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## **Priorities for HIV and chronic pain research: Results from a survey of individuals with lived experience**

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### **Abstract**

The Global Task Force on Chronic Pain in HIV published seven research priorities in the field of HIV-associated chronic pain in 2019: 1) causes; 2) management; 3) treatment individualization and integration with addiction treatment; 4) mental and social health factors; 5) prevalence; 6) treatment cost effectiveness; and 7) prevention. The current study used a web-based survey to determine whether the research topics were aligned with the priorities of adults with lived experiences of HIV and chronic pain. We also collected information about respondents' own pain and treatment experiences. We received 311 survey responses from mostly US-based respondents. Most respondents reported longstanding, moderate to severe, multisite pain, commonly accompanied by symptoms of anxiety and/or depression. The median number of pain treatments tried was 10 (IQR=8, 13), with medications and exercise being the most common modalities, and opioids being viewed as the most helpful. Over 80% of respondents considered all research topics either "extremely important" or "very important." Research topic #2, which focused on optimizing management of pain in people with HIV, was accorded the greatest importance by respondents. These findings suggest good alignment between the priorities of researchers and people with lived experience of HIV-associated chronic pain.

**Keywords (3-6):** HIV, chronic pain, research priorities, pain treatment, patient engagement, good health and well-being

## **Introduction**

Chronic pain is a prevalent and burdensome problem among people with HIV throughout the world. In a US based primary care sample, 40% of people with HIV carried one or more chronic pain diagnoses.(Jiao et al., 2015) In a UK based-study 60-70% of people with HIV reported pain within the past month.(Sabin et al., 2018) A South African study examined pain by bodily location in people with HIV and discovered that over 30% of people had pain in the commonest locations (e.g., head, and ankles and feet).(Wadley et al., 2022) However, there is a very limited evidence-base for the effective treatment of chronic pain in people with HIV.(Bruce et al., 2017) To address this challenge, in 2019 a Global Task Force on Chronic Pain in HIV (referred to hereafter as “the Task Force”) was convened with the aim of systematically advancing clinical care and research in HIV and chronic pain through multinational, interdisciplinary collaboration. Using a multi-step process (which has been described previously)(J. S. Merlin et al., 2021) the Task Force identified and published seven research priorities in the field of HIV-associated chronic pain pertaining to its: 1) causes; 2) management; 3) treatment individualization and integration with addiction treatment; 4) mental and social health factors; 5) prevalence; 6) treatment cost effectiveness; and 7) prevention.(J. S. Merlin et al., 2021)

The Task Force includes people with lived experiences of HIV and chronic pain. However, members agreed that it was critical to seek the feedback of a larger group of people with lived experience to determine whether the research topics were aligned with their priorities. This was also in keeping with the rich tradition of patient and public involvement in HIV research and its growing role in pain research as a means of enhancing clinical relevance.(Harrison et al., 2022) For example, the activism of people with HIV in the late 1980s and early 1990s is considered by some to be a watershed moment in which researchers and regulatory bodies such as the Food and Drug Administration (FDA) and its European equivalents first began collaborating with patient stakeholders to provide accelerated access to life-saving treatments.(Haerry, 2021) This idea of including diverse perspectives in research has only gained momentum since then, including the recognition in the late 1990s of patient and community engagement as a potential tool to ameliorate health disparities, the rise of community based participatory research (CBPR) in the early 2000s,(Holkup et al., 2004) and the establishment of the US Patient-Centered Outcomes Research Institute (PCORI) in 2010. ("Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute," 2019) The field of pain research has followed suit with regard to prioritization of the patient perspective including initiatives from the International Association for the Study of Pain (IASP),(Harrison et al., 2022) and from the National Institutes of Health’s (NIH) Helping to End Addiction Long Term (HEAL) initiative,(Baker, 2022) a major funder of pain research in the US.

Herein, we describe the results of a novel survey designed primarily to assess views on the importance and prioritization of research topics pertaining to HIV and chronic pain from the perspectives of persons with lived experiences of HIV and chronic pain. As a secondary aim, we also sought to describe pain and treatment experiences as reported by the survey respondents and to determine whether their experiences and personal and HIV characteristics were associated with differences in views on the research topics.

## **Materials and Methods**

**Study overview.** The study was a cross-sectional web-based survey. Participants accessed the survey via a link which was publicized online on the websites of *POZ* and *The Body* (US-based periodicals serving

the community of people affected by HIV). In addition, members of the Task Force circulated the link within their own networks and community connections. The survey instructions indicated that it was intended for “people with lived experience of HIV and chronic pain” and that respondents “must be at least 18 years old to participate.” However, given that the link was freely accessible to the public, there were no verifiable inclusion/exclusion criteria. Responses were collected from November 2020 through July 2022.

Survey development. Survey development was an iterative process conducted over two months (via email and video conference) and led by a core group of eight co-authors (JRP, WS, KO, CP, JJ, LU, MCG, JSM) including two authors with lived experiences of chronic pain and HIV. In the first round, the research topic language was rephrased to be more suitable for a lay audience and a brief preliminary survey was produced, which asked respondents to: 1) rate the importance of each research topic on a 5-point Likert scale ranging from “not at all important” to “extremely important;” and 2) prioritize the research topics in rank order of importance (from 1-7, participants were also given the option of rating any item “not at all important” instead of including it in the rankings). The entire Task Force was then invited to comment on the draft survey. In the course of this comment period, it was suggested that the survey be expanded to better characterize the experiences of respondents, including personal and HIV health characteristics and experiences living with HIV and chronic pain. This ultimately resulted in a significant expansion of the survey to include seven sections: 1) rating of the importance of the research topics; 2) ranking of the importance of the research topics; 3) demographics; 4) description of pain and related symptoms, pain diagnoses, and access to care; 5) treatments tried and perceived efficacy (rated on a 7-point Likert scale ranging from “very much improved” to “very much worse”); 6) mood; and 7) impact of the COVID-19 pandemic.

Survey questions were selected with the goal of maximizing consistency with other pain and HIV research initiatives and were based on: 1) items used by the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) and the Ontario HIV Treatment Network Cohort Study (OCS);(Kitahata et al., 2008; Rourke et al., 2013) 2) the Helping to End Addiction Long Term (HEAL) common data elements for chronic pain;(Wandner et al., 2022) and 3) the International Classification of Diseases-11 (ICD-11) Chronic Pain Classification.(Treede et al., 2015) Validated scales that were included within the survey were the PEG (for pain, three items each scored 0-10),(Krebs et al., 2009) the GAD-2 (for anxiety, scored 0-6),(Kroenke et al., 2007) and the PHQ-2 (for depression, scored 0-6).(Kroenke et al., 2003) This expanded survey was circulated via email to all Task Force members and additional suggestions and edits incorporated. In addition to the choice-based items, free text responses were solicited in two places within the survey. The first immediately followed the ranking of the research topics and stated: “Please use the space to add any other areas of research that are important to you but were not mentioned above.” The second was at the end of the survey and stated: “Please use the space to add anything else about your pain that is important to you but was not mentioned above.”

Survey dissemination and ethics statement. The project, including the final version of the survey (see Supplementary Materials), was reviewed by the Icahn School of Medicine at Mount Sinai (ISMMS) Program for the Protection of Human Subjects and it was determined that the project was exempt human research as defined by the US Department of Health and Human Services (DHHS) regulations (45 CFR 46. 101(b) (2)). Personally identifiable information was not collected. Survey data were collected and managed using REDCap (Research Electronic Data Capture) hosted at ISMMS.(Harris et al., 2019; Harris et al., 2009) There was no financial compensation for participation.

*Analytic considerations.* The primary results are descriptive statistics of survey responses. Participants' ratings of the research topics (on the 5-point Likert scale ranging from "not at all important" to "extremely important") were transformed to a scale of 1-5, and median and interquartile range (IQR) were calculated for each research topic. We performed limited inferential statistics. Ordinal regressions (with proportional odds ratios determined by logit, and loglog links where necessary) were used to establish whether there was a statistically significant difference between the median ratings accorded to each of the seven research topics; this was repeated for the rankings. Goodness of fit was checked using the Lipsitz, and Hosmer-Lemeshow tests. (M. W. Fagerland & Hosmer, 2013; Morten W. Fagerland & Hosmer, 2016; Lipsitz et al., 1996) We also explored whether respondent characteristics (e.g., demographics, pain characteristics etc.) influenced the rating of research topics. To do so, principal component analysis (PCA) was first used to summarize the rating of research topics overall. We then used a multinomial linear regression model to assess whether respondent characteristics were associated with the main principal component (PC1) representing the rating of research topics.

Finally, we performed qualitative analyses on the free text responses. One individual from the team (AW) conducted a content analysis of the qualitative data using NVivo (Release 1.7.1, QSR International). (Hsieh & Shannon, 2005; Kondracki et al., 2002) After reviewing the data, she produced initial codes to summarize key topics within the data. A consensus meeting was held with two other team members (JRP & WS) to review the initial coding against the data to ensure the relevance and appropriateness of the codes. In this process, some codes were refined, while some of the primary data were re-allocated to other codes. Frequencies were then tabulated for each code.

## **Results**

*Participant characteristics.* The survey received a total of 311 responses between November 2020 and July 2022. Self-reported participant demographics are summarized in Table 1. Most participants (77%) were in their 50s or 60s and had longstanding HIV, with 30.6% reporting disease duration of over 30 years and only 13.5% reporting a disease duration of less than 10 years. Nearly 90% of respondents resided in the U.S., and the majority identified as white, men, and as LGBTQ (i.e., lesbian, gay, bisexual, transgender and/or queer). About 2/3 were not currently working (either unemployed, disabled or retired).

*Rating and Ranking of Research Topics.* Figure 1 summarizes the overall importance ratings of each of the research topics. Over 80% of respondents considered all research topics either "extremely important" or "very important." Research to establish the best management for chronic pain among people with HIV (Research Topic #2) received the strongest support, whereas research on the cost-effectiveness of chronic pain treatments (Research Topic #6) received the least. Figure 2 shows the participants' ranking of the research topics (i.e., relative to one another) from one to seven where one is the most important.

Ordinal regression confirmed that the "best management" research topic was considered significantly more important than the other topics. The likelihood of "best management" being rated "extremely important" was at least 19% higher than the other topics overall and 50% higher than the lowest rated topic ("cost-effectiveness"). "Best management" also received the highest importance ranking, with over half of participants assigning it the highest or second highest priority. Determining the causes of chronic pain in HIV (Research Topic #1) was also ranked highly with just under 50% of participants ranking it first or second. Prevention of chronic pain in HIV (Research Topic #7) displayed an interesting

bimodal pattern in that a large number of respondents ranked it first or second (just below 40%) but also nearly 30% ranked it 7<sup>th</sup> or “not important at all.” Ordinal regression using these ranking data revealed that there was no significant difference between the ranking of the top two (“best management” and “causes”) research topics.

*Lived experiences of chronic pain, and treatments.* Respondents’ chronic pain experiences are summarized in Table 2. The majority (n=296, 95%) replied affirmatively to the question “Is pain a problem in your life?” Most participants had pain of long duration, with about 2/3 reporting pain for six or more years. Over 90% reported that the pain over the preceding week had been at least “moderate,” with almost half of all participants reporting “severe” or “very severe pain.” Pain was commonly multisite with a median of 4 (IQR=2, 5) distinct pain locations and a median of 2 (IQR=1, 4) self-reported pain diagnoses. Pain consistent with peripheral neuropathy was the single most commonly reported pain symptom, reported by 70.1% of respondents, followed by low back pain which was reported by 66.2%. Symptoms of anxiety and depression were present in 41% and 44% of respondents, respectively.

A multinomial linear regression was used to establish whether any of the demographic or pain characteristics were associated with differences in overall ratings of the research topics (as summarized using PCA). We found that the model explained only about 10% of the variance and most of the factors were not associated with differences in survey response patterns. However, overall, respondents who identified as transgender rated the research topics more favorably ( $p < 0.001$ ), whereas respondents who reported being Latinx/Hispanic and respondents who endorsed pain “everywhere in your body” rated the research topics less favorably ( $p = 0.038$ ,  $p = 0.046$  respectively).

Figure 4 summarizes the various treatment modalities tried by respondents and their impression of the treatments’ efficacy. Respondents reported trying a median of 10 (IQR=8, 13) of the 21 listed therapies. Of all the treatments queried, prescription opioids were considered most helpful by most participants. A total of 199 had tried prescription opioids (currently or in the past) of whom 68% reported that their pain was “very much improved” or “much improved” by opioids. Other treatments which were rated as “very much improved” or “much improved” by >40% of those who reported trying them were: interventional pain management (53%), massage (49%), cannabinoids (48%), and physical therapy (44%).

*Qualitative analyses of free text responses related to research priorities.* Thirty percent of respondents answered the open-text prompt about additional research priorities for chronic pain. Most responses were related to pain in HIV, and many overlapped with the seven research topics. In addition, some respondents used this space to comment on research priorities more broadly (i.e., not clearly related to pain). Free-text response categories are summarized in Table 3.

Overlapping with Research Topic #2, the most frequent free-text category was management of pain, particularly management with medication. Most of these comments related to opioid policy and access, or potential interactions between medications. Regarding opioid policy and access, eight individuals’ comments were in relation to policy and guidelines. Two individuals spoke of how their pain had not been managed as well following the publication of the US Center for Disease Control (CDC) opioid prescribing guidelines, (Dowell et al., 2022) another spoke of the need and right for patients to be involved in their pain management choices. One participant articulated the need to describe the spectrum between effective opioid-assisted chronic pain management and addiction. Eleven individuals wanted greater focus on complementary/alternative treatments including acupuncture (n=4), massage

therapy or manual treatments (n=4), and the impact of nutrition (n=1). Two individuals requested more research into treatments for peripheral neuropathy.

There were several requests for research on causes of pain (overlapping with Research Topic #1), including links between antiretroviral therapy and pain, and inflammation and pain. Two participants made comments about mental and social health factors (Research Topic #4). These included understanding the mind-body connection in pain including the role of financial insecurity, stigma, intimate partner violence, grief and loss, spirituality, past and inter-generational traumas.

The free text comments which were directly related to pain research but did not fit into one of the seven research topics mostly provided suggestions for study design including: consistent inclusion of HIV-negative control groups, broadening of inclusion criteria in recognition of the many co-morbidities affecting people with HIV, the development of more objective pain outcome measures, and prioritizing research on treatments that will be broadly accessible.

Other comments related to pain, but not directly to research. For example, the comments included in the “medical professionals” category generally addressed the desire for improved interactions with health care providers on the subject of pain. Respondents reported feeling stigmatized, or as though the pain were being ignored, or not agreeing with medical professionals on desired treatment outcomes and feeling powerless within these interactions. Some of these respondents advocated for better training for medical professionals including training on how to recognize and diagnose pain or painful conditions early on, including neuropathy, and on pain management strategies beyond prescribing opioids. Additionally, five participants highlighted the need for better patient education on chronic pain.

Some free text comments did not appear to relate to pain. For example, the “comorbidities” category included thirteen free text responses that emphasizes the importance of research into other bothersome but not necessarily painful problems including fatigue, kidney and liver problems, arthritis, lipodystrophy, muscle wasting and sexually transmitted diseases. In addition, four individuals requested more focus on aging related issues such as menopause, the effect of age on medication efficacy, vision, urinary issues, weight gain, swelling and joint pain.

*Qualitative analyses of free text responses related to the respondents’ own pain.* Thirty-seven percent of respondents gave one or more responses (Table 4) to the second free-text prompt which stated: “Please use the space to add anything else about your pain that is important to you but was not mentioned above.”

Sixteen participants shared details of their pain experience including the interference with physical activity, impact on mood and the complexity, intensity and variation of the pain. The topic of medication was comprised of comments about opioids, treatment complications and over the counter medications. There was a mixed reaction towards opioids from eight participants: some people found them very helpful, others did not, and others were concerned about side effects. Two participants commented on over the counter medications including that they were a daily feature of their lives. Sixteen participants shared the perceived cause of their pain. In the quantitative question asking whether participants had ever been diagnosed with certain pain conditions, we neglected to include peripheral neuropathy as an option. Twelve participants pointed this out and spoke of their painful neuropathy. A further three participants reported other reasons for pain including a blood clot, car accident and pain attributed to nutritional abnormalities. Fifteen individuals shared how their access to therapies was limited. Five



individuals commented on limited access to medications that helped them because of changes in prescribing policies. Three participants reported that treatments were too expensive or not covered by insurance. The distance to treatment clinics and spaces to engage in physical activity was also a barrier to pain management. Regarding communication, 11 participants described not feeling believed by healthcare providers, and their frustration at providers' lack of knowledge about pain conditions and their treatment. Three participants shared feeling stigmatized by health care providers, particularly around taking opioids, and not wanting to be seen as addicts. Seven participants described the effects of the COVID-19 pandemic including worsened mental health, and inability to access health care services, physiotherapy or the gym. Participants described a wide range of different treatments and practices that helped their pain. These include yoga and stretching, chiropractic, muscle techniques, acupuncture, electrostimulation, marijuana, topical therapies, and access to nature.

## **Discussion**

The purpose of the present study was to understand: 1) how important the Task Force's research topics (in the area of chronic pain and HIV) were to people with lived experiences with these conditions, and 2) to gather information on pain and treatment experiences and how personal or HIV health characteristics might relate to respondents' priorities for research. We found that overall respondents agreed with the importance of the research topics, and that establishing the best management for pain in people with HIV was considered the most important. This was not strongly influenced by the personal characteristics of the respondents. This prioritization of pain management was unsurprising given the severity, long duration, and treatment resistant nature of respondents' symptoms. Nearly half of respondents described their pain as present in multiple body parts, severe or very severe, and of over 10 years duration.

Relevant to the topic of "best management," respondents emphasized the issue of opioids for pain in both the quantitative and qualitative data, with 68% of respondents who had used opioids (currently or in the past) reporting that they were "very much improved" or "improved" while taking them. These responses contrast with other less favorable data on the effect of opioids for chronic pain (which are not specific to people living with HIV). A 2006 meta-analysis concluded that strong opioids improved pain but not function, whilst weak opioids and non-opioids improved function and not pain.(Furlan et al., 2006) A more recent systematic review and meta-analysis found a small but significant benefit of opioids on health related QOL, but also noted that most trials were of relatively short duration (average of 15 weeks).(Thornton et al., 2017) Epidemiologic data on the effect of opioids is generally even less positive showing poorer outcomes, including decreased likelihood of return to work, among patients receiving opioids.(Eriksen et al., 2006; Sullivan & Howe, 2013) Our study was not specifically designed to focus on opioids, and so details are lacking (e.g., dose, duration of treatment). Nonetheless, it is thought provoking that opioids were the therapy that this highly experienced and long-term chronic pain population considered the most helpful, with very few reporting harm. Although potential for bias among respondents must be considered, their views on opioids could also reflect deficiencies in education and communication about alternative approaches and/or lack of access to such therapies. This is potentially supported by numerous free-text comments describing sub-optimal interactions with healthcare providers and systems, and the relatively low importance respondents assigned to the "psychosocial contributors" research topic. Regardless, the respondents' preference for opioids stands in sharp contrast to the risks as generally perceived by the medical community, and speaks to the need for safer, more effective pain medications that will be acceptable to both patients and prescribers.

A recent study by Uebelacker et al also examined the self-reported effectiveness of various treatments for chronic pain in a US clinic-based sample of people with HIV.(Uebelacker et al., 2022) Similar to our findings here, oral medications were the most commonly used category of treatment, specifically non-steroidal anti-inflammatories (NSAIDs) followed by opioids. The study only queried the perceived efficacy of the non-pharmacologic treatments. Nonetheless there was some similarity in the perception of physical therapy efficacy between the studies with 39% describing it as “moderately helpful” or “very helpful” in the prior study and 44% describing the outcome from physical therapy as “very much improved” or “improved” herein. There are also some data in people with HIV to support the efficacy of some of the other treatments which were used commonly and viewed favorably by respondents including cannabinoids, massage, and exercise.(Amaniti et al., 2019; Jessica S. Merlin et al., 2016)

This study has important limitations. In an oversight, peripheral neuropathy was omitted from the list of painful diagnoses despite its high prevalence among people with HIV (although neuropathy symptoms were queried elsewhere). Also, the overlap of the survey period with the COVID-19 pandemic could have impacted the results. Although we aspired to reach an international sample of respondents, we ultimately received responses mostly from within the US, with a preponderance of responses from older, white men who identified as LGBTQ. This is likely related to the demographics of the readers of the publications in which we were able to promote the survey. We also received feedback from some persons with lived experience that lack of financial compensation for completing the survey may have discouraged responses within their communities. The results of this survey may not be generalizable to more diverse groups of people with HIV and chronic pain, however it is encouraging that the analysis demonstrated that in general the research topics were viewed positively regardless of the demographics of the respondents.

In addition, it appears that the research topics identified as most important by respondents aligned well with the topics of recently published studies in the field. A PubMed search for articles with “HIV” and “pain” in the title from 2019 (when the Task Force research topics were established) until June 2023 produced 128 records. Of these 34 addressed “best management,” 30 addressed “psychosocial contributors,” 25 addressed “causes,” 7 addressed “prevalence,” and 2 addressed “treatment individualization.” An additional 29 did not fit into any one particular topic. These included review articles covering multiple topics, studies that addressed characterization or assessment of pain, and those that studied pain in the context of another area of focus (e.g., smoking cessation). There were no studies specifically addressing prevention or cost-effectiveness. This suggests good alignment of the priorities of researchers and survey respondents given that “best management,” the topic rated the most important by persons with lived experience, was also the one with the most publications over the past 4 years. Similarly the cost-effectiveness topic included no publications and was rated the least important by survey respondents.

In summary, the results of this study suggest substantive alignment between the priorities of researchers and persons with lived experience in the area of HIV and chronic pain. The results also suggest areas outside of research in which the Task Force might support people with HIV and chronic pain. We designed this survey to assess research priorities, but the free-text responses suggest other important areas for action including fair and consistent opioid prescribing policies, provider education, and advocacy for equitable access to treatment.

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**Declaration of Interest**

The authors report no conflicts of interest.

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## Tables

<b>Table 1. Participant demographics (N=311)</b>	
	n (%)
Age, years	
18-29	7 (0.3%)
30-39	19 (6.2%)
40-49	29 (9.4%)
50-59	124 (40.3%)
60-69	113 (36.7%)
70-79	21 (6.8%)
80-89	1 (0.3%)
Gender	
Cis-gender man	222 (72.5%)
Cis-gender woman	76 (24.8%)
Transgender man	14 (0.6%)
Transgender woman	14 (0.6%)
Non-binary	5 (1.6%)
Prefer to self-describe	3 (1.0%)
Race and ethnicity (as many as apply)	
Asian	5 (1.5%)
Black	64 (19%)
Hispanic	23 (6.8%)
Middle Eastern/North African	2 (0.6%)
Native American/First Nations	12 (3.6%)
Native Hawaiian/Pacific Islander	2 (0.6%)
Other	10 (3.0%)
Prefer not to say	3 (0.9%)
White	216 (64.1%)
HIV disease duration, years	
< 1	5 (1.6%)
1-5	16 (5.3%)
6-10	20 (6.6%)
10-15	36 (11.8%)
16-20	35 (11.5%)
20-25	49 (16.1%)
25-30	50 (16.4%)
>30	93 (30.6%)
LGBTQ	
Yes	198 (65.1%)
No	96 (31.6%)
Prefer not to say	10 (3.3%)
Location	
Africa	4 (1.3%)
Australia or New Zealand	8 (2.6%)
Europe	17 (5.5%)
North America	278 (90.0%)
Canada	13 (4.7%)

U.S. Northeast	61 (22.1%)
U.S. Southeast	80 (29.0%)
U.S. Midwest	35 (12.7%)
U.S. Southwest	26 (9.4%)
U.S. West	61 (22.1%)
Employment status	
Employed full time	67 (21.8%)
Employed part time	24 (7.8%)
Unemployed	19 (6.2%)
Disabled/unable to work	125 (40.6%)
Retired	66 (21.4%)
Student	4 (1.3%)
Homemaker	3 (1.0%)



<b>Table 2. Participants' lived experiences of chronic pain<sup>a</sup></b>	
Duration of pain	
< 6 months	1 (0.3%)
6-12 months	13 (4.2%)
1-5 years	75 (24.1%)
6-10 years	62 (19.9%)
>10 years	143 (46%)
Severity of pain (over the past week)	
None	1 (0.3%)
Very mild	4 (1.3%)
Mild	21 (6.8%)
Moderate	125 (40.2%)
Severe	112 (36.0%)
Very Severe	32 (10.3%)
Average pain severity over the past week (0-10), mean (SD)	6.5 (2.0)
Average pain interference over the past week (0-10), mean (SD)	
General activity	6.2 (2.7)
Enjoyment of life	6.4 (2.9)
Sleep	5.6 (3.0)
Pain locations (as many as apply for at least 3 months)	
Headache	128 (41.2%)
Shoulder pain	171 (55%)
Abdominal pain	85 (27.3%)
Low back pain	206 (66.2%)
Hip pain	141 (45.3%)
Knee pain	141 (45.3%)
Numbness, tingling, burning or pain in feet, legs and/or hands	218 (70.1%)
Pain everywhere in your body	65 (20.9%)
Other	59 (19%)
Number of self-reported pain locations, median (IQR)	4 (2, 5)
Pain diagnoses	
Arthritis	152 (48.9%)
Cancer-related pain	20 (6.4%)
Migraine	39 (12.5%)
Chronic widespread pain or fibromyalgia	63 (20.3%)
Complex regional pain syndrome	11 (3.5%)
Degenerative spine disease	130 (41.8%)
Irritable bowel syndrome	46 (14.8%)
Musculoskeletal pain	81 (26.1%)
Other headache	35 (11.3%)
Pelvic pain	21 (6.8%)
Post-injury pain	39 (12.5%)
Post-surgery pain	31 (10%)
Tension-type headache	42 (13.5%)
Number of pain diagnoses, median (IQR)	2 (1, 4)
Mood symptoms <sup>b</sup>	

GAD-2	2 (1, 4)
PHQ-2	2 (1, 4)
Symptoms of anxiety (GAD-2 score >2)	122 (41.2%)
Symptoms of depression (PHQ-2 score >2)	130 (44.1%)
Effect of the COVID-19 pandemic	
Worse pain during the pandemic	153 (49.2%)
Worse access to pain treatment during the pandemic	144 (46.3%)

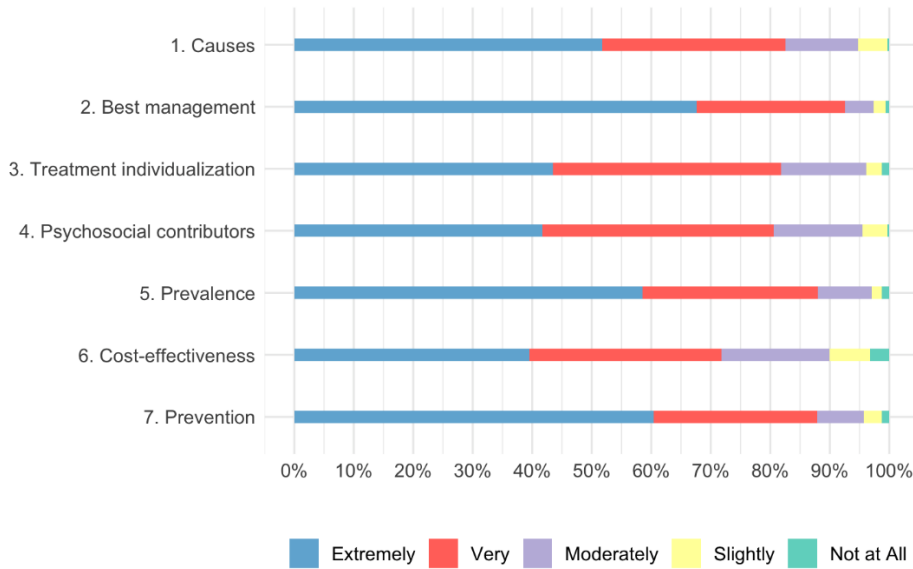
- a. Values are n (%) unless otherwise indicated.
- b. GAD-2 and PHQ-2 have a possible range of 0-6 with 6 indicating the most severe symptoms.

<b>Table 3. Categorization of free-text responses to research priorities related to HIV and chronic pain prompt</b>	
	<b>Number of responses</b>
<b>Free text response categories which overlapped with the Research Topics</b>	
Causes of pain (Research Topic #1)	19
Management of pain (Research Topic #2)	
Medication management	21
Non-pharmacologic management	11
Finding a cure	6
Neuropathy treatment	2
Mental and social health factors (Research Topic #4)	2
<b>Other categories of free text responses</b>	
Comorbidities	13
Medical professionals	7
Patient education on pain	5
Study design considerations	5
Aging	4

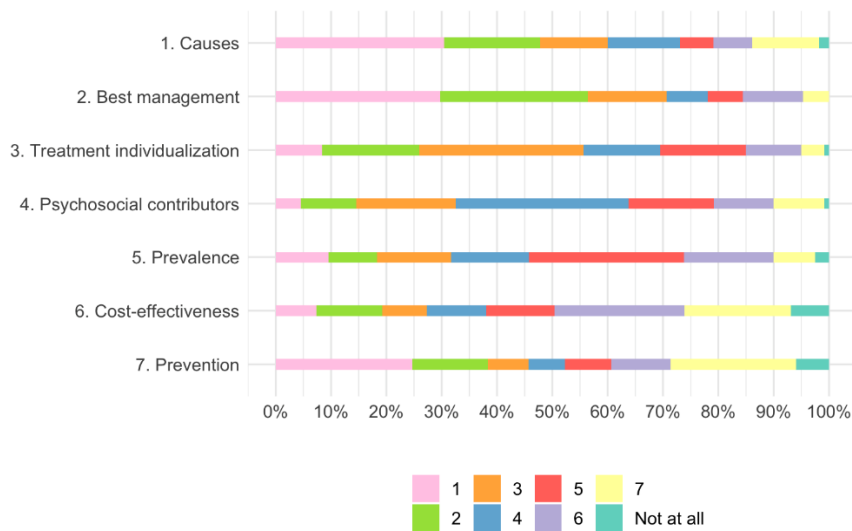
<b>Table 4. Categorization of free-text responses regarding the respondents' own pain</b>	
<b>Topic</b>	<b>Number of responses</b>
Pain experiences	16
Medication	16
Causes of pain	16
Access to things that could improve quality of life	15
Communication frustrations with medical professionals & stigma	11
Impact of COVID-19	7
Beneficial practices	6
Mental health	2
Aging	2

## Figures

**Figure 1. Importance ratings assigned by respondents to of each of the seven research topics.** Length of bar indicates the percent of responses in each importance category for each research topic.



**Figure 2. Importance rankings assigned by respondents to of each of the seven research topics.** Length of bar indicates the percent of responses in each importance rank for each research topic (1 is the most important).



**Figure 3. Treatments tried by respondents for pain and perceived efficacy.** Abbreviations: OTC = over the counter, OT = occupational therapy, PT = physical therapy, CBT = cognitive behavioral therapy

