COVID-19 CHECK IN
Brief Interviews with PLWH in the NYC CHAIN Study Cohort

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In response to a pause of all in-person research due to the COVID-19 pandemic, in early March, a modified protocol for outreach to NYC CHAIN study participants via telephone or mail was implemented.   The initial effort during March and April was designed as a brief check-in to see how participants were doing regarding general health, medical or social service needs for which we might provide information, and confirming contact information for their next in-person interview. However, so many participants reported multiple concerns about the pandemic, and unmet needs, that we expanded the phone survey instrument. Beginning in late April we included additional questions, focused specifically on COVID-19 issues.[1] We interviewed on a total of 305 NYC CHAIN study participants between March 24 and October 1, 2020.

This Brief Report is a descriptive analysis of results of the CHAIN inter-wave COVID-19 check-in. Analyses focus on experiences and concerns of study participants in the early phase of the pandemic in NYC when rates of infection were highest (over 50%) with 4,000+ cases per day diagnosed; a state of emergency declared; mandated restrictions on non-essential business, gatherings of any size, and social distancing were strongest; as well as recommendations for sheltering in place. We also compare results during early and later phases of the pandemic, with 'later' corresponding to phase three of reopening when positivity rate in NYC fell below 2% and most restrictions lifted.

Research questions we explore: How are CHAIN study participants doing with regard to threats, stresses, and restrictions associated with COVID-19 pandemic? What are their informational, medical, behavioral health, and supportive service needs during COVID-19 social and economic disruption, restricted access and/or capacity strain of health and essential services?

SUMMARY OF FINDINGS

<u>Sample characteristics.</u>   The Inter-wave COVID-19 sub-sample is comparable to the full CHAIN cohort study population at last interview, completed 2016-2019 with regard to gender, age, race/ethnicity, poverty level, history of problem substance use or low mental health functioning. The major difference is recent homelessness or unstable

METHODOLOGY

- Data for analysis were provided by a phone survey with persons living with HIV/AIDS in New York City, a subsample of CHAIN study participants (n=305)

- The original CHAIN sample was designed to be representative of the HIV-infected population receiving medical and/or social services in New York City or the Tri-County northern suburban region https://nyhiv.org/nyhiv-archive/data_chain.html

- This report is based on 305 NYC PLWH interviewed by phone between March 24 and Oct 1, 2020. Analyses compare results from earlier (March-June) and later (July-Sept) periods of the pandemic.

- Study participants answered questions about health status, informational and service needs, experiences and worries due to COVID-19 pandemic.

- Measures are based on items used in national surveys, found in the Societal Experts Action Network COVID-19 survey compendium, a research resource supported the National Academies and the NSF https://covid-19.parc.us. com/client/index.

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[1] We also arranged to respond to requests for information and service needs using an online resource guide providing details about eligibility, languages spoken, COVID-19 related restrictions; access facilitated by NYC DOHMH.

housing at most recent CHAIN study interview. Only about half of the proportion of respondents who were homeless/unstably housed have been located for the Inter-wave interview (Table 1).

Risk for COVID-19.   Among the COVID-19 subsample, as well as the general CHAIN cohort sample, three-fourths (74%) of study participants   report one or more of CDC listed medical conditions increasing risk for COVID-19 serious illness: asthma, other respiratory conditions (COPD, emphysema, chronic bronchitis), heart condition, diabetes, cancer, or BMI >40. Almost half (46%-47%) are medically at higher risk for COVID indicated by Age 55+ yrs and two or more COVID-19 related health comorbidities. Almost all are at increased risk for COVID-19 infection and serious illness based on one or more 'structural disparity' indicator: Race /ethnicity African American or Latinx, income below poverty level, recent homelessness/unstable housing, or ever jail/prison.

FINDINGS FROM EARLY PHASE OF COVID-19 PANDEMIC IN NEW YORK CITY

Table 2 presents findings on general health, self-reported service needs, and COVID19 specific experiences and concerns among CHAIN study participants interviewed in the early phase of the pandemic, March 24 to June 30, 2020. Note that a total of 241 individuals were interviewed during this time period, however, most COVID-19 specific questions were answered by 100 respondents who completed the expanded data collection form. Case base for each question is reported on the tables.

Current Health.   When asked to rate their current health as excellent, very good, good, fair, or poor, the most common answers were very good or good. However, 11% rated their health as only fair or poor. Nine individuals volunteered being diagnosed with COVID-19 infection, and an additional participant was reported as having died from coronavirus.

Informational needs. Almost all respondents had received information about coronavirus but partici-pants reported information was not always sufficient. Most felt they knew the basics on how to reduce risk for COVID transmission but 14% answered that they did not get enough information or did not understand information received from doctors office or case manager about how coronavirus might affect their health. Similarly, the same percentage reported they did not get enough information or did not understand information about how to get medical or other services they might need when offices were closed due to the virus.

Subsistence needs.   The greatest reported needs in the earlier period of the pandemic have been for food, financial assistance, and/or housing.   The need for food was described, often with grave concern, by more than one in four (28%) participants and 38% reported needing money or financial assistance (n=241). In a set of questions asking specifically about experiences due to the coronavirus (n=100), half of study participants answered they experienced financial hardship and were struggling to make ends meet. Housing issues, especially concern about ability to pay rent, were described by 19% of study participants. An important concern in the early part of the pandemic continuing was the inability to get cleaning supplies or hand sanitizer.

Health care needs. Combining all available information including qualitative reports, about one-quarter of respondents interviewed during the earlier period of the pandemic reported need for medical or mental health care or substance use services (data not shown). In response to a specific question, 14% answered that they were unable to get medical care not related to COVID-19, which included care related to HIV or non-HIV chronic illness comorbidities (n=100).

Psychological Distress. A standardized measure of event related psychological distress developed specifically for COVID-I9 community studies included depression and anxiety symptoms as well as questions about loneliness and feeling hopeful (or not hopeful) about the future. One-third of the sample answering the distress questions (n=100) scored 'high' (n=36) on the summary measure.

COVID-19 worries. When asked specifically whether participants were worried about coronavirus infection, 55% answered that they were very or somewhat worried that they or someone in their family will get sick from coronavirus (n=100). Worries about economic fallout and financial consequences of shut down were common; when asked specifically, 54% were worried that their financial situation will get even worse than it is now.

Barriers to telehealth. Almost all (95%) of respondents reported that they had a computer, smart phone or tablet with internet access in their home. However one in five (20%) did not have capacity or weren't sure of capacity for videoconferencing, describing reasons including their phone had limited minutes, no internet in the home or internet was not broadband, the computer was not theirs but someone else's in the household. A bigger barrier seems to be digital literacy - one-third of respondents answered that they did not know how to use their phone or a computer to participate in a video conference for a medical or other appointment.

COMPARING EARLIER AND LATER PHASE OF COVID-19 PANDEMIC IN NEW YORK CITY

Tables 3 and 4 examines service needs, telehealth resources, and COVID-19 experiences and concerns, comparing CHAIN participants interviewed during the earlier (March 24 to June 30) and later (July 1 to October 1) phases of the pandemic. There were no significant differences in background characteristics among the two sub-samples. The case base for service needs is the full sample, n=305 and the subsample who answered COVID-19 specific questions is n=164, (n=100 interviewed in the earlier period and n=64 interviewed later)

Subsistence needs among CHAIN study PLWH were high during the first phase of the epidemic but even higher during the later phase. Over half (53% vs. 37%) of participants interviewed after July 1 reported need for food, groceries or meals; assistance with obtaining housing or paying rent; and/or general financial assistance to cover living expenses.

Health care needs. Indicators of need for medical care were consistent; at both interview periods, 16% of participants answered that their health was only fair or poor and/or reported need for medical services. Need for behavioral health services (substance use or mental health) were higher in the later period, driven primarily by the increase in self-reported need for mental health services or treatment (28% vs. 11%).

Informational needs were less during the later phase of the epidemic with fewer respondents answering that they did not get enough information or did not understand information received about how coronavirus might affect their health (25% vs. 13%). The biggest reduction in information needs was percentage of respondents who reported that they did not have information about how to get medical or other services they might need when offices were closed due to coronavirus (9% in the later period compared to 17% in the first months of the pandemic).

Barriers to telehealth/ digital health resources. Rates of both lack of devices (computer, tablet, smart phone) or limited connectivity (no or inadequate internet access) were lower in the later period (32% vs 18%). However, close to one in five (18%) continue to report lack of technology or digital literacy as a barrier to accessing telehealth resources.

<u>Worries due to COVID-19 Pandemic</u> remain high in the later period. Worry that they or a family member will get sick from the virus was less than at the peak of the pandemic but remained at over 40%. Worry about worsening financial situation decreased slightly but was still at 50%.

<u>Psychological Distress</u> indicators are higher among CHAIN respondents interviewed more recently compared to those interviewed in the earlier period. Almost half (48%) scored high on a standardized measure of event-related psychological distress, compared to 35% who completed the measure during the prior four months. There is a reduction in the percent who <u>do not</u> feel hopeful about the future (62% vs. 49%) but relatively few report feeling hopeful.

<u>Experiences because of COVID-19</u>. Consistent with descriptions of service needs, answers to specific questions about loss of financial resources and increase in financial hardship due to the pandemic have only increased during the later period. Need for food assistance has remained constant. There was a slight increase in reports of increased use of alcohol or drugs. Need for cleaning supplies and hand sanitizer remained constant from March through June but fewer participants in the later period report being unable to get these supplies .

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Table 1. Sample Characteristics – COVID-19 Subsample and Full CHAIN Study Cohort

	(n=)	COVID-19 check-in (n=305)[1]	CHAIN 2016-19 (n=618)[2]
Cisgender male		23%	26%
Sexual or gender minority[3]		43%	43%
55+ Years Old		18%	19%
Medical Comorbidities[4]		74%	74%
Black/Latinx		91%	89%
Household below poverty level		55%	62%
High risk neighborhood[5]		45%	45%
Recent homelessness/ unstable housing[6]		18%	30%
History of problem substance use[7]		45%	44%
Low mental health functioning score[8]		50%	56%
Ever jail or prison		33%	31%
Higher risk for serious illness from COVID-19[9]		46%	47%
Increased risk - structural disparity indicator[10]		97%	97%

[1] Phone interviews with sub-sample of CHAIN cohort respondents March 24 – October 1, 2020

[2] Full CHAIN cohort, last interview completed 2016-2019.

[3] Self-identification as gay or lesbian, history of same sex behavior, transgender or gender nonconforming.

[4] In addition to HIV infection, any CDC listed medical conditions increasing risk for COVID-19 serious illness: asthma, other respiratory conditions (COPD, emphysema, chronic bronchitis), heart condition, diabetes, cancer, BMI $\geq$40.

[5] Residence in high poverty neighborhoods burdened by poor health established as priority for Neighborhood Health Action initiative established by NYC DOHMH Center for Health Equity and Community Wellness.

[6] Homeless (on the street or other place not intended for sleeping, in a homeless shelter, limited stay SRO or welfare hotel); or unstably housed (in a transitional housing program or residential treatment or temporarily doubled with others in someone else's home) reported at most recent CHAIN study regular interview.

[7] Use of heroin, cocaine, crack or methamphetamine, or problem drinking (CAGE) Ewing JA. Detecting Alcoholism: The CAGE questionnaire. JAMA. 1984; 252: 1905-1907.

[8] MOS-SF36 Mental Component Summary Score <42.0 indicating clinically significant mental health symptoms (depression, anxiety, impairment) at most recent CHAIN study interview. McHorney CA et al. (1993). The MOS 36- item short-form health survey (SF-36). Medical Care, 31, 247–263.

[9]   Age 55+ yrs and two or more COVID-19 related health comorbidities.

[10] Black/Latinx, below poverty level, recent homelessness/unstable housing, or ever jail/prison.

Table 2. COVID-19 Experiences among New York City CHAIN Study Participants – Early Epidemic

	COVID-19 Check-In March 24 – June 30, 2020	
	N[1]	%
Quality of Life (n=241)		
Very well, could hardly be better	20	8%
Pretty good	91	38%
Good	112	47%
Pretty bad	15	6%
Very bad, could hardly be worse	2	1%
Current Health (n=238)		
Excellent	36	15%
Very good	86	36%
Good	90	38%
Fair	24	10%
Poor	2	1%
Current Self-Reported Service Needs (241)[2]		
o Food	67	28%
o Financial/money	67	38%
o Housing	45	19%
o Mental Health care	27	11%
o Medical care	14	6%
o Transportation	6	3%
o AOD help	5	2%
o Child Care	1	<1%
COVID-19 Infection (n= 241)[3]		
o Reported COVID-19 infection (including 1 death)	10	4%
COVID-19 Pandemic Information Needs (n=100)		
o Do not have enough or don't understand information received to protect self and family from coronavirus	6	6%
o Did not get enough or don't understand information from doctor or case manager about how CV might affect your health	14	14%
o Did not get enough or don't understand info from MD or CM about how to get services when offices closed due to CV	14	14%
Because of the COVID-19 Outbreak (n=100)		
o Lost job, laid off, work hours reduced without pay	30	30%
o Experienced financial hardship, struggling to make ends meet	49	49%
o Unable to get food, groceries, or meals	27	27%
o Unable to get cleaning supplies or hand sanitizer	50	50%
o Unable to get prescription medications	6	6%
o Unable to get medical care not related to COVID-19	11	11%
o Increased use of alcohol or drugs	6	6%
Currently "sheltering in place" (n=100)		
o You don't leave your home except for essential things such as food or medicine	87	87%

Table 2. COVID-19 Experiences among New York City CHAIN Study Participants (continued)

	N	%
Worried that you or family will get sick from CV (n=100)		
Very worried	17	17%
Somewhat worried	38	38%
Not too worried	32	32%
Not worried at all	13	13%
Worried that you will put yourself at risk of CV because unable to afford to stay home and have to go out to work (n=100)		
Very worried	4	4%
Somewhat worried	13	13%
Not too worried	38	38%
Not worried at all	46	46%
Worried that financial situation will get even worse (n=100)		
Very worried	12	12%
Somewhat worried	42	42%
Not too worried	26	26%
Not worried at all	21	21%
Psychological distress (n=100)[4]		
In the past 2 weeks, more than half the days or nearly every day		
o Felt nervous, anxious, or on edge	19	29%
o Felt depressed	14	14%
o Felt lonely	14	14%
o Felt hopeful about future	38	38%
o Had trouble sleeping	15	15%
o High psychological distress score	36	36%
Current Living Situation (n=98)		
Own place	89	91%
SRO or shelter	3	3%
Temp doubled up or other	6	6%
Household composition (n=100)		
Lives alone	65	65%
Lives with one other person	23	23%
3 or more persons in household	13	13%
No computer, tablet, smartphone with internet access (n=100)	5	5%
Resources for Telehealth (n=100)		
o Do not have enough minutes on the phone	9	9%
o Computer/phone may not allow for video conferencing[5]	20	20%
o Don't Know how to use computer/phone for video conference for medical or other appointment	32	32%

[1] Results based on 241 CHAIN cohort study participants contacted by phone between March 24 and June 30, 2020. Questions about general health and information and service needs were answered by all participants.   A subset of participants (n=100) completed a revised questionnaire that included additional COVID-19 specific questions.

[2] Any indicator of service needs based on answers to specific questions and coding answers to open-ended questions about service needs.

[3] COVID-19 diagnosis based on volunteered self-report from respondent or death reported by contact person.

[4] Psychological Distress Scale comprised of five standard questions adapted from GAD-7, CES-D, and the Impact to Event Scale Revised. NIH PhenX COVID-19 Toolkit; PEW Research Center. Cronbach's alpha .811

[5] No or limited internet service, phone with limited minutes, phone does not or may not allow video conferencing

Table 3. Informational and Service Needs – Early and Later in the COVID-19 Pandemic

	Total Sample[1]	Early in Pandemic (Mar- June)	Later in Pandemic (July- Sept)
	(n=305)	(n=241)	(n=64)
Subsistence Needs[2]	**40%**	**37%**	**53%**
Need food, groceries, meals	*25*	*25*	*32*
Need financial assistance, money	*21*	*18*	*38*
Need housing, assistance with housing	*18*	*16*	*24*
Health Care Needs[3]	**16%**	**16%**	**16%**
Health now poor or only fair	*11*	*11*	*11*
Report need medical care or prescriptions	*8*	*8*	*10*
Behavioral Health Needs[4]	**14%**	**11%**	**28%**
Report need for mental health services	*12*	*10*	*21*
Report need substance use services	*3*	*2*	*8*
	(n=164)	(n=100)	(n=64)
Informational Needs[5]	**20%**	**25%**	**13%**
Did not get or don't understand information about how coronavirus might affect your health	*12*	*14*	*13*
Did not get or don't understand information about how to get medical or other services when offices closed due to coronavirus	*14*	*17*	*9*
Barriers to Telehealth/ Digital Resources[6]	**27%**	**32%**	**18%**
No or limited technology - device or connectivity	*12*	*15*	*8*
Don't know how to use computer/phone for video conference for medical or other appointment	*18*	*30*	*15*

[1] Phone interviews with CHAIN cohort respondents March 24 –October 1 2020.

[2] Any indicator of subsistence needs based on answers to specific questions and coding answers to open-ended question about needs

[3] Any indicator of need for medical, based on answers to specific questions and coding answers to open-ended questions about needs.

[4] Any indicator of need for mental health or substance use services based on answers to specific questions and coding answers to open-ended questions about needs.

[5] Did not get enough information or got information but don't understand how to protect self or family from coronavirus; or how the coronavirus might affect your health; or how to get medical or other services when offices closed due to coronavirus

[6] No or limited internet service, phone with limited minutes, phone does not or may not allow video conferencing, or don't know how to participate in video conference for medical or other service appointment

Table 4. COVID-19 Worries and Psychological Distress Earlier and Later in the Pandemic

	Total Sample (n=164)[1]	Early in Pandemic (Mar- June) (n=100)	Later in Pandemic (July- Oct) (n=64)
Worries Due to COVID-19[2]			
Worried you or family will get sick from COVID-19	51%	57%	42%
Worried about putting self at risk of COVID-19 because can't afford not to go out to work	20%	18%	22%
Worried financial situation will get worse than now	53%	53%	50%
Event Psychological Distress[3]			
Felt nervous, anxious, on edge	22%	18%	24%
Felt depressed	15%	13%	18%
Felt lonely	15%	13%	18%
Not hopeful about the future	57%	62%	49%
Had trouble sleeping	20%	14%	29%
High Psychological Distress scale score	40%	35%	48%
Because of the COVID-19 Outbreak[4]			
Lost job, laid off, work hours reduced without pay	31%	29%	33%
Experienced financial hardship, struggling to make ends meet	50%	48%	53%
Unable to get food, groceries, or meals	27%	26%	28%
Unable to get cleaning supplies or hand sanitizer	39%	50%	23%
Unable to get medical care or prescriptions	13%	13%	13%
Increased use of alcohol or drugs	7%	6%	9%

[1] Phone interviews with sub-sample of CHAIN cohort respondents answering COVID specific questions, March-September 2020.

[2] Somewhat or very worried

[3] Psychological Distress Scale comprised of five standard questions adapted from GAD-7, CES-D, and the Impact to Event Scale Revised. NIH PhenX COVID-19 Toolkit; PEW Research Center. Symptoms reported every day or more than half the days in the past two weeks.

[4] Experiences happened because of coronavirus.