Ethical considerations for collecting and using participatory data

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Overview

People participating in decisions that affect their lives is a core value of open and democratic societies. This value is an important starting point for how to plan, implement and manage participatory data and engagement processes in international development. Programmes are more likely to succeed if the people they aim to reach are directly involved in them. This is particularly true for vulnerable people who tend to be excluded. Yet it is also true that participation may expose people to risks, requiring programmes to think carefully about ethics.

What is participatory and systemic data and why do we need it?

Participatory data is data that is generated and analysed by people who have a stake in an issue (hereafter referred to as stakeholders) and are affected by the issue.

It is important because:

• Stakeholders often have better access to valid and meaningful data about their own circumstances
• Understanding stakeholders' own experience is crucial to understanding the context of an intervention
• Stakeholders have a deeper contextual knowledge and therefore can analyse it from the position of being inside it
• Involving diverse stakeholders allows meaning to be subjected to contestation and challenge through deliberation and dialogue, as with triangulation in research, it can lead to more robust understanding.
• Just like outside experts, stakeholders will have a view on the appropriateness and viability of particular solutions to problems, however they are far more likely to understand the norms and power relations which make any intervention realistic or not, and the means by which they can be challenged where necessary
• Participants generating their own data feel more ownership of the results of their own analysis, and as a result are more likely to act on it

What characterises participatory data is that people have collected and analysed it themselves (often with the support of others). The analysis and sense making itself is, therefore also part of the data. The data that is generated from participatory research and development processes is very varied. It can include, among others: stories people tell about their lives or experiences, rankings, system maps which result from local analysis and/or records of action research meetings.

Systemic data is data that helps us to understand how systems work. Systems are both physical and conceptual. They are made of parts that are interconnected to form a whole. A systemic approach to engaging with the specific problem requires that we try to understand the causalities, patterns and dynamics of that system (system dynamics) to understand why things are as they are. If we can understand these dynamics, then we should be able to
make better interventions and consequently will have a better chance of assessing the impact of those interventions.

The system dynamics can be represented in narratives and stories, in system maps, in network maps and many other forms of data. Sometimes the knowledge about the system held within the data needs to be distilled (requiring tools) and sometimes it is manifest directly in the outputs of the research or development process.

Amongst other things systemic data allows us to:

- Visualise and understand complex causalities (some of which may exist outside of the originally defined 'programme' domain)
- Identify multiple points within a system dynamic which might be 'entry points/ leverage points' for effective intervention
- See latent changes (or emergence) within a system which might later impact on the system. These might be the start of what complexity theory calls 'alternative attractor patterns' which can inspire people to shift longstanding norms, identities and behaviours or indeed could suggest the converse.

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Ethical Considerations:

Maintaining the participatory integrity as data travels through layers of interpretation, analysis and packaging to build systemic understanding and inform programming is not straightforward.

Tips for ensuring that ethical approaches are applied to the collection, management and use of participatory data include:

- Creating data plans that map what programmes are trying to achieve. What the minimum data requirements will be and how this data will be collected, stored and disposed of.

- Giving thought to who will handle the data - where does responsibility begin and end?

- Thinking about the methods and tools that can be used to manage, analyse and store data. How will the data sources be labelled so that versions can be tracked? What are the relevant standards and data types that can help to make information interoperable?

- Establishing how to ensure informed consent is gained is also important. Is a consent form really enough if people are illiterate or do not understand the context of the programme?

How can legal requirements stimulate greater engagement with ethical issues?

In May 2018 changes to EU regulations will see the introduction of the General Data Protection Regulation (GDPR). This will mean that public authorities and organisations that handle large quantities of personal data will be required to appoint Data Protection Officers who will be responsible for advising colleagues on GDPR and other data protection regulations.

It may mean that the data protection point person in an organisation is also the person who thinks about the data ethics but thought needs to be given to the skills sets needed to do this work. To do it well requires an understanding of the programme context, as well as a combination of the ethics and the external compliance issues.

- Thought needs to be given to how data will be presented - the chances are that if the programme is participatory in nature then you will want it to be published in open formats but it is important to think about what that means.

- Consideration also needs to be given to organisational needs and how institutional policies for ethical data management can adapt in order to maintain relevance and accompany the rapid pace of technological innovation.

Resources:

Prepare, Explore, Strategise and Act - The Holistic Security Manual is founded on the understanding that 'security' is a deeply personal, subjective and gendered concept.

Good Data Collaborative Consultation Report A joint project with the Center for Democracy and Technology, Future of Privacy Forum, The Engine Room, and SimLab to develop resources to help social change organisations to manage data more responsibly.

Digital Impact Toolkit is designed to help non-profit organisations and foundations use digital data ethically, safely and effectively.

Responsible Data Handbook Illustrated Guide to Responsible Data Usage, Manners and General Deportment

Responsible Data Management training pack Adaptable training pack designed by Oxfam for humanitarian organizations on managing programme data

Data during Ebola - Report about ethical violations during the Ebola crisis

Responsible Municipal Data Management Protecting Data, Protecting Residents

Stanford Digital Civil Society Lab investigates the challenges and opportunities facing civil society organizations in the digital age, and develops resources to help organizations use digital resources safely, ethically and effectively.

The Signal Code: A Human Rights Approach to Information During Crisis

Data, Human Rights, & Human Security How can technologies be used responsibly to assist those in need, prevent abuse and protect people from harm?

Benefits-Risk Analysis for Big Data Projects This analysis provides guidance for organizations in their weighing of the benefits of new or expanded data processing against attendant privacy risks.

IDS Research Ethics Policy promoting and upholding the highest ethical standards in research

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