

RESEARCH THAT MATTERS

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# EXPLORING INTERNATIONAL PRIORITIES AND BEST PRACTICES FOR THE COLLECTION OF DATA ABOUT GENDER MINORITIES

A Focus on South America

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## INTRODUCTION

Data that identify and describe the experiences of gender minorities can help foster evidence-based policymaking and bring increased visibility to gender minority populations. Currently, such data collection is limited, particularly data collection conducted by governmental and inter-governmental institutions.

On November 2, 2018, the Williams Institute at the UCLA School of Law, and a steering committee of international advisors, convened a meeting in Buenos Aires, Argentina, to study the development of best practices for the collection of data on gender minorities in South America. Participants included academics, government officials, community members, researchers, advocates, and funders. These individuals were based in 12 countries, including Argentina, Australia, Brazil, Canada, Chile, Colombia, New Zealand, Peru, South Africa, Spain, the United Kingdom, and the United States of America, and represented international institutions such as The Joint United Nations Programme on HIV/AIDS (UNAIDS), Transgender Europe (TGEU), and the International Lesbian, Gay, Bisexual, Trans, and Intersex Association (ILGA). The meeting took place on the first day of the 25<sup>th</sup> scientific symposium of the World Professional Association for Transgender Health (WPATH), which co-sponsored the meeting.

This meeting was the second iteration of an international effort begun in Amsterdam, the Netherlands, in 2016 to consider the desirability and feasibility of producing international best practices for gender minority data collection. The 2016 meeting, which similarly convened experts in gender minority data collection, established in a final meeting report a set of next steps. Principally, these included making regionally-focused determinations regarding best practices and expanding networks of researchers and other experts to support this effort. Drawing on experiences and feedback from participants at the meeting in Amsterdam, the recent meeting in Buenos Aires focused specifically on a region of the Global South: South America. The primary objectives of the meeting were to:

- Further develop an international network of academics and other experts who study the collection of data about gender minorities;
- Update participants on the network's knowledge of current data collection research and official data collection efforts around the world;
- Draft a model for the development of best practices for data collection about gender minorities in South American countries.

The meeting took place over a full day and included four different sessions. The first two sessions included presentations from experts on gender minority data collection; the latter sessions included discussions, both within small groups and among the full contingent of participants.

The four sessions focused on:

- Reviewing research and data collection on gender minorities globally and in South America;
- Presenting research and considerations on gender identity measurement from experts in South America and discussion from a panel of advocates, community members, researchers, and other experts;

- Discussions in small groups about considerations for the development of best practices on gender minority data collection in South America;
- Discussions of conclusions and next steps.

This report is intended to describe the proceedings of the recent meeting in Buenos Aires and present conclusions and potential next steps based on participants' discussions and feedback. We note that this report does not attempt to establish best practices for the region but, rather, to catalyze the process by which such best practices may be determined. It is not intended to represent the viewpoints of gender minority communities, governments, researchers, or other stakeholders broadly, but instead to summarize the discussions that took place at this meeting. The Williams Institute developed this report with feedback and review from members of the steering committee and other meeting participants, including in response to separate English and Spanish-language drafts.

## TERMINOLOGY

There are many different terms, in English, Portuguese, and Spanish, used to describe various aspects of individuals' gender. In this report, we use terms including "gender identity," "gender minority," "transgender," "trans," and "travesti," for example. We use the term "gender identity" to refer to an individual's internal sense of their own gender and connection with a particular gender label. We use the term "gender minority" to describe individuals whose current gender identity differs from their sex assigned at birth, including those who do and do not identify as "transgender" or "trans."

During the meeting, participants also employed a diverse set of terms to describe people's identities and communities, including those used in this report and others, such as "transsexual," "trans woman," "trans man," "transgender woman," "transgender man," "woman," "man," "gender non-binary," and "gender non-conforming." Meeting participants discussed the extent to which terminology, its use, meanings, and connotations, differed across cultures, nations, and communities within South America.

### *Travesti*

*The term "travesti" is used in different communities in South America (as well as other areas in Latin America and the Iberian Peninsula) to refer to people who were assigned a male sex at birth and who have a feminine/femme gender identity. The term, in some localities and cultures in South America, is seen as pejorative. In other communities, the term has a political connotation associated with reclaiming a positive connotation from a previously derogatory term.*

# CURRENT DATA COLLECTION PRACTICES AROUND THE WORLD

## GOVERNMENT DATA COLLECTION PRACTICES

Prior to the meeting, participants were asked to provide information about official efforts by governments or intergovernmental agencies to collect data on gender minorities, either in their country or others. Participants reviewed a compilation of this information during the first session of the meeting, which is reproduced here, organized by region, to provide context regarding data collection practices. Presenters gave additional focus to data collection undertaken by institutions in South America. The following description of these practices is not exhaustive; rather, it reflects the information provided by participants prior to the meeting.

### Africa

While a few participants based in African countries participated in the meeting, we received no reports of any official efforts to collect data on gender minorities in Africa.

### Asia & the Pacific

In New Zealand in 2015, Statistics New Zealand drafted a statistical standard for gender identity data collection. This document standardized definitions of gender minority terminology and recommended a number of gender identity measures for inclusion on surveys conducted by New Zealand's Official Statistics System (OSS).

More recently, Statistics New Zealand tested a question from its statistical standard for inclusion in that country's 2018 census. This measure asked respondents whether they were male, female, or gender diverse. Ultimately, Statistics New Zealand cited a lack of confidence in the measure's ability to produce high-quality data and decided not to include it on the census, though data from tests of this measure will inform future study. Presently, there is no collection of gender minority data in official data collection efforts in New Zealand.

In Australia, the 2016 national census collected data, for the first time, allowing for the identification of some gender minorities. Respondents were able to select "other" as their sex instead of "male" or "female" and then may provide more information about their gender identity. However, this option was only made available if respondents made a special request to the census inquiry service. This effort revealed new questions and challenges for the government regarding reporting procedures for non-binary individuals, the conflation of sex and gender, and other issues for consideration in future data collection efforts.

While participants based in other countries in Asia and the Pacific were invited, no individuals from additional countries were able to attend the meeting or provide information about current official data collection practices.



## Europe

In the United Kingdom, the office of National Statistics is considering measures of gender identity for inclusion in the 2021 national census, including a question that would ask respondents if they consider themselves to be trans and another question that would ask respondents if their gender is the same as their sex registered at birth. Additional survey research allowing for the identification of gender minorities in the United Kingdom has been conducted by the BBC, National Health Service, and Solicitors Regulatory Authority.

In Germany, the Robert Koch Institute, a federal agency and research center, conducts data collection through multiple national health surveys, including on gender identity.

## North America

In the United States, there are a number of national and state-level surveys that collect data on gender minorities in representative samples of the general population. The Behavioral Risk Factor Surveillance System (BRFSS), an annual, state-administered health survey conducted in every state, the District of Columbia, and multiple US territories, collects data on transgender identity, including through an optional measure in 2014. In 2018, these data were collected in 26 states. The Youth Risk Behavior Surveillance System (YRBS), a similar health and risk behavior survey conducted among youth, has also collected data on perceived gender expression in some states and localities since 2017. Other surveys, such as the National Inmate Survey of incarcerated adults and the National Crime Victimization Survey of US households, have asked questions to identify transgender people.

Some administrative programs at the federal level also collect information about gender identity. For example, the U.S. Department of Health and Human Services' Ryan White HIV/AIDS Program has collected gender identity data to inform its work with people living with HIV, including transgender people.

At the state level, surveys in some states, such as the California Health Interview Survey (CHIS), collect data about gender minorities. The CHIS, in fact, is the only representative state survey in the country to include a two-step approach to identifying transgender individuals. The two-step approach collects data about both sex assigned at birth and current gender identity in order to identify those whose gender identity is different from their sex assigned at birth.

At the local level, some municipal governments in the US have collected data on gender identity. For example, the New York City Community Health Survey has included multiple measures of gender identity in the past, and the San Francisco Department of Public Health has provided guidance since 2013 on gender identity measurement for city surveys and administrative data collection.

In Canada, there have been numerous changes in the past few years to the collection of gender identity data. In April of 2018, Statistics Canada adopted new definitions and standards for the collection of data on sex and gender, including a two-step measure to identify gender minorities. Since then, at least 25 surveys have adopted this method of measurement, and a similar measure has been under consideration for inclusion in the next census. Statistics Canada is currently studying how the agency might recommend that data users impute, disseminate, and otherwise analyze these data.

Statistics Canada has also taken the lead, in partnership with the UK's Office of National Statistics, in developing a review of gender identity measurement for the UN Economic Commission for Europe.

These guidelines are intended to inform data collection in the region.

Canada has also implemented other gender identity measures, including, in 2018, a two-step measure of gender identity in its national version of the Health Behaviour of School Age Children Survey (HBSC). This international survey of high school youth is administered in 40 countries, including versions which have collected data on gender identity in Canada.

At the provincial level, additional surveys in Canada have collected data on gender identity, such as the BC Adolescent Health Survey in western Canada, a survey of youth that has included a two-step measure to identify gender minority youth.

## South America

National governments across Spanish-speaking South America differ in their official efforts regarding data collection about gender minorities. Some countries, such as Uruguay and Argentina, have been particularly supportive of research about gender minority communities. In 2017, the Ministry of Social Development in Uruguay partnered with academic researchers and community members to develop a national census of transgender and other gender minority people in the country. In Argentina, there has been a similar effort to develop and field a census of transgender people in the country. While the survey has yet to be completed, preliminary tests of a census have been administered at the provincial level. The Argentine National Institute of Statistics and Censuses is currently in the process of developing a module for inclusion in the upcoming 2020 national census related to gender identity.

Different government entities in Argentina have led their own efforts, over the years, to collect data about gender minorities, including a survey of the living conditions of transgender people by the Ministry of Social Development in 2017; a survey of transgender residents of Buenos Aires by the city's Public Ministry of Defense; and a pilot survey of transgender people by the National Institute of Statistics and Censuses in 2012. Government bodies in Argentina have also supported the collection of gender identity data through administrative systems, including through mandatory reporting of gender identity in the employment portal of the Ministry of Production and Labor and official registrations of changes of gender.

In Peru, the official statistical body for the nation, the National Institute of Statistics and Information, developed a study in 2017 to better understand the characteristics and needs of transgender and other gender minority people in the country using an online survey.

In Brazil, the public health care system collects data on gender minorities who undertake gender-affirming treatment, including hormone therapy and surgery. Other state institutions in Brazil collect administrative data on gender minorities, such as through police surveillance records under state violence registries. Starting in January 2020, the Municipal Secretariat for Human Rights under the Bruno Covas administration will conduct a census of transgender people in São Paulo. Transgender advocates and the Federal Public Defender's office have asked the Brazilian Institute of Geography and Statistics to include questions about sexual orientation and gender identity to the 2020 national census, but the Institute has not responded.

At the international level, participants also noted that UNAIDS, among other entities, collects data on gender minorities living with HIV in South America through its Stigma Index Study.



## HIGHLIGHTED STUDIES FROM SOUTH AMERICA

In addition to providing information about official efforts to collect data about gender minorities, participants also submitted information about research and non-governmental data collection efforts focused on gender minorities in which they were personally engaged. The steering committee organized and presented this information to the full body of participants during the first session of the day. Given the meeting's regional focus, two presenters from the steering committee highlighted information gathered from participants pertaining to data collection efforts in South America. During the second session of the meeting, three additional participants based in South America gave detailed presentations of research regarding gender minorities in the region. In this section, we describe the information pertaining to data collection practices and research in South America that each of these five presenters described.

### Data Collection Initiatives about Gender Minorities in Spanish-Speaking South America (Alfonso Silva-Santisteban, Peru)

During the first session of the meeting, Alfonso Silva-Santisteban, a research professor at Universidad Peruana Cayetano Heredia (UPCH) and a member of the meeting's steering committee, gave a presentation on information provided by participants about unofficial data collection and research conducted in Spanish-speaking South America.

In this discussion, Silva-Santisteban reviewed the history of research in the region about gender minorities; he cited research by community organizations in Argentina, led by the efforts of Lohana Berkins, founder of Asociación de Lucha por la Identidad Travesti y Transexual (ALITT), as an early catalyst for the development of this body of research. In particular, this early research centered on documenting the experiences of gender minorities. As in other regions, governments' primary focus on gender minorities at this time, after 2008, was on collecting data related to HIV.



*Photo by Jim Carey*

Since 2010, there has been a proliferation of data about gender minorities in South America, and that has come with increased visibility and opportunities for gender minority communities to position themselves as key stakeholders in the collection of these data. According to Silva-Santisteban, the development of these new initiatives has in some countries, such as Argentina and Uruguay, increasingly focused on informing policy-making; in other countries, such as Chile, Colombia, and Peru, data collection has primarily been led by those in academia. In still other countries, research and data collection about gender minorities remains limited and has been restricted to the domain of community organizations.

Silva-Santisteban identified a number of influential efforts to collect data about gender minorities in the region. One of these initiatives is the 2016 Trans Census in Uruguay. This survey project, which was managed by the Uruguayan Ministry of Social Development and a team of academics and community organizations, collected data about gender

minorities through the use of a nation-wide survey, which allowed for participation based on self-identification. A subsequent publication of the procedures, practices, and lessons learned from this project has provided detailed guidance for data collection by other governments in and out of South America. In addition to this effort, Silva-Santisteban also identified the work of RedLacTrans, a regional network of transgender people across Latin America and the Caribbean, in documenting experiences of gender minorities as an important contribution to research in the region.

Despite these and other efforts, Silva-Santisteban reiterated, there is still a great need for official data collection, in particular through the inclusion of variables to identify gender minorities in official data collection instruments. The standardization of methodologies and terminologies used in collecting data about gender minorities is also a pressing need for the future development of research in South America.

### Data Collection Initiatives about Gender Minorities in Brazil (Angelo Brandelli Costa, Brazil)

Also during the first session, Angelo Brandelli Costa, associate professor at Pontifícia Universidade Católica do Rio Grande do Sul and a member of the meeting's steering committee, delivered a presentation reviewing information about data collection and research on gender minorities in Portuguese-speaking South America, that is, Brazil.

Brandelli Costa identified a number of research centers and networks in and outside of Brazil supporting research and data collection on gender minorities in the country. Among these organizations are the Núcleo de Pesquisa em Direitos Humanos e Saúde LGBT+ (NUDHES) at the College of Medical Sciences of Santa Casa de São Paulo and Preconceito, Vulnerabilidade e Processos Psicossociais (PVPP) at the Pontifical Catholic University of Rio Grande do Sul. Approaches to gender



Photo by Jim Carey

identity data collection, such as the types of questions used to identify gender minorities, vary across these organizations.

Brandelli Costa also provided a detailed description of one particular study, entitled "The Impact of the Parental Support on Risk Factors in the Process of Gender Affirmation of Transgender and Gender Diverse People." The study, which collected a sample of over 700 gender minorities across two Brazilian states, aimed to provide new information about relationships between family support and gender minority identities in processes of gender affirmation. This study utilized the two-step method to collect gender identity data.

Among their findings, the authors found evidence that

a lack of parental support was associated with low self-esteem and greater odds of living without stable housing among gender minority participants. This study adds to the growing body of research in Brazil supporting greater study and collection of data on gender minority populations.

## The Characteristics, Health, and Well-being of Transgender People (Jaime Barrientos Delgado, Chile)

During the second session of the meeting, Jaime Barrientos Delgado, a professor of psychology at the Universidad de Santiago de Chile, presented information about two studies that he co-authored about transgender people in Chile.



Photo by Jim Carey

The first study, “Subjective Wellbeing and Levels of Clinical Symptomatology in a Trans Women Sample and Men Who Have Sex with Men in Chile,” provided new information about the health and sociodemographic characteristics of transgender women in Chile. Given the lack of representative data on transgender people in Chile, the study relied on data from two purposive samples, comparing responses from a sample of transgender women against those of a sample of men who have sex with men (MSM). The study found significantly lower levels of reported happiness, satisfaction with life, and perceived purpose in life among transgender women than MSM. Transgender women also indicated significantly higher levels of anxiety, depression, somatization, hostility, and phobic

anxiety. Barrientos Delgado, in describing the data, indicated that transgender women in the sample were significantly disadvantaged compared to the MSM sample.

The second study that Barrientos Delgado presented, “Minority Stress: The Effect of Sexual Stigma and Prejudice on the Subjective Well-being and Mental Health of the Transgender Population in Chile,” also used a purposive sample of transgender adults and MSM to examine the wellbeing of transgender people and the effects of sexual stigma and prejudice. In this study, Barrientos Delgado and his colleagues also sought to better understand the makeup of the transgender population in the country. The study found that a majority (80%) of the sample participants were Chilean, and a sizable minority were immigrants from Ecuador, as well as other countries. The sample included a greater number of participants assigned male sex at birth than assigned female sex at birth. By comparing gender identity and sex assigned at birth, the study also found that those assigned female sex at birth were much less likely to indicate a binary gender identity and more likely to indicate they are gender non-conforming than those assigned male at birth. This information, while not representative of the general population in Chile, provides a baseline of understanding about the makeup and experiences of transgender people in the country.

## Collecting Gender Minority Data in Santa Fe, Argentina (Esteban Paulón, Argentina)

In addition to presentations from academic researchers, meeting participants heard about data collection efforts conducted by governments and community organizations. Esteban Paulón, vice president of the Argentina LGBT Federation and undersecretary of sexual and diversity policies for the government of the province of Santa Fe in Argentina, presented information about ongoing programming and research led by the provincial government.

Paulón identified a number of data sources at the provincial level. These included administrative records maintained by government agencies in Santa Fe, and, likely, other provinces in Argentina,



Photo by Jim Carey

which allow for individuals to register their gender identity. These records, therefore, contain information to identify a portion of gender minorities in the province. Similar data are collected, for example, from school teachers within the provincial public school system, through the official employment registry by the provincial secretariat, and through the public health system's records of those seeking gender-affirming treatment.

Other records maintained by state agencies, such as for individuals participating in subsidy and pension programs, also allow for identification of transgender people. Additionally, Paulón described how the provincial government's statistical unit, Instituto Provincial

Estadísticas y Censos, is undertaking an initiative to study the living conditions and experiences of gender minorities in Santa Fe. Additionally, since the 2012 enactment of Argentina's Gender Identity Law (Number 26743), which recognizes a person's gender identity, allows for changes of gender on official records, and addresses access to health care, the state has collected data on the number of individuals who have registered a change in gender. Currently, the government of Santa Fe is conducting a province-wide survey of transgender residents, collaborating with local community organizations and municipal governments. These efforts in Santa Fe province exemplify the data collection and research being undertaken at subnational levels in the region.

## Guaranteeing the Recognition of Gender Identity in Employment Policy (Marcelo Mangini, Argentina)

Marcelo Mangini is an official in the Gender and Sexual Diversity Advisory Office in the Argentine Ministry of Production and Labor and an activist with Futuro Trans, an organization advocating for the rights of gender minorities in Argentina. Mangini presented information about efforts by the Ministry of Labor, Employment, and Social Security and other departments of the federal government of Argentina to collect data and support research on gender minorities in the country.

Mangini described one initiative in detail, a collection of programs inclusive of, or focused specifically on, gender minorities. In 2013, the Ministry issued Resolution 331, which recognized gender minorities as a particularly vulnerable population that would be eligible and prioritized for participation in a set of employment programs. With Resolution 331, gender minority adults in Argentina became eligible to participate in SCyE, a training and employment insurance program. Between 2013 and 2015, 1,022 gender minority individuals participated in the program. Data on these program participants are a new source of information on the lives of gender minorities in Argentina. Mangini also showed that a slight majority of these participants had not previously registered a change of gender in the official federal registry and had, therefore, been excluded from prior analyses of those data. This experience by the Ministry demonstrates how government's use of different methodologies and terminologies to collect data on gender minorities can result in distinct samples from subsets of the population.



Photo by Jim Carey

Mangini also provided information about the Ministry's efforts, supported by the International Bank



for Reconstruction and Development, to collect data about gender minority youth and integrate the population into national employment programs. In 2016, the Ministry conducted an anonymous survey of gender minority youth, developed with input from local communities, to gather information about identity. Data from the survey were used to inform the development of employment programming. Mangini explained that this work provided the Ministry new experience with and important lessons for collecting data about gender minority youth.

## PANEL DISCUSSION

**Panel Participants:** Jaime Barrientos Delgado, Chile; Lukas Berredo, Germany; Manuel da Quinta, Argentina; Claudia Vásquez Haro, Argentina; Jana Villayzan, Peru; Marlene Wayar, Argentina

**Panel Moderator:** Alfonso Silva-Santisteban, Peru

In addition to presentations from individuals engaged in gender minority data collection in South America, the second session of the meeting also included a panel discussion. All individuals who served on this panel were either from or worked in South America. Among panelists, there was an academic researcher, an official from an international institution, two community organizers and



Photo by Jim Carey

activists, and one advocate from an international organization. Each participant had engaged with research in a variety of capacities and was able to offer a wealth of knowledge on working in and with gender minority communities. Panelists discussed three broad topics, including: collaborations between gender minority communities and researchers,

the roles of governments and international organizations in research, and considerations of safety and security for gender minority communities in research.

At the outset of this discussion, the moderator asked panelists to share their experiences and thoughts regarding how researchers and community members in South America have worked together to collaborate on gender minority data collection and research and the challenges that have existed in that work. One panelist from Chile described how much of the early research about gender minorities in the region and in Chile focused on HIV. He described this initial engagement with communities as, often times, the source of the mistrust that exists in many settings today between researchers and community members. Panelists identified challenges in this early research as including researchers' conflation of transgender and MSM populations and the burdens placed on gender minority communities for data collection. One panelist spoke about her experience supporting gender minority research as a transgender woman and being denied opportunities to review documentation of findings or conclusions, saying, "I was the link with the community, but I could not review the report, see the report, even have my opinion." Another panelist encouraged others to recognize that some transgender people and other gender minorities are also researchers and that these groups are not mutually exclusive.

The moderator also asked panelists to share their knowledge of and experiences with government and international organizations engaging in gender minority research. A panelist from UNAIDS described how the United Nations supports data collection to empower national governments to support and improve the lives of their people. Different countries throughout South America have reacted differently to UNAIDS' efforts to collect gender minority data. In separate instances, national governments



Photo by Jim Carey

have resisted the inclusion of transgender people in decision-making regarding data collection methods and refused to consider research focused on gender. For example, a panelist from Peru stated that the Peruvian government cares nothing about gender minority data collection. In considering factors that may influence support for gender minority data collection across South America, panelists discussed concerns about low levels of support for democratic norms in the region, particularly among youth. Multiple panelists also addressed the fact that, while some are advocating for governments to collect data about gender minorities, some government entities are, themselves, engaged in marginalizing and harming gender minority people.

From these discussions, the moderator turned to addressing issues of safety and security in research. With limited time for the panel discussion, participants raised concerns about violence, both by state and non-state actors, against transgender people. A panelist described the situation faced by gender minorities in Chile by stating that “these conditions in our country are brutally violent.”

Another panelist described how the election of new governments opposed to the rights of gender minorities has led to continuing violence against gender minority communities. Although there was not a specific discussion about the safety and security of gender minority communities in research and data collection, participants did review these issues in the third session of the day, which included small group discussions.



Photos by Jim Carey



## DISCUSSION

The second half of the meeting was devoted to small and full-group discussions about developing best practices for gender minority data collection in South America. In the third session of the day, groups of approximately eight participants convened to discuss broad topics central to the development and implementation of best practices, including: collaboration, measurement, cultural contexts, safety, and resources and support. Each group was asked to consider questions pertaining to three of the five topics. Group conversations in the third session were in English and Spanish, and translation assistance was available. Following these discussions, each group gave a brief presentation of their deliberations.



Photos by Jim Carey



During the fourth session, two steering committee members led an open discussion focused on areas of consensus and divergence stemming from the small group discussions and prior presentations. The two facilitators also invited participants to share their thoughts about the topics on a set of posters located throughout the room. A conversation about next steps for the development of best practices concluded the meeting.

## COLLABORATION

On the topic of collaboration, participants considered how researchers and members of gender minority communities have and can work together to develop and utilize best practices for data collection. Participants described how gender minority communities have worked with researchers to support and conduct research, such as in advising researchers, supporting subject recruitment, testing and designing measures, facilitating the development of networks, and drafting publications. In this discussion of community collaborations, there were three broad points of consensus. These included the perception that there is a base of mistrust between researchers and research institutions, on the one hand, and gender minority communities, on the other, and that future collaborations

*"There is an issue of trust, trust in researchers, institutions, governments, including changing governments"*  
-participant

need to address this tension. Many participants described personal experiences and local histories of exploitation by researchers and the need for mutual trust to ground future collaborations. Participants also articulated a concern that research should involve meaningful community engagement and participation at all stages, and, related to this, that gender minority communities should be appropriately recognized and compensated for their support of research collaborations.

Beyond these broad areas of consensus, participants differed in their views on the details of these points and on other considerations. On the issue of community engagement, some participants indicated that involving community members in research generally is important, while others expressed concern that research needs to be led and controlled by community members. This and related conversations revealed that while some participants spoke specifically about community-based research, others were speaking about large-scale government-led research, such as national health surveys or a census. Each type of research creates different, but overlapping, concerns.

One participant described how different types of research require different approaches to community engagement, while safety and security concerns are important for all types of research. Multiple participants and small groups also indicated that data and other research products should be useful to communities if research is to be undertaken and that researchers' motivations for conducting research must be transparent.

*"You need to separate two different conversations about community studies and general population surveys because they're just really two different pieces in terms of how they should be done."*

*-participant*



Photos by Jim Carey



On the issue of community compensation, participants voiced a variety of perspectives on the motivations for and implications of compensation. One participant, presenting the discussions of their group members, made clear that they viewed the benefits of collaboration as multidirectional and called for equity among researchers and community members.

Whereas researchers gain knowledge and credibility from successful community collaborations, community members can and should be recognized as equal partners and co-authors in publications resulting from this research. A participant from another group described how collaborations with researchers can create work opportunities and advance the skills of community members. Addressing equity in relationships between researchers and community members not only helps foster greater trust, building a foundation for meaningful and impactful work in the future; it can also lead to higher quality research that is valued by communities.

## MEASUREMENT

Central to participants' deliberations about best practices was discussion about how, in what contexts, and with what considerations researchers can collect data about gender minorities in South America that is valid and informed by local communities. In these discussions, there was consensus among participants that quality data about gender minorities is important in South America but its collection should reflect findings from prior empirical research and local contexts and needs.

Conversations in small groups and among the full body of meeting participants initially focused on illuminating the challenges to measurement. One of the central challenges noted by participants was the tension between developing measures that are inclusive of diverse identities and limiting the categorization of identities in order to produce data that are valid and meet analytic requirements for quantitative research. Other participants described challenges stemming from a desire by some gender minorities to reject identity labels entirely, changes in terminologies and definitions over time, and the limited and inconsistent understandings of less commonly-used terms.

*Despite the challenges that participants identified, there was consensus around the use of a particular approach to measuring gender minorities in survey research: the two-step approach.*

Despite the challenges that participants identified, there was consensus around the use of a particular approach to measuring gender minorities in survey research with the general population: the two-step approach. This method of measurement, corresponding to its name, calls for two separate measures, one for the sex assigned to an individual at birth and another for the individual's current gender identity, which analysts can cross-reference to identify both those who identify with a particular gender minority label and those whose gender identity is different from what is associated with their sex assigned at birth. Participants described how a two-step approach to survey measurement was appropriate depending on the particular survey design. For example, one participant explained how a two-step measure was appropriate for large-scale surveys representative of the general population but that such a measure was not necessarily designed for survey research targeted only to gender minority communities. Instead, these community-based studies can be valuable vehicles for collecting information about gender identities and terms used by community members, including changes in definitions and use over time. Researchers can then use this information to select the most appropriate terms for inclusion in two-step measures for large-scale surveys.

## CULTURAL CONTEXTS

Participants also discussed how best practices should address cross-cultural concerns in South America related to the collection of data about gender minorities. One of the principal topics of discussion focused on the use of different terminology by gender minority communities across the region and the implications of this diversity of language for research. Participants described how different communities across the continent use different terms to refer to specific groups of gender minority people; in addition, communities differ in their definitions for and the connotations applied to similar gender minority identities. One participant described how, in Brazil, the term *travesti* is used to describe a person who was assigned male sex at birth and who has a feminine gender identity and that some see it as a term that, once derogatory, has been "reclaimed." Another participant noted



that, in other countries, such as Colombia, the term is often considered to be exclusively associated with sex work and is rejected as a pejorative label by many gender minority people. Given this diversity of language, multiple participants expressed that best practices for the continent had to include a recommendation that researchers consider pre-existing and indigenous terms and contexts when conducting research about gender minorities in the region. Some participants also suggested that best practices recommend the creation of national advisory boards to support research about gender minorities in local communities.

Many participants voiced support for a recommendation that researchers adapt measures of gender identity to local contexts, including the two-step approach in its question about current gender identity, and that such measures should not prescribe an immutable set of response options. This would mean that researchers would be advised to include *travesti* or another term, for example, in a measure if the use of such terms in a local community was appropriate. Stemming in part from this discussion, participants also discussed the use of much more open measures of identity, such as those that solicit write-in responses to questions about gender identity. Participants indicated mixed views on the validity of data resulting from such questions, given the potential for a large variety of response options and inconsistent use of terms, but expressed interest in the value that such new information about the use of identity labels could provide.

## SAFETY

Participants discussed concerns about safety in collecting data about gender minorities that centered on both the security of the data and the safety of those involved in research, including researchers, community members, research participants, and others. While safety concerns were discussed generally for all regions of the world, some of the concerns that participants cited were specific to conducting research about gender minorities in South America and were focused on the risks posed by unsupportive governments in the region. This includes security challenges resulting from hostile governments and governments in transition which may reverse positive policies or advance adverse policies and practices. Participants noted, too, that being a gender minority is itself dangerous in South America, as it is throughout the world. In different sessions throughout the day, participants described the risks and dangers experienced by gender minorities and how governments can perpetuate or cause these risks and dangers, including when governments are in periods of crisis or when government sanctions and perpetrates violence. Participants also referenced risks to safety coming from the public when research is conducted in open, public spaces. In considering best practices for conducting and managing research safely, participants suggested that researchers undergo training for international research and data collection and that questions regarding gender identity be optional for research participants. Other participants emphasized the need for researchers to consider the safety of all involved in research as well as the implications of collecting data about gender minority communities altogether.



Photo by Jim Carey

Given the intrinsic political nature of collecting data about gender minorities in the region, participants recommended that researchers consider how data resulting from their research may affect local gender minority communities, in particular whether there is the potential for findings to negatively impact communities. While there is much that researchers and community members engaged in research may do to support safety and security in data collection, participants also suggested that in some cases it may be appropriate for international governmental organizations to play a role in oversight to ensure safety. International governmental organizations and other third-party entities may serve as allies in supporting safety and security in research.

## RESOURCES AND SUPPORT

Participants also discussed the importance of and strategies for enlisting support and resources for the collection of gender minority data in South America. Documentation of best practices for the collection of data can provide guidance based on empirical evidence and the experiences of experts and can be a powerful tool to encourage governments and funders to commit new resources to these efforts. Participants described how the report from the first convening of this kind in Amsterdam in 2016 had already been useful in their research and in attempts to convince governments and other entities to support greater collection of data on gender minorities. Additionally, participants cited the potential for tertiary entities, such as the Inter-American Commission for Human Rights (IACHR) at the Organization of American States (OAS), to leverage their decision-making and policy recommendations to encourage and insist that governments in the region do more to support data collection.

With regard to securing financial support for the development of best practices, multiple participants argued that it is essential to develop and share knowledge about the current landscape of funding with others leading gender minority data collection efforts. Other participants suggested collaborating with those organizations which have traditionally provided funding for work focused on gender minority communities in South America. Of course, the support of organizations that are new to the region or to this body of work will be important for future funding. In order to ensure that gender minority communities in the region are not left behind in the mix of funders' priorities, participants also suggested that the placement of experts who are transgender or another gender minority in decision-making positions at these entities is critical. Ultimately, the development of best practices may, itself, help catalyze additional interest from funders and governments.

## RECOMMENDATIONS

This meeting achieved two of its three initial goals: to foster and expand a network of researchers, community members, and other experts in gender minority data collection in South America, and to share information about current research practices, as well as findings and ideas for future development. Participants' discussions built upon prior deliberations and recommendations made at the first meeting in Amsterdam in 2016, in which participants determined that the development of best practices was desirable and feasible and that it should begin at a regional level.

Participants' discussions at this meeting yielded a consensus on two principles to guide the development of best practices for gender minority data collection in South America:

- Gender minority communities should always be engaged in the development of research and data collection about those communities. There should be appropriate recognition and compensation for all involved in research about those communities.
- Regarding measurement, a two-step measure to identify gender minorities is appropriate for surveys of the general population in South America with adaptation of gender identity measures to local terminology and contexts. Researchers must consider the safety of all involved in research.

These two areas of consensus may serve as the foundation for future experts to develop detailed best practices for gender minority data collection in South America.

## NEXT STEPS

In this meeting, participants did not reach the detailed conclusions critical to developing comprehensive guidance on best practices for gender minority data collection in South America, though consensus around the two-step approach was reached. In order to continue these efforts, researchers, community members, and other experts in South America should establish a body which these individuals invest with the authority to make determinations about best practices with consideration of the initial guidance stemming from this meeting. This body's next steps, as previously outlined in the report from the initial meeting in Amsterdam in 2016, would include making determinations about best practices, securing financial support, securing support from governmental and non-governmental organizations, and further building the international network of experts.



Photo by Jim Carey



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## ABOUT THE WILLIAMS INSTITUTE

The Williams Institute is dedicated to conducting rigorous, independent research on sexual orientation and gender identity law and public policy. A think tank at UCLA Law, the Williams Institute produces high-quality research with real-world relevance and disseminates it to judges, legislators, policymakers, media and the public. These studies can be accessed at the Williams Institute website.

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RESEARCH THAT MATTERS



## APPENDIX

This appendix includes a bibliography of publications about gender minorities and gender minority data collection from around the world. All of these publications were identified by individuals invited to participate in the two WPATH meetings, in 2018 in Buenos Aires and in 2016 in Amsterdam. This list primarily includes publications in English and Spanish and does not include any publications not provided by meeting invitees. It is, therefore, not an exhaustive list of research about gender minority data collection.

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