Enhancements to the IeDEA data

Patient tracing

Constantin T. Yiannoutsos

Co-PI IeDEA-EA

Limitations to routinely collected data

The routinely collected IeDEA data have one major limitation:

- They are focused on the care program rather than the patient

As such, these data cannot address questions prior to the patient being enrolled in care or after disengaging from a care program

Why do patients leave a program?

Patients leave (are “lost” to) a care program because

- They have died (un-reported mortality)
- They have disengaged from care
- They have transferred out to another program without documentation (“silent” transfers)

All of these events are collectively known as “losses to follow-up”.

How does this affect research?

Losses to follow-up have dramatic impact on program monitoring and evaluation because

- They result in (possibly dramatic) under-estimation of mortality
- They over-estimate disengagement from care
- They (generally over-estimate) long-term outcomes such as
  - Viral suppression rates
  - Adherence to medications
  - Immune reconstitution (i.e., CD4 counts over time)

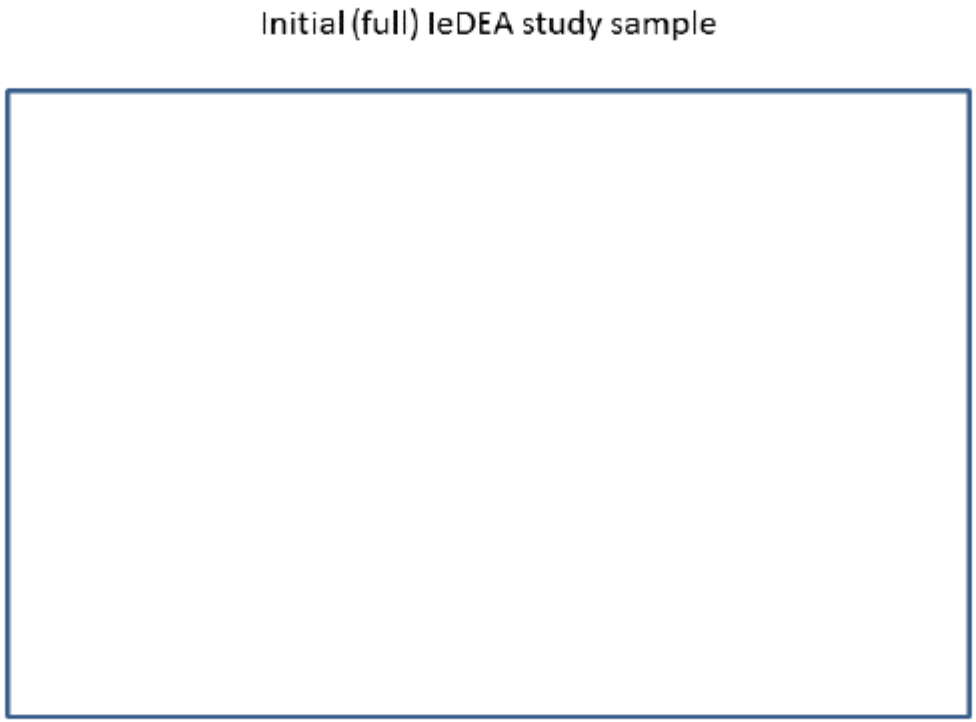
The 90-90-90 guideline

But the 90-90-90 guideline is inherently focused on the patient. Thus

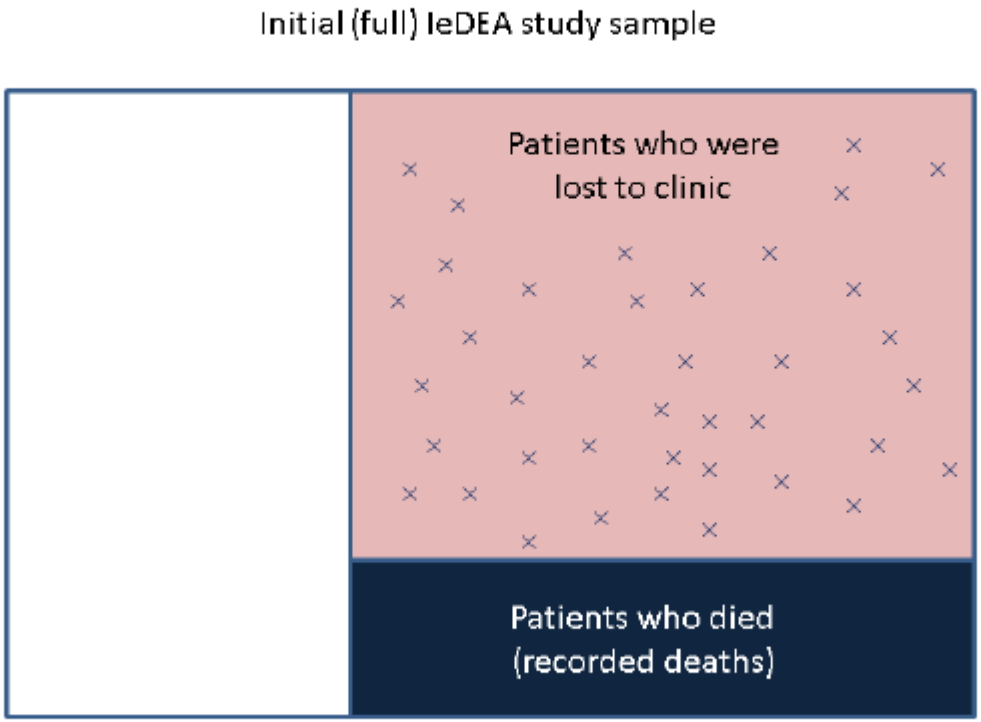
- Without enhancements, IeDEA data cannot acurately address any of the 90-90-90 questions!

Actually, no clinical data on their own can address the 90-90-90 questions.

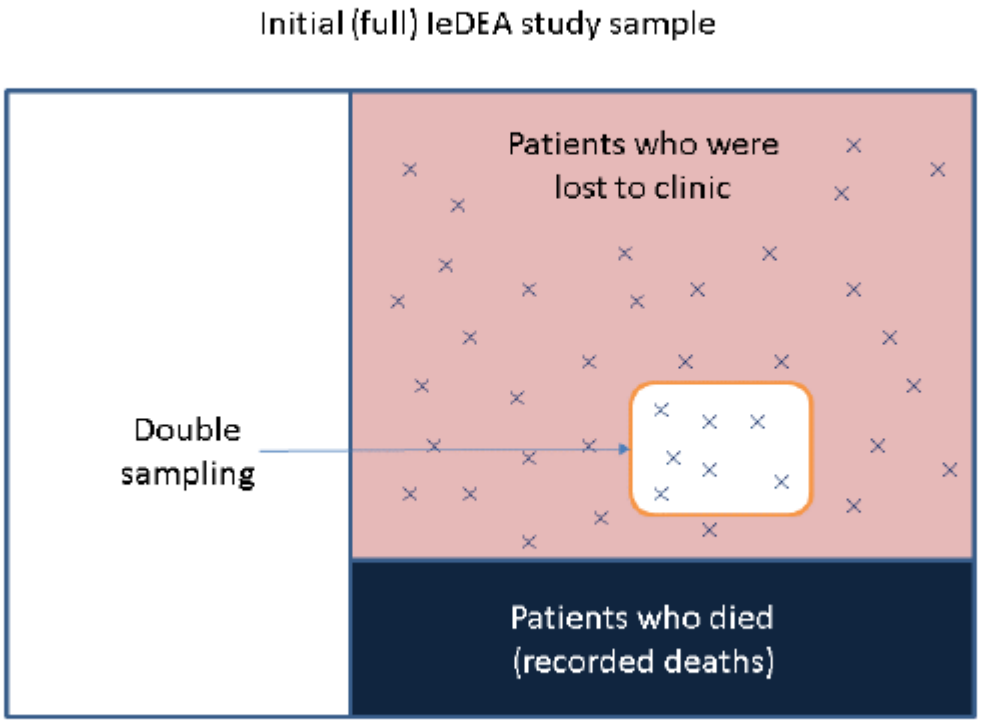
Double sampling



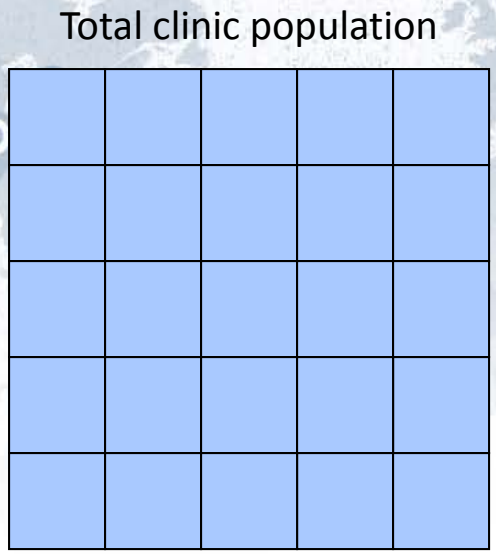
Double sampling



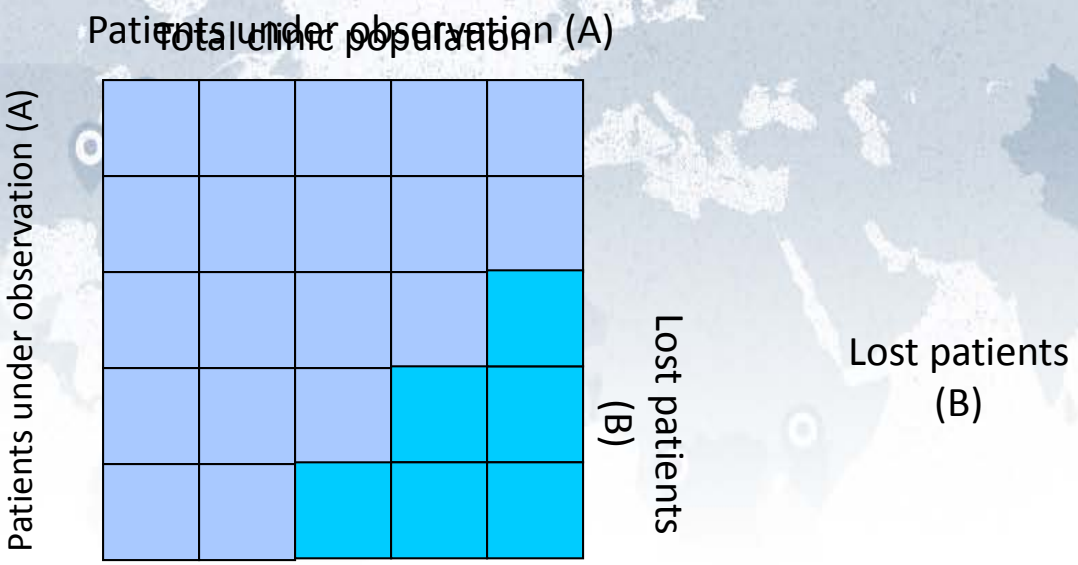
Double sampling



Sampling-based approaches to account for losses to follow-up

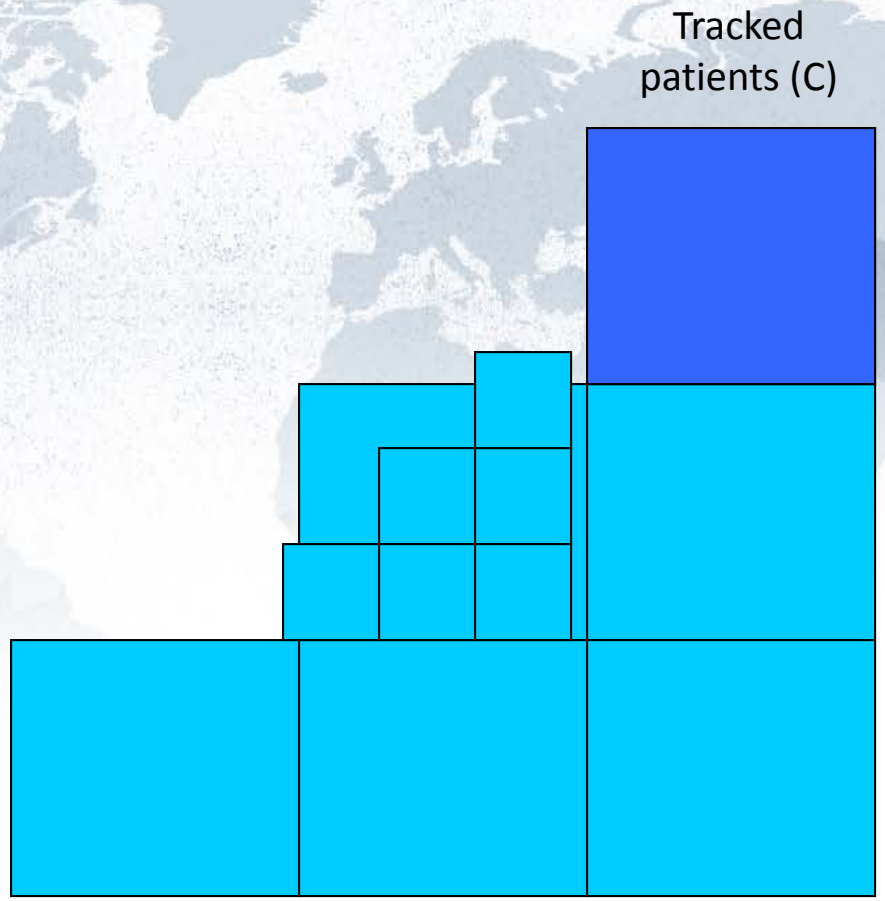


Sampling-based approaches to account for losses to follow-up



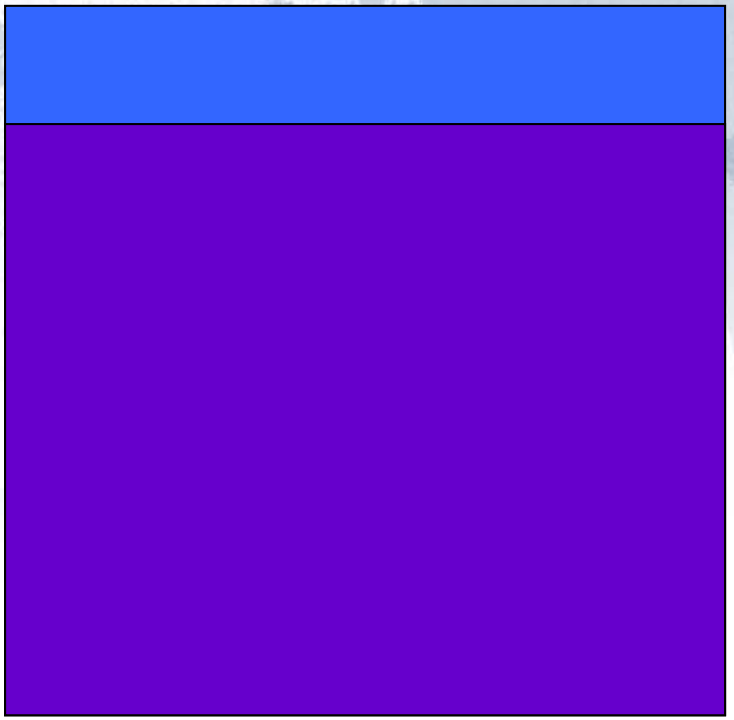
Lost patients

Tracked patients



Tracked patients

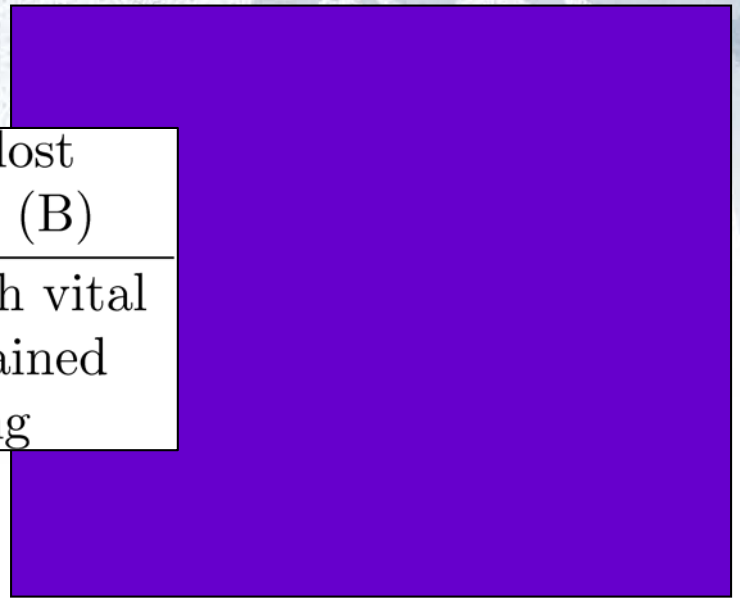
Found patients



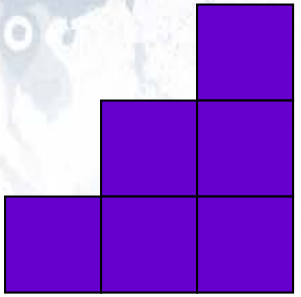
Create pseudo data by inversely weighing the found patients

Found patients

Found patients (D)



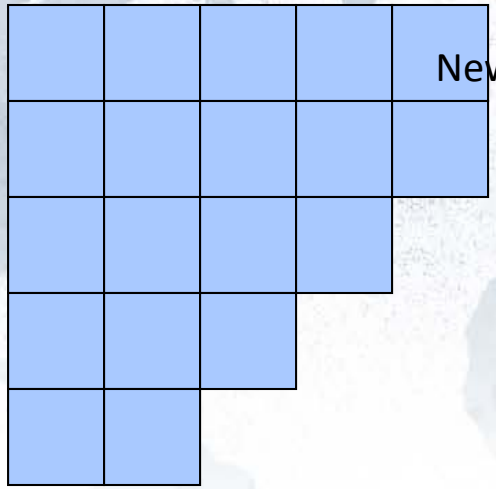
$$p_w = \frac{\#\text{ Patients lost to follow-up (B)}}{\#\text{ Patients with vital status ascertained by tracking}}$$



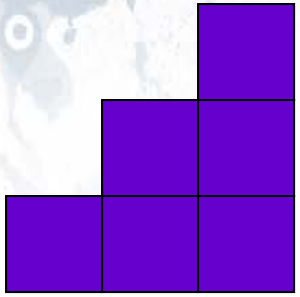
Pseudo data

Fill in original data by weighted pseudo data

Patients under observation (A)



New adjusted dataset



Pseudo data

Minimum data collected

Data collected during the tracing encounter

- Vital status
- Among patients found alive
  - Treatment status (currently)
  - POC testing data (e.g., DBS for VL; proposed)

How can the tracing data be used?

Tracing data can be used to

- Update mortality estimates
- Accurately estimate rates of disengagement from care
- With plausible assumptions (e.g., similar outcome among transfer-outs)
  - VL suppression rates
  - Adherence
  - CD4 counts
  - Other longitudinal outcomes (e.g., WHO stage, occurrence of major OIs, change to second line, etc.)

Is there anything else we can do?

Absent patient tracing methods proposed include

- Meta-analysis (from studies which have patient tracing information or linkage to registries)
- Use of inflation factors (or, more recently, estimates of sensitivity/specificity of correct mortality identification)
- Link with community-based studies

Caveats

There are serious limitations with all of these methods however:

- Meta-analysis methods do not account for change in context (location) and time of the data collection
- Inflation factors assume similar errors and prevalence as in the areas where data exist
- Community studies have traditionally (at best) weak links with clinical studies

Conclusion

- Enhancements of routinely collected data are needed to allow correct M&E and epidemiology
- Very few (any?) “shortcuts” exist outside linkage to registries and patient tracing
- Linkages needed between community-based surveys and testing with clinical studies