

Gaps in Primary Care: Client Perspectives from the 2009 Return to Care Survey

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Background: Definition of return to care (RTC)

- PLWHA who have recently been re-connected to HIV primary care, after a lengthy absence from such care
 - This survey report excludes those “never in care” since HIV diagnosis

Background: RTC Pilot Survey 2008

- Highlights of findings:
 - 41 participants
 - Services most frequently used: Primary Care, HIV Counseling, Treatment Adherence
 - Service not received and needed: Dental care
 - Reasons for lapse in care: Not wanting to think about/deal with HIV/AIDS, alcohol or drug use, transportation problems, other concerns, and not sick enough to go for care
 - Motivators for care: Seeing the positive effects of primary care (for example, getting better/healthier)
- **More details were needed**

Background: Goal of RTC 2009

- Expand the survey scope
 - More providers
 - More respondents
 - Increased number of questions
- Understand the range of factors behind lapses and returns
- Examine the role of service interventions

Methods: Participant Sampling

- Worked with Ryan White Part A Maintenance in Care (MIC) service providers to verify clients
 - A return to care service between September 2008 and July 2009
 - ≥ 6 month gap in HIV primary care prior to return to care
 - ≥ 3 months of continuous enrollment in the program since return to care
- Collaborated with providers to schedule interview times and space

Methods: Survey Instrument

- Questions included:
 - Current health services and/or social services utilization
 - Reasons for not getting regular HIV primary care
 - Other services used when not getting primary care
 - Any specific person who facilitated the return to care
 - Any other reasons client returned to care
 - What keeps client in care now
 - Demographics

Methods: Survey Platform

- In-person, face-to-face interviews using ACASI (Audio Computer Administered Self Interview)

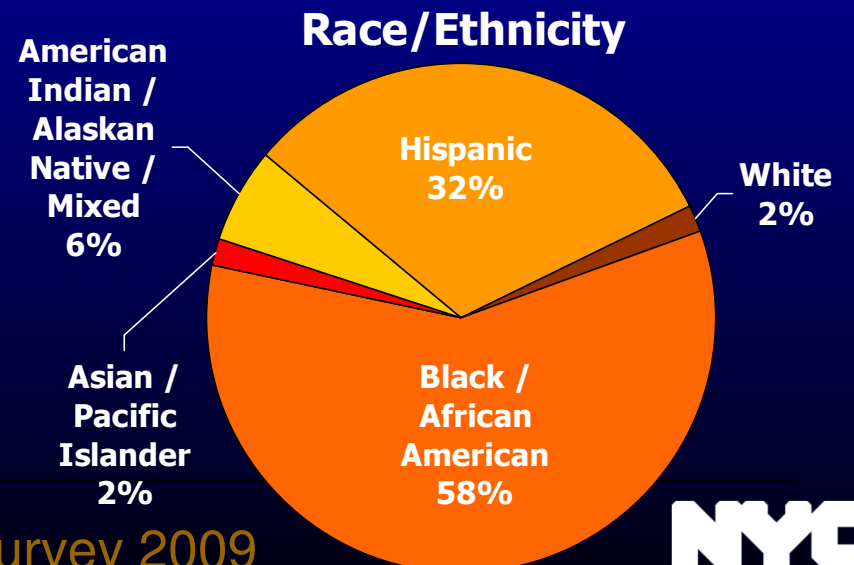
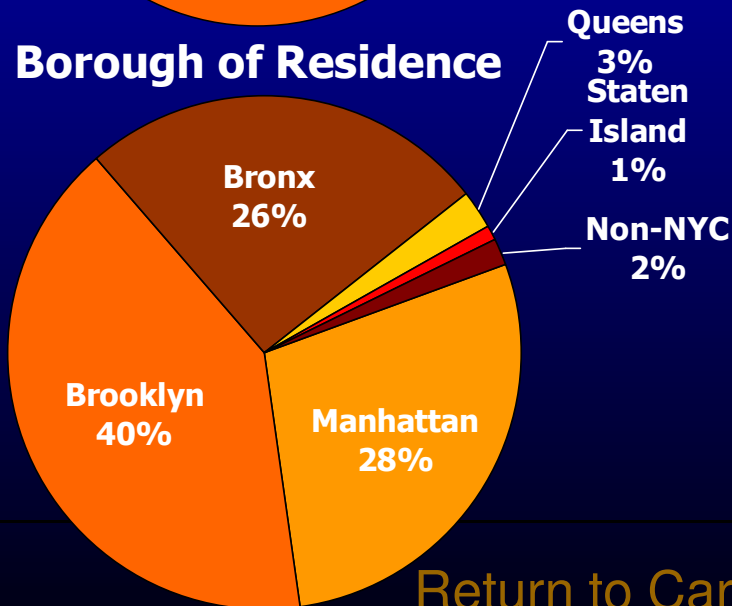
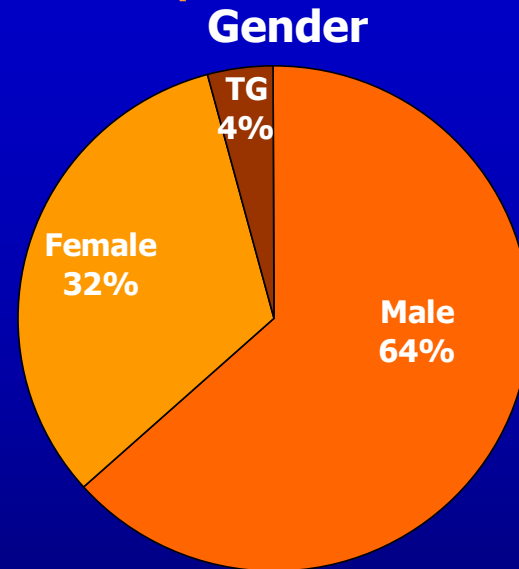
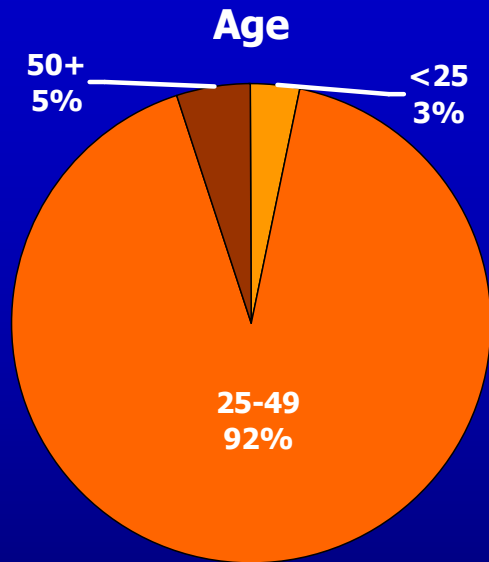
What health or social services have you used during the past three months? (Check all that apply.) Did you use:

Primary medical care	Alcohol or drug treatment	Case management	Don't Know
Housing assistance	Home care services, from a nurse, home health aide or homemaker	Other services	Refuse to Answer
Childcare services	Help with meals or grocery pantry bags		Not Applicable
Mental health services	Transportation to healthcare or social service appointments		Previous Question
			Next Question
			Repeat the Question

Results: Summary of Completion

	#	%
Total eligible	147	100
Surveys completed	117	79.6
Surveys not completed	30	20.4
<i>Difficulty contacting</i>	<i>14</i>	<i>46.7</i>
<i>Data lost/computer error</i>	<i>2</i>	<i>6.6</i>
<i>Refused</i>	<i>14</i>	<i>46.7</i>

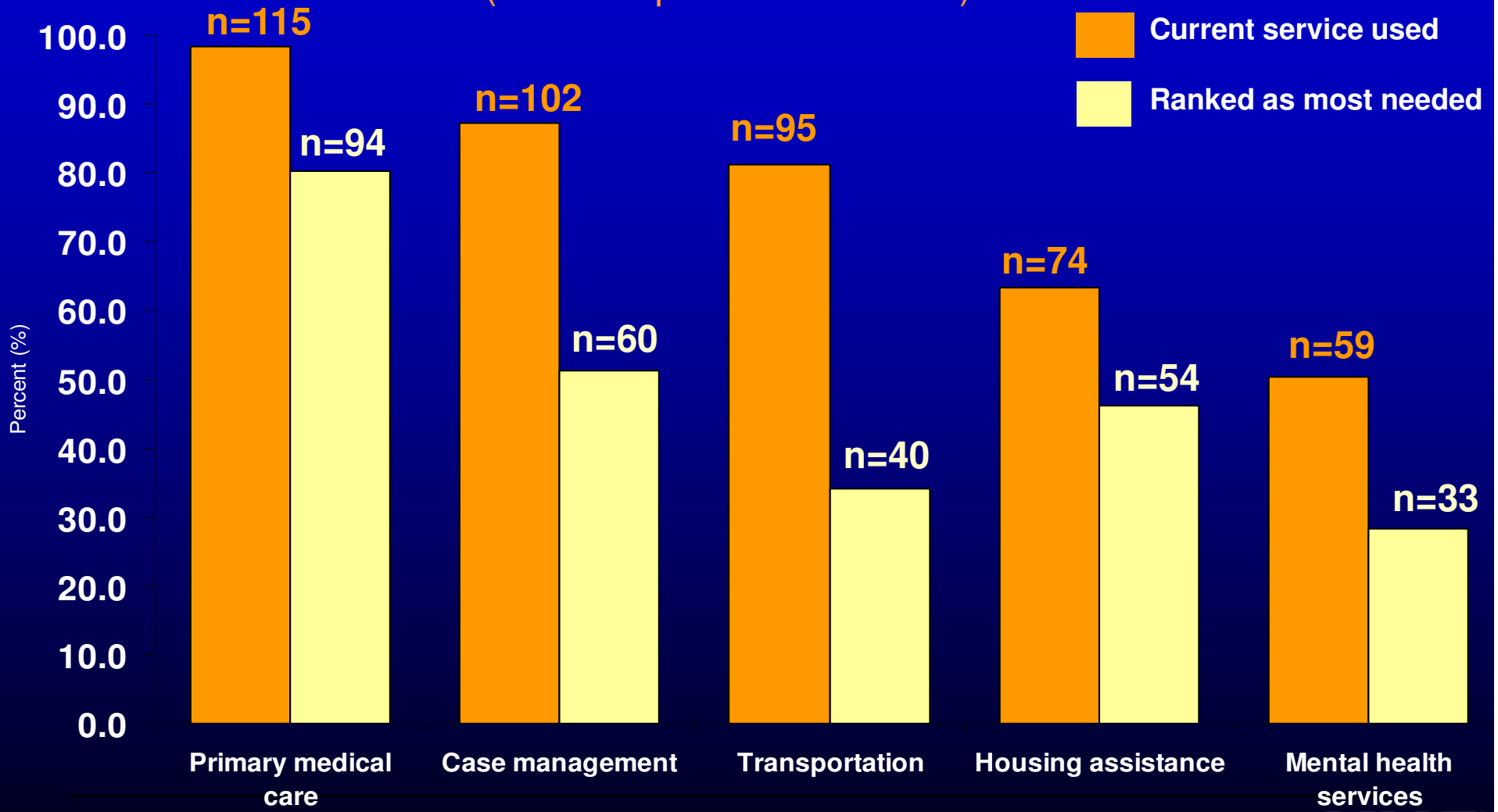
Results: Demographics (N = 117)



Return to Care Survey 2009

Results: Current service utilization compared to ranked service need

(Total respondents N=117)



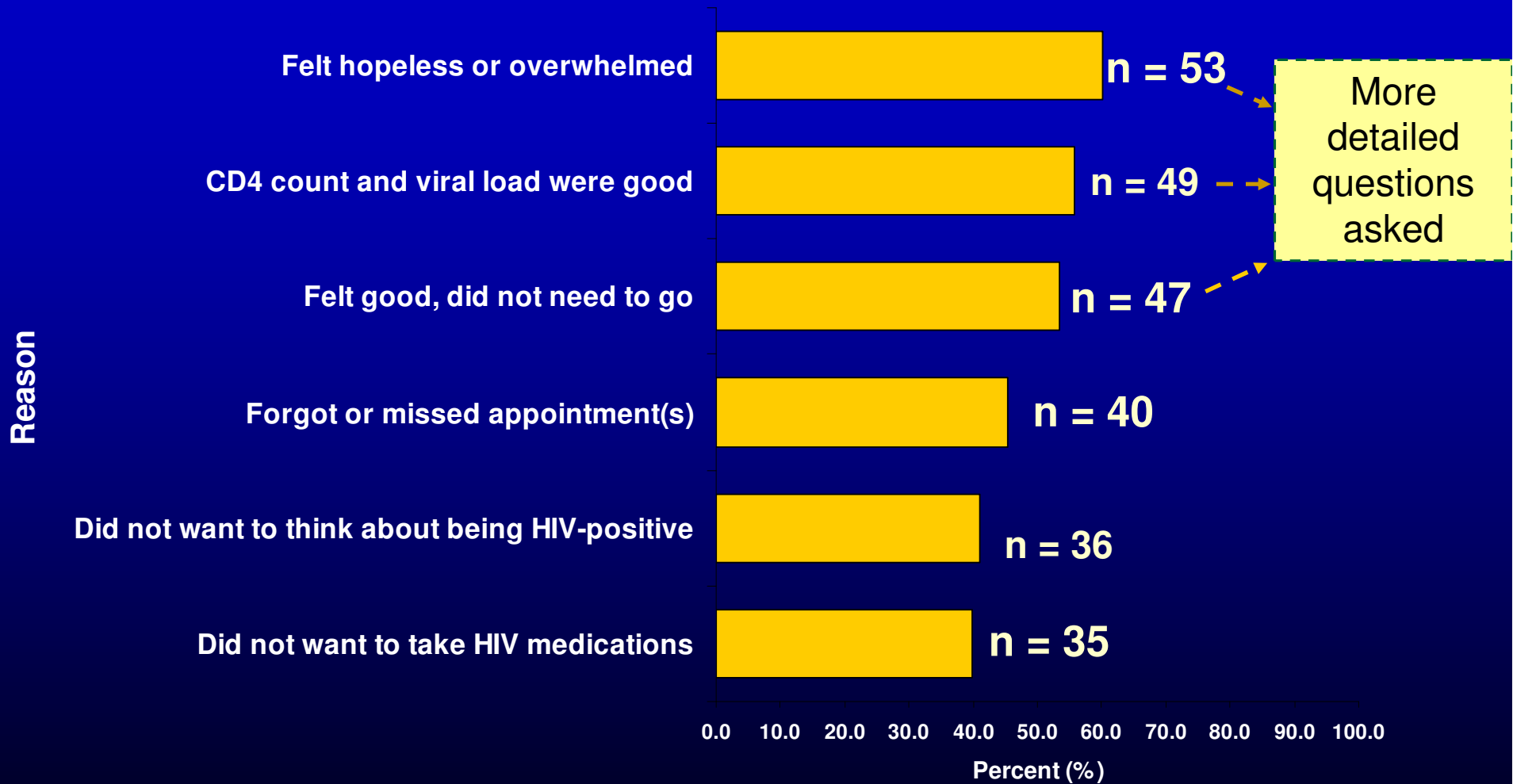
Return to Care Survey 2009

Results: Verifying Care Status

	#	%
Out of care by chart review	117	100
Self-report out of care	88	75.21
Self-report in care	29	24.79
<i>Same location</i>	<i>10</i>	<i>34.48</i>
<i>Different locations</i>	<i>19</i>	<i>65.52</i>

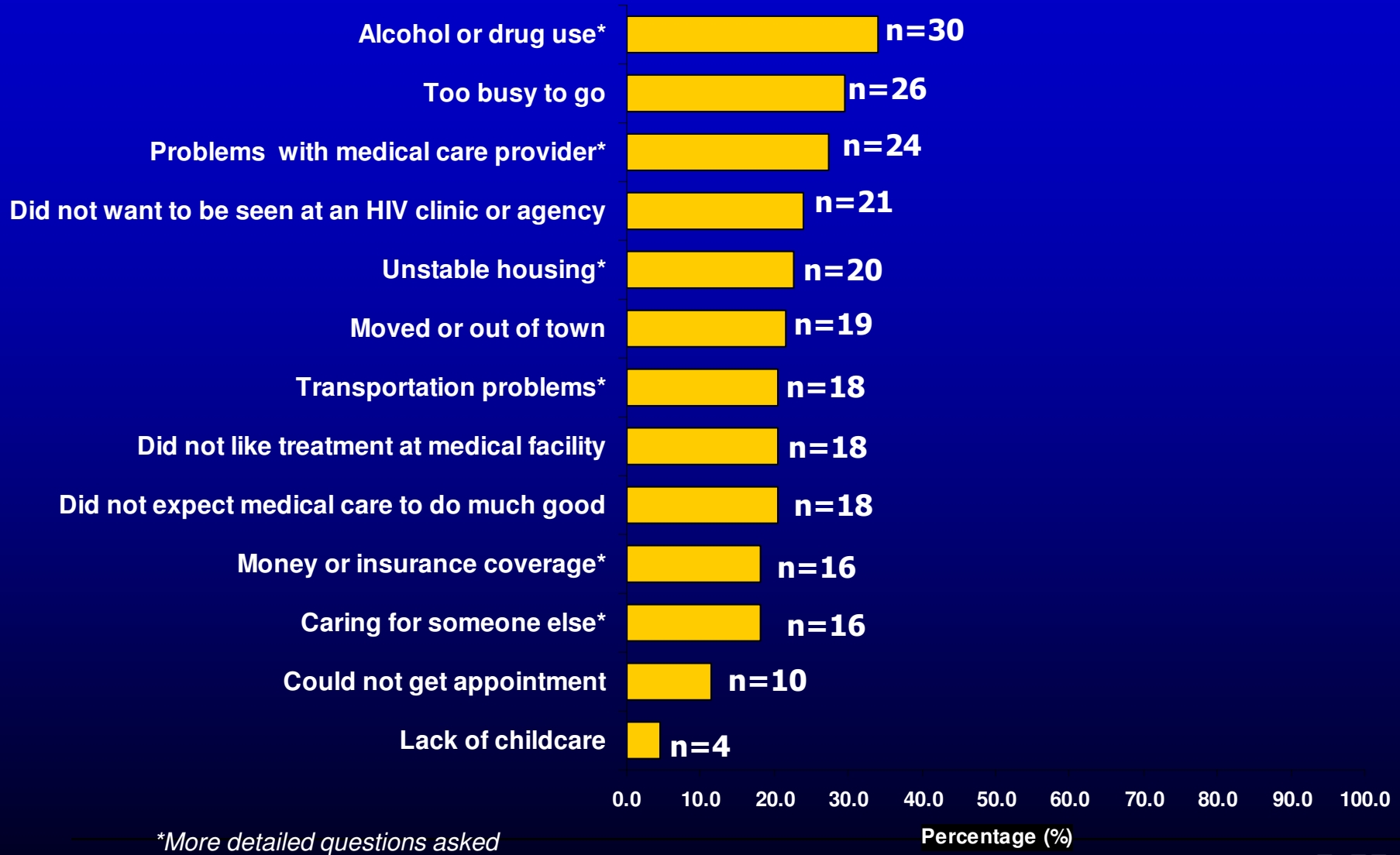
Results: Reasons for not receiving care

(Total respondents N=88, rated “somewhat” to “very” important)



Results: Other reasons for not receiving care

(Total respondents N=88, rated “somewhat” to “very” important)



Results: Felt hopeless or overwhelmed

(53 out of 88 (60%) rated as a somewhat to very important reason)

- Center for Epidemiologic Studies Depression Scale (CES-D)[†]
 - 20 additional questions, range of possible scores 0-60
 - Participant mean score = 20.25
 - 49 out of 52 (94%) had CES-D scores ≥ 16
 - **CES-D score ≥ 16 suggests a clinically significant level of psychological distress**
 - 20 out of 52 (38%) received counseling while out of care

[†]Radloff, L.S. (1977) 'The CES-D scale: A self report depression scale for research in the general population'. Applied Psychological Measurement 1: 385-401.

Results: CD4/VL were good or felt good

(61 out of 88 (69%) rated as a somewhat to very important reason)

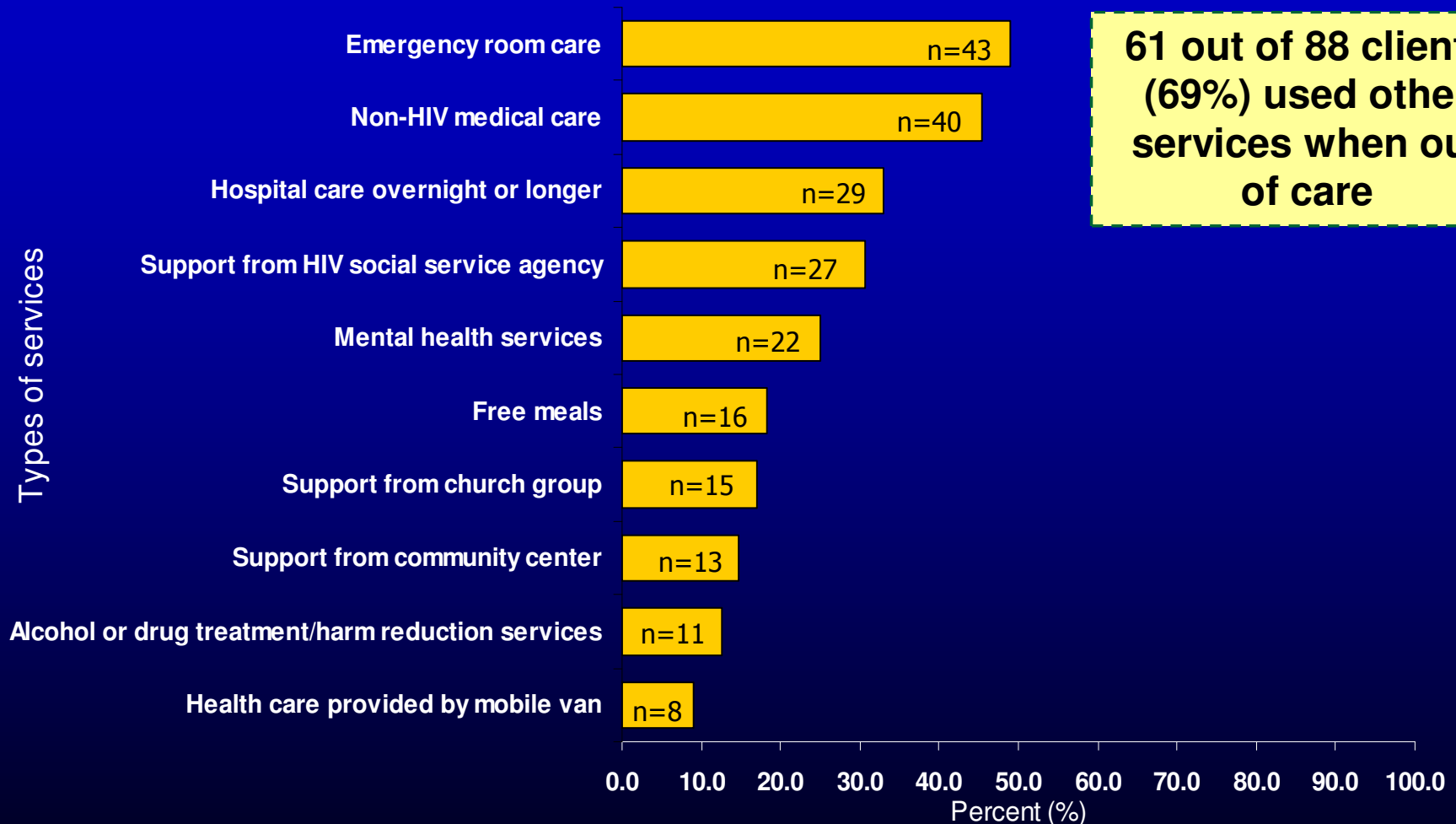
- *What did you know about your CD4 count?*
 - 33 out of 61 (67%) recalled CD4>200
- *How did you feel your health was at that time, in general?*
 - 40 out of 61 (82%) said their health was good to excellent

Results: Was not in stable housing

(20 out of 88 (23%) rated as a somewhat to very important reason)

- 15 out of 20 (75%) did not live in their own home or apartment
- 13 out of 20 (65%) said it was less stable than usual
- 13 out of 20 (65%) were not able to stay in the same place for more than 30 days

Results: Other services accessed when out of care



61 out of 88 clients (69%) used other services when out of care

Results: Reasons for returning to care

- 49 (56%) received encouragement from current primary care site.
- 30 (34%) got encouragement from other non-primary care sites.
- 70 (80%) said they returned for another reason
 - 55 (79%) said their personal attitude or outlook changed
 - 40 (57%) got support from family, friend, or peer
 - 35 (50%) felt sick/got ill

Results: Most important reason for returning to care

	N	%
Total respondents†	85	100
Interest in specific services at current agency	4	4.7
Outreach from staff at other or current agency	25	29.4
Change in personal circumstance (personal attitude/outlook, support, illness, found another provider, etc)*	40	47.1
Something or someone else (unspecified)	16	18.8

†Total number who completed questions at this point of survey. Clients could stop or skip questions at any time during the interview.

**This other reason was other than specific services and other than or in addition to outreach or assistance from a specific worker mentioned as linking or encouraging them back into care.*

Results: Barriers and any changes

Barrier to care	% citing reason out of care	% citing persistent barrier
Hopeless or overwhelmed	60 %	25%
CD4/VL good	56%	33%
Feel good/well (not ill)	53%	23%
Forgot/missed appointments	46%	7%
Not wanting to think about HIV status	41%	14%
Not wanting to take HIV medications	40%	16%
Unstable housing	23%	7%

Discussion: Highlights of findings

- Gaps in care influenced by:
 - Depressive symptoms
 - Health beliefs (no need for visits if not sick or if CD4/VL are good)
- 70% of clients used other services even while not getting primary care
 - Non-PCP HIV services
 - Urgent care
 - Social services
- 79% of clients attributed return to care to changes in personal attitude/outlook
 - *“I want to live”, “Want to be around for my kids”*
- Barriers to receiving care decreased after returning to care
 - *Felt hopeless or overwhelmed, 60% to 25%*
 - *CD4/VL 56%-33%, Felt good 53%-23%*
 - *Did not want to think about being HIV+, 41% to 14%*
 - *Did not want to take medications, 40% to 16%*

Discussion: Limitations

- For reasons of feasibility, we focused on MIC providers, but other RW Part A service categories also have clients with RTC experience.
- Some survey participants had been out of care multiple times in the past.
 - This report only reflects their most recent experience
- Recall issues with window of time out of care, reasons for lapse, prior service use, and reasons for return.
- Difficult to conduct survey with a population that goes in and out of care.
 - Lost/hard-to-reach respondents
 - Missed interview appointments

Discussion: Recommendations

- **Improve integration of the following services in HIV primary care:**
 - Mental health assessments
 - Mental health services
 - HIV health education
 - Social services
- **Increase collaboration with non-primary care service providers to identify and link out of care PLWHA to HIV primary care.**
 - Non-HIV-specific medical care facilities (especially ER and inpatient units)
 - HIV-specific social services
 - Mental health services
- **Increase partnership between providers of RW Part A services to continue to improve client engagement in HIV primary care.**

Acknowledgments and Thank You

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Questions and Comments

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Thank you for your time!