Community-Led Monitoring Treatment Access

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EA TG European AIDS Treatment Group
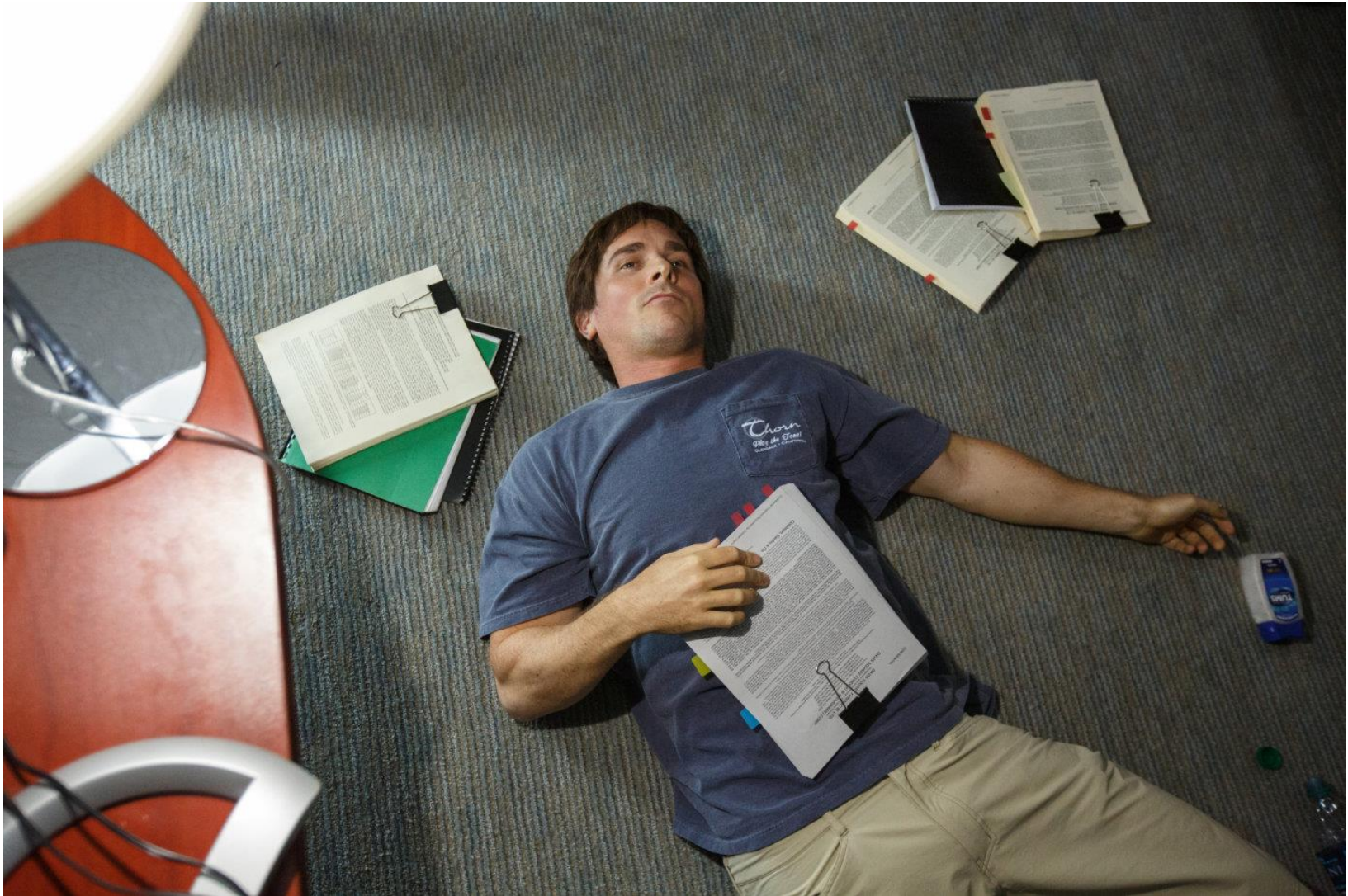
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Why monitoring?

- What is the biggest problem related to HIV in your country now?

- How do you know this?

- Can you prove it?

What is monitoring?

- Collecting data (in real time) using a specific **methodology**

- Results are ideally presented in the form of **periodic reports**

- Reports are an **advocacy instrument**

What data can you collect?

- Any data. But your resources are limited.
- Depends on your advocacy goal

Advocacy Goal	Examples of data to be collected
Reduce drug prices	
Adapt/change laws	
Improve therapy standards	
Improve access to treatment for migrants	
Improve treatment adherence	

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How to collect data

- Methodology! Enables anyone to reproduce your results using your methods

- The more "scientific" your methodology is, the more likely you are to get "correct" results (in theory). But your resources are limited.

- Remember your advocacy goal! Do not let sociology beat advocacy ☺

"A good article text consists of the section "Methodology" and the phrase "The results are summarized in Table 1 and Figure 1". ©
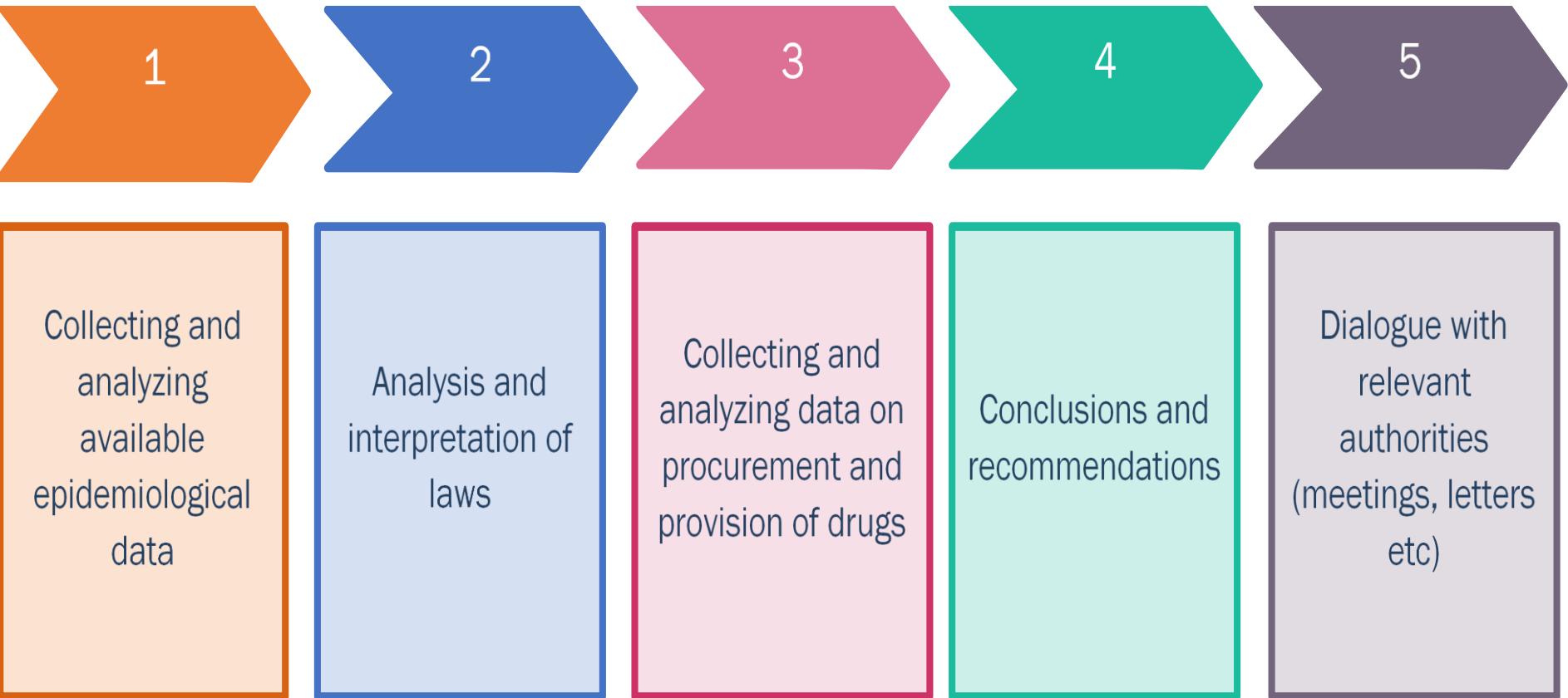
Methodology Examples

- Cabinet Studies / desk reviews

- Data collection and analysis

- Interviews (using different methodology; qualitative and quantitative studies)

- Focus groups

- Experiments

- …

Monitoring Stock-Outs

- Communication with patients by means of:

   - **A system of websites**: pereboi.ru; pereboi.kz, pereboi.by, pereboi.md, pereboi.kg

   - **Letters** sent to an e-mail advertised on special websites visited by patients

   - **Any other public data** available (media, forums, partner organizations etc.)

- Every case is supported by **advocacy work** – letters sent to clinics and/or controlling authorities (a number of sample letters available already)

Drug Procurement and Provision monitoring

1	2	3	4	5
Collecting and analyzing available epidemiological data	Analysis and interpretation of laws	Collecting and analyzing data on procurement and provision of drugs	Conclusions and recommendations	Dialogue with relevant authorities (meetings, letters etc)

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Key Parameters

- Total money spent

- List of drugs procured

- Total volume of each drug

- Total number of patients

- Price per patient per year (or per treatment course)

- Key producers and distributors

- .....

Scaling Up

- Country reports (can also be on the level of a city or a province)

- Regional reports based on country reports

- Different diseases (HIV, HCV, TB)

Other monitoring examples

- Monitoring HIV, HCV, TB treatment pipeline (annual Treatment Action Group [Pipeline reports](#))

- Monitoring global prices for ARVs (Untangling the web of antiretroviral [price reductions](#))

- Monitoring patents for HIV, HCV, TB and malaria drugs ([medspal.org](#))

- HAND Project (monitoring access to HCV treatment and care for migrants and people and detention), EATG

- Monitoring access to HCV treatment in Europe ([HEP-Core Study](#))

- More examples?

TASK

- Describe in detail a monitoring system (options):
  - a) in which you have participated; OR
  - b) which you know well and consider effective; OR
  - c) which you would like to set up in the future.

Describe in details:

1. Why do you collect the data? Which goal do you want to achieve?
2. What kind of data are being collected?
3. How often do you collect the data? Does it happen regularly, or was it a one-time project?
4. How do you collect the data? What methods are used?
5. How do you analyze the data? Are there reports based on the monitoring results
6. What are the advocacy activities after the monitoring?
7. What do you need to make the system more effective?

Basic principle of community-led monitoring

- Is meant for <u>specific advocacy goals (resources are limited)</u>
- Ideally should be continuous.
- Requires a sustainable system with a fairly simple and flexible methodology which is in line with the goal.
- Ideally the results are summarized in the form of reports
- Ideally should be linked to advocacy.
- Monitoring results is your proof that the problem exists
- Advocacy instruments – letters, reports, rallies, meetings, mass media publications etc