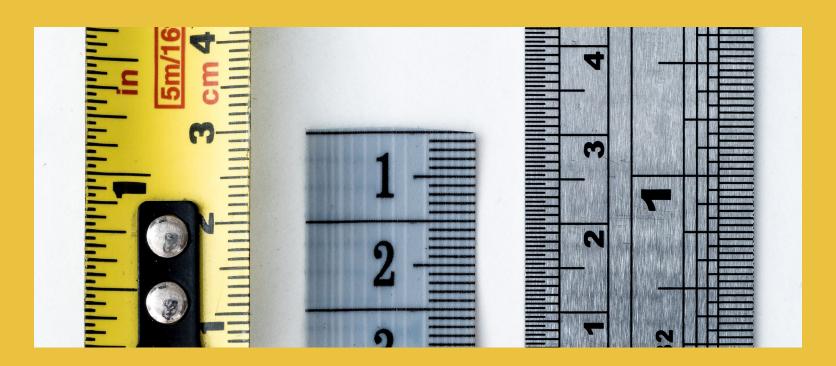
ILLUMINATE 02 COLLECTING PRIMARY DATA



In this second note of the *Decoding Injustice* Illuminate module, we dive into different ways of gathering first-hand data. Here, activists and changemakers will find tools to collect and interpret information that will be used to decode injustice.

Key Questions

What is primary data, and what are some common ways to collect it?

What is a human rights-based approach to collecting primary data for research?

What are the practical steps involved in gathering primary data?



ILLUMINATE 02 COLLECTING PRIMARY DATA

Introduction

While secondary data can be a valuable resource for illuminating the problems in the economic system that you've interrogated, it can also be incomplete. It often focuses on issues at the macro, or big picture, level, so it may not be specific enough to be useful in analyzing more specific or localized issues. For this reason, collecting primary data may be necessary to give a fuller picture of the dynamics that are creating — or sustaining the problem you're researching.

Primary data is first hand data, meaning it is collected for the specific task at hand using methods that can be tailored to the problem with the economic system that you're trying to illuminate. Collecting primary data is also one of the most in-depth ways of engaging the community or communities you're working with in the research process.

Collecting primary data can be time-consuming, and it can also be resource-intensive. In some contexts, concerns about safety and privacy may arise. That said, it can be extremely useful because you have control over the research methods (i.e., the manner in which the data is collected). Some of these methods will be introduced in this note, which also examines some of the challenges associated with them, and suggests ways to address them.

How Can We Collect Primary Data?

Primary data can be collected using a number of methods that produce both quantitative and qualitative data. In the context of

illuminating a human rights problem, collecting qualitative data can be especially helpful.

DIRECT OBSERVATIONS

Both qualitative and quantitative data can be collected through direct observation. For example, if you are collecting data about a hospital, you might describe the condition of a hospital building (qualitative) or count the medicine it has in stock (quantitative). In some cases, direct observation has the advantage of minimizing human error. For example, instead of asking someone how much water they use, which they might not always pay close attention to, you could simply read the water meter. However, without talking to people about their access to water, you run the risk of losing analytical depth and missing important aspects of the story.

INTERVIEWS AND FOCUS GROUPS

Interviews, which can be done individually (face to face, via telephone or virtual call) or in a group setting (often called a focus group) are important tools for collecting testimony. Focus group discussions emphasize the interactions among group members and the moderator (i.e., the interviewer) to provide a unique understanding of the participants' perceptions and experiences. For example, a researcher could interview a group of people with disabilities about the access issues they face in their daily lives. Qualitative approaches such as these help capture experiences that shed light on how the deprivation of human rights impacts people's daily lives. These insights are critical for unpacking the reasons they are unable to exercise their rights.

This document is organized according to an innovative method for collecting, analyzing and presenting evidence around three steps:



INTERROGATE

Map the problem in depth using OPERA to identify indicators and benchmarks.



ILLUMINATE

Spotlight the underlying issues by collecting, analyzing and visualizing data.



INSPIRE

Take action to build power and hold decision-makers accountable.





EXAMPLE: KEY INFORMANT INTERVIEWS WITH STAKEHOLDERS ON MENTAL HEALTH IN KENYA

To gain a deeper understanding on the state of mental health in Kenya, CESR and the Kenya National Commission on Human Rights conducted key informant interviews with stakeholders including the Ministry of Medical Services, hospital staff and administrators, psychiatrists in practice and academia, and non-governmental organizations providing services to people with mental health disorders. Their expertise and unique knowledge helped researchers to understand the dynamics of mental health as a human rights deprivation in different contexts. For more, check out this case study on the right to health of miners in Botswana.

SURVEYS

Quantitative and qualitative data can be collected through individual, household or community surveys or similar tools, such as written questionnaires, score cards or verbal interviews. One clear advantage of surveys is that they offer a standardized way of gathering data to fill a knowledge gap and build evidence. They can transform stories into numbers and allow us to make statistical comparisons, including over time, across regions or across groups. However, surveys can be resource-intensive. Depending on their design, they can also be too broad to comprehensively analyze specific issues. Finally, surveys can be more difficult to administer in situations where translation is required.

COMMUNITY SCORE CARDS

Community score cards are "a community-based monitoring tool with a strong focus on empowerment and accountability as it includes an interface meeting between service providers and the community that allows for immediate feedback on quality and adequacy of services provided in the community".

Source: World Bank (2005), Social Development Notes.

There are various approaches for conducting CSC surveys. A rather lighthearted approach is shown in the example below.

EXAMPLE: SCORING BUDGETARY INFORMATION

Transparency Indicator

Availability of budget information
Timeliness of budget information
Accuracy of budget information
User-friendliness of budget information
Comprehensiveness of budget information

Grading Key

- A Out of this world
- B Damn good
- C Not too impressive
- D Quite bad, actually
- E Very disappointing
- F Terrible
- G Worse than you can imagine

Source: OHCHR, HRBA Training Materials (undated)

As a type of survey, community score cards (CSC) can be a useful data collection tool for uncovering gaps in the inputs (what funds did the community receive?), outputs (how were the funds used?) and outcomes of government expenditures (how did the projects affect the community?). A key feature of CSCs is that they allow the **community as a whole** to express its **level of satisfaction** with a particular service or facility.

Although CSC focuses on the community as a whole, it is crucial to ensure that different perspectives within the community are captured, including those of the most disadvantaged. For example, women, ethnic minorities and others may have very different experiences of service provision. In order to capture these perspectives in a CSC study, questions should be framed to accommodate different perspectives, and it might be useful to conduct scoring exercises with particular groups.

EXAMPLE: THE EGYPTIAN HOSPITALS COMMUNITY ASSESSMENT PORTAL

Egyptian Hospitals Community Assessment Portal is a community-based initiative that carries out periodic patient-centered performance assessments of hospitals around Egypt. Primary data collected through this community score card (CSC) is used to measure the quality of healthcare, one of the indicators in the Egypt Social Progress Indicators.



The Egyptian Hospitals CSC collects data about how users experience hospitals, measured against specific indicators. Examples include medical diagnosis, hygiene and waste management practices, infection control protocols and availability of medical equipment. To limit subjectivity and bias, the evaluation of the hospital is confirmed by two separate community assessment teams from another geographical area than that of the hospital; only the identical results are approved for each hospital.

This CSC collects and publishes very valuable primary data of the community assessment of an important aspect of the right to health, quality of care - in particular, quality of service provided by hospitals. This is especially important in the absence of official data on the quality of other services, such as primary healthcare or ambulatory services.

BUDGETARY DATA

As budgets are original government documents, they are considered primary data sources. Budget documents are important sources of public finance data, but they are typically long and largely technocratic in nature. Trying to read and make sense of them can be a daunting exercise. The good news is that not all budget analysis techniques are highly technical and sophisticated. With some basic familiarity with budget terminology and using straightforward arithmetic — adding and subtracting, multiplying and dividing — we can use some simple techniques to analyze budgetary data. First and foremost the principles of accountability, transparency and participation demand that all budgetary documents at all tier levels of governance are open and accessible to the public - although this is not always the case in practice. Secondly, qualitative techniques can help to gather feedback from particular rights holders. Quantitative perception surveys and indicators (e.g. the Open Budget Index) can provide a general overview of the country's situation. Rights-based methods can be used to reveal whether the allocations made in previous years and the current fiscal year in key social sectors are done in an equitable and efficient manner. Some relevant methods/calculations include:

- Calculate the percentage of the State's budget allocated to social spending relevant to the total budget. Place the relevant benchmarks and the outcome-out-put indicators set by the respective department/ Ministry in comparison with the specific human right.
- 2. Identify which community groups are benefitting either directly or indirectly from the spending; contrast spending disparities with progress made towards each of the outcomes of the identified state interventions from a rights-based lens.
- 3. Compare allocations to previous budgets to see how spending has evolved over time, taking into account economic growth over the period.
- 4. Track utilization levels of key social sector schemes for the current fiscal year with previous years (e.g. using public expenditure tracking surveys or <u>social audits</u>).
- 5. Collect feedback on public participation in the design, implementation and evaluation of fiscal and monetary policies (e.g. through interviews or other qualitative methods and quantitative data, if available). Perception surveys too

- can be useful in analyzing whether policy processes are participatory, transparent and accountable.
- 6. Analyze indicators related to transparency of economic policy process.

A human rights-based approach ties the main objectives of development-related policies, legislation, regulations to budgets that have the potential to actually fulfill rights equally for all people. In future Decoding Injustice resources, we will dive into budget analysis in more detail.

Budgets: a glossary

The terminology used in budgets differs significantly from country to country, so it is difficult to compile a common glossary for all countries. Nevertheless, there are some basic concepts that can help us better understand where, and how much, public money is being allocated.

The first distinction is between two main kinds of expenditures:

Recurrent expenditures are expenses incurred year after year for running public administration, such as salaries, procuring goods and services, and providing subsidies.

Capital expenditures are one-off expenses for building assets to improve the productive capacity of the economy, such as purchasing land and developing infrastructure.

The second distinction relates to the way allocations are presented in the budget:

Economic classifications provide limited information, simply identifying how much money is being allocated to different "inputs", such as salaries and wages, utilities, travel, or printing costs. They may also be referred to as line items or object classifications.

Administrative classifications identify the entity responsible for managing the allocated funds, such as the ministry of education and health or, at a lower level, schools and hospitals.

Functional classifications categorize expenditure according to the purposes and objectives for which they are intended.

Source: International Monetary Fund, Manual on Fiscal Transparency: Glossary, 2007

INNOVATIVE TOOLS FOR PRIMARY DATA COLLECTION

The rise of social media and the spread of services offered via mobile phones has led to an explosion in the quantity and diversity of digital data, generated by people in real time. If it is adequately harnessed and analyzed, there is huge potential for agile and responsive decision-making based on this data. It allows for mapping and "crowdsourcing" information from a large, relatively open, and often rapidly changing group of participants that can be geographically analyzed and shared. Data about access to water and sanitation across a country is one example. However, this deluge of digital data brings its own

challenges with regard to privacy, accessibility, accuracy and selection bias. For example, the experiences of those who have access to the internet or have time to fill out an online survey may not be the same as those who don't.

What Types Of Primary Data Can We Use With OPERA?

Collecting primary data is likely to be relevant for many — if not most — of the indicators identified across all four dimensions of the OPERA Framework. These are summarized in the table and unpacked further below.

Outcomes	Policy Efforts	Resources	Assessment
Direct observation Surveys (especially perception and opinion surveys)	Direct observation Surveys and score cards Interviews and focus groups	Direct observation Budgetary data	Perception surveys Interviews and focus groups

DATA ON OUTCOME INDICATORS

Questions posed directly to rights holders — for example, through surveys, focus groups or interviews — can be used to collect data on their wellbeing. Wellbeing indicators can be a proxy for rights enjoyment that can then be disaggregated and compared over time. Perception surveys can be particularly important in this regard, because wellbeing has a subjective dimension to it: in other words, how do people *feel* about their living situation?

Direct observation can also be a relevant way to collect primary data on outcome indicators. For example, you might measure the height and weight of children in a particular community to collect data on malnutrition.

DATA ON POLICY EFFORTS

Primary data on the **implementation of laws and policies** — that is, how laws and policies translate into goods and services on the ground — can be collected through direct observation. For example, if a government procures the services of a private contractor to build low-income housing, we could gather useful primary data by physically going to the housing development to evaluate whether the project was actually completed and is of an adequate standard.

Surveys or score cards with individuals, households or communities can also be used to gather data on the **accessibility of goods and services**; for example, the distance to the nearest school, daily meal consumption, or the percentage of household income spent on housing.

Perception surveys can be useful to analyze whether **legal** and policy processes are participatory, transparent and accountable.

DATA ON RESOURCES

Because it focuses on how **public resources** are allocated, generated and spent, budgetary data are the main type of data used for the third step of OPERA, as well as secondary data like government economic statistics and parliamentary standing committee and audit reports. Perception surveys can also be useful in analyzing whether policy processes are participatory, transparent and accountable.

DATA FOR ASSESSMENT

Understanding the broader contextual factors affecting rights holders and duty bearers is part of the analysis in step four of OPERA. Primary data on these questions can be gathered via surveys, interviews and focus group discussions.

EXAMPLE: INTERVIEWING MINERS IN BOTSWANA ON THE RIGHT TO HEALTH



In 2020, CESR co-published a report with the Botswana Labour Migrants Association (BoLAMA) and Northwestern Pritzker School of Law Center for International Human Rights, documenting two years of research on the health issues that miners and ex-miners face. The research aimed to put miners' and ex-miners' own voices and experiences at the center of the analysis of the structural problems they confront in realizing their rights. The research team conducted interviews and focus group discussions with more than 50 miners, ex-miners, family and community members, doctors and nurses, and government and industry officials in Botswana. Drawing together personal stories and testimonies —accompanied by socio-economic statistics and other relevant data — showed significant legislative, policy and budgetary deficiencies. These put miners at undue risk of workplace injuries, accidents and illness, and prevented them from accessing care and compensation.

What Is A Human Rights-Based Approach To Collecting Primary Data?

When we conduct primary research for social change, whether through interviews, focus groups, or surveys, community members need to know why the information is being collected and how it will be used. This means adopting a participatory approach that involves the community in analyzing problems. To inspire action, the community must also be involved in identifying and developing solutions to those problems. The target

population of the research must be recognized as active rights holders, not simply sources of information. The information we gather should be relevant to the interests of the community — as a whole, and as individual members of the community, without discrimination — in accordance with the objectives of the monitoring activity.

To adopt a rights-based approach to collecting primary data, consider the following "questions to ask frequently" (QAFs), developed by the Responsible Data Forum, when working with marginalized communities.

QAFs about empowerment and capacity building QAFs about privacy, security, threats and **QAFs** about the community safety · Who is the community? What · Who is making the decisions about the Do you have a full understanding are the **boundaries** that surdata and what are the implications? of what is sensitive data in the round it in terms of ethnicity. context of this community? Are your activities disempowering the gender, race, class, sexuality, · Can you detail the risks and the community? disability, language, religion, etc? threats? · What are the forces that are mar-Who should analyze the data? Is anonymizing names enough to ginalizing this community? protect the community? · What does the data tell them? Do you understand your own Is there a possibility the data prejudice about the community? · Do they understand the **implications** of can be **misused** (e.g., a property sharing the findings? Do you fully understand the developer using data about an context and nuances of this informal settlement)? Does the community have capacity to community? **store and protect** the data adequately? Do you have ongoing informed Does the community have appropriate consent from the community for access to the data if they aren't storing it your activities? themselves?

a rights-based approach into practice. It means that data collection and analysis are done with, not about communities. It values the knowledge and experience that everyone brings to the process, in order to create new insights. Its primary aim is

Participatory action research (PAR) is an approach that puts to produce data that is practically useful, supporting victims of human rights violations to become active defenders of their rights and to develop creative solutions to human rights challenges. In this way, PAR seeks to empower people, particularly groups, to contribute to their struggles.

SIX KEY FEATURES OF PARTICIPATORY ACTION RESEARCH

- 1. Participatory action research is a process People engage in, examine and interpret the world around them to build a more systemic understanding of the problems they are facing.
- 2. It is participatory People carry out action research on themselves; it cannot be done by others.
- 3. It is practical and collaborative People engage and connect with others, and through these social interactions, are able to explore and work on reconstructing the dynamics underpinning social problems.
- 4. It is emancipatory Its purpose is to support people to challenge the unjust social structures that "limit their self-development and self-determination".
- 5. It is critical It is a process of reflection in which people learn to theorize about the social structures that constrain them, and this is done with others who share the same struggle for justice.
- 6. It is reflexive It requires ongoing reflection on different social injustices that exist across communities.

Source: Dr Rory Hearne and Dr Mary P. Murphy. Participatory Action Research: a Human Rights and Capability Approach

Practical guidance for collecting primary data

When conducting a focus group, it is important to think about the four steps shown in the diagram and discussed below.

HELPFUL TIP

WITNESS: using video for human rights documentation

- Be prepared
- · Record date, time and location
- Document who is filming
- Film with intention
- Capture details
- Document those affected
- Contextualize with interviews or narration
- Ensure the sound quality is good
- Protect identities
- Keep and organize your content

Source: WITNESS

DOCUMENTING DIRECT OBSERVATIONS

It is important to be consistent in the way data is recorded, using harmonized definitions and appropriate classifications of the issues being studied. Developing standardized templates and checklists can be helpful.

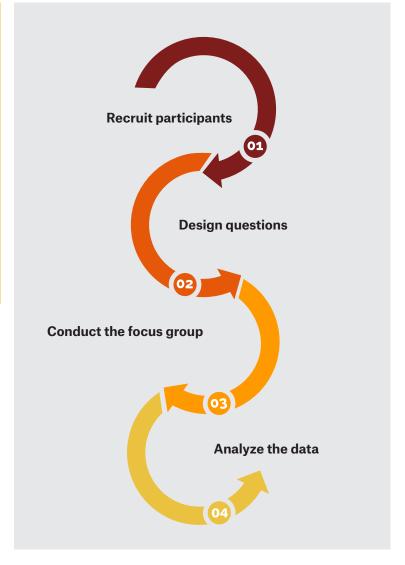
It is also important to think about what tools you will need for documenting your observations. Will you take photos? Record video? Do you need specialist measurement equipment (e.g., tape measures, scales, calculators)?

You will also need to justify why the site was selected. Was it a random sample (as discussed further below)? Was it a site identified as "best practice"? Was it a site that you had received particular information about? This should be explained in the report's methodology section.

Remember that collecting data through direct observation can also become biased by the "Hawthorne Effect", when human subjects change their behavior because they know they are being observed. This is important to bear in mind when conducting prearranged site visits.

CONDUCTING A FOCUS GROUP

Focus groups can generate analytically rich information, as one participant's insights will tend to trigger others to share their perspectives. This allows us to explore the nuances of complex subjects. Focus groups also have the advantage of gathering information directly from individuals invested in the issue, who can provide insights about conditions on the ground.



Step 1 | Recruit participants that fit the criteria established for inclusion in the study. If, for example, a researcher wants to learn about access to justice for indigenous people from a certain community, participation in the focus group should be limited to indigenous people from that community.

Focus groups normally have seven to ten participants. Groups of fewer than seven can result in a limited range of ideas and opinions being represented. Groups larger than ten may be hard to manage and record.

Additionally, when studying a complex issue such as access to services, it is important to learn from those who have successfully navigated such systems, as well as those who have struggled to do so. As there may be an element of shame associated with those who have been less successful, these conversations may need to take place in different focus groups.



Step Two | Design questions with the overall research goal in mind. Questions should be crafted to elicit the sharing of experiences among participants in a focused and meaningful manner. "When", "what", "where", "how" and "which" questions should be asked, as they encourage more detailed responses. It can be helpful to structure the focus group around three types of questions:

- **1. Engagement questions:** introduce participants to and make them comfortable with the topic.
- 2. Exploration questions: get to the heart of the discussion.
- **3. Exit questions:** check to see if anything was missed in the discussion.

Certain types of questions should be avoided. For example, "yes or no" questions ("closed" questions) will not stimulate discussion; "why" questions can put people on the defensive and should be used carefully.

Step Three | Conduct the focus group with a skillful facilitator who can remain neutral, engage with participants, and obtain clear, detailed responses. A good facilitator is an active listener who asks probing questions ("Could you tell me more about ...") and avoids leading questions ("Don't you think that ...")

The facilitator must ensure that the conversation is not sidetracked or dominated by a few vocal individuals. Every effort should be made to allow everyone in the room to express their views, including women, young people and LGBTQ+ community members. A good facilitator should do everything possible to disrupt oppressive group dynamics. It may help to hold separate focus groups, e.g., for women and men or for youth and elders.

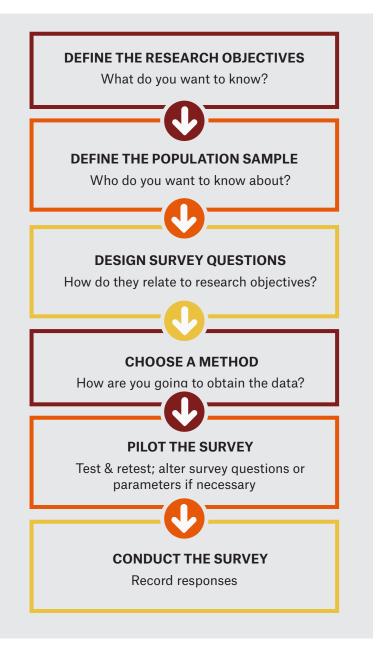
Step Four | Analyze the data captured through recordings or notes during the focus group. Responses can be organized according to common categories or themes for ease of analysis, and to allow researchers to identify gaps in information.

Carrying Out A Survey

Collecting data through a survey can turn qualitative data, or stories, into quantitative information and allow for comparison. Surveys can collect many types of valuable data; for example, they can be useful for perception studies (how a population perceives or feels about something), information about respondents' income and expenditure, or information related to how a population accesses services.

In the OPERA Framework, surveys are helpful in assessing policy efforts and analyzing policy processes. For example, communities might be surveyed about how actively they participated in the design and implementation of particular policies or programs, or whether there are avenues available to them to seek remedies for human rights violations.

There are several steps in the survey process:



Step One | Define the research objectives: what do you want to learn? You should be able to clearly and concisely state your overall research goals, as well as the specific research questions to be answered. When designing the survey, refer back to these objectives to ensure that the questions are the right ones.

Step Two | Define the population sample: who will be surveyed to answer these research questions? This will involve choosing the target population (i.e., what kind of people to survey) as well as the sample size (i.e., how many people to



survey). Determining the target population will depend on the parameters of the study, such as the social group or geographic region that the community you are working with represents. Determining the sample size will depend on factors such as the time available, the research budget and the necessary degree of precision. Generally, the larger the sample, the more accurately the sample reflects the target population.

Step Three | Design survey questions, which usually take three basic forms:

- The most common type of question is multiple choice. These are easy to tabulate and compare. Multiple-choice questions can be basic and factual (e.g., "Where do you live?"), with a choice of answers listing different locations. Multiple-choice questions can also work as rating scales and agreement scales, such as a range from "strongly disagree" to "strongly agree".
- Survey questions can also be numeric open-ended, meaning there is no limit to the value of the numeric answer to a question (e.g., "How old are you?").
- Finally, survey questions can be entirely open-ended (e.g., "How can the company improve its working conditions?").

Step Four | Choose a method for administering your survey. There are many options, and all have advantages and disadvantages:

HELPFUL TIP

Ten steps to effective survey design:

- 1. Keep it simple and make it interesting.
- 2. Keep it short, as attention spans will wane.
- 3. Use simple language that respondents would likely use.
- 4. Think about question order: ask general questions before specific ones, as specific ones will color respondents' answers.
- 5. Avoid subjective terms such as "frequently" and "often".
- 6. Include a middle option on scales (such as "neutral"), if it is warranted.
- 7. Avoid double negatives as they can be confusing (question prompts should never be negative).
- 8. Make scales logical for the responses.
- 9. If designing a question around a 10-point scale, don't forget to include "0".
- 10. Put personal questions at the end, as participants may be uncomfortable answering them.

Source: RCU, 10 Step Guide to Questionnaire Design [VIDEO]

Method	Advantages	Disadvantages	
Personal interviews	You know who you're talking to. Respondents are generally more willing to answer long questions and can clarify unclear responses.	They are costly. Interviewers must travel to the location of the target population. Variations in the style of interview- ers can cause variations in responses.	
Telephone surveys	Nearly everyone has a phone. Interviewers can call randomly and they can clarify unclear responses.	There tends to be a negative association with sales calls. Few people are generally at home during the working day.	
Mail surveys	Can be sent out easily when addresses are accessible. Respondents can respond at leisure.	This method takes time. There is generally a low response rate for populations with lower levels of literacy and formal education.	
Email surveys	Email is extremely fast and low cost. Surveyors can attach pictures and sounds.	There is a general dislike of unsolicited email. There is also little control over who responds.	
Web surveys	Web surveys are extremely fast and low cost. Surveyors have lots of formatting options. Questions can be automated and anonymous.	Internet usage is not universal. Respondents can easily quit before completing the survey. There is little control over who responds.	

identify and correct any errors in the questionnaire before it is response questions into closed response or multiple-choice sent to the entire sample. Based on responses received during questions, for example.

Step Five | Pilot the survey with a smaller sample size to the pilot, researchers may opt to make revisions; turning open



CONCLUDING THOUGHTS

As observed at the start of this note, collecting primary data can be time- and resource-intensive, so it may not be feasible to do all, or as much, of this work as you might wish. That said, a number of the techniques outlined here are ones that civil society groups use regularly in their daily work. Key informant interviews, direct observation and focus group discussions will be familiar techniques to many.

In some cases, collecting primary data may involve doing what you are already doing, but taking a more methodical approach. This can provide more standardized information that is easier to analyze and is more directly relevant for illuminating the four dimensions of the OPERA Framework. In particular, primary data is helpful for capturing the subjective aspects of OPERA's four dimensions, such as how people *feel* about their wellbeing, about the goods and services they're able to access, about how participatory and transparent policy-making is, etc.

To recap, using these techniques more methodically requires asking these key questions at the start of your research:

- What are you using the data to illuminate?
- How will you identify the sites where you intend to collect the data? Are they random samples? If not, what criteria will you use to select them?
- Who will collect the data? Will it be staff from your organization? Partner groups? Community representatives?
- What role will the community play? How will you ensure that your data collection is

- participatory and empowering and follows a human rights-based approach?
- What data collection tools will you use? Have these been standardized? Have data collectors received adequate instructions on how to use them?
- Over what time period will you collect the data? Is it a week? Month? Three months? Be generous when estimating the time required.
- How will you ensure the security of the data you collect? Establishing protocols is particularly important if you are collecting data that identifies individuals.

To become evidence, data needs to be analyzed and interpreted. For our purposes, this means asking: What does the data tell us about the indicators we've identified for each of the dimensions of OPERA? What does this illuminate about the problems in the economic system that we've interrogated? As highlighted in note four of the first module, comparisons against benchmarks help us with this. But, it also requires some basic data analysis techniques. These are introduced in the third note in this module (Illuminate 3 - Analyzing Data).

