peer supporter.
    a. How was it organised?
    b. Where did you meet?
    c. How long did the meeting last?

2. What challenges did you experience when meeting a peer supporter? Is there something you believe should be improved or changed?
3. What experiences did you think a peer supporter could contribute to your daily life?
4. Can you share any experience where you realised that the peer support meeting became important or valuable?
5. What are your expectations when meeting a peer supporter?
6. What do you want to achieve when meeting a peer supporter?
7. Is there something you think is challenging about meeting a peer supporter?
8. How are the expected negative effects or challenges mentioned?
9. What is required for you to meet a peer supporter? Does it imply any costs?
10. In what way do you think meeting a peer supporter could affect your health?
11. Do you have any ethical concerns about meeting a peer supporter?
12. Do you think it is realistic (feasible) that people living with HIV can be offered to meet a counterpart?
13. Is there anything you want to add / do you have any further comments?

## Your experiences related to social support and stigma

1. To what extent and how do you experience support from your surroundings regarding your HIV diagnosis?
2. Can you come up with a situation that describes your need for support?
3. Have there been periods or situations where you experienced a greater degree of uncertainty and predictability related to your situation?
4. Have you experienced periods of lack of control?
5. Can you come up with a situation that describes how social support has been helpful?
6. What expectations do you have for your surroundings related to your diagnosis?
7. Have you been exposed to, or have you heard of others with the same diagnosis experiencing any form of discrimination or stigma?
8. If you have experienced this situation, can you tell us about it?

Data analysis process according to Assarroudi et al. [36]

| *Phase* | *Steps* | *Description* |
|---|---|---|
| Preparation | Acquiring the necessary general skills | The first author familiarised herself with the concept of social support, stigma, and existing peer support programs for people living with HIV through a review of available research and the current body of knowledge. |
| | Selecting the appropriate sampling strategy | Participants were purposively recruited from outpatient clinics, with variations in their sociodemographic characteristics. Saturation was reached; all participants willing to participate in the study were recruited based on the study's purpose. |
| | Deciding on the analysis of manifest and/or latent content | To address the study aim, both manifest and latent content was analysed to gain a deeper understanding. |
| | Developing an interview guide | The interview guide was developed with the advisory group, containing semi-structured, open-ended questions based on previous research and the current study's aims [34,35]. We asked what the participant thought about peer support and their thoughts related to stigma and social support in general. |
| | Conducting and transcribing interviews | The interviewer was provided with an interview guide for the session. Interviews were transcribed verbatim by the first author. |
| | Specifying the unit of analysis | The transcribed data were used as the unit of analysis. |
| | Immersion in data | During the coding process, the transcribed interviews were read several times while listening to the recordings, ensuring that all latent content was captured, differentiating between speaker and context. |
| Organisation | Developing a formative categorisation matrix | The pre-determined categories were derived from previous research [34,35]. Then, potential sub-categories were identified through an inductive approach [37]. |
| | Theoretically defining themes and sub-themes | The definition of each category was checked for accuracy and objectiveness based on the existing body of knowledge [23] and theories [34,35]. |
| | Determining coding rules for themes | Rules were created for themes to ensure their trustworthiness. Following these rules informed the coder of the clear distinction between the categories. |
| | Pre-testing the categorisation matrix | Two researchers coded the interviews. Each tested the categorisation matrix independently and they discussed challenges in using the matrix. This was repeated after coding more interviews as new categories emerged, facilitating the refinement of categories and increasing inter-coder reliability and the study's trustworthiness. |

| | | |
|---|---|---|
| | Choosing and specifying the anchor samples for each theme | Explicit and concise sample quotes were selected for each theme. |
| | Performing the main data analysis | Meaningful units were derived based on the study’s aim and categorisation matrix, and summarised into codes. The advisory group was involved in the coding process. |
| | Inductive abstraction of themes from preliminary codes | The preliminary and emerging codes were grouped based on their similarities, resulting in ‘generic categories’ for this study. This grouping was conducted with the advisory group. |
| | Establishment of links between generic categories and themes | The conceptual and logical links were created through constant comparison of the generic categories and themes throughout the coding process, facilitating the nesting of the generic categories into new or pre-existing categories. |
| Reporting | Reporting all steps of directed content analysis and findings | A detailed report of the findings is reported in the Results section. |

Definition of categories, operationalisation, and the meaning of each provision from the perspective of peer support

| *Category* | *Definition* | *Operationalisation* | *Examples of participants' narratives* |
|---|---|---|---|
| Attachment | Emotional closeness from which one derives a sense of security. | Receiving emotional support from people living with HIV when needed | 'I got support here at the hospital, and this is like my 'health family', talking to the nurse and the peer supporters. That is important'. (Cries when saying this) (P1) |
| Social integration | A sense of belonging to a group that shares similar interests, concerns, and recreational activities | Receiving encouragement, sharing experiences, and helping people deal with potential stress related to living with HIV | 'It was good. I am not alone. I knew I was not alone, but I knew no one else. So really, meeting someone was ...' (P3) |
| Opportunity for nurturance | The sense that others rely upon one for their well-being | Mutual support in the sense that you help others through sharing personal experiences of living with HIV | 'It is good to have someone to relate to who has some of the same struggles. The help often goes both ways. Our conversation probably also helps peer supporters'. (P16) |
| Reassurance of worth | Recognition of one's competence, skills, and value by others | Helping people living with HIV understand that the diagnosis does not affect their value as a person | 'There are many times I feel I do not deserve to be as healthy as I am now. However, at the same time, you need to talk to the people who understand you. It is hard to accept. I have accepted a lot in my life. I have a diagnosis. I have some bad days, and then, it is good to be able to talk about everything, right; it is not just about the HIV diagnosis, but about everything'. (P6) |
| Reliable alliance (Practical help) | The assurance that others can be counted upon for tangible assistance | Serving as a liaison between patients and clinical care, motivating patients to communicate and assert themselves to obtain regular and quality care, helping to identify local resources when needed | |
| Guidance | Advice and information | Helping people living with HIV apply disease | 'We also talked about the importance of diet. You are especially vulnerable. Learning about what you can do in everyday life is related to |

| | | | |
|---|---|---|---|
| | | management in their daily lives | exercise and diet, like regular life habits. The importance of taking medicine regularly is an important topic'. (P7) |
| Program-related factors | Factors related to peer support situated in outpatient clinics | Aspects concerning the suitability of locating peer support for people living with HIV in outpatient clinics | 'The hospital is experienced as a safe environment for all involved because it is a neutral place. I think that this is important. You get to talk in peace. If you meet at a cafe, you cannot be as open or honest. Sitting in a closed room makes it much easier to share your feelings. Therefore, offering an HIV-infected person to meet a peer can be valuable because you can avoid ending up in the dark as I did all alone, without anyone to talk to'. (P16) |

# Paper IV

“They make a difference”: A qualitative study of providers’ experiences of peer support in outpatient clinics for people living with HIV

Øgård-Repål *et al.*
*BMC Health Services Research (2022) 22:1380*
https://doi.org/10.1186/s12913-022-08810-9

BMC Health Services Research

**RESEARCH** **Open Access**

# “They make a difference”: a qualitative study of providers’ experiences of peer support in outpatient clinics for people living with HIV

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## Abstract

**Background:** Although the life expectancy of people living with HIV has increased, they are still often disconnected from society through stigma and discrimination. Peer support has been found to increase social support. Given the limited research on peer support from the providers’ perspective, this study explored how peer supporters experience their roles and contributions in outpatient clinics (OPCs). Additionally, healthcare professionals’ perceptions of working with peer supporters in OPCs were examined.

**Methods:** This qualitative study included purposively selected peer supporters ($n=10$) and healthcare professionals ($n=5$) from five OPCs in Norway in 2020. In-depth interviews and focus group discussions were conducted in Norwegian or English, using interview guides. Interview transcripts were analysed in NVivo 12 using reflexive and collaborative thematic analysis.

**Results:** The results show that peer supporters experience mutual support through emotional and honest interactions. Further, the peer supporters found it essential to negotiate with the service users about their preconception of HIV, confront their views through dialogue, and replicate positive experiences by being credible role models. The participants expressed that integrating peer support in the OPCs’ usual care processes increased the prospect of equitable services. Quality of peer support and role clarity were identified as critical components. The results demonstrate that emotional and honest conversations promote support between peers and that peer supporters identify a need for a reframed understanding of HIV by modelling plausible alternative interpretations and coping experiences.

**Conclusions:** This study contributes to knowledge on how peer support can meet the needs of people living with HIV. Incorporating people living with HIV in the co-production and distribution of healthcare services may improve the knowledge and perspectives in healthcare services. However, the skill standards of peer supporters should be addressed when implementing peer support in usual care.

**Keywords:** HIV, Peer support, Outpatient clinics, Social support, In-depth interviews, Thematic analysis

## Background

At the end of 2020, approximately 37.6 million people worldwide were living with HIV, with approximately 25.4 million undergoing antiretroviral therapy (ART) [1]. Global and national actions, particularly the availability of ART treatment, have halted and reversed the AIDS epidemic and dramatically reduced HIV incidence [2],

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causing HIV to be increasingly described as a chronic lifelong condition (CLLC) [1].

The life expectancy of people living with HIV (PLHIV) has approached that of the general population [3]. However, they are often burdened with coinfections and comorbidities [4], with non-communicable diseases (NCDs) and mental health disorders as some of the most prevalent comorbidities [4–6]. Unfortunately, since the beginning of the epidemic, HIV infection has been associated with social stigma and prejudice. Societal reactions indicate that HIV is one of the most stigmatised diseases in almost every culture worldwide [7–9]. Societal prejudice directed towards PLHIV can be severe, harming them in numerous ways [8, 10, 11]. Being socially stigmatised negatively affects people's psychological functioning and well-being [12], and many PLHIV become disconnected from society [8, 13]. As PLHIV are often already members of marginalised groups, such as sexual minorities and people who inject drugs, they frequently experience intersectional stigma [14, 15].

The range of challenges many PLHIV experience indicates a need for continued strengthening of established healthcare services and self-management of PLHIV. In Norway, healthcare services are organised according to the Nordic healthcare model, which is based on solidarity, focusing on universal civil rights and the protection of minorities [16]. As a national standard, outpatient clinics (OPCs) located at hospitals provide free medical follow-ups and treatment to people infected with HIV [17]. Norway has a low prevalence of HIV, with 6,778 people diagnosed with the virus by the end of 2020 [18], and seems to have achieved the first UNAIDS 90–90-90 target, with approximately 93% knowing their HIV status, 98% of people living with HIV are on treatment, and 96% being virally suppressed [19, 20]. Despite this, there is a lack of expertise about HIV within the national healthcare services. Additionally, PLHIV in Norway, who often do not disclose their diagnosis, report feeling lonely [21].

Greater involvement of users in the healthcare services may contribute to increased empowerment and a more tailored, people-centred healthcare service [22, 23]. Peer support is one way of involving service users, strengthening supportive resources in healthcare services, and increasing self-management, and it is a recognised outreach method for PLHIV [24–26]. Supported by the knowledge that individuals are socially embedded [27], social support is associated with decreased anxiety and depression, and higher resilience. Given the interrelationship between social support and health [13], social support can be a potential resilience resource when PLHIV experience stress in response to HIV-related stigma [28–30]. In particular, peer support from the larger HIV community seems crucial to PLHIV; it has been found to not only increase social support but also reduce HIV-related stigma [31, 32].

Dennis et al. defined peer support as "the giving of assistance and encouragement by an individual considered equal" ([33] p. 323). This definition is reflected in WHO's definition of individualised peer support as "one-to-one support provided by a peer who has personal experiences of issues and challenges similar to those of another peer who would like to benefit from this experience and support" ([34] p. 1). Peer supporters (PSs) offer support and encouragement to their counterparts through meetings ranging from informal visits and sharing experiences to formal appointments focused on practical information sharing. Diverse peer support models have been applied across various health contexts [24, 35, 36]. For PLHIV, peer support grew out of the 1980s activists' reactions to combat stigma, challenge discrimination, and advocate for better treatment and care. Peer support was first organised into small groups of PLHIV supporting each other and sharing knowledge. However, since the introduction of ART, peer support has become a tailored, people-centred outreach method to provide linkage and adherence to HIV medical care and support PLHIV in taking an active role in self-management of their CLLC [4, 24].

Systematic reviews of peer support indicate that the effects of peer support vary [26, 37]. Nonetheless, findings suggest that peer support is flexible enough to be applied across healthcare contexts [27–29] and that it positively affects communities, especially in middle- and low-income countries [38]. According to a qualitative metasynthesis exploring PSs' perceptions of their role across a range of disciplines, the core of the effectiveness of peer support was found to be in equalising the provider–client power differential. It places the peer supporter in a unique situation that facilitates sharing personal experiences through reciprocal relations [35]. Unlike the numerous studies investigating the effects of peer support, only a handful of studies have examined peer support for PLHIV from the providers' perspective [39–42]. These qualitative studies highlight that PSs provide valuable practical, informational, emotional, and social support, and often model healthy behaviour. In addition, these studies emphasise that PSs feel empowered and gain self-awareness through the process [41, 43].

Given the increased valuation of peer support in care for PLHIV but limited scholarly knowledge of peer support from the providers' perspective, this study explores how PSs experience their role and contributions in OPCs. Additionally, the study explores healthcare professionals' (HP) perceptions of working with PSs in OPCs.

## Methods

### Design

This was an exploratory qualitative study with an interpretive, reflective approach to understand peer supporters' and healthcare professionals' sense-making related to peer support [44, 45], and gain an in-depth understanding of the participants' lived experiences. Individual qualitative interviews [44–46] and focus group discussions (FGDs), which allowed reflections through interaction between participants [45], were used as data collection tools.

### The advisory group

Five people from the community were invited to form an advisory group because we considered it essential to include lay community experts' perspectives and feedback throughout the research process. To optimise diversity, the advisory group consisted of two user representatives (PLHIV), one representative of a non-governmental organisation, one nurse, and one medical doctor. The nurse and the medical doctor worked at separate HIV-OPCs. The two user representatives represented the male and female genders and included an immigrant and a member of a sexual minority group. The advisory group contributed to clarifying terms, exploring research questions, developing the interview guides together with the researchers, and providing continuous input to the data analysis process.

### Study setting

Norway has four regional health authorities, with hospitals located throughout the country. The setting for the peer programme (described below) was five public OPCs situated in local hospitals in Norway, two of which were university hospitals.

#### *The peer programme*

A peer programme for PLHIV in Norway has existed for nearly ten years. It was user-initiated and started as a part of the standard healthcare services at one user-driven OPC serving PLHIV. In 2011, a committee of PLHIV developed targets for services based on their needs and experiences. One target was to establish peer support [47, 48]. As a result of the user-involvement process, five OPCs incorporated the peer programme as part of their healthcare services for PLHIV. Since then, in larger cities, peer support for PLHIV has been provided.

through non-governmental organisations; however, opportunities to reach people in smaller cities and towns have remained limited. The HPs at the OPCs recruit PLHIV, who receives care at their clinic, to be involved in the peer programme. The HPs approached all PLHIV connected to their clinic with information about the peer support programme. PLHIV who showed interest in the programme was invited to a meeting with the HPs for more information and a reflection about competencies required to be a PS, i.ex communication skills, personal stability, willingness and ability to sufficient knowledge about self-management, as pointed out in guidelines and recommendations [49, 50]. The HPs aimed to recruit PSs with diverse experiences and cultural background.

Through the peer programme, HPs at the five OPCs aim to provide peer support to every PLHIV enrolled at the respective OPC. Once a service user agrees to meet a PS, HPs arrange and organise the meeting. Thereby the HPs ensure to connect service users with a PS without breaking confidentiality. The HPs aimed to match the service users with suitable PSs by identifying the needs and preferences of the service users and the strengths of the PSs, as recommended in CATIE Best Practice Guidelines [49]. The HPs are responsible for providing the PSs with ongoing supervision, debriefing and support in advance and directly after the peer meetings. The supervision is one-to-one support as the PSs addressed a need to debrief emotional distress and potential challenges. The one-to-one supervison was conducted by the HPs involved in the peer programme who was trained together with the PSs. The one-to-one support allows the HPs to tailor the support to different needs of PSs. In addition, the PSs organise meetings through peer networks regularly for peer discussions,. Thereby, the content of the peer programme correspond with guidelines and recommendations related to supervision of PSs [49, 50]. Although OPCs do not employ PSs, the PSs receive a payment (72 USD per consultation) as compensation for their contribution and coverage of travel expenses.

In the current study, a PS is a person living with HIV for at least five years and being virally suppressed. The PS is receiving treatment and care at the OPCs they provide peer support and is formally trained to be a PS through a training programme developed by the OPCs. The non-peer-reviewed literature of Bloomsbury Patient Network (http://www.bloomsusers.net/), Positively UK's National Training Programme of Peer Mentors *Project 100* (http://positivelyuk.org/project-100/), and National Standards for HIV Peer Support (http://hivpeersupport.com/) inspired PSs training programme as well as implementation in OPCs. The programme included facilitation of reflections related to role description for the PS and how the PS and HP could cooperate to guide the implementation. The training programme and implementation were conducted jointly between the HPs and PS across the included OPCs. Through this training, the PS gained and developed knowledge to provide support on a variety of issues faced by PLHIV. A PS was suggested to offer guidance grounded on values of equality and thus provide an opportunity to focus the support on the immediate here-and- now needs of the service users.

### Recruitment strategy

The HPs purposively selected a sample of PSs enrolled in the OPCs and invited them to participate in the study [51]. They approached the PSs with study information, explained both verbally and in writing. The information described the study's goals and research design. We strove for maximum variation sampling and also used snowball sampling, whereby key informants suggested other participants they believed would be valuable for increasing study insights [52–54]. Given their knowledge of the service users and PSs at their OPCs, the HPs could offer invaluable assistance in securing sample variation and suitability concerning the service users' and PSs' knowledge and experience of the topic. In addition, the HPs involved in peer support at the OPCs were asked to participate in both individual interviews and FGDs. PSs' and HPs' viewpoints were collected through 14 individual interviews, followed by two focus group discussions.

The following eligibility criteria were used for PSs: 1) enrolled in HIV clinical care at one of the OPCs, 2) aged 18 years or older, and 3) experience of being a PS at least twice by the initiative of a HP at a participating OPC (minimum two weeks before the interview). Eligible HPs had to work at one of the OPCs, collaborate with PSs, and initiate peer support meetings. Both PSs and HPs needed to be willing to sign written informed consent for participation in the study. There were no study invitation refusals; all 15 individuals who were invited, agreed to participate. We covered the participants' travel expenses and provided light refreshments during the interviews.

#### *Data construction*

The first author conducted face-to-face, in-depth, semi-structured interviews and FGDs during the spring and autumn of 2020. The first author informed the participants that she is a registered nurse with previous experience of FGD interviewing and qualitative methods, but limited experience with HIV. The first author met the PSs for the first time when conducting individual interviews. She met the HPs face-to-face twice prior to the interviews to discuss recruitment and provide study information.

According to the participants' convenience, interviews and FGDs were conducted at the OPCs, except for three individual interviews with PSs. Two were conducted at a café pursuant to the PSs' request, and one was conducted digitally because of the pandemic situation related to Coronavirus Disease 2019. One of the FGDs included four PSs and one HP, and the other consisted of two PSs and two HPs.

The interviews and FGDs were audiotaped with the participants' permission and transcribed verbatim. The first author made field notes immediately after the interviews and FGDs. Data saturation was considered after each interview transcription, reading through the transcripts, and initiating coding. After the twelfth interview, we found that additional interviews did not expand or elaborate on the existing themes [51]. The participants were asked if they wanted to read the transcripts, but all declined the offer.

The nine interviews with PSs lasted 23–102 min, with an average of 60 min, and the five interviews with HPs lasted 32–52 min, with an average of 39 min. The FGDs lasted 60–99 min, with an average of 80 min.

The interview guide was not pilot-tested but developed jointly by the authors and the advisory group. The interview guides for the PSs and HPs included 16 and 13 open-ended questions, respectively, whereas the FGDs included 14 open-ended questions. The questions concerned the participants' experiences and perceptions of PSs and HPs at the OPCs. As follow-up questions for PSs, we explored HIV status disclosure experiences, their concerns and perceptions of social stigma, and how these aspects relate to their work as PSs. Further, we explored PSs' personal experiences with social support in general and related to their HIV diagnosis.

### Analysis

We conducted a reflexive and collaborative thematic analysis with an inductive approach to identify, analyse, and report patterns in the collected data. The analysis process followed the analysis phases proposed by Braun and Clarke [55–58]. In the first phase, the four researchers became familiar with the data by repeatedly reading the transcripts. In the second phase, to develop the initial codes, the NVivo software program for qualitative data analysis was used to structure the coding of the data [59]. Two of the researchers conducted this phase following Tjora's stepwise-deductive inductive approach [48] to ensure descriptive, semantic-oriented coding. Empirical close coding reduced the potential influence of researchers' presumptions and theories as well as the volume of empirical material. Through this, empirical close codes could be shared with the advisory group without risking the participants' confidentiality [60]. In the third phase, the four researchers generated themes by sorting the codes into potential larger groups according to the shared meanings underpinning them, and then searching for sub-themes and overarching themes representing several codes. This phase was completed together with the advisory group to obtain a more nuanced understanding of the data [58]. Since contradictory data were almost non-existent, the process did not result in an expansion

**Table 1** Examples of the coding procedure

| Quotes | Empirical close coding | Group | Initial theme | Sub-theme | Theme |
|---|---|---|---|---|---|
| 'I think that's what they need, or what we all need. It's a break. Stop being afraid, stop feeling alone, stop being the only one, just being together' (P7) | Free from the feeling of being alone | Mutual experiences of belonging | Mutual support | Reciprocal backing between the supporter and the service user | Emotionally honest conversations promote mutual support |
| 'There is something about credibility, in that you live with it yourself that has a greater effect and a different effect than with healthcare professionals' (P2) | It gives greater credibility that I have experienced it myself | Role model | The power of a good example | Credible lived experiences | Negotiation of preconceptions create reframed understandings of HIV |
| Not everyone gets what is being said. People have a lot of pictures and ideas in their head so that what is said is sorted into the pictures that are already there, which can be very distorted according to reality (P8) | Fear of stigma because of preconceptions | Confronting preconceptions | To challenge the individual preconception of HIV | Replicating positive experiences | Negotiation of preconceptions create reframed understandings of HIV |

of the themes. The fourth phase comprised a process of reviewing and refining the themes. The researchers checked the data and the coding structure several times to determine whether the overarching themes represented the data or whether there were any missing links in the analysis. In the fifth phase, the final process of defining and naming the themes was conducted to capture each theme's essence [55, 56]. The last step, writing the report, involved providing representative, illustrative quotes from the participants to illustrate the themes, and wrapping up the analytical work. The quotes are presented verbatim, except repeated words and word fillers that were deleted to improve readability. Table 1 displays examples of the coding procedure and analysis.

### Trustworthiness of the results

Several strategies were used to enhance the credibility of the results [51, 56, 61]. Data from both PSs and HPs were included, an advisory group was involved, and the first and last authors analysed the data separately and arrived at a consensus on their interpretations. The study and its findings are auditable, as we have preserved the documentation of the process for developing themes.

Furthermore, recognising that we, the researchers, are 'outsiders' not living with HIV, we needed to acknowledge how this could affect our situatedness in the project and the outcomes [62]. The final step of the analysis process aimed to provide a report of the perceptions and experiences of the participants deemed most salient by the researchers. Although this could constitute bias and allow the researchers to influence what is presented, cooperation with the advisory group provided an opportunity to ensure that the analysis process produced a valid and reliable report [56]. The advisory group's perspective was crucial in contextualising the data and, thereby, the trustworthiness of the data. We believe the dialogue contributed to creating broad and rich knowledge that the researchers alone could not have created, and increased the transferability of the result to other similar settings [63].

### Research ethics

The study was approved by the Regional Ethics Committee for Medical Research and the Norwegian Social Science Data Services. All participants were given oral and written information about the study. They were informed about the voluntary nature of participation and that they could withdraw from the project if and whenever they wished without any negative consequences. Written informed consent was thereafter obtained from each participant. They were required to indicate that they understood the purpose of the research and consented to participate before the interview started. Furthermore, they were informed that all data were anonymous, that their confidentiality was safeguarded, and that the data were stored following the applicable rules and guidelines for storing research material.

The manuscript preparation adhered to the 32-item checklist for interviews and focus groups, *criteria for reporting qualitative research* (COREQ) [64].

## Results

### Description of participants

We interviewed 15 individuals including 10 PSs and 5 HPs. There were nine women and six men, aged 37–65 years (mean, 49 years). All ten PSs had attended the peer support training organised by the OPCs, and all five HPs were employed at one of the participating OPCs. Supplementary characteristics of the participants are shown in Table 2, but minimal information about each participant is provided to preserve confidentiality.

### Themes

The qualitative analysis revealed three overarching themes: 1) how emotionally honest conversations that involve sharing experiences promote mutual support, 2) how negotiating preconceptions create reframed individual understandings of HIV, and 3) critical components for facilitating peer support in the professional OPC setting. Each theme included different aspects that were sorted into sub-themes (Table 3).

In our presentation of the findings below, the quotes illustrating the themes are accompanied by a number, which represents the ID of the participant who contributed the quote (Table 2).

### Emotionally honest conversations promote mutual support

The results demonstrated that talking with a PS provided support to PLHIV by sharing common emotions related to experiences living with HIV. This sharing of thoughts, experiences, and honest emotions decreased feelings of being alone with the diagnosis through reciprocal backing between peers. The participants emphasised that sharing emotions had value for both parties, the PS and the service user. As different challenges arise throughout the lifespan, peers can provide mutual support when new situations occur.

#### *Recognisable experiences and emotions*

PSs recognised the experiences and emotions of service users. When providing support, the PSs recalled and described their own fears as well as concealing and self-quarantine behaviours to avoid being exposed as living with HIV. They also recognised loneliness, as described below.

**Table 2** Description of the Study Participants ($n = 15$)

| Participant ID | Gender | Service provider ID Peer supporter (PS) or Healthcare professionals (HP) | Data Individual interviews (I) and/or focus group discussions (FGD) |
|---|---|---|---|
| P1 | Male | PS | I and FGD |
| P2 | Female | PS | I and FGD |
| P3 | Female | PS | I |
| P4 | Male | PS | I |
| P5 | Male | PS | I and FGD |
| P6 | Female | PS | I and FGD |
| P7 | Male | PS | I |
| P8 | Female | PS | I and FGD |
| P9 | Male | PS | I |
| P10 | Male | PS | FGD |
| P11 | Female | HP | I |
| P12 | Female | HP | I and FGD |
| P13 | Female | HP | I and FGD |
| P14 | Female | HP | I and FGD |
| P15 | Female | HP | I |

**Table 3** Themes and sub-themes

| Emotionally honest conversations promote mutual support | Negotiation of preconceptions create reframed understandings of HIV | Critical components for facilitating peer support |
|---|---|---|
| •Recognisable experiences and emotions<br>•Reciprocal backing between the peer supporter and the service user | •Credible lived experiences<br>•Replicating positive experiences | •Integration of peer support into usual care<br>•Skill standards<br>•Occupying the middle ground |

> *I think that loneliness has to do with HIV. One isolates oneself. No one is isolating you. We choose to isolate ourselves (P3).*

PSs recognised the service users' emotions and drew on their personal experiences of what worked for them in similar situations.

> *Meeting someone who has been through the same.... We are not in the same situation, you cannot compare, but you can recognise - and it is quite strange - regardless of gender, sexual orientation, ethnicity, age, it is almost like a blueprint (P7).*

When service users met HPs at the OPCs, the latter did not share personal stories. However, HPs recognised the loneliness of the service users associated with HIV as a common outcome and believed it would be useful to offer a peer meeting. The PSs' perception was that most people newly diagnosed with HIV had a shared response involving fear and uncertainty about meeting other people. The PSs, therefore, wanted to provide support by disclosing their personal experiences. However, our findings further show that when PSs only shared positive experiences of living with HIV, service users did not believe or recognise the presented narrative, and peer support was not considered valuable.

> *The peer supporter showed that she was healthy and had taken the medication for a while, and everything was well. So that's a nice value in itself. But when she signals that there was no problem, you don't get the mastery story. What worked and made it go well? One skips a few points…they do not find a deeper and mutual connection through sharing troubled emotions. So the good thing about it is that you signal hope that there does not have to be a problem and that you can fix it just fine. While it can also be a bit strange, how is it possible that there are no problems (P13).*

### *Reciprocal backing between the peer supporter and the service user*

The results show that sharing lived experiences affected both PSs and service users. PSs expressed that every peer meeting of sharing their personal stories contributed to a development in their own life, while the meetings also increased their feeling of being helpful to others. Given that their unique lived experiences and ability to create emotional closeness were crucial to their role as PSs, they reported being emotionally and personally affected by the peer meetings. Through their explored perspectives, PSs wanted to contribute to the same process of discovery and improvement in service users. Thus, they strove to make the peer meeting a safe place, a kind of sanctuary. Since the service users had disclosed their diagnosis only to a few people, if any at all, the peer support meeting was, for many, a first opportunity to interact and connect with someone who thoroughly knew them and supported them. Peer meetings seemed to contribute to a sense of mutual belongingness between peers.

> *I think that's what they need, or what we all need. It's a break. Stop being afraid, stop feeling alone, stop being the only one, just be together (P7).*

The PSs expressed that different life situations actualised uncertainty of living with HIV. However, several PSs experienced that being connected to other PLHIV led to a discourse around HIV-related topics. These discussions helped when current challenges arose in their own lives, for example, several mentioned the Coronavirus Disease 2019 pandemic as a situation that raised the need to talk to peers. HPs agreed that the necessity of meeting a peer could occur when living with a CLLC.

> *We all experience fluctuations through life, some good days and some bad days. But it's just like when you have a chronic illness, and you have HIV on the top; it's just like it weighs you down a little extra in the periods where it goes down, and it's difficult. So, you may have coped living with HIV for many years, but then comes the downturn and then maybe fear from the past comes up... (P13).*

### Negotiation of preconceptions create reframed understandings of HIV

PSs found it crucial to negotiate with the service users about their preconception of HIV and replicate positive experiences by being credible role models and confronting their views through dialogue.

#### *Credible lived experiences*

PSs are expected to be aligned with their message by being role models in how they appear and behave in living with HIV. The information provided by PSs to the service users in peer meetings could often be the same given by the HPs. However, as the information, when provided by PSs, came through the lens of experience, it could be received as more credible by the service users.

> *There is something about credibility, in that you live with it yourself that has a greater effect and a different effect than with healthcare professionals (P2).*

The PSs shared personal stories and coping strategies to increase awareness of how it is to live with HIV. The PSs believed they could normalise living with HIV as a CLLC, helping service users cope with their cognitive barriers related to HIV. The PSs perceived themselves to be living examples of "normal" people, modelling and visualising a good life, thereby contributing to a reconstruction of the unique understanding of HIV.

> *It's all about normalisation. Knowing that there are others and that it's going to be fine. We are completely ordinary, and there are several of us. You are not alone. It is breaking down the barriers that society also has. Look at him; he is HIV-positive, he looks completely healthy (P1).*

#### *Replicating positive experiences*

PSs reported personally experiencing that meeting a peer with an alternative understanding of living with HIV as early as possible after being diagnosed helped them decrease self-stigma, negative attitudes, and shame based on their preconceptions of HIV. Consequently, based on their own positive peer meeting experiences, the PSs dared to confront and challenge opinions and fears, but in a careful and respectful manner.

According to our participants, PLHIV often lack updated, factually correct knowledge of HIV, and they interpret the information they receive through that incomplete and skewed mental frame. Moreover, they expect relatives and friends to have the same lack of updated knowledge. Thus, PLHIV fear stigmatisation and rejection when disclosing their diagnosis.

> *Not everyone gets what is being said. People have a lot of pictures and ideas in their head so that what is said is sorted into the pictures that are already there, which can be very distorted according to reality (P8).*

Our participants claimed that, over time, the longer they waited, the more complex the service users found it to talk about their situation, which affected their HIV disclosure attitude. The HPs experienced that meeting a PS reduced the service users' fears, thereby underscoring the need for newly diagnosed patients to meet a PS as early as possible. PSs hoped to negotiate with the service users about their skewed preconceptions of HIV and hopefully contribute to an adjusted understanding of HIV.

> *I have experienced that their eyes get quite big when I say how long I have been HIV-positive. They ask,*

> *'and you are not sick?' and they ask several times. And it's like that – 'no, I'm not sick, I go here for a check-up and take my blood tests and live a normal life with my children. It's fine.' And that does not match their terrain at all. I think it's great to be allowed to be a part of telling them that it's going to go fine (P2).*

PLHIV represent different backgrounds, both culturally and socially, and thereby carry diverse preconceptions of barriers related to HIV. HPs emphasised that if individuals already represent a minority group when diagnosed with HIV, HIV can increase their burden. They further shared that offering such individuals a conversation with a PS, who themselves cope with the diagnosis every day, is essential to stress the importance of confronting or adjusting established preconceptions of HIV.

## Critical components for facilitating peer support

Both HPs and PSs found it essential to integrate peer support services into usual care, such that every person living with HIV has the same, equal opportunity to participate in peer support in a familiar and safe environment. All participants also emphasised that it was critical to ensure specific peer support skills when providing peer support at the OPCs. Nevertheless, the PSs experienced a challenge in being "in-between" regarding providing what they believed the service users needed and attending to the HPs' expectations.

### *Integration of peer support into usual care*

Our findings revealed several reasons for integrating peer support as part of usual care at OPCs. First, the HPs at the OPCs recognised that PLHIV needed a place to meet peers. The OPCs ensure equal opportunities when delivering peer support as an integrated part of the usual care reaching out to every PLHIV in their district.

Another reason for integrating peer support into OPCs is the powerful response they received from service users. The HPs' experiences of offering peer support at the OPCs were overwhelmingly positive.

> *I feel that it gives greater security, that they develop in a short time, those who are offered to meet a peer supporter. That they lower their shoulders a little and it becomes easier afterwards (P11).*

Although several non-governmental organisations offer peer support, our findings show that service users preferred to meet a PS connected to OPCs, to a greater degree, to ensure confidentiality. According to HPs, service users often asked an HP to join the first meeting with a PS or be available after their encounter with a PS. Both PSs and HPs believed that this indicated trust in the system that the service users knew and were comfortable with. The HPs emphasised that meeting a PS should be voluntary. At the same time, they had a lifespan perspective and stressed the importance of providing peer support to every PLHIV as usual care. They also stressed that new challenges may arise in PLHIVs' lives, which may actualise the need for peer support.

The HPs' narratives show that they integrated PSs' contributions and perspectives as part of the knowledge production at the OPCs, thereby improving the quality of healthcare services. This shows how PSs sometimes have a "bridging function," being both a service provider and a service user. Thus, they gave HPs continuous insight into how it is to live with HIV and their perspectives on the quality of services at the OPCs.

> *I have learned a lot. I have become a better, at least more conscious nurse because I dare to ask more questions than I did before, maybe a little more in-depth questions than before because I have learned a lot from peer supporters. When we talk, it is easier to get into topics that we do not necessarily address often. So, I have become more aware of holistic care. (P12).*

Despite this positive attitude towards peer support, the narratives show that peer support is not sufficiently integrated into the OPCs. The HPs clearly expressed that organising peer support is resource-intensive, and figuring out how to manage peer support efficiently is an ongoing process.

### *Skill standards*

As a consequence of having peer support located at the OPCs, the HPs felt responsible for the quality of the PSs' services, and they communicated these expectations to the PSs. Although no formal qualifications are required to be a PS, they have been trained in line with the peer programme described above. Both PSs and HPs stated that peer training is essential to ensure sufficient skill standards. Once PSs had attended peer training, the HPs were better informed about what to expect and what they offered as a part of the OPC services.

> *We do not want to inflict on them [the patients] anything difficult that can make life even more difficult than it is. On the contrary, we want to give them something that can help make it easier. But we have no guarantee that it is a good peer meeting. You have no control. But otherwise, I have no qualms because it brings people many good experiences (P11).*

The PSs, in turn, expressed loyalty and support towards HPs' work, especially medical advice. They struggled when the service users were reluctant to take their medications, but the PSs tried to nudge service users to follow HPs' advice.

> *I have experienced people who say that it may help to pray. I find that difficult. Then you have to say that you can do that too. You can pray if you think it is comforting to pray to God or to angels or whoever it may be, or that you have friends who are praying for you. But do not stop taking the medicines (P2).*

To minimise the possibility of conflicting medical advice, the HPs, on their part, recruited individuals they believed were best fit to be PSs in terms of their communication skills, such as their ability to listen and regulate their emotions, and their ART adherence.

> *We cannot have peer supporters who suddenly make someone stop taking medications. Then it doesn't help if they otherwise are trustworthy and steady (P14).*

### *Occupying the middle ground*

The PSs' narratives showed that they found being a PS a positive but challenging experience. They wanted to be both professionals, as a part of the formal healthcare system, and laypersons, with the liberty to operate more like "friends." The PSs experienced the same challenges expressed by service users.

> *I feel that people I have met wanted to date or have sex. And that's perfectly normal: You have found HIV positives like yourself and want to get in touch. Thus, it may be that they want to have sex with that person. But I do not know what is right, because I am not a professional, I am not their doctor (P4).*

Given that PSs, in addition to getting involved with the service users' emotions, had to share and handle their own feelings, HPs could help with debriefing. The PSs appreciated and found support through being an integrated part of a formal system. They expressed a need to discuss peer meetings with HPs on personal boundaries, reactions, and medication adherence. The PSs found these discussions with HPs essential but challenging. Both PSs and HPs valued confidentiality, although PSs worried about breaking the confidentiality between themselves and the service user by sharing stories with the HPs. PSs felt that this sharing of stories could be understood as disclosing a friend's secret and exemplifying paraprofessional peer support.

> *Those who say that they intend to take their own lives because they believe it's no point living with HIV then you are afraid of what the person will do. If you do not tell the healthcare professionals about this because you were told not to tell, but you think this person needs help. So, I think it's important that we share such information with healthcare professionals. The problem is that if I say I have to tell the nurse, they might shut up and stop sharing (P6).*

Additionally, the PSs expressed the need for flexibility in deciding the time and place for the meetings. At the same time, they tried to personalise the support by adjusting it to the condition and need of the service user.

> *It is all about the need of the individual you are meeting. I can go on a full day with someone if I have the time and energy to do so and they need it (P7).*

Likewise, the PSs feared that having meetings at the OPCs could accidentally validate HIV stigma. Therefore, they preferred to meet the service users in informal locations. The PSs experienced that meeting outside the OPC opened up the possibility of discussing other, more personal topics.

> *I think you have to challenge their comfort zone. If you have a 'closed' space to make them feel safe, you confirm their feelings. It's almost a validation; you validate that we have to hide (P4).*

Nearly all PSs believed that the emotional component of peer support suggests more personal meeting surroundings. However, they also experienced that meeting informally made it more challenging to balance the role and expectations of the formal system and the service user, thus highlighting the need for them to occupy the middle ground. Because there are not-yet-clear formalised codes of conduct for PSs, they searched for some consensus of behaviour. The HPs believed that service users were sceptical of meeting an unknown PS informally outside of the OPC. HPs expressed concern that service users, especially those living in small communities, were reluctant to disclose their diagnosis, and thought that organising peer support meetings at the OPC made the service user feel safer. Even though the OPCs organised peer support as a part of their services, nearly all PSs and HPs found that they needed further dialogue and considerations concerning how and where to arrange the peer meetings.

## Discussion

This study explored PSs' experiences of their role and contributions in providing peer support to service users in OPCs and HPs' perceptions of working with PSs in OPCs.

PSs experience mutual support through emotional and honest interactions during support meetings. Peer support at the individual and interpersonal levels for both service user and PSs is perceived as a positive experience. The results also show that the PSs and HPs experience working together and integrating peer support into usual care at the OPCs as possibly contributing to improved services. This collaboration between PSs and HPs offers PLHIV equitable opportunities within healthcare services. However, for peer support at the OPCs to be successful, considering various critical aspects is required, such as equal services, PSs' skill standards to ensure quality care, and how PSs balance both their roles as service providers and service users.

Our findings indicate that the uniqueness of peer support lies in the emotional and honest conversation between peers. This sharing of common personal experiences has the potential for mutual support, which has been described in several studies as a core element of peer support [24, 35]. In addition, studies have shown that expressing personal emotions through social support can increase people's resilience to stigma [30, 63, 64]. Mutual support, as experienced through peer support, can be of particular importance in "non-disclosure communities" with less access to other PLHIV sharing their experiences. Therefore, our findings add to previous work documenting the complexities of HIV, social support, and disclosure [28, 29].

Furthermore, the helper therapy principle introduced by Riessmann [65], which focuses on what the helper receives from being in the helper role, as exemplified by the PSs in the present study, is congruent with studies emphasising that PSs feel more empowered and self-aware through helping others [41, 66]. In addition, consistent with previous findings [35, 42], reciprocal backing between peers was found to increase the participants' sense of belongingness. Human beings have the drive to form and maintain positive interpersonal relationships in which mutual care is perceived. A sense of belonging is a crucial human motivation and desire [27]. Baumeister and Leary [27] describe the anxiety arising from imagined or expected social rejection, which can be seen in the non-disclosure behaviour of PLHIV as mentioned by the HPs and PSs in this study. Given that many PLHIV in Norway report situational loneliness despite excellent treatment adherence and linkage to care [19–21], providing the opportunity for a meeting with a peer is expected to allow them to experience belongingness to a group without the anxiety of being rejected because of HIV. This supports the role of PSs at the OPCs as a potential transition from social marginalisation to active participation.

PLHIV experience an ambient cultural devaluation due to HIV, which increases negative feelings and the possibility of self-stigma [9, 14]. Moreover, our participants remind us that HIV-related stigma varies between sociocultural contexts [15]. Recognising that the societal narratives of HIV are cultural constructions situated in history offers an understanding of the narratives as multiply negotiable [44, 67]. The PSs in our study aimed to contribute to a reframed individual understanding of HIV. Further, the PSs and HPs wished to decrease the service users' internalisation of others' negative views [12] by helping them avoid absorbing the cultural narratives of HIV. They did so by presenting a positive affirmation of credible lived experiences with alternative understandings and positive coping. Therefore, our findings resonate with studies that emphasise social support assisting individuals in cognitive restructuring after negative experiences such as discrimination [68, 69].

The literature documents peer support as a flexible approach applied to varied settings [25, 26, 37]. The PSs and HPs, through their experiences of working together at the OPCs, found it crucial to adjust the peer support to the context in which it is hosted to limit peer support barriers [36]. Our findings support that a critical component is the question of how to offer equitable services. Geographical distances challenge the opportunities to meet people with shared experiences regarding a non-disclosure diagnosis of HIV. Our participants emphasised that incorporating peer support at the OPCs increases the likelihood of providing people-centred peer support as part of the usual care if and when such a need arises for people living with a CLLC [24, 36]. The findings also identify the shortcomings of the HIV response and the opportunities to address them by involving PSs in the distribution of services. PSs find themselves in a unique but complex position alternating between the service user and service provider roles. The frequent interaction between PSs and HPs described in this study enriches HPs' perspectives, which has been identified by previous studies as a critical element [35]. Thus, cooperation between PSs and HPs seems to sharpen HPs' delivery, adding continuous perspectives and knowledge [48, 70].

Our findings reveal that we must be careful when focusing on PSs who only demonstrate the successful mastery of living with HIV, instead of sharing their vulnerability and the coping strategies they have found to be most effective in promoting new behaviours, aspects with which others can identify [36]. This can be seen as a contrast to the traditional provider–client boundaries that originated in the medical model of clinical care, where emotional attachment could be understood as professional misconduct. However, we found increased recognition of a deconstruction of power relations between PSs and HPs, where the use of self is promoted [71, 72].

The integration of PSs at the OPCs, followed by the professionalisation of the PSs' personal experiences, raises the question of who defines quality in the delivery of peer support. To acknowledge peer support without adjusting the support to the medical model and losing the core element of peer support seems challenging but essential for PSs. On the other hand, HPs have a significant responsibility for the services integrated into usual care, which is reflected in their expectation of PSs' to maintain certain skill standards. Nevertheless, the increased recognition of modest self-disclosure among professionals contributes to HPs' recognising using oneself in the delivery of services to increase competence [71, 72], which is prominent in our findings. However, the OPC setting for providing peer support increases the need to clarify PSs' role, to decrease potential boundary issues [73]. The informal interactions between peers seem to provide opportunities for authentic interaction and mutuality. This authentic interaction through emotional, honest self-disclosure of shared experiences can be essential to the process [71]. Still, the use of self-disclosure demonstrates how the PSs find themselves in a unique but complex position and supports the need for peer training and emotional support for the PS as described in the peer programme to balance the different demands. This might raise the question of whether organising meetings in more informal settings supports the interaction's personal component. Therefore, the flexibility implied by PSs can be understood as a prerequisite and contrast to the peer support programme on the one hand, and raising the need for role clarity for the PSs on the other hand.

### Implications

Improved understanding of the providers' experiences related to the benefits and challenges found in this study calls for the greater availability of peer support programmes in usual care. The findings can inform the development of peer support programmes. Furthermore, an increased formalisation of the peer supporter role will benefit PSs, service users, and HPs by informing expectations. Further studies on implementing peer support in professional settings should be carried out, focusing on how HPs experience developed perspectives and care by working with PSs. Power dynamics are relevant when adding voluntarism to professional settings and imply further research. In addition, future research exploring whether peer support affects service users' perceptions of living with HIV, specifically if peer support impacts HIV-related stigma, would be valuable.

### Strengths and limitations

Few studies related to peer support and HIV from the providers' perspective have been conducted in high-income countries, highlighting the need for further research. To the best of our knowledge, this is the first study to examine peer support for people living with HIV from the providers' perspective in a Scandinavian country.

One strength of our study is that we explored both PSs' and HPs' experiences, which broadened the scope of the study. In addition, participants were allowed to select the most comfortable setting to enhance the likelihood of capturing rich narrative data on sensitive topics. Moreover, the advisory group contributed an emic perspective to ensure trustworthiness, which we believe enhanced our ethical research approach. Finally, the involvement of all authors in interpreting data further strengthens the credibility of the results [51, 61].

The study also has some limitations. First, the peer support programme was at different implementation stages at the OPCs, which might have affected the participants' experiences and reflections. Second, the HPs participated in the peer support training, increasing the possibility of them being favourable in their perceptions of peer support as well as the risk that more critical voices were not included in the study. Nonetheless, the results highlight that formalising the PS's role will benefit PSs, service users, and HPs by informing expectations and facilitating positive relationships for PSs' time and expertise.

## Conclusion

This study contributes to existing knowledge about peer support for PLHIV and provides insights into how peer support, situated at OPCs for PLHIV, is experienced from the providers' perspective. This study demonstrates that emotional and honest conversations promote support between peers and enhances resilience at the individual and interpersonal levels through social support. An important finding is that peer support emphasises the need for a reframed understanding of HIV by modelling plausible, alternative interpretations and positive coping experiences. Furthermore, it is essential to consider the increased knowledge of healthcare services by incorporating PLHIV into the development and distribution of services. Finally, we note that integrating peer support in OPCs' usual care increases equalising services. However, quality of peer support and role clarity are identified as critical components and should be addressed when implementing peer support in usual care.

### Abbreviations

ART: Antiretroviral Therapy; CLLC: Chronic Lifelong Condition; PLHIV: People Living with HIV; NCD: Non-Communicable Diseases; OPC: Out-Patient Clinics.

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-022-08810-9.

**Additional file 1.** COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.

**Acknowledgements**

The authors are grateful to the peer supporters and healthcare professionals who participated in our study and the healthcare professionals' recruitment efforts. This study would not have been possible without their invaluable contributions. We would also like to acknowledge and thank the advisory group, a wise and reflective sounding board at every step of the study.

**Authors' contributions**

AØ-R: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Writing- Original draft preparation RB and VS: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Supervision, Writing-Reviewing and Editing. MF: Conceptualisation, Data Curation, Methodology, Investigation, Formal analysis, Supervision, Validation, Writing- Reviewing and Editing. All authors critically read and provided input on the manuscript, and approved the final manuscript.

**Funding**

This work was financially supported by the Dam Foundation and Northern Norway Regional Health Authority. The Dam Foundation was not involved in the study's design, collection, analysis, and interpretation of the data, and in writing this manuscript.

**Availability of data and materials**

The datasets used in this study are presented in this article. Approval from the NSD and the participants were only linked to this study. Further information is available from the corresponding author upon request.

## Declarations

**Ethics approval and consent to participate**

The study was approved by the Norwegian Centre for Research Data (NSD; reference number 184248). The study was approved by the Registered Norwegian Regional Ethics Committee for Medical and Health Research (REK; reference number 28944). We confirm that all methods were performed in accordance with the relevant guidelines and regulations.

All participants in the study were given oral and written information about the project, and they provided written informed consent. In addition, the participants were informed of the possibility of withdrawal from the study.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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Received: 1 August 2022 Accepted: 8 November 2022

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## Publisher's Note

# Appendix 1

Approval from Norwegian Centre for Research Data (NSD)

NSD NORSK SENTER FOR FORSKNINGSDATA

## NSD sin vurdering

### Prosjekttittel

Peer-support programmes in healthcare services for people living with HIV: Perspectives from users, peers and professionals

### Referansenummer

184248

### Registrert

24.09.2019 av Anita Øgård-Repål - anita.ogard-repal@uia.no

### Behandlingsansvarlig institusjon

Universitetet i Agder / Fakultet for helse- og idrettsvitenskap / Institutt for helse- og sykepleievitenskap

### Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Anita Øgård-Repål, anita.ogard-repal@uia.no, tlf: 4748129983

### Type prosjekt

Forskerprosjekt

### Prosjektperiode

01.02.2019 - 31.12.2022

### Status

03.10.2019 - Vurdert

### Vurdering (1)

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### 03.10.2019 - Vurdert

Prosjektet er vurdert av REK sør-øst A i vedtak av 23.09.2019, deres referanse 28944 (se under Tillatelser). REK vurderer at studien framstår som forskning, men ikke som medisinsk eller helsefaglig forskning. Prosjektet er følgelig ikke omfattet av helseforskningslovens saklige virkeområde, jf. helseforskningslovens §§ 2 og 4. Prosjektet vil derfor bli gjennomført og publisert uten godkjenning fra REK.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 03.10.2019 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:

https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html
Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle særlige kategorier av personopplysninger om rasemessig eller etnisk opprinnelse, helseopplysninger og seksuelle forhold eller orientering, og alminnelige kategorier av personopplysninger frem til 31.12.2022. Av dokumentasjonshensyn skal data med personopplysninger oppbevares til 31.01.2027.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER
Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19) og dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/ pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

Kontaktperson hos NSD: Ina Nepstad
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

# Appendix 2

Approval from the Regional Ethics Committee for Medical Research (REK)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

| **Region:** | **Saksbehandler:** | **Telefon:** | **Vår dato:** | **Vår referanse:** |
|---|---|---|---|---|
| REK sør-øst A | Tove Irene Klokk | 22845522 | 23.09.2019 | 28944 |
| | | | **Deres referanse:** | |

Anita Øgård-Repål

## 28944 Likepersonsarbeid for personer som lever med HIV

**Forskningsansvarlig**: Universitetet i Agder

**Søker**: Anita Øgård-Repål

### Søkers beskrivelse av formål:

*Det er behov for å få økt kjennskap til likepersonsarbeid, hva likepersoner kan bidra med og hvorfor dette eventuelt oppleves å ha en effekt. Vi trenger mer kunnskap om hvordan likepersonsarbeid kan ses i sammenheng med det øvrige tilbudet i helsetjenesten, og hvordan helsepersonell opplever å jobbe side om side med likepersoner. Det er også av interesse å se nærmere på hvordan det er å være likeperson, samt hvilke muligheter/utfordringer likepersoner har erfart. Det er ønskelig å få belyst flere perspektiver rundt likepersonsarbeid dersom man ser for seg at helsetjenesten i større grad skal utvide tilbudet med likepersoner i tråd med samfunnsutviklingens økte behov for tjenesteutvikling og brukerinvolvering. Det er planlagt å benytte ulike forskningsmetoder i delstudiene: 1) En systematisk kunnskapssammenstilling av likepersonsarbeid for personer med HIV; 2: Survey og intervjuer av personer (HIV-positive) som mottar støtte fra likepersoner. 3) En kvalitativ studie av tjenesteytere*

### REKs vurdering

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 22.08.2019. Vurderingen er gjort med hjemmel i helseforskningslovens § 10.

Formålet med prosjektet er, slik komiteen forstår det, å få økt kunnskap om likepersonsarbeid og hvordan likepersonsarbeid kan ses i sammenheng med det øvrige tilbudet i helsetjenesten. Etter komiteens vurdering vil ikke prosjektet, slik det er beskrevet i søknad og protokoll, kunne bringe ny kunnskap om helse eller sykdom. Prosjektet faller derfor utenfor helseforskningslovens virkeområde.

Hva som er medisinsk og helsefaglig forskning fremgår av helseforskningsloven § 4 bokstav a hvor medisinsk og helsefaglig forskning er definert slik: «virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom».

Det er institusjonens ansvar å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern.

**Vedtak**

Avvist (utenfor mandat)

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2, og kan derfor gjennomføres uten godkjenning av REK.

Vennlig hilsen

Knut Engedal
Professor dr. med.
Leder REK sør-øst A

Tove Irene Klokk
Rådgiver
Sekretariatet REK sør-øst

Kopi til: post@uia.no; veslemoy.rabe@uia.no

**Klageadgang**
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK sør-øst A. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst A, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

# Appendix 3

Approval from the Ethical Committee at the Faculty for Health and Sports Sciences, University of Agder (FEK)

UNIVERSITETET I AGDER

Anita Øgård-Repål

Besøksadresse:
Universitetsveien 25
Kristiansand

Ref: 19/07709

Tidspunkt for godkjenning: : 21/10/2019

**Søknad om etisk godkjenning av forskningsprosjekt - Peer-support programmes in healthcare services for people living with HIV: Perspectives from users, peers, and professionals**

Vi informerer om at din søknad er ferdig behandlet og godkjent.

Kommentar fra godkjenner:
Søknaden godkjennes under forutsetning av at prosjektet gjennomføres som beskrevet i søknaden.

Hilsen
Forskningsetisk komite
Fakultet for helse - og idrettsvitenskap
Universitetet i Agder

# Appendix 4

Approvals from the included HIV outpatient clinics

NORDLANDSSYKEHUSET
NORDLÁNDA SKIPPIJVIESSO

Til: Anita Øgård-Repål - anita.ogard-repal@uia.no

Saksnr i Elements .: 2020/1157 Dato: 19.02.20

# Vedrørende innmeldt forskningsprosjekt

**Prosjektnummer: 98**

**Prosjekttittel: Peer-support programmes in healthcare services for people living with HIV**

**Prosjektperiode: 05.02.20 – 01.02.22**

## 1. Vurdering fra personvernombudet

Det presiseres at det er prosjektleders ansvar å påse at prosjektet følger gjeldende lovkrav.

**Rettslig grunnlag**
Det legges til grunn at det i prosjektet skal behandles både alminnelige personopplysninger og særlige kategorier av personopplysninger (helseopplysninger). Basert på prosjektets formål defineres prosjektet som et forskningsprosjekt, og behandling av personopplysninger i prosjektet har hjemmel i følgende behandlingsgrunnlag:

- Personvernforordningen artikkel 6 første ledd bokstav c) og artikkel 9 annet ledd bokstav i).

Vår vurdering er at prosjektet legget opp til et samtykke i samsvar med kravene i art.4 nr11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte selv kan trekke tilbake.

Lovlig grunnlag for behandlingen vil være den registrertes uttrykkelige samtykke.

**Personvernprinsipper**
Personvernombudets vurdering er at den planlagte behandlingen av personopplysninger vil overholde prinsippene i personvernforordningen.

Det anses at det ikke er behov for gjennomføring av personvernkonsekvensutredning i dette prosjektet ut fra opplysningene gitt i meldeskjema.

**Håndtering av personopplysningene**
Personopplysningene i prosjektet skal håndteres på sikker måte.

**Personvernombudets anbefaling**

- Alle endringer i prosjektet må meldes til personvernombudet.
- Det skal ikke samles inn og behandles flere personopplysninger enn det som er nødvendig for å oppfylle formålet med prosjektet.
- Alle personopplysninger skal slettes eller anonymiseres ved prosjektets avslutning.
- Det skal gis tilbakemelding til personvernombudet når personopplysningene er slettet.

Personvernombudets vurdering er at behandlingen av personopplysningene i prosjektet vil være i samsvar med personvernlovgivningen, forutsatt at behandlingen gjennomføres i tråd med opplysningene i meldeskjemaet.

Det minnes om at ved eventuell viderebehandling av personopplysningene til nye formål kreves nytt behandlingsgrunnlag (lovhjemmel eller samtykke).

Med hilsen

Alisa Larsen
Personvernombud

**Anita Øgård-Repål**

**Fra:** Odd-Harald Olsen <odd.harald.olsen@sshf.no>
**Sendt:** fredag 20. desember 2019 10:28
**Til:** Anita Øgård-Repål
**Kopi:** Ole Rysstad
**Emne:** SV: Mottok dere skjemaene?

Hei.

Prosjekter er nå godkjent av Forskningsenheten, med følgende kommentar:

## Godkjenning Forskningssjef

Viser til 22 filer og 8 dokumenter i saken i 360.
Studien er NSD godkjent 3. oktober. REK vurdere studien å ligge utenfor REKs mandat/helseforskningsloven og mer å regne som en kvalitetssikringsstudie.
Intervensjonen er godkjent av aktuell avdelingsleder ved med. avd. SSK.
Studien er forskningsfaglig godkjent forutsatt at vilkår i NSD godkjenningen følges og at studien gjennomføres slik nevnt i protokollen.

Lykke til videre med prosjektet.

Mvh
Odd-Harald Olsen

**Emne:** VS: Tilbakemelding: Forskningstilgang ved St.Olavs Hospital

---

**Fra:** Martinsen, Tom Christian <Tom.Christian.Martinsen@stolav.no>
**Sendt:** 17. februar 2020 12.28
**Til:** Anita Øgård-Repål <anita.ogard-repal@uia.no>
**Kopi:** Hannula, Raisa <Raisa.Hannula@stolav.no>; Ingrid Slørdal <Ingrid.Slordal@stolav.no>; Morken, Gunnar <Gunnar.Morken@stolav.no>
**Emne:** RE: Tilbakemelding: Forskningstilgang ved St.Olavs Hospital

Hei det er greit i forhold til Medisinsk klinikk, jeg har avklart med Ingrid og avd. sjef Raisa Hannula, vi vil måtte følge opp med oversikt over evt. merarbeid for poliklinikken. Om det viser seg å bli mye vil vi være tvunget til å revurdere vårt bidrag underveis.
Lykke til.

Mvh
Tom Christian Martinsen
Klinikksjef

---

**Fra:** Skogseth, Haakon Robin <Haakon.Robin.Skogseth@stolav.no>
**Sendt:** onsdag 8. januar 2020 10:55
**Til:** Anita Øgård-Repål <anita.ogard-repal@uia.no>
**Kopi:** Martinsen, Tom Christian <Tom.Christian.Martinsen@stolav.no>; Morken, Gunnar <Gunnar.Morken@stolav.no>
**Emne:** RE: Forskningstilgang ved St.Olavs Hospital

Kjære Anita,
I forståelse med direktør Morken og klinikksjef Martinsen cc. så er det sistnevnte som godkjenner og gir deg eventuelle rettigheter på relevant klinikk.

Lykke til,
Haakon

---

**Fra:** Anita Øgård-Repål
**Sendt:** torsdag 19. desember 2019 10:45
**Til:** Skogseth, Haakon Robin <Haakon.Robin.Skogseth@stolav.no>
**Emne:** SV: Forskningstilgang ved St.Olavs Hospital

Hei,
Søker om godkjenning av forskningsprosjekt «likepersonsarbeid for mennesker som lever med HIV».
Involverte i prosjektet, i tillegg til undertegnede, er Professor Mariann Fossum ved Universitetet i Agder (hovedveileder), Professor Rigmor Berg ved Folkehelseinstituttet/Universitetet i Tromsø (medveileder), samt Vegard Skogen ved Universitetet i Tromsø/Universitetssykehuset Nord-Norge (medveileder). I tillegg er det etablert en referansegruppe hvor blant annet overlege Ole Rysstad er med.
Fra Sørlandet Sykehus HF, Kristiansand, har både Ole Rysstad og Kristin Bårdsen Aas (sykepleier HIV-poliklinikk) vært involvert i oppstartsfasen.

Jeg er stipendiat og skal evaluere/utforske erfaringer på likepersonsarbeid (organisert fra poliklinikk) for mennesker som lever med hiv. Jeg har fått midler fra stiftelsen Damm.

Jeg har **derfor behov for å snakke med pasienter** som møter
- Likepersoner
- likepersonene selv
- helsepersonell som har erfaringer med å jobbe sammen med likepersoner.

For å kunne:
- få Ingrid og øvrig helsepersonell sin bistand til å rekruttere deltakere til min studie- ved at de f.eks skal bistå i å gjennomføre en spørreundersøkelse(e-post eller under samtale, alt avhengig av pasientenes og helsepersonells ønsker)
- invitere pasienter til deltakelse i intervju.

Jeg trenger i den forbindelse godkjenning av St.Olavs Hospital til å rekruttere deltakere. Ingrid Slørdal, sykepleier ved HIV-poliklinikk, er allerede involvert i min referansegruppe og godt kjent med prosjektet. Hun har også, i samarbeid med flere, søkt om innovasjonsmidler til å bruker erfaringskonsulenter (likepersoner) i hiv-omsorgen, så dette er i ferd å igangsettes.

Var det klargjørende? 😊

Vennlig hilsen
**Anita Øgård-Repål**
Universitetslektor/PhD stipendiat
Institutt for helse- og sykepleievitenskap
Fakultet for helse og idrett

UiA Universitetet i Agder

tlf: 48129983
epost: anita.ogard-repal@uia.no

## Anita Øgård-Repål

**Fra:** Hege Karine Jacobsen <Hege.Karine.Jacobsen@so-hf.no>
**Sendt:** torsdag 13. februar 2020 20:50
**Til:** Anita Øgård-Repål; Britt Andersen
**Kopi:** Jetmund O. Ringstad
**Emne:** PVOs tilrådning

Hei

Personvernombudet ved SØ har behandlet saken om tilgang til pasienter ved SØ. PVO har ingen innvendinger mot at SØ bidrar til dette og forutsetter kun forankring i avdelingsledelsen ift ressursbruk. Lykke til i prosjektet! Se vurdering under:

«PVO (KH) har ingen innvendinger mot at helsepersonell ved SØ gir ut samtykke til pasienter med HIV for deltakelse i studie ved Universitetet i Agder. Ettersom pasientene kun skal rekrutteres ved SØ, og det faktum at det ikke skal samles eller utleveres noe data fra SØ, er det Universitetet i Agder som er behandlingsansvarlig for studien, og det er PVO v/ Universitetet i Agder som må sikre at samtykket som benyttes er godt nok.

Det forutsettes at avdelingssjef ved den aktuelle avdelingen godkjenner at sine medarbeidere bruker tid på denne rekrutteringen og eventuell bistand som trengs i forbindelse med prosjektet.»

Med vennlig hilsen
Hege Karine Jacobsen
Rådgiver
Sykehuset Østfold

Forskningsavdelingen
Postboks 300, 1714 Grålum
Besøksadresse: Kalnesveien 300
Telefon +47 90118193

UNIVERSITETSSYKEHUSET NORD-NORGE
DAVVI-NORGGA UNIVERSITEHTABUOHCCEVIESSU

Vegard Skogen
Hematologisk, infeksjonsmedisinsk, geriatrisk
og endokrinologisk avdeling

| Deres ref.: | Vår ref.: | Saksbehandler/dir.tlf.: | Dato: |
|---|---|---|---|
| | 2020/1260 | Kristin Andersen/77626506 | 3.2.2020 |

## ANBEFALING – BEHANDLING AV PERSONOPPLYSNINGER

Det vises til Meldeskjema for forsknings- og kvalitetsprosjekt og annen aktivitet som medfører behandling av personopplysninger, mottatt 7.11.2019, senere avklaringer på e-post angående henvendelser til deltakere og reviderte samtykkeskriv

Meldingen gjelder prosjektet:

> ***Nr.02390***
> ***Navn på prosjektet:*** *Peer-support programmes in healthcare services for people living with HIV: Perspectives from users, peers, and professionals*
> ***Prosjektperiode: 6.11.2019 – 1.5.2022***

Prosjektet er et ***forskningsprosjekt*** hvor Universitetssykehuset Nord-Norge HF rolle er å dele ut informasjon om prosjektet til potensielle deltakere. Universitetet i Agder (UiA) er dataansvarlig og vil bli kontaktet direkte av de deltakerne som ønsker å delta i prosjektet.

> ***Formål:*** *«This project focuses on peer-support for people living with HIV in contexts where the peer-supporters are organized by- and located in hospitals. The overall aim of the project is to explore the perspectives of users, peers, and professionals in terms of peer-support programmes offered as part of healthcare services for people living with HIV. The project will contribute to the knowledge base on peer-support programmes in general, and peer-support programmes for HIV-positive persons in particular. The project will examine peer-support as a specific aspect of user involvement. We will examine how peer-support programmes are experienced by the health professionals, healthcare service users (referred to here as "the supported"), and peers ("the supporters").»*

REK har vurdert prosjektet og finner at behandlingen av personopplysningene ***ikke faller inn under medisinsk- og helsefaglig forskning etter Helseforskningsloven*.**

Personvernombudet ved UiA (NSD) har vurdert at lovlig grunnlag for behandlingen vil være den registrertes uttrykkelige samtykke, jf. Personvernforordningen artikkel 6.1.a), jf. artikkel 9.2. a) jf. Personopplysningsloven § 10, jf. § 9 (2).

PVO har på bakgrunn av tilsendte meldeskjema med vedlegg registrert prosjektet og finner at UNNs rolle vil være å dele ut informasjonsskriv/samtykkeskriv og det vil være opp til pasientene å ta kontakt ved å sende inn samtykket.

PVO forutsetter at rekrutteringen skjer som beskrevet i e-post 24.1.2020:

- *Papirversjon av spørreskjema deles ut til pasienter som kommer til kontroll. Før den deles ut blir pasientene spurt om det er greit for de å motta denne, og med informasjon om at det er en frivillig og anonym undersøkelse, og at det er en ferdig frankert konvolutt vedlagt, samt ytterligere informasjon om studien.*
- *I tillegg blir pasientene spurt om det er greit at sykepleier sender de en lenke til spørreundersøkelsen. Dersom dette samtykkes fra pasienten, så vil sykepleier sende en melding med informasjon og lenke til pasientens mobil fra prosjektets egeninnkjøpte mobil. Denne mobilen har kodelås, samt skal ligge nedlåst i en skuff inne på avdelingen. Det er kun to sykepleiere, som er involverte i prosjektet, som skal ha tilgang på denne mobilen/kodelåsen.*

Anbefalingen forutsetter at revidert infoskriv etter kommentarer i e-post 22.1.2020 benyttes.

PVO skal ha melding når rekrutteringen på UNN er avsluttet.

Med hjemmel i Personvernforordningens artikkel 39, anbefaler PVO at behandlingen kan iverksettes.

Med vennlig hilsen

UNIVERSITETSSYKEHUSET NORD-NORGE HF

for Personvernombudet

Kristin Andersen

Kopi: Markus Rumpsfeld

## Om personvernombud

Personvernombudet er utpekt av Universitetssykehuset Nord-Norge HF (UNN) og meldt til Datatilsynet. Personvernombudet har som oppgave å bidra til at UNN følger gjeldende regelverk for behandling av personopplysninger. Oppgaven innebærer blant annet å kontrollere overholdelsen av regelverket, informere og gi råd til virksomheten og de ansatte, og gi råd i vurdering av personverskonsekvenser. Personvernombudet er uavhengig og kan ikke instrueres av UNN i gjennomføring av sine oppgaver.

## Om uttalelsen

Personvernombudets uttalelse er ikke selvstendig juridisk bindende og du kan selv velge hvordan du ønsker å forholde deg til denne. Du er imidlertid selv ansvarlig for at du følger gjeldende personvernregler innenfor ditt ansvarsområde. Velger du å avvike fra personvernombudets uttalelse bør du begrunne dette skriftlig i ditt arbeid.

## Klageadgang

Personvernombudets uttalelse er har ingen selvstendig juridisk virkning og det finnes ingen adgang til å klage på uttalelsen. Dersom uttalelsen konkluderte på annen måte enn du ønsket kan personvernombudet bistå.

## Taushetsplikt

Personvernombudet har taushetsplikt ovenfor opplysninger om personlige forhold, enkeltpersoners varsling om mulige brudd på personvernlovgivningen, forretningshemmeligheter eller sikkerhetstiltak som det får kjennskap til i utførelsen av sitt arbeid. Dersom slike opplysninger er nødvendig for å gjennomføre lovpålagte oppgaver kan den registrerte bli bedd om samtykke til å gi nødvendige opplysninger videre.

For mer informasjon om personvernombud se Datatilsynets sider om personvernombud
For mer informasjon om pasientens rettigheter se Dine rettigheter på Datatilsynets sider
For mer informasjon om virksomheten (UNN) sine plikter se Virksomhetenes plikter

# Appendix 5

Information about study 2 and informed consent

# VIL DU DELTA I FORSKNINGSPROSJEKTET «LIKEPERSONSARBEID FOR MENNESKER SOM LEVER MED HIV»?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Denne studien er en del av et doktorgradsprosjekt hvor vi ønsker å få økt innsikt i hvordan det er for deg som lever med HIV å motta støtte fra en annen med samme diagnose, også kalt en *likeperson*.

## HVA ER FORMÅLET MED PROSJEKTET?

Vi ønsker å få frem ulike erfaringer knyttet til det å møte likepersoner. For å få denne innsikten har vi behov for å gjennomføre intervjuer, samt at vi vil gjennomføre en spørreundersøkelse relevant for alle som har en avtale med gjeldende poliklinikk.

## HVA INNEBÆRER DET FOR DEG Å DELTA?

Vi har både behov for å få gjennomført en spørreundersøkelse og flere individuelle intervjuer. Hvis du velger å delta i spørreundersøkelsen, vil du kunne velge mellom å besvare den via papirversjonen eller via en lenke du får tilsendt på melding. Vi ønsker å spørre deg om dine erfaringer med å møte en likeperson i tillegg til at vi også trenger noen opplysninger knyttet til din bakgrunn.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre oppfølging. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), tlf: 918 54 845.

## HVA SKJER MED OPPLYSNINGENE OM DEG?

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger, og det er ingen personidentifiserende data som lagres relatert til spørreundersøkelsen. Ved å delta på et intervju, vil det være en kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Øgård-Repål som har tilgang til denne listen.

Av dokumentasjonshensyn vil opplysningene om deg bli oppbevart i fem år etter prosjektslutt. Vi oppbevarer informasjonen på nettverk i Universitetet i Agder sin server. I tillegg oppbevares den på minnepenn i PDF format og på bærbar PC med brukernavn og passordbeskyttelse som kun prosjektleder har tilgang til. Datamaskinen oppbevares i låsbart rom. Papirbaserte notater og minnepenn i forbindelse med intervjuene oppbevares i låsbart skap. Prosjektleder har tilgang til nøkkelen. Hovedveileder professor Mariann Fossum ved

Universitetet i Agder og medveiledere professor Rigmor Berg og førsteamanusensis Vegard Skogen, vil også ha tilgang til datamaterialet.

All informasjon om deg vil bli anonymisert. Ved publikasjon av resultatene av studien skal det ikke være mulig å gjenkjenne deg.

## HVA GIR OSS RETT TIL Å BEHANDLE PERSONOPPLYSNINGER OM DEG?

Vi behandler opplysninger om deg basert på ditt samtykke.

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet.

### *Dine rettigheter*

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

## ØKONOMI

Du vil få kompensasjon for nødvendige utgifter til reise i forbindelse med intervjuet. Dette må avtales på forhånd. Det vil ikke forekomme noen økonomisk kompensasjon i forbindelse med deltakelse i spørreundersøkelsen.

## GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og anser det ikke som nødvendig med forhåndsgodkjenning for dette prosjektet.

Etter ny personopplysningslov har dataansvarlig, veileder Mariann Fossum og prosjektleder Anita Øgård-Repål, et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2. På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

## KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet, kan du ta kontakt med:

- Universitetet i Agder ved PhD-stipendiat Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), Tlf: 918 54 845.
- Personvernombud ved Universitetet i Agder: Ina Danielsen, (personvernombud@uia.no).
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

## SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om prosjektet *«Likepersonsarbeid for mennesker som lever med HIV»* og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ At mitt navn og kontaktinformasjon gis prosjektleder Anita Øgård-Repål
- ☐ å delta i intervju
- ☐ å delta i spørreundersøkelsen
- ☐ å delta i et gruppeintervju
- ☐ *at mine personopplysninger lagres etter prosjektslutt, til forskningsformål – hvis aktuelt*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2022.

------------------------------------------------------------------------------------------------

Sted og dato                                        Deltakers signatur

------------------------------------------------------------------------

Deltakers navn med trykte bokstaver

## INFORMASJONSSKRIV OM FORSKNINGSPROSJEKT

# LIKEPERSONSARBEID FOR MENNESKER SOM LEVER MED HIV

Dette er et informasjonsskriv om et pågående forskningsprosjekt. Denne studien er en del av et doktorgradsprosjekt hvor vi ønsker å få økt innsikt i hvordan det er for en som lever med HIV å møte en annen med samme diagnose, også kalt en *likeperson*. I den forbindelse har vi behov for og et ønske om at du som helsepersonell har mulighet til å bistå i **rekrutteringen av deltakere** til studien.

## HVA INNEBÆRER PROSJEKTET?

Vi ønsker å få frem ulike erfaringer knyttet til det å møte likepersoner. For å få denne innsikten har vi behov for å gjennomføre et intervju med de som har erfaring med å møte likepersoner.

I prosjektet trenger vi derfor informasjon fra personer som lever med HIV ved å gjennomføre et intervju. Vi vil spørre de om erfaringer, og også noen opplysninger knyttet til deres bakgrunn. Dette vil skje både i intervju og via spørreskjema. Varighet på intervjuet vil være maksimalt 60 minutter. Vi vil avtale sted for gjennomføring ut fra hvor de finner det praktisk å møtes. Dersom de ønsker det, har de full anledning til å ta med seg en støtteperson under selve gjennomføringen av intervjuet.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom deltakeren ønsker å delta, undertegner de en samtykkeerklæring. De kan når som helst og uten å oppgi noen grunn trekke sitt samtykke. Dette vil ikke få konsekvenser for videre oppfølging. Dersom deltakeren senere ønsker å trekke seg eller har spørsmål til prosjektet, kan de kontakte prosjektleder Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), tlf: 918 54 845.

## HVA SKJER MED OPPLYSNINGENE OM DELTAKERNE?

Opplysningene som registreres skal kun brukes slik som beskrevet i hensikten med prosjektet. De har rett til innsyn i hvilke opplysninger som er registrert og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. De har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deltakeren til opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Øgård-Repål som har tilgang til denne listen.

Opplysningene vil bli anonymisert eller slettet senest fem år etter prosjektslutt. Vi oppbevarer informasjonen på nettverk i Universitetet i Agder sin server. I tillegg oppbevares den på minnepenn i PDF format og på bærbar PC med brukernavn og passordbeskyttelse som kun prosjektleder har tilgang til. Datamaskinen oppbevares i låsbart rom. Papirbaserte notater og minnepenn oppbevares i låsbart skap. Prosjektleder har tilgang til nøkkelen. Hovedveileder professor Mariann Fossum ved Universitetet i Agder og medveiledere professor Rigmor Berg og førsteamanuensis Vegard Skogen, vil også ha tilgang til datamaterialet.

All informasjon vil bli anonymisert. Ved publikasjon av resultatene av studien skal det ikke være mulig å gjenkjenne deltakerne.

## ØKONOMI

Deltakerne vil få kompensasjon for nødvendige utgifter til reise i forbindelse med intervjuet. Dette må avtales på forhånd.

## GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk (REK) har vurdert prosjektet, og har vurdert det som ikke nødvendig med forhåndsgodkjenning fra REK.

Etter ny personopplysningslov har dataansvarlig, veileder Mariann Fossum og prosjektleder Anita Øgård-Repål, et selvstendig ansvar for å sikre at behandlingen opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2 og deltakernes samtykke.

Deltakerne har rett til å klage på behandlingen av opplysninger til Datatilsynet.

## KONTAKTOPPLYSNINGER

Dersom du eller deltakerne har spørsmål til prosjektet kan du/de ta kontakt med:

- Universitetet i Agder ved PhD-stipendiat Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), Tlf: 918 54 845.
- Personvernombud ved Universitetet i Agder: Ina Danielsen, (personvernombud@uia.no).
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

# Appendix 6

Interview guide, study 2

# Intervjuguide

**Hensikten med dette intervjuet er at du forteller meg mest mulig om dine erfaringer med å få støtte fra en likeperson, slik at vi kan få utvidet kunnskap om de erfaringene du har gjort deg. Jeg ønsker også å snakke med deg om hvordan du har blitt informert om tilbudet, og hvordan møtene har vært organisert. I tillegg ønsker jeg å høre om dine erfaringer i møte med dine omgivelser i etterkant av at du fikk din hiv-diagnose.**

## Innledning

- ✓ Presentasjon av prosjektet (tema, problemstilling, hva informantene kan bidra med)
- ✓ Praktisk gjennomføring av intervjuet (tidsbruk, praktisk gjennomføring - mulighet for fleksibilitet dersom noe interessant dukker opp).
- ✓ Det forskningsetiske knyttet til intervjuet og prosjektet som helhet. Spesielt fokus på min taushetsplikt og konfidensiell behandling av informasjonsmaterialet (vektlegger åpenhet og ærlighet; finnes ingen rette svar og at informantene selv avgjør hva de vil dele underveis)

*Navn, etternavn og kontaktinformasjon innhentes og kodes med respondent 1-4.*

For å hindre at det fremkommer personopplysninger om tredjepersoner vil vi i forkant av intervjuet diskutere personvern med informanten. Vi vil være oss bevisst hvordan vi stiller spørsmålene, og gi beskjed om at informantene må bruke andre navn/la være å bruke navn når de omtaler folk og unnlate karakteristikker som kan knyttes til enkeltpersoner.

## Bakgrunnsinformasjon

1. Alder
2. Kjønn
3. Hvor lenge hatt diagnosen HIV?
4. Hvilket land kommer du fra/hvor er du født?
5. Seksuell orientering?

## Tema for samtalen

### Om selve møtet med en likeperson

1. Hvordan ble det til at du fikk møte en annen med samme diagnose som deg?
    a. Hvem kom med tilbudet om et slikt møte?
    b. Har du fått et slikt tilbud i andre sammenhenger?
2. Fortell om dine erfaringer med likepersoner
    a. Hvordan det ble organisert?
    b. Hvor møttes dere?
    c. Hvor lenge varte møtet?

3. Hvilke utfordringer opplevde du i møte med likepersoner? Noe du tenker bør endres eller være annerledes?
4. Hva opplevde du at likepersoner kunne bidra med i din hverdag?
5. Kan du komme på en situasjon hvor du så at møtet med en likeperson ble viktig eller nyttig?
6. Hvilke forventinger har du til et møte med en likeperson?
7. Hva ønsker du å oppnå med et slikt møte?
8. Er det noe du tenker er utfordrende ved å møte med en likeperson?
9. Hvor store er de forventede uønskede effektene, de nevnte utfordringene?
10. Hva kreves av deg for å møte en likeperson? Har det noen omkostninger for deg?
11. På hvilken måte tenker du at et møte med en likeperson vil kunne påvirke din egen helse?
12. Har du noen etiske betenkeligheter med å møte en likeperson?
13. Tenker du det er realistisk (gjennomførbart) at personer som lever med HIV kan få tilbud om å møte en likeperson?
14. Er det noe du ønsker å legge til/eventuelt kommentarer?

## Om erfaringer relatert til sosial støtte og stigma

1. I hvilken grad og på hvilken måte erfarer du støtte fra dine omgivelser relatert til din hiv-diagnose.
2. Kan du komme på en situasjon som beskriver ditt behov for støtte?
3. Har det vært perioder eller situasjoner hvor du opplevde større grad av usikkerhet og forutsigbarhet relatert til din situasjon?
4. Har du hatt perioder med opplevelse av manglende kontroll?
5. Kan du komme på en situasjon som beskriver hvordan sosial støtte har vært til hjelp?
6. Hvilke forventninger har du til dine omgivelser relatert til din diagnose?
7. Har du vært utsatt for, eller har du hørt om andre med samme diagnose ha erfaring med, noen form for diskriminering eller opplevelse av stigmatisering?
8. Dersom du har erfaring, kan du fortelle noe om en slik situasjon?

# Appendix 7

Information about study 3 and informed consent

# VIL DU DELTA I FORSKNINGSPROSJEKTET
# «LIKEPERSONSARBEID FOR MENNESKER SOM LEVER MED HIV»?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Denne studien er en del av et doktorgradsprosjekt hvor vi ønsker å få økt innsikt i hvordan det er for deg som helsepersonell å utøve din jobb side om side med likepersoner.

## HVA ER FORMÅLET MED PROSJEKTET?

Vi ønsker å få frem helsepersonells ulike erfaringer og perspektiver på arbeid knyttet til likepersoner for mennesker som lever med HIV. For å få denne innsikten har vi behov for å gjennomføre et intervju med de som har erfaring med å jobbe sammen med likepersoner.

## HVA INNEBÆRER DET FOR DEG Å DELTA?

Hvis du velger å delta i prosjektet, ønsker vi å spørre deg om dine erfaringer med å jobbe med mennesker som har HIV, og videre om erfaringer med likepersoner i ditt system. Dette vil foregå i et intervju. Varighet på intervjuet vil være maksimalt 60 minutter. Vi vil avtale sted for gjennomføring ut fra hvor du finner det praktisk å møtes, fortrinnsvis ved din arbeidsplass.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), tlf: 918 54 845.

## HVA SKJER MED OPPLYSNINGENE OM DEG?

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Øgård-Repål som har tilgang til denne listen.

Av dokumentasjonshensyn vil opplysningene om deg bli oppbevart i fem år etter prosjektslutt. Vi oppbevarer informasjonen på nettverk i Universitetet i Agder sin server. I tillegg oppbevares den på minnepenn i PDF format og på bærbar PC med brukernavn og passordbeskyttelse som kun prosjektleder har tilgang til. Datamaskinen oppbevares i låsbart rom. Papirbaserte notater og minnepenn oppbevares i låsbart skap. Prosjektleder har tilgang til nøkkelen. Hovedveileder professor Mariann Fossum ved Universitetet i Agder, medveileder professor Rigmor Berg og medveileder overlege/PhD. Vegard Skogen, vil også ha tilgang til datamaterialet.

All informasjon om deg vil bli anonymisert. Ved publikasjon av resultatene av studien skal det ikke være mulig å gjenkjenne deg.

## HVA GIR OSS RETT TIL Å BEHANDLE PERSONOPPLYSNINGER OM DEG?

Vi behandler opplysninger om deg basert på ditt samtykke.

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet.

***Dine rettigheter***

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

## ØKONOMI

Du vil få kompensasjon for nødvendige utgifter til reise i forbindelse med intervjuet. Dette må avtales på forhånd.

## GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og anser det ikke som nødvendig med forhåndsgodkjenning for dette prosjektet.

Etter ny personopplysningslov har dataansvarlig, veileder Mariann Fossum og prosjektleder Anita Øgård-Repål, et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2. På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

## KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet, kan du ta kontakt med:

- Universitetet i Agder ved PhD-stipendiat Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), Tlf: 918 54 845.
- Personvernombud ved Universitetet i Agder: Ina Danielsen, (personvernombud@uia.no).
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

## SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om prosjektet *«Likepersonsarbeid for mennesker som lever med HIV»* og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju
☐ å delta i et gruppeintervju
☐ *at mine personopplysninger lagres etter prosjektslutt, til forskningsformål – hvis aktuelt*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2022.

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Sted og dato

Deltakers signatur

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Deltakers navn med trykte bokstaver

# VIL DU DELTA I FORSKNINGSPROSJEKTET
## «LIKEPERSONSARBEID FOR MENNESKER SOM LEVER MED HIV»?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Denne studien er en del av et doktorgradsprosjekt hvor vi ønsker å få økt innsikt i hvordan det er for deg som lever med HIV å være en støtte for andre som lever med HIV, som en likeperson.

## HVA ER FORMÅLET MED PROSJEKTET?

Vi ønsker å få frem ulike erfaringer knyttet til det å være likeperson. For å få denne innsikten har vi behov for å gjennomføre et intervju med de som har erfaring med å være likepersoner.

## HVA INNEBÆRER DET FOR DEG Å DELTA?

Hvis du velger å delta i prosjektet, ønsker vi å spørre deg om dine erfaringer med å være likeperson. Vi trenger derfor informasjon fra deg gjennom et personlig intervju. Vi vil spørre deg om erfaringer, og også noen opplysninger knyttet til din bakgrunn. Dette vil skje gjennom et intervju. Varighet på intervjuet vil være maksimalt 60 minutter. Vi vil avtale sted for gjennomføring ut fra hvor du finner det praktisk å møtes.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre oppfølging. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), tlf: 918 54 845.

## HVA SKJER MED OPPLYSNINGENE OM DEG?

Vi behandler opplysninger om deg basert på ditt samtykke.

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Øgård-Repål som har tilgang til denne listen.

Av dokumentasjonshensyn vil opplysningene om deg bli oppbevart i fem år etter prosjektslutt Vi oppbevarer informasjonen på nettverk i Universitetet i Agder sin server. I tillegg oppbevares den på minnepenn i PDF format og på bærbar PC med brukernavn og passordbeskyttelse som kun prosjektleder har tilgang til. Datamaskinen oppbevares i låsbart rom. Papirbaserte notater og minnepenn oppbevares i låsbart skap. Prosjektleder har tilgang til nøkkelen. Hovedveileder professor Mariann Fossum ved Universitetet i Agder og medveileder professor Rigmor Berg og overlege/PhD. Vegard skogen, vil også ha tilgang til datamaterialet.

All informasjon om deg vil bli anonymisert. Ved publikasjon av resultatene av studien skal det ikke være mulig å gjenkjenne deg.

## HVA GIR OSS RETT TIL Å BEHANDLE PERSONOPPLYSNINGER OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet.

***Dine rettigheter***

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

## ØKONOMI

Du vil få kompensasjon for nødvendige utgifter til reise i forbindelse med intervjuet. Dette må avtales på forhånd.

## GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og anser det ikke som nødvendig med forhåndsgodkjenning for dette prosjektet.

Etter ny personopplysningslov har dataansvarlig, veileder Mariann Fossum og prosjektleder Anita Øgård-Repål, et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2. På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

## KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet kan du ta kontakt med:

- Universitetet i Agder ved PhD-stipendiat Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), Tlf: 918 54 845.
- Personvernombud ved Universitetet i Agder: Ina Danielsen, (personvernombud@uia.no).
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

## SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om prosjektet *«Likepersonsarbeid for mennesker som lever med HIV»* og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ At mitt navn og kontaktinformasjon gis prosjektleder Anita Øgård-Repål
- ☐ å delta i intervju
- ☐ å delta i spørreundersøkelsen
- ☐ å delta i et gruppeintervju
- ☐ *at mine personopplysninger lagres etter prosjektslutt, til forskningsformål – hvis aktuelt*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2022.

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Deltakers signatur

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Deltakers navn med trykte bokstaver

## INFORMASJONSSKRIV OM FORSKNINGSPROSJEKT

# LIKEPERSONSARBEID FOR MENNESKER SOM LEVER MED HIV

Dette er et informasjonsskriv om et pågående forskningsprosjekt. Denne studien er en del av et doktorgradsprosjekt hvor vi ønsker å få økt innsikt i hvordan det er for en som lever med HIV å møte en annen med samme diagnose, i form av å være *likeperson*. I den forbindelse har vi behov for og et ønske om at du som helsepersonell har mulighet til å bistå i **rekrutteringen av deltakere** til studien.

## HVA INNEBÆRER PROSJEKTET?

Vi ønsker å få frem ulike erfaringer knyttet til det å være en likepersoner. For å få denne innsikten har vi behov for å gjennomføre et intervju med de som har erfaring med å møte andre som lever med HIV i form av å være en likeperson.

Vi vil spørre de om erfaringer, og også noen opplysninger knyttet til deres bakgrunn. Dette vil skje gjennom intervju. Varighet på intervjuet vil være maksimalt 60 minutter. Vi vil avtale sted for gjennomføring ut fra hvor de finner det praktisk å møtes. Dersom de ønsker det, har de full anledning til å ta med seg en støtteperson under selve gjennomføringen av intervjuet.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom deltakeren ønsker å delta, undertegner de en samtykkeerklæring. De kan når som helst og uten å oppgi noen grunn trekke sitt samtykke. Dette vil ikke få konsekvenser for videre oppfølging. Dersom deltakeren senere ønsker å trekke seg eller har spørsmål til prosjektet, kan de kontakte prosjektleder Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), tlf: 918 54 845.

## HVA SKJER MED OPPLYSNINGENE OM DELTAKERNE?

Opplysningene som registreres skal kun brukes slik som beskrevet i hensikten med prosjektet. De har rett til innsyn i hvilke opplysninger som er registrert og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. De har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deltakeren til opplysninger gjennom en navneliste. Det er kun prosjektleder Anita Øgård-Repål som har tilgang til denne listen.

Opplysningene vil bli anonymisert eller slettet senest fem år etter prosjektslutt. Vi oppbevarer informasjonen på nettverk i Universitetet i Agder sin server. I tillegg oppbevares den på minnepenn i PDF format og på bærbar PC med brukernavn og passordbeskyttelse som kun prosjektleder har tilgang til. Datamaskinen oppbevares i låsbart rom. Papirbaserte notater og minnepenn oppbevares i låsbart skap. Prosjektleder har tilgang til nøkkelen. Hovedveileder professor Mariann Fossum ved Universitetet i Agder, medveileder professor Rigmor Berg og medveileder overlege/PhD. Vegard Skogen, vil også ha tilgang til datamaterialet.

All informasjon vil bli anonymisert. Ved publikasjon av resultatene av studien skal det ikke være mulig å gjenkjenne deltakerne.

## ØKONOMI

Deltakerne vil få kompensasjon for nødvendige utgifter til reise i forbindelse med intervjuet. Dette må avtales på forhånd.

## GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk (REK) har vurdert prosjektet, og har vurdert det som ikke nødvendig med forhåndsgodkjenning fra REK.

Etter ny personopplysningslov har dataansvarlig, veileder Mariann Fossum og prosjektleder Anita Øgård-Repål, et selvstendig ansvar for å sikre at behandlingen opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2 og deltakernes samtykke.

Deltakerne har rett til å klage på behandlingen av opplysninger til Datatilsynet.

## KONTAKTOPPLYSNINGER

Dersom du eller deltakerne har spørsmål til prosjektet kan du/de ta kontakt med:

- Universitetet i Agder ved PhD-stipendiat Anita Øgård-Repål (anita.ogard-repal@uia.no), tlf: 481 29 983 eller hovedveileder professor Mariann Fossum (mariann.fossum@uia.no), Tlf: 918 54 845.
- Personvernombud ved Universitetet i Agder: Ina Danielsen, (personvernombud@uia.no).
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

# Appendix 8

Interview guides, study 3

# Intervjuguide individuelt intervju med helsepersonell

## Innledning (5 min.)

- ✓ Presentasjon av prosjektet (tema, problemstilling, hva informantene kan bidra med)
- ✓ Praktisk gjennomføring av intervjuet (tidsbruk, praktisk gjennomføring - mulighet for fleksibilitet dersom noe interessant dukker opp).
- ✓ Det forskningsetiske knyttet til intervjuet og prosjektet som helhet. Spesielt fokus på min taushetsplikt og konfidensiell behandling av informasjonsmaterialet (vektlegger åpenhet og ærlighet; finnes ingen rette svar og at informantene selv avgjør hva de vil dele underveis)

*Navn, etternavn og kontaktinformasjon innhentes og kodes.*

For å ivareta pasienter i størst mulig grad, og gi rom for selv i større grad velge hvorvidt de ønsker å delta i prosjektet, så vil rekrutteringen skje via snøball-metoden.Dette tilsier at rekrutteringen skjer via anbefalinger og møter på de ulike institusjonene. Dette innebærer flere ledd; for det første vil helsepersonell på sykehusene som er forskningsinstitusjonene bistå med å kontakte personer til denne studien, da de møter de på sykehusets poliklinikk. I tillegg vil de som er likepersoner ved forskningsinstitusjonene også bistå i å rekruttere deltakere til denne studien.

## Spørsmål før intervjuet starter:

1. Alder:
2. Kjønn:
3. Hvor lenge har du jobbet med mennesker som lever med HIV?

**Hensikten med dette intervjuet er at du forteller meg mest mulig om dine erfaringer med å jobbe sammen med likepersoner, slik at vi kan få utvidet kunnskap om de erfaringene du har gjort deg. I tillegg ønsker jeg å snakke med deg om hvordan organiseringen har vært.**

## Spørsmål:

1. Fortell litt om din motivasjon for å jobbe med mennesker som lever med HIV.
2. Fortell om dine erfaringer med å jobbe sammen med likepersoner; hvordan det hele startet, hvordan det blir organisert, hvordan dere samarbeider o.l.
3. Hvilke utfordringer opplever du ved å jobbe sammen med likepersoner? Noe du tenker bør endres eller være annerledes?
4. Hva tenker du likepersoner kan bidra med i pasientenes hverdag?
5. Kan du komme på en situasjon hvor du så at møtet ble viktig eller nyttig?
6. Hva forventer du å få ut av å jobbe side om side med en likeperson?
7. Hvor store er de ønskelige effektene?
8. Hva er de forventede uønskede effektene?
9. Hvor store er de forventede uønskede effektene?
10. Hva kreves av ressurser/omkostninger av deg?
11. På hvilken måte tenker du slike møter vil kunne påvirke egen helse?
12. Er intervensjonen etisk akseptabel?
13. Er intervensjonen gjennomførbar?
14. Er det noe du ønsker å legge til/eventuelt kommentarer?

# Intervjuguide fokusgruppeintervju

## Innledning (5 min.)

- ✓ Presentasjon av prosjektet (tema, problemstilling, hva informantene kan bidra med)
- ✓ Praktisk gjennomføring av intervjuet (tidsbruk, praktisk gjennomføring - mulighet for fleksibilitet dersom noe interessant dukker opp).
- ✓ Det forskningsetiske knyttet til intervjuet og prosjektet som helhet. Spesielt fokus på min taushetsplikt og konfidensiell behandling av informasjonsmaterialet (vektlegger åpenhet og ærlighet; finnes ingen rette svar og at informantene selv avgjør hva de vil dele underveis)

*Navn, etternavn og kontaktinformasjon innhentes og kodes.*

For å ivareta pasienter i størst mulig grad, og gi rom for selv i større grad velge hvorvidt de ønsker å delta i prosjektet, så vil rekrutteringen skje via snøball-metoden.Dette tilsier at rekrutteringen skjer via anbefalinger og møter på de ulike institusjonene. Dette innebærer flere ledd; for det første vil helsepersonell på sykehusene som er forskningsinstitusjonene bistå med å kontakte personer til denne studien, da de møter de på sykehusets poliklinikk. I tillegg vil de som er likepersoner ved forskningsinstitusjonene også bistå i å rekruttere deltakere til denne studien.

## Spørsmål før intervjuet starter:

1. Alder:
2. Kjønn:
3. Hvor lenge har du jobbet med mennesker som har HIV?

**Hensikten med dette intervjuet er at dere forteller meg mest mulig om deres erfaringer med å jobbe sammen, slik at vi kan få utvidet kunnskap om deres erfaringer. I tillegg ønsker jeg å snakke med dere om hvordan organiseringen har vært.**

## Spørsmål:

1. Fortell litt om deres motivasjon for å jobbe med mennesker som lever med HIV.
2. Fortell om deres erfaringer med å jobbe sammen; hvordan det hele startet, hvordan det blir organisert, hvordan dere samarbeider o.l.
3. Hvilke utfordringer opplever dere ved å jobbe sammen? Noe dere tenker bør endres eller være annerledes?
4. Hva tenker dere at samarbeidet kan bidra med i pasientenes hverdag?
5. Kan dere komme på en situasjon hvor dere så at møtet og samarbeidet mellom sykepleier, likeperson og pasient ble viktig eller nyttig?
6. Hva forventer dere å få ut av et møte med en likeperson?
7. Hvor store er de ønskelige effektene?
8. Hva er de forventede uønskede effektene?
9. hvor store er de forventede uønskede effektene?
10. Hva kreves av ressurser/omkostninger av dere?
11. På hvilken måte tenker dere slike møter vil kunne påvirke egen helse?
12. Er intervensjonen etisk akseptabel?
13. Er intervensjonen mulig/gjennomførbar?
14. Er det noe dere ønsker å legge til/eventuelt kommentarer?

# Intervjuguide individuelt intervju med likepersoner

## Innledning (5 min.)

- ✓ Presentasjon av prosjektet (tema, problemstilling, hva informantene kan bidra med)
- ✓ Praktisk gjennomføring av intervjuet (tidsbruk, praktisk gjennomføring - mulighet for fleksibilitet dersom noe interessant dukker opp).
- ✓ Det forskningsetiske knyttet til intervjuet og prosjektet som helhet. Spesielt fokus på min taushetsplikt og konfidensiell behandling av informasjonsmaterialet (vektlegger åpenhet og ærlighet; finnes ingen rette svar og at informantene selv avgjør hva de vil dele underveis)

*Navn, etternavn og kontaktinformasjon innhentes og kodes.*

For å ivareta pasienter i størst mulig grad, og gi rom for selv i større grad velge hvorvidt de ønsker å delta i prosjektet, så vil rekrutteringen skje via snøball-metoden.Dette tilsier at rekrutteringen skjer via anbefalinger og møter på de ulike institusjonene. Dette innebærer flere ledd; for det første vil helsepersonell på sykehusene som er forskningsinstitusjonene bistå med å kontakte personer til denne studien, da de møter de på sykehusets poliklinikk. I tillegg vil de som er likepersoner ved forskningsinstitusjonene også bistå i å rekruttere deltakere til denne studien.

## Spørsmål før intervjuet starter:

1. Alder:
2. Kjønn:
3. Hvor lenge har du hatt diagnosen HIV?
4. Opprinnelsesland?

**Hensikten med dette intervjuet er at du forteller meg mest mulig om dine erfaringer med å gi støtte som likeperson, slik at vi kan få utvidet kunnskap om de erfaringene du har gjort deg. I tillegg ønsker jeg å snakke med deg om hvordan organiseringen har vært.**

## Spørsmål:

1. Fortell litt om din motivasjon for å være en likeperson.
2. Hvordan ble det til at du valgte å være en likeperson? Hvordan foregikk forespørselen/rekrutteringen?
3. Fortell om dine erfaringer med å være likeperson; hvordan det blir organisert, hvor dere møttes, varighet o.l.
4. Hvilke utfordringer opplever du i møte med andre som lever med HIV som likeperson? Noe du tenker bør endres eller være annerledes?
5. Hva opplevde du, som likeperson, å kunne bidra med i deres hverdag?
6. Kan du komme på en situasjon hvor du så at møtet ble viktig eller nyttig?
7. Fortell om ditt siste møte. Hva tenker du fungerte bra?
8. Fortell om et møte du opplevde ikke gikk så bra. Hvilke tanker gjør du deg rundt det møtet i dag?
9. Hva forventer du å få ut av et møte som en likeperson?
10. Hvor store er de ønskelige effektene?
11. Hva er de forventede uønskede effektene, og hvor store er de?
12. Hva kreves av ressurser/omkostninger av deg?
13. På hvilken måte tenker du slike møter vil kunne påvirke din egen helse?
14. Er intervensjonen etisk akseptabel?
15. Er intervensjonen mulig/gjennomførbar?
16. Er det noe du ønsker å legge til/eventuelt kommentarer?