Bridging practice and research: A Survey of evidence-based practices used in HIV Care for linkage, retention and adherence support

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No conflicts of interest

After well over a decade of targeted efforts, and marked successes in public and individual health, HIV treatment remains limited in impact by:

- Delays in entry into care post diagnosis
- Cyclical use/discontinuation of HIV-care
- Sub-optimal adherence to or non-persistence with ART

While local and international ART treatment guidelines have recommended the monitoring of and intervention with adherence for several years, recommendations for how to do so have been limited

In an effort to facilitate the identification of evidence based monitoring and support strategies for both engagement in HIV-care (linkage and retention) and adherence, *CLINICAL GUIDELINES* were recently released.

Clinical Guidelines

Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel

Melanie A. Thompson, MD; Michael J. Mugavero, MD, MHSc; K. Rivet Amico, PhD; Victoria A. Cargill, MD, MSCE; Larry W. Chang, MD, MPH; Robert Gross, MD, MSCE; Catherine Orrell, MBChB, MSc, MMed; Frederick L. Altice, MD; David R. Bangsberg, MD, MPH; John G. Bartlett, MD; Curt G. Beckwith, MD; Nadia Dowshen, MD; Christopher M. Gordon, PhD; Tim Horn, MS; Princy Kumar, MD; James D. Scott, PharmD, MEd; Michael J. Stirratt, PhD; Robert H. Remien, PhD; Jane M. Simoni, PhD; and Jean B. Nachega, MD, PhD, MPH

- **Systematic review of the international literature since 1996 culling across 46,000 citations producing over 300 studies in the evidence base**

  - Entry and retention in HIV care
  - Monitoring ART adherence
  - Interventions to improve ART Adherence
  - Adherence tools for patients
  - Education and counseling interventions
  - Health system and service delivery interventions
  - Special populations

GUIDELINES FOR IMPROVING ENTRY INTO AND RETENTION IN CARE AND ANTIRETROVIRAL ADHERENCE FOR PERSONS WITH HIV

Quality	Interpretation
Excellent (I)	RCT evidence without important limitations
	Overwhelming evidence from observational studies
High (II)	Strong evidence with important limitations
	Strong evidence from observational studies
Medium (III)	RCT evidence with critical limitations
	Observational study evidence without important limitations
Low (IV)	Observational study evidence with important or critical limitations

TOTAL OF 12 RECS FOR MOST/ALL FOR GENERAL POPULATION

Strength	Interpretation
Strong (A)	Almost all patients should receive the recommended course of action
Moderate (B)	Most patients should receive the recommended course of action. However, other choices may be appropriate for some patients
Optional (C)	There may be consideration for this recommendation on the basis of individual circumstances. Not recommended routinely

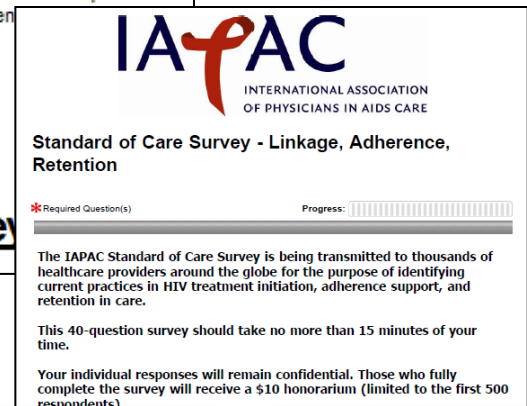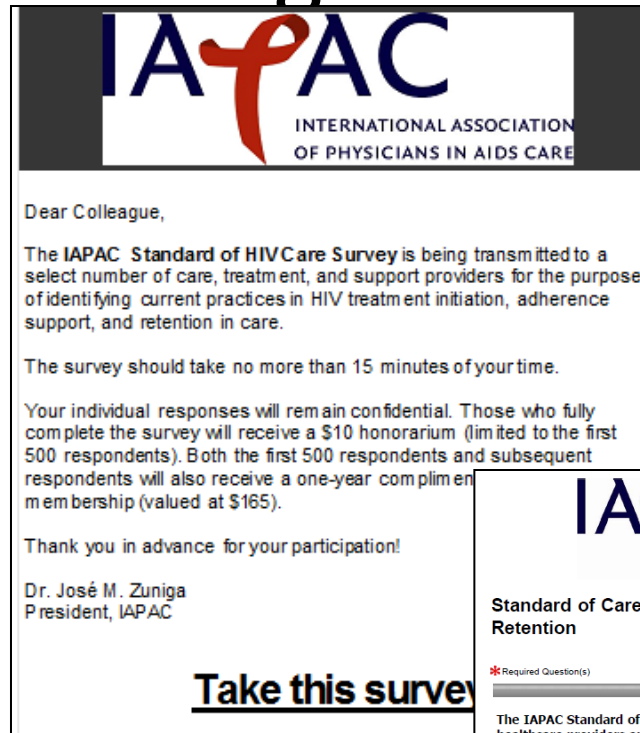# How do these recommendations map onto current practice?

- OBJECTIVE:
  - Characterize clinics/providers in terms of use/offering the recommended monitoring and support strategies for linkage, retention and adherence.
  - Characterize other aspects of "commonly provided" adherence support.

Characterizing Standard of Care in relation to these guidelines

- METHOD:
  - We surveyed providers of HIV-care on the use of various recommended retention and adherence monitoring and support strategies from the guidelines and from our experiences with standard of care offerings

Characterizing Standard of Care in relation to these guidelines

- METHOD:
  - E-blast to 1,500 IAPAC members w/ two reminder blasts (Jan 2012)
  - Link to survey (40 item measure on web)
  - Surveys completed between Jan 2012 and May 2012 compiled and analyzed

Approach

- Characterize monitoring and support strategies (generally and in relation to guidelines where applicable)

    - *Proportion reporting a strategy used with or offered to <u>most</u> or <u>all</u> patients/clients*

- Evaluate potential differences in strategy use between groups of respondents

RESULTS- Respondents

- A total of **395** surveys were partially (n=65) or entirely (n=330) completed.

- Response rate based on estimated number of e-blast recipients= 26.3%

- Completion rate= 84%
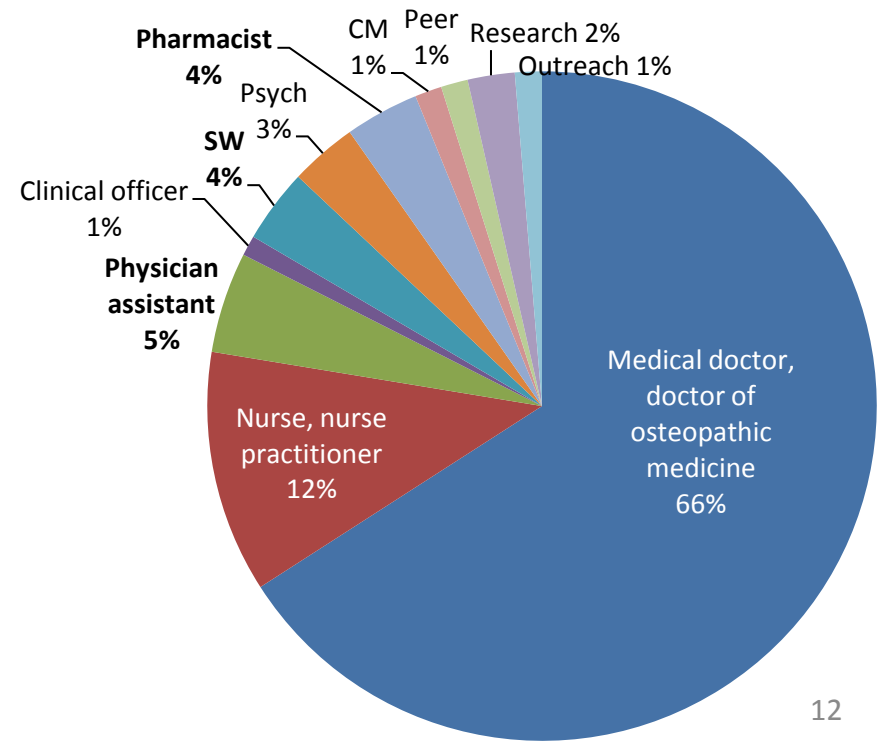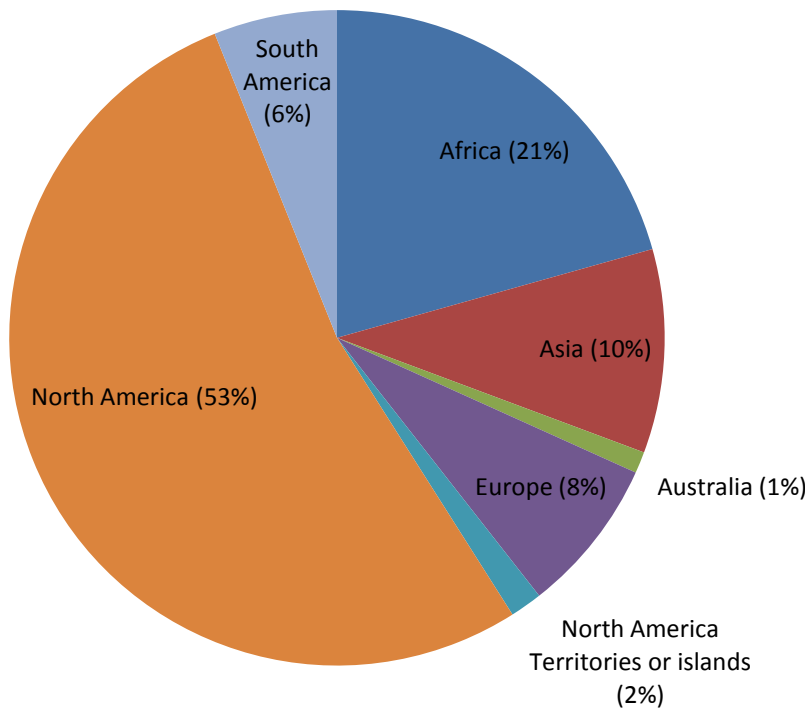
RESULTS- CLINICS/CARE SITES

- 70% of respondents reported working with medium to large (>200 to >1000) clinic populations

- Cumulative estimated number of patients represented by respondents:
  - 170,866 to 279,807 patients

- Most patients on ART (77%)

- Diverse subgroups within treatment populations

Porportion of respondents reporting clinic populations that included...

Population	Percentage
PLWH with comirdib medical conditions	79.7%
PLWH with Mental Health Concerns	75.4%
PLWH who live in poverty	74.9%
Pregnant Women	73.2%
PLWH with Substance Abuse Problems	62.8%
PLWH who are homeless	58.2%
Children	53.7%
PLWH transitioning our of incarceration	49.6%
PLWH in methadone maintenance	48.1%
PLWH who are incarcerated	47.6%
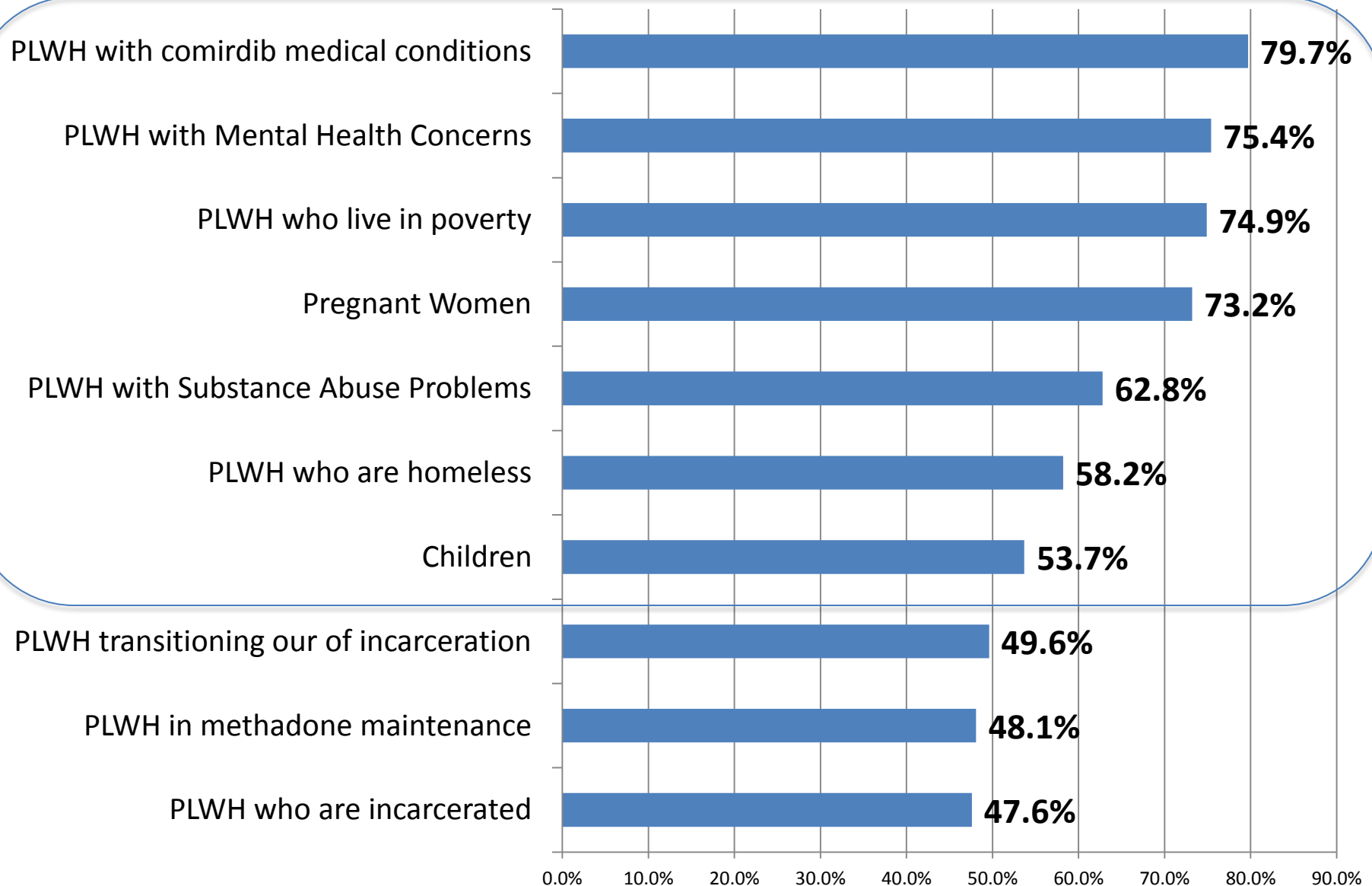
RESULTS-Estimates from Respondents

What percentage of your HIV-positive patients, once diagnosed, is typically lost-to-follow-up after their first clinic visit?

- 5.9%
- 22.6%
- 71.5%

28.5%
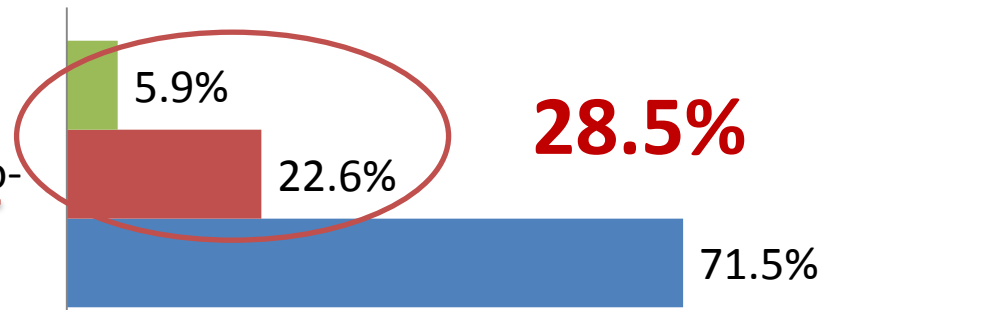
What percentage of your HIV-positive patients, once linked to care and prescribed an ART regimen, is typically lost

- 1.1%
- 5.6%
- 93.3%

6.7%
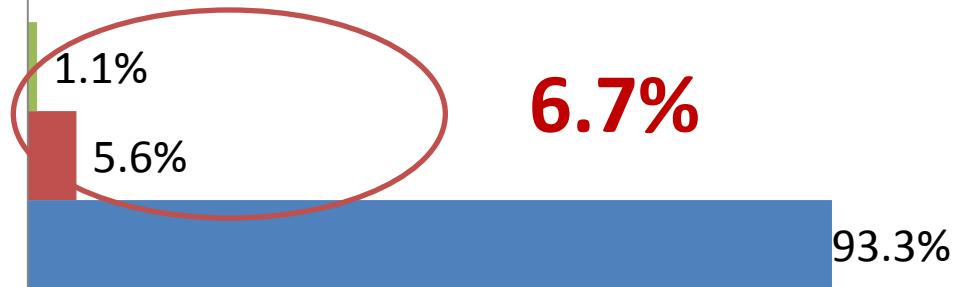
Of those HIV-positive patients currently on ART at your clinic, what percentage do you estimate are suboptimal adherers (meaning they miss more than three prescribed doses/month)?

- 76.6%
- 12.9%
- 10.5%

89.5%

0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0% 100.0%
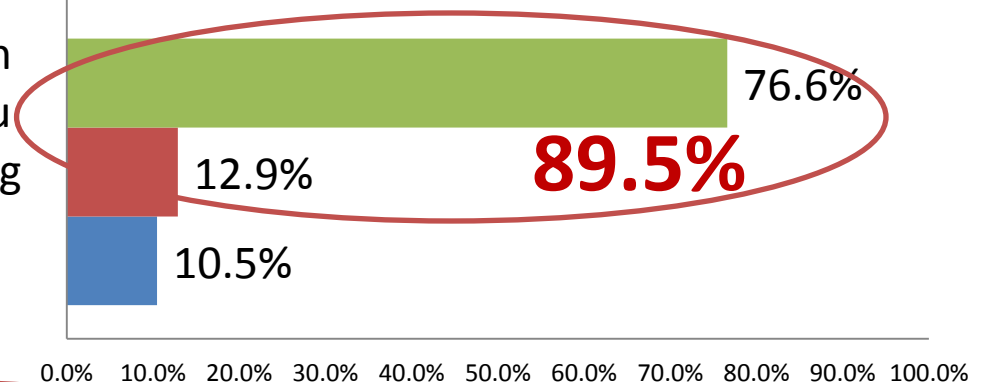
■ Most (over half) ■ About half ■ Some (1 to 25%)

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REPORTED STRATEGY USE

- Over all respondents and specific to grouped respondents
  - Size of clinic population
  - Reporting from a site inside or outside of the US
  - Reporting from a site inside or outside of Africa

> **LARGE (~240) vs SMALLER (~92) CLINICS**
>
> **US (~185) vs OUTSIDE OF US (~179) CLINICS**
>
> **AFRICA (~74) vs OUTSIDE OF AFRICA (~291)**

RESULTS- RET MONITORING (N 365)

Documentation of frequency of visits
- None/Not Used or Not Avail: 6.3%
- Some/As Needed: 9.6%
- All/Most patients: **84.1%**
- **US 79% vs Not 89%**

Documentation of linkage to care/treatment initiation ⭐
- None/Not Used or Not Avail: 12.3%
- Some/As Needed: 13.2%
- All/Most patients: **74.5%**
- **US 67% vs Not 80%**

Standardized linkage to care protocol
- None/Not Used or Not Avail: 18.4%
- Some/As Needed: 11.5%
- All/Most patients: **70.1%**
- **Small 58% vs Larger 75%**

Standardized retention in care monitoring ⭐
- None/Not Used or Not Avail: 21.6%
- Some/As Needed: 14.0%
- All/Most patients: **64.4%**
- **US 64% vs Not 76%**

Integrated data sources to enhance patient linkage to care and retention in care monitoring (medical records,…
- None/Not Used or Not Avail: 23.6%
- Some/As Needed: 15.3%
- All/Most patients: **61.1%**

X axis: 0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0%

Legend: ■ None/Not Used or Not Avail ■ Some/As Needed ■ All/Most patients

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RESULTS- RET SUPPORT (N 365)

Case management for newly diagnosed patients — **78.6%**

US 74% vs Not 84%

Identification of patients out of care for 6 months or more to providers or care team — **58.4%**

Small 49% vs Larger 62%

Phone or text contact for patient not returning to care for a defined period — **51.8%**

Phone or text contact for missed visits — **51.0%**

Phone or text reminder of upcoming appointment — **49.9%**

US 73% vs Not 26%

Link to peer navigators advocates or community workers on entry into care — **34.2%**

Link to peer navigators, advocates or community workers when out of care for a defined period of time — **28.8%**

Going to home or residence when patient has not returned to care as expected — **21.4%**

US 12% vs Not 31%

■ None/Not Used or Not Avail   ■ Some/As Needed   ■ All/Most patients

18

RESULTS- RET SUPPORT (N 365)

Case management for newly diagnosed patients — **78.6%**

Identification of patients out of care for 6 months or more to providers or care team — **58.4%**

Phone or text contact for patient not returning to care for a defined period — **51.8%**

Phone or text contact for missed visits — **51.0%**

Africa 19% vs Not 56%

Phone or text reminder of upcoming appointment — **49.9%**

Africa 39% vs Not 54%

Link to peer navigators advocates or community workers on entry into care — **34.2%**

Africa 47% vs Not 31%

Link to peer navigators, advocates or community workers when out of care for a defined period of time — **28.8%**

Going to home or residence when patient has not returned to care as expected — **21.4%**

Africa 39% vs Not 17%

0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0%

■ None/Not Used or Not Avail   ■ Some/As Needed   ■ All/Most patients

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RESULTS- ADH MONITORING (N 367)

Ask about adherence during check-up/check-in
- None/Not Used or Not Avail: 1.6%
- Some/As Needed: 4.9%
- All/Most patients: **93.5%**

Use a self-reported measure of adherence
- None/Not Used or Not Avail: 20.7%
- Some/As Needed: 17.4%
- All/Most patients: **61.9%**
- **Africa 74% vs Not 59%**

Review pharmacy refill data
- None/Not Used or Not Avail: 19.1%
- Some/As Needed: 35.4%
- All/Most patients: **45.5%**
- **Africa 58% vs Not 52%**

Perform pill counts of returned medication
- None/Not Used or Not Avail: 44.7%
- Some/As Needed: 35.4%
- All/Most patients: **19.9%**
- **US 6% vs Not 34%**
- **Africa 49% vs Not 13%**

Use drug concentration analyses
- None/Not Used or Not Avail: 78.2%
- Some/As Needed: 16.1%
- All/Most patients: **5.7%**

Use electronic monitoring device for opening of pill case or pill bottle
- None/Not Used or Not Avail: 91.6%
- Some/As Needed: 6.3%
- All/Most patients: **2.2%**
- **US 0% vs Not 4%**

Axis: 0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0% 100.0%

Legend: ■ None/Not Used or Not Avail   ■ Some/As Needed   ■ All/Most patients

20
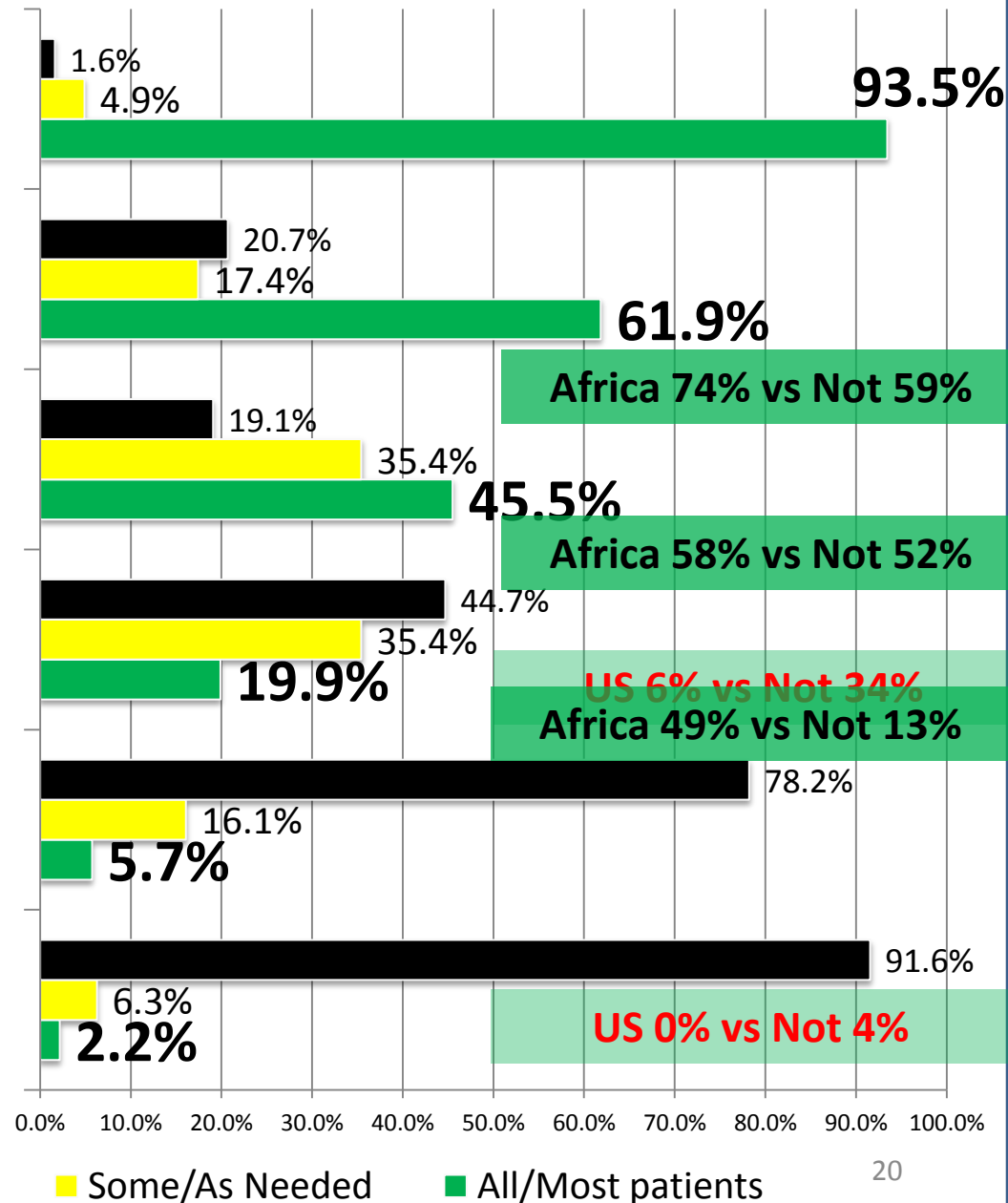
RESULTS- ARV Rx STRATS (N 358-366)

Current regimen contained a fixed-dose combination (FDC) ARV drug
- 6.3%
- 19.9%
- **73.8%**

Africa 64% vs Not 76%
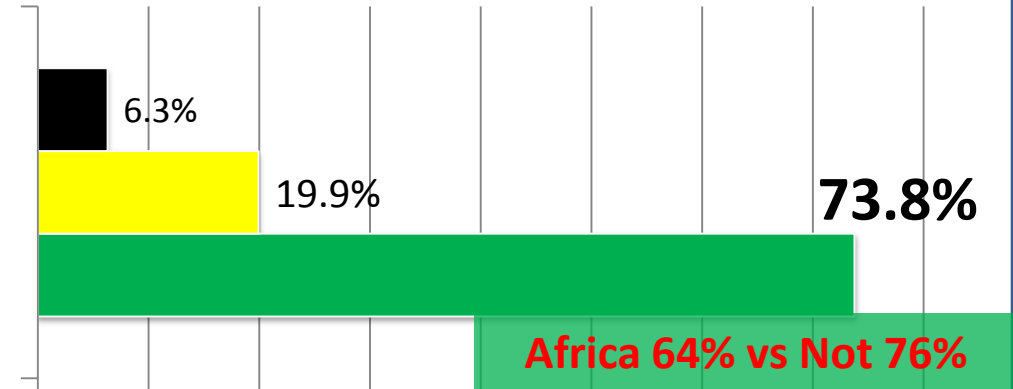
First-line regimen is once daily dosed for treatment-naive patients ⭐
- 11.2%
- 24.0%
- **64.8%**

US 79% vs Not 50%
Africa 44% vs Not 70%
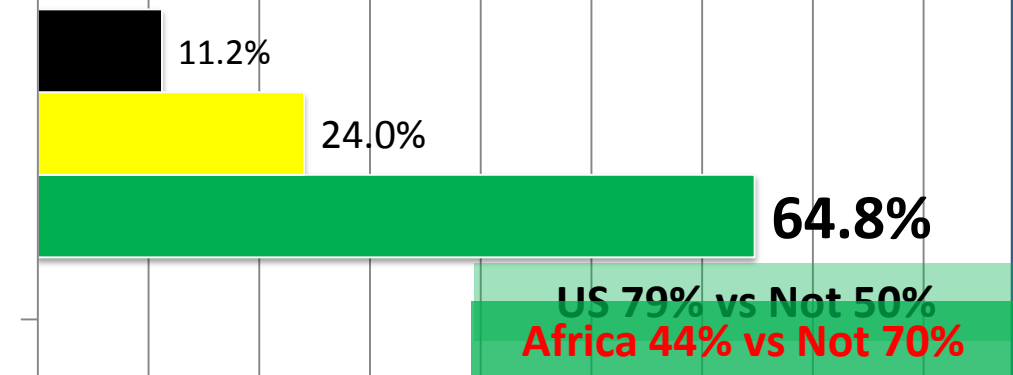
Treatment-experienced patients are reviewed for potential switch to simplified regimens
- 9.8%
- 33.6%
- **56.6%**

US 69% vs Not 43%
Africa 45% vs Not 60%

Axis: 0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0%

■ None/Not Used or Not Avail   ■ Some/As Needed   ■ All/Most patients

21
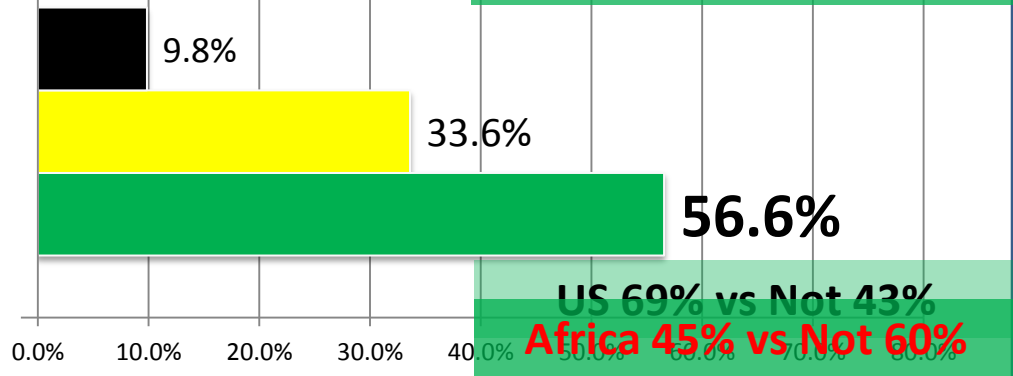
RESULTS- ADH TOOLS (N 366)

Provide pill case or other organization tools (diary)
- 28.7%
- 37.7%
- **33.6%**

US 44% vs Not 23%
Africa 19% vs Not 37%

⭐Provide a device for reminders/dose-time alerts or assist in programming cell phones for alerts
- 54.1%
- 32.2%
- **13.7%**

Send text messages that are motivational to promote adherence
- 82.8%
- 11.5%
- **5.7%**

Small 10% vs Larger 4%

Send text messages for reminder or dose-times
- 80.3%
- 14.8%
- **4.9%**

Axis: 0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0%

■ None/Not Used or Not Avail   ■ Some/As Needed   ■ All/Most patients

22
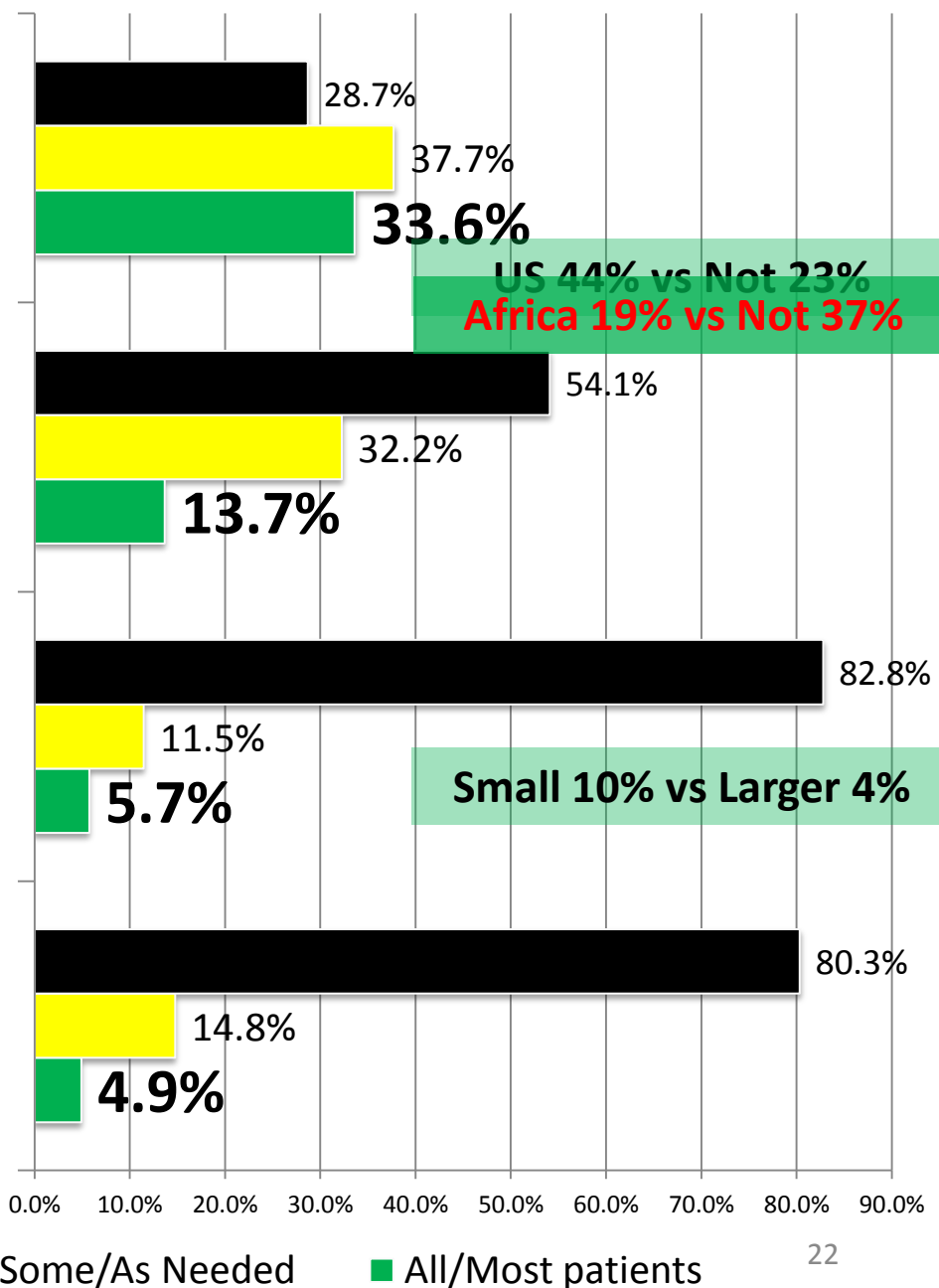
RESULTS- GEN ADH STRATS (N 356-357)

One-on-one education about ART and HIV — **85.4%**

Patients are reminded of expectation to be perfect or near-perfect adherers — **84.9%**
  Africa 94% vs Not 83%

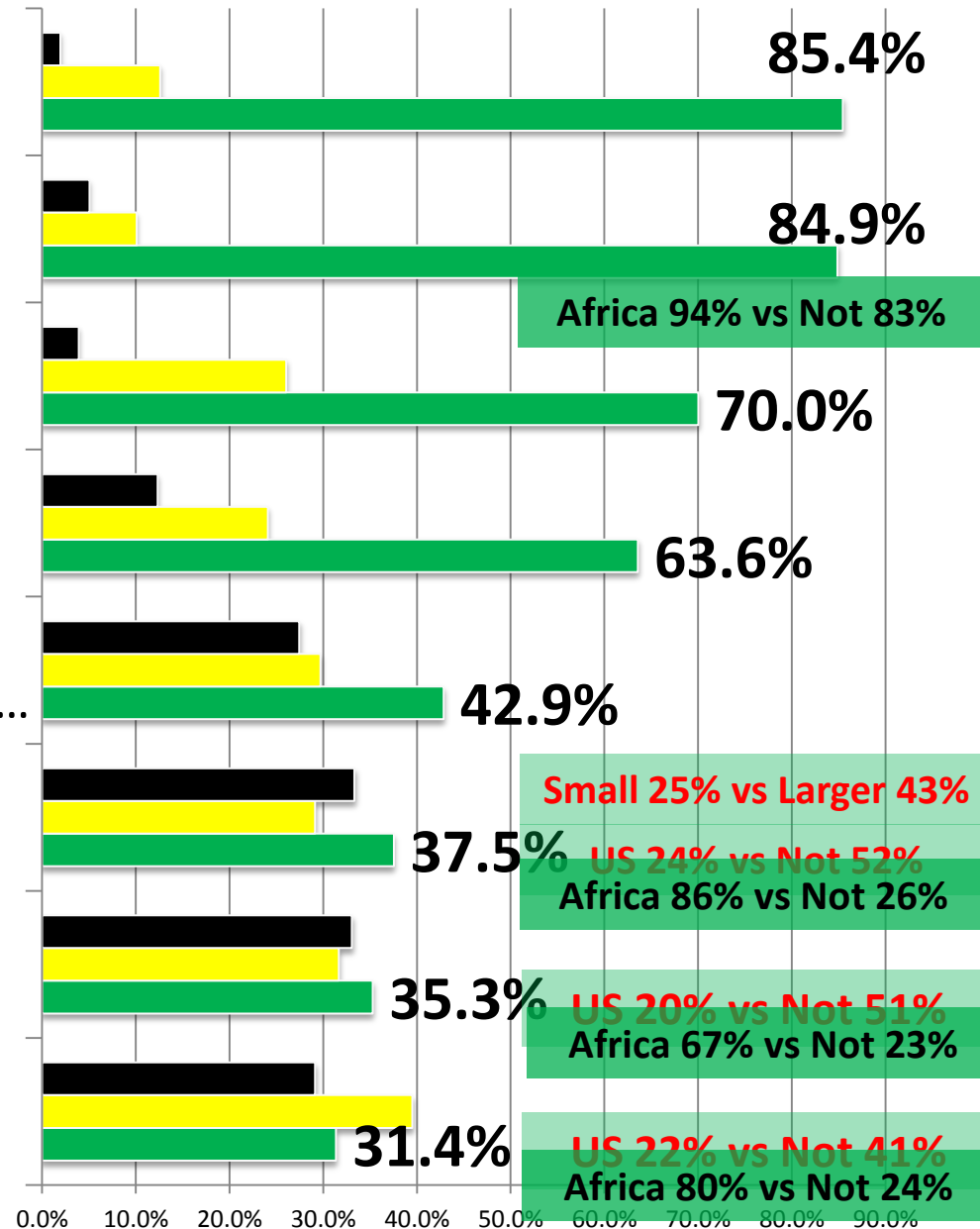One-on-one counselling focused on adherence and living with HIV — **70.0%**

Multidisciplinary resources are coordinated for/with patients… — **63.6%**

Non-adherence or occasional difficulties with adherence is explicitly… — **42.9%**

Group education about ART and HIV — **37.5%**
  Small 25% vs Larger 43%
  US 24% vs Not 52%
  Africa 86% vs Not 26%

Group counselling focused on adherence and living with HIV — **35.3%**
  US 20% vs Not 51%
  Africa 67% vs Not 23%

Peer support programs for adherence — **31.4%**
  US 22% vs Not 41%
  Africa 80% vs Not 24%

0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0%

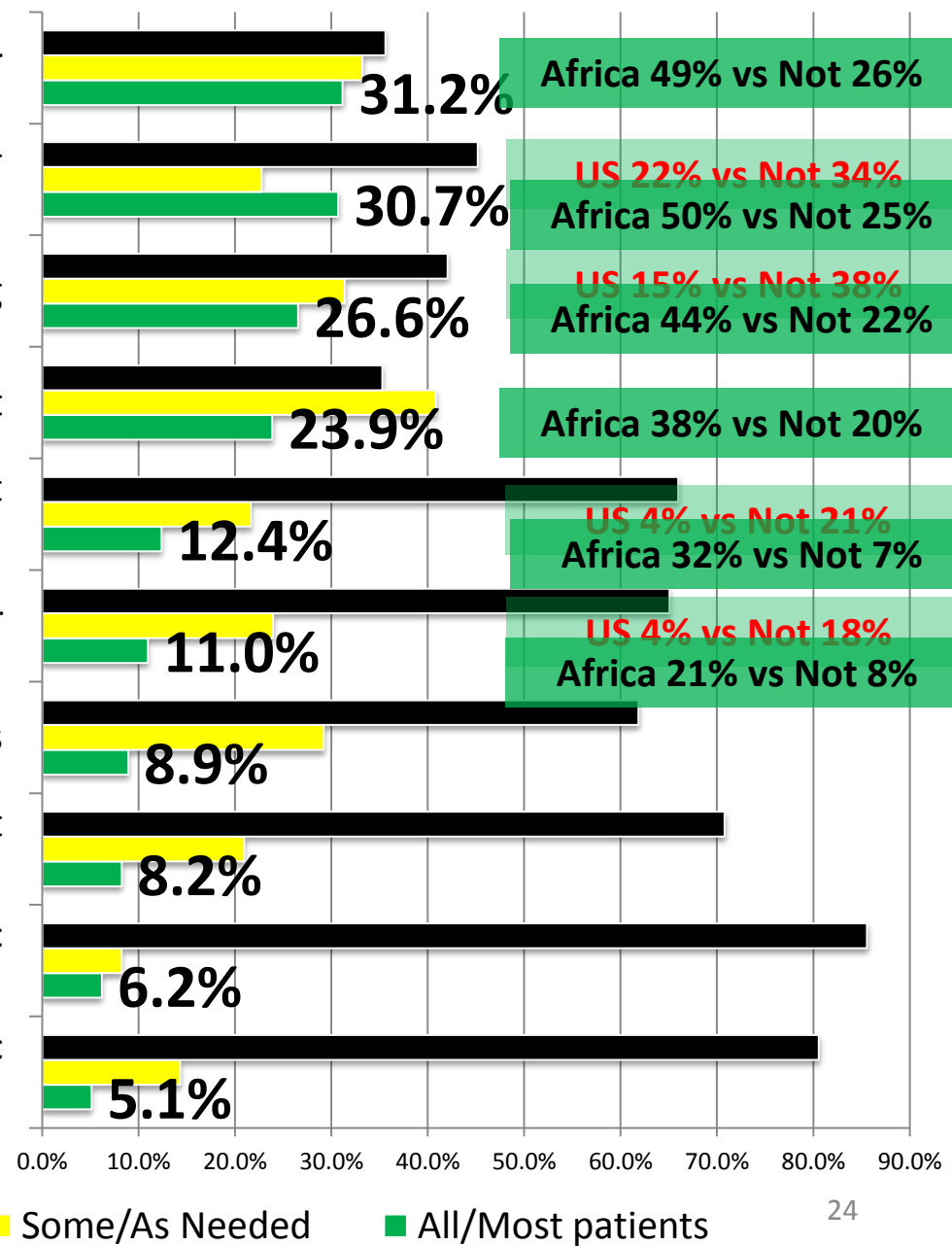■ None/Not Used or Not Avail ■ Some/As Needed ■ All/Most patients

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RESULTS- GEN ADH STRATS IN RLS (N 291-293)

Non-physician clinicians managing patients on ART
31.2% — Africa 49% vs Not 26%

Structured teaching modules as a form of pre-treatment education
30.7% — US 22% vs Not 34% / Africa 50% vs Not 25%

Peer-driven, pre-treatment educational counseling
26.6% — US 15% vs Not 38% / Africa 44% vs Not 22%

One-on-one peer support
23.9% — Africa 38% vs Not 20%

Use of a trained, patient-nominated treatment supporter to provide partial DAART
12.4% — US 4% vs Not 21% / Africa 32% vs Not 7%

Clinic- or home-based DAART
11.0% — US 4% vs Not 18% / Africa 21% vs Not 8%

Monthly food supplementation packages
8.9%

Technological interventions (interactive text messages) integrated with clinic contact
8.2%

Electronic drug monitoring (EDM) linked to clinic contact
6.2%

Weekly text message reminders without clinic contact
5.1%

Legend: ■ None/Not Used or Not Avail ■ Some/As Needed ■ All/Most patients

X-axis: 0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0% 90.0%

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RESULTS- STRUCTURAL STRATEGIES (N 361)

Onsite treatment for various comorbidities
- None/Not Used or Not Avail: 11.4%
- Some/As Needed: 25.2%
- All/Most patients: **63.4%**
  - **Small 53% vs Larger 68%**

Patients are screened systematically for depression
- None/Not Used or Not Avail: 16.1%
- Some/As Needed: 33.0%
- All/Most patients: **51.0%**
  - **US 73% vs Not 26%**
  - **Africa 24% vs Not 58%**

Patients are screened systematically for adjustment or for mental health issues...
- None/Not Used or Not Avail: 17.2%
- Some/As Needed: 33.0%
- All/Most patients: **49.9%**
  - **US 74% vs Not 27%**
  - **Africa 25% vs Not 56%**

Case management to coordinate care services secure food or basic resources
- None/Not Used or Not Avail: 32.7%
- Some/As Needed: 36.0%
- All/Most patients: **31.3%**
  - **US 50% vs Not 12%**
  - **Africa 6% vs Not 38%**

Transportation to clinical care
- None/Not Used or Not Avail: 42.7%
- Some/As Needed: 42.4%
- All/Most patients: **15.0%**
  - **US 19% vs Not 11%**
  - **Africa 4% vs Not 17%**

Vouchers to cover costs associated with coming to care
- None/Not Used or Not Avail: 52.4%
- Some/As Needed: 33.2%
- All/Most patients: **14.4%**

Food packets
- None/Not Used or Not Avail: 58.7%
- Some/As Needed: 33.8%
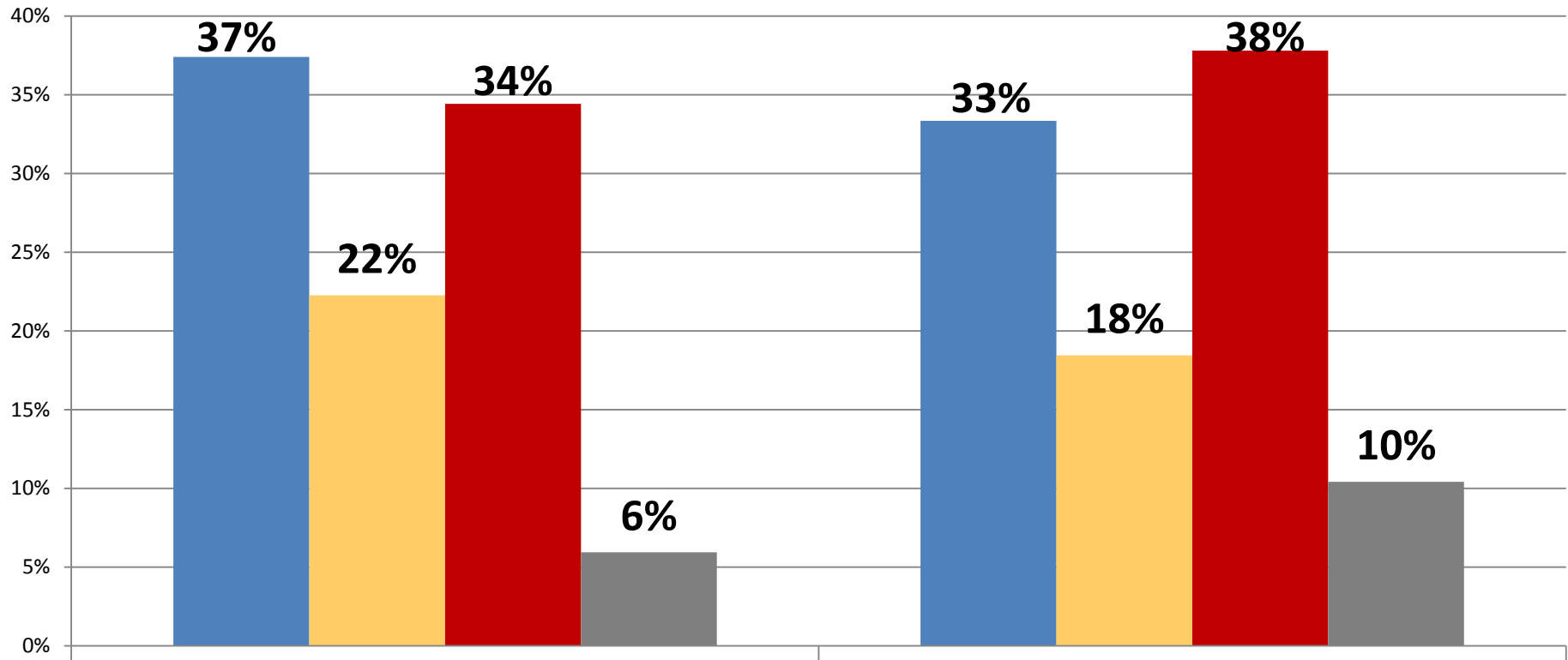- All/Most patients: **7.5%**

Legend: ■ None/Not Used or Not Avail ■ Some/As Needed ■ All/Most patients

25
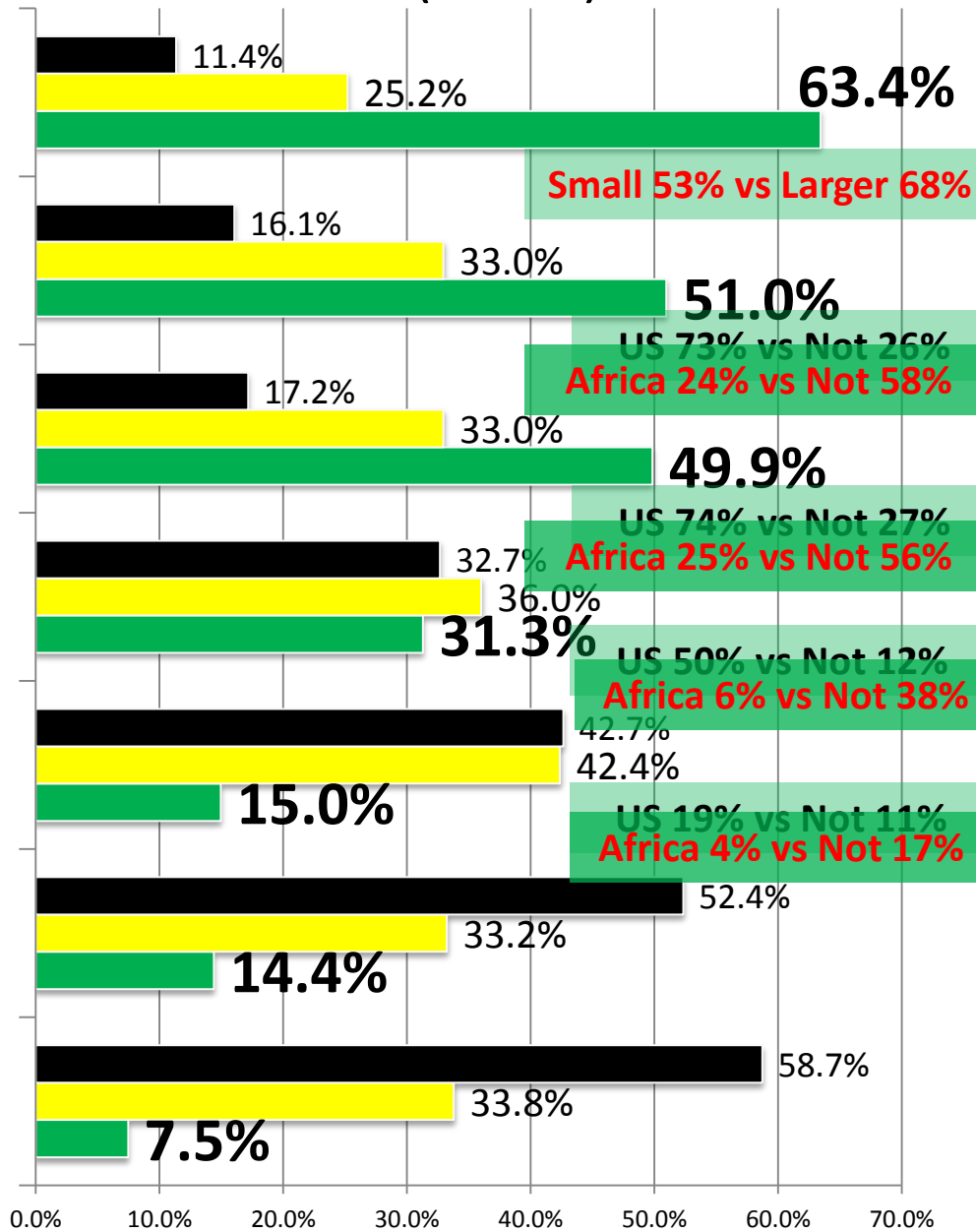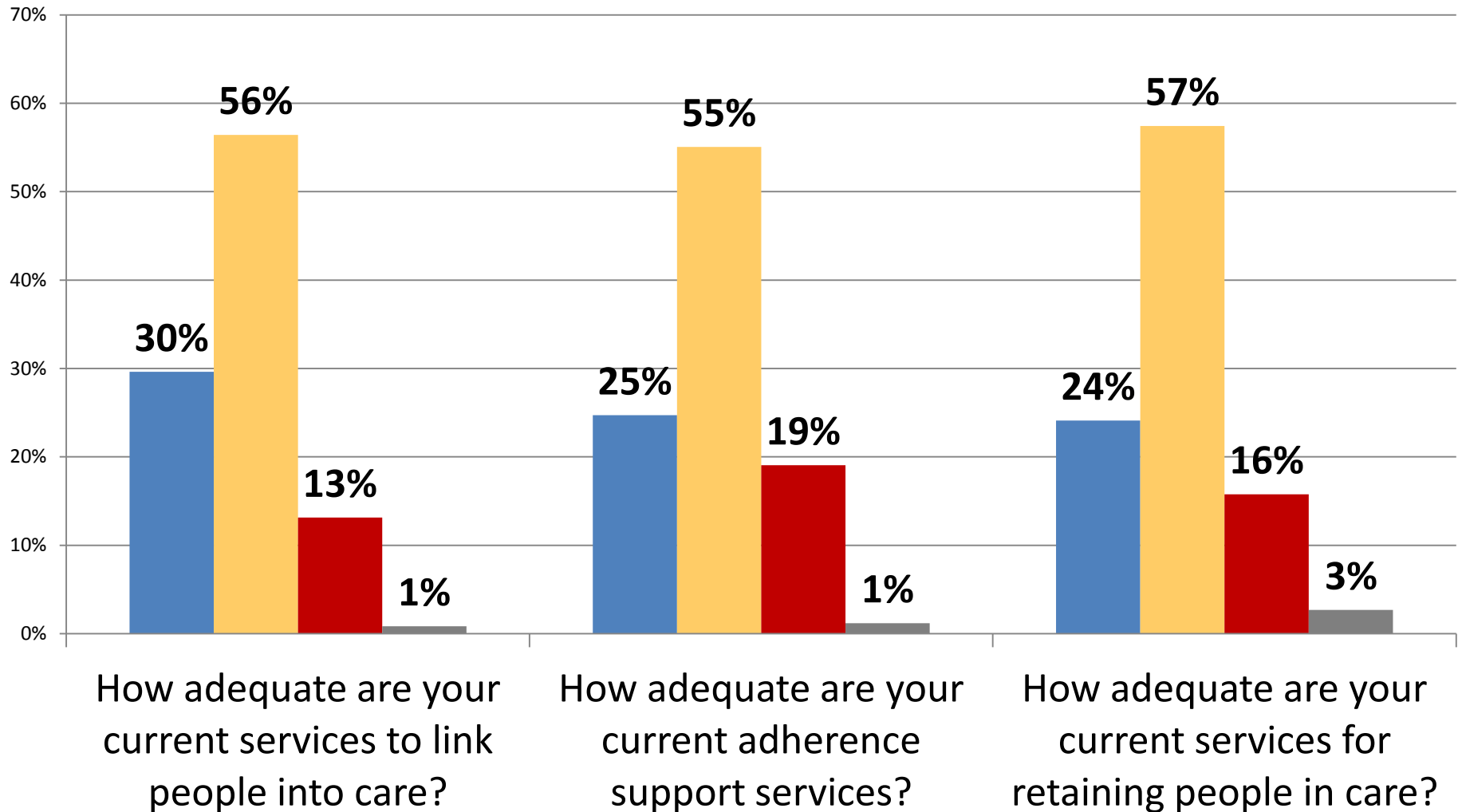
RESULTS- USE OF SERVICES?

How many patients in your clinic/center make use of available support services for adherence?

How many patients in your clinic/center make use of available support services for retention?

- Sig higher estimated use of available adherence support strategies from respondents in Africa (52% vs 37% estimating use by over half of population)

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RESULTS- ADEQUACY OF SERVICES?

How adequate are your current services to link people into care?
- 30%
- 56%
- 13%
- 1%

How adequate are your current adherence support services?
- 25%
- 55%
- 19%
- 1%

How adequate are your current services for retaining people in care?
- 24%
- 57%
- 16%
- 3%

US vs Not: Sig higher reported adequacy of
- linkage strategies in use (41% vs 19%)
- adherence strategies in use (33% vs 15%)
- retention strategies in use (30% vs 18%)

Africa vs Not: Sig lower reported adequacy of
- linkage strategies in use (12% vs 34%)
- adherence strategies in use (9% vs 29%)
- retention strategies in use (12% vs 28%)

Funding (24.2%)

Peer information exchange/referral network (technical assistance) (18.7%)

Performance measures (15.4%)

Additional staff (13.3%)

Practice guidelines (10.6%)

Best practices clearinghouse/portal (7.6%)

Workshops/training opportunities (5.1%)

Management support (e.g., decision support tools) (5.1%)

(technical assistance) (18.7%)

SUMMARY

Majority of individuals completing the survey felt that the strategies used for monitoring and supporting linkage, adherence and retention could use improvement.

- Aside from funds to resource clinics, technology transfer, information and skills sharing and implementation support is needed.

RECOMMENDATIONS I/II AND A/B

Quality/ Strength	Recommendation
II A ✔	Systematic monitoring of successful entry into HIV care is recommended for all individuals diagnosed with HIV (74%)
II A 🟡	Systematic monitoring of retention in HIV care is recommended for all pts (64%)
II B ✔	Brief, strengths-based case management for individuals with a new HIV diagnosis is recommended (79%)
II A 🟡	Self-reported adherence should be obtained routinely in all patients (62%, 94%)
II B 🔴	Pharmacy refill data are recommended for adherence monitoring when medication refills are not automatically sent to patients (46%)
II B 🟡	Among regimens of similar efficacy and tolerability, once-daily (QD) regimens are recommended for treatment-naive patients beginning ART (65%)
I B 🔴	Reminder devices and use of communication technologies with an interactive component are recommended (14%)
I A	Education and counselling using specific adherence-related tools is recommended
II A ✔	Individual one-on-one ART education is recommended (85%, 70%)
II A	Providing one-on-one adherence support to patients through 1 or more adherence counselling approaches is recommended

RECOMMENDATIONS I/II AND A/B

Quality/ Strength	Recommendation
II B ✔	Using nurse- or community counsellor-based care has adherence and biological outcomes similar to those of doctor- or clinic counsellor-based care and is recommended in under-resourced settings (31%)
I A ✔	Directly administered ART is not recommended for routine clinical care settings (11-12%)
	SPECIAL POPULATIONS (only 1 reviewed here)
II A ✔	Screening, management, and treatment for depression and other mental illnesses in combination with adherence counselling are recommended (51%)

Limitations

Self-report and self-section for survey completion

The extent to which self-report of strategy use matches up with actual use or knowledge of availability from patient perspectives is not quantified here

Greater emphasis on characterizing use of recommended [evidence based] strategies than characterizing other strategies used commonly in care

FUTURE DIRECTIONS

Planning research, funding, and implementation agendas are needed to promote use of recommended strategies.

HOW use or non-use of specific strategies may associate with clinical outcomes is an important method for identifying practice-based-strategies and practice-based evidence.

Current practice and gaps between practice and evidence based recommendations should guide agendas for supporting dissemination and implementation of recommended approaches.

Thank you!

Thank you to all the providers who took the time to complete the survey and the IAPAC team that helped program and run the survey!

With deep appreciation for the efforts and contributions of
Steve Ketchum