Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research

Transcript

[Kelly Maxwell] Welcome everyone to this webinar, which is focused on developing data sharing agreements to use early care and education administrative data. I’m Kelly Maxwell, co-director of early childhood research at Child Trends and I’ll be serving as the facilitator for today’s webinar. Next slide, please.

You’re going to hear today from 5 presenters:

I’m going to begin with an overview of the Child Care Administrative Data Analysis Center, which we call CCADAC. This webinar focuses on one of the resources we have developed as part of this project. Before we dive into data sharing agreements though, I’m going to briefly describe the other resources we’ve developed as part of CCADAC.

Next, I’ll turn it over to my Child Trends and CCADAC colleagues, Van-Kim Lin and Sara Shaw, who led the development of the data sharing agreement resource. They will highlight some of the key points from the resource, describing suggested steps in developing a data sharing agreement and common components of an agreement.

You will then hear from Pam Joshi, (of the Institute on Children, Youth and Families at Brandeis University. Pam is a researcher who has partnered with state agencies to use administrative data in her work. She will discuss her experiences as a researcher and offer lessons learned in developing data sharing agreements.

Finally, you will hear from Naneida Lazarte, a researcher in the Oklahoma State Department of Education, who will share her experiences and offer suggestions for working with state agencies to develop a data sharing agreement.

We will not pause during the presentations to take questions. We have instead saved time for questions and discussion at the very end, after all of the presentations. As you think of questions, though, please type them into the Questions box so that we can address them during the discussion period. Next slide, please.

The Child Care Administrative Data Analysis Center is supported by the Office of Planning, Research and Evaluation in the Administration for Children and Families, in the US Department of Health and Human Services, with funds set aside for research in the Child Care and Development Block Grant Act. CCADAC is part of a larger contract with Child Trends to support child care and early education policy analysis.

The primary purpose of CCADAC is to support the use of administrative data to address policy-relevant early care and education questions for state child care administrators and their research partners. I would like to recognize Kathleen Dwyer and Jenessa Malin, our OPRE team leaders for CCADAC, and thank them for their support and guidance throughout this project.

I also want to note that we use the term “administrative data” to refer to information about children, families, or service providers that is collected and maintained as part of regular program operations. Next slide, please.
There are several resources related to using administrative data in research—but they can sometimes be hard to find. CCADAC collaborates with the Child Care and Early Education Research Connections team to bring together multiple resources related to administrative data all in one place. The link on this slide will take you to a webpage on Research Connections that describes various resources. The resources are organized by the four topics listed on this slide, to make it easier to find what you’re looking for. So I really encourage you to visit this link and explore the many resources that are available there. Next slide.

The CCADAC team has also developed several resources to support the use of state administrative data in early childhood research. You can find them all on the website listed here. I’m going to quickly review these other resources.

This first resource provides tips for building a strong partnership between researchers who want to analyze administrative data and the state partners who oversee the administrative data. It’s particularly useful for researchers who have not worked with a state agency before. State agency staff may also find it useful to learn about the possible benefits of partnering with researchers to address shared questions of interest. Next slide.

This resource raises issues to consider when determining whether it’s feasible to use administrative data to address a particular research question. It covers topics like determining the availability of data, the process for sharing data, and coordination between the research and program staff. Next slide.

This resource is a follow up to the previous resource on determining feasibility. Once a researcher has determined that it’s feasible to use administrative data, this resource can help the researcher prepare to analyze administrative data. It covers topics such as determining which data variables to include and preparing a dataset that is ready for analysis. Next slide.

Over the years, we have heard both researchers and state agency staff say things like, “we wish we knew how best to define a data variable.” So, we created a document that highlights four existing resources that provide guidance about defining data elements. Next slide.

This resource highlights 3 examples of partnerships between researchers and staff in state agencies—in Georgia, South Carolina, and Oregon. We describe each partnership and provide examples of the kinds of research they’ve done together. Next slide.

Our latest resource focuses on guidelines for developing a data sharing agreement and is the focus of today’s webinar. Next slide.

So we’re going to transition now to presentations. As a reminder, we will have time at the end of all of the presentations for questions and discussion. If you have a question during the presentations, please type it into the question box so that we can discuss it at the end of the webinar.

Now, I’ll turn it over to my CCADAC colleagues, Van-Kim Lin and Sara Shaw, to provide more information about developing a data sharing agreement.

[Van-Kim Lin] Thank you, Kelly. So this particular resource, *Guidelines for Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research* was developed based on feedback we were hearing from the field. We heard that states have a wealth of data that may be beneficial for research, so being able to set these agreements up will ensure that data are being
accessed securely and that data can be shared to answer key questions about early care and education. So while this resource focuses on state level data, particularly around early care and education data, the same principles can be used in different contexts to set up data sharing agreement for other research questions.

Researchers and state agencies that have done this in the past wanted a space to share tips and lessons learned when setting up a data sharing agreement, and others who were new to this wanted to know where to start and how to begin. When we were developing this resource, we first compiled and summarized information from existing resources (that are also linked in the document if you go to the website) and we also included information that may be relevant for early care and education research that we gleaned from key experts.

In this resource and for the purpose of the webinar, we will be calling these agreements data sharing agreements, which is a formal document between two entities that specifies the conditions under which data are to be shared. However, this type of agreement can be called by other terms, such as a memorandum of understanding (MOU) or a data security agreement.

Today, we will provide a brief overview of what you can find in the resource so that you know what to look for. Next slide.

I’m going to highlight some of the steps you may need to take in order to set up a data sharing agreement and then highlight how each step may take time and what considerations you may want to think through. They’re laid out in such a way that you may start at one point go to the next step and may need to revisit the step before so it’s not linear but there are different things for you to consider. So Step 1 is to identify the data that you need to answer the research question for your project. There is so much data available at the state level, but researchers will really want to hone in on the data elements or data sources that are going to be most relevant for your project. Limiting your request to only what is needed is particularly important if you need to access different data sources and have different permission from different state agencies. In particular, state agency staff are going to be incredibly important at this step because they know the data. They can help you decide which data elements are most relevant. They can explain to researchers what data elements mean and help you decide between two different sources. Additionally, the data that may be best suited for answering your questions may be found in different locations, so you’ll also want to think at this step whether there is information that will help match individuals across data set (for example, using a unique identifier) and you’ll also want to decide how and who will be able to combine and link the datasets.

Step 2 can be made in conjunction with Step 1, but it is important to understand who owns the data you would like to access. These owners or managers will eventually need to sign off on the data sharing agreement and may have unique stipulations about what and how data are accessed, so knowing that at the beginning will be very important. Next slide.

Step 3 is identifying the individual who is going to be responsible for developing and then reviewing or proofing the data sharing agreement. Does the state agency already have a template that you can use? Is there someone who is knowledgeable about that template? If there isn’t an agreement, is there someone on the research or stateside who can put forth an agreement that can be discussed with the two parties or vice versa? There may also be a combined effort where each party pulls together parts of an agreement as well, so you’ll want to decide that early on. When you’ll be developing these
agreements, you’ll also want to consider whether there are legal concerns that you’ll need to think about as well. For example, will you need to involve legal counsel, or is there someone that can provide a legal review? Once the process has been determined, it’s really important to create a timeline so that you know which pieces of the agreement are due when, who’s doing that, to keep the process moving along.

And then Step 4 is to then actually develop that draft agreement as discussed by all parties. Again, if you have is an existing template, that’s really helpful, or if there’s someone that you know who has shared information before with the state agency, you can ask them for their template or you can use some of the examples that we included in our resource as well. You’ll want to adapt those obviously and create one that meet your needs. You’ll want to be sure to include any federal and state regulations that need to be included in this data sharing agreement. For example, how does FERPA or HIPAA affect the data you want to access?

Next slide.

Finally once that draft agreement has been made, you’ll want to share that with all the relevant parties. Again, this is really important to allot time for review from everyone involved. You’ll want everyone to agree to all of the terms and leave enough room for discussion,

And once the agreement meets the needs of everyone involved, then you can finalize that agreement, getting the appropriate approval signatures from any appropriate party and properly file these for your records. So again, these are suggested steps for developing an agreement. You may revisit one after completing one. It is important to understand each of these steps and consider the time it may take to complete each step. So now, I’m going to pass it along to my colleague Sara who will share more about what you may want to include in your agreement.

[Sara Shaw] Thank you, Van-Kim. In addition to describing the process for developing these data sharing agreements, our resource often talks about some of the most common elements that are found in data sharing agreements. These elements that Van-Kim mentioned were identified both by researchers that we’ve worked with as well as through various resources on the topic. It should be noted however that this list of common elements is not meant to be an exhaustive list and that each individual agreement may require different components. Researchers and agency staff will need to work closely with one another to identify the necessary components for their specific agreement. One of the common components is the contact information for key personnel. First, this may include the name of an organization authorized to share the data. In some cases, a researcher will begin discussing the proposed research with an individual or organization who houses the data but will then need to work with another person to receive permission to actually use the data. Ultimately the agreement will need to be signed by the person with legal authority over that data. You may also need to include the name of the organization requesting the data. This may include the contact information for the principle investigator or the lead researcher on the topic as well as the person at the research organization with legal authority to sign the agreement.

Finally, you may wish to include a list of project contacts or approved researchers. This may include the key contacts at both the state agency and on the research team. The section may also highlight the process for revising key contacts as member of the project change over time.
Another common component to include is the purpose of the research. This section may describe the research question to be answered as well as the benefits of the project to a state agency. It will be important to discuss how research project will align with the agency’s needs at the outset of the project.

Data sharing agreements also often include information about the data being requested, including the specific data element as well as the period of data use. For the description of data element it may be useful for researchers to work together with state agencies to identify the datasets needed to answer the team’s research question. This section may also include the month and year in which the data is requested.

Finally, if the project requires linking data sets, a description of the process for linking data may also be included in this section. For the period of data use may include a specific termination date for the data sharing agreement. This date should include enough time to allow to analyze data or write up any report and address any necessary follow-up questions.

Many researchers also include sections on key personnel expectations and responsibilities. This may include the roles and responsibilities of participating parties which may include information about who is responsible for funding the work, merging the data set and answering questions about the data. This section may also include information about compensation. For example, if the research organization will be compensating the state agency for their time, this may be added to the agreement. Agreements may also delineate who has ownership over the analyzed data. For example, if the research team creates new variables, the agreement may describe if the research team is responsible for sharing these new variables with the state agency.

Finally, if the state agency wishes to review any reports, articles, or presentations prior to the release, this should be delineated in the data sharing agreement as well.

Agreements also commonly include information on managing the security of any data, including security guidelines for both the storage and management of data, as well as any agency specific requirements for securing data. A description of the protocol for reporting any issues or breaches may also be included in this section.

Agreements may also include a section on the expectations for managing the project. This may include a description of the process for making modifications to the agreement including what, if any, changes can be made without approval and the process for requesting any revision. This may also include a description of the methods for destroying the data at the end of the project, including whether the state regulations relating to the process, such as the types of software programs from the computer. And finally, the agreement may include information about the retention of de-identified data for restricted use access. Including any procedures for retaining this data.

One final component to this task is whether the project requires an Institutional Review Board approval. If it is required, the agreement may include information about who is responsible for gaining this approval. In some cases, IRB approval may be required to finalize the data sharing agreement.

To learn more about the process for developing these agreements and practice, we will now hear from both the researcher and state agency perspectives. To start us off I will turn it over to Pam Joshi from Brandeis University to discuss this process from a researcher’s perspective.
My name is Pam Joshi, and I am the Principle Investigator of the MA Child Care Research Partnership grant, which is a collaborative partnership with the Boston University School of Social Work and the MA Department of Early Education and Care (or EEC for short). Our research focuses on evaluating the effects of changes to child care subsidy policy and administrative changes on subsidy benefit stability and continuity of care especially in Massachusetts. Today I will be discussing our process of obtaining and maintaining a data sharing agreement with our state partner. And for those who are interested, the agreement is actually included in the appendix of the Child Trends report.

So before talking to a state, I think it’s important to keep in mind a few questions.

Our research partnership with EEC began when we responded to a RFP released by OPRE in 2013 to conduct child care policy and practice research in partnership with the state lead child care subsidy agency. The RFP clearly stated that if administrative data was going to be used, a MOU or a data sharing agreement had to be submitted with the grant application.

When approaching a state agency, it is important to think about a range of research questions that your research team and the state would be interested in answering as well as how the research will contribute to a broader conversation in academia and policy, and whether the research is relevant to community and parent stakeholders.

Also, it is important to think about whether administrative data is needed to answer your research questions and if yes, what type of administrative data.

There are multiple levels that admin data is collected, which can be stored across different data systems or at the back end, in multiple files. Before talking to the state agency, it’s important to think about the level of data that you need, meaning at the provider, child, family levels (or all three). Also consider whether the subsidy system in your state has vouchers, contracts or both. As part of our conversations with the state, we learned that vouchers and contracts were in separate data systems.

Also, the type of data that you need is important – program data is often not necessarily linked to outcome data that you may be interested in studying. It is important to think about whether you would need to link across systems and agencies, for example one question is, if you want to link to child health outcomes – does the state already have an integrated data system, or an existing data sharing agreement with the department of public health?

Finally, save yourself some time and look around on the website or ask around to your colleagues to see if there is a data request process that is already established. Next slide, please.

So I’m going to talk about our process for the partnership grant.

In thinking back to 2013, the RFP that we were responding to, had a broad set of child care research questions, and a deadline, which always speeds up the pace of conversations. Before talking to the state we established a list of questions that we were interested in, that we had the expertise to answer and that we thought would be of interest to the state. We also identified topics that the state may be interested in, but we as a research team could not answer.
Once we had our list of questions, we went about identifying a contact at EEC. Since we did not have a direct contact at the agency at the time, we searched the web, talked to our networks and approached colleagues who either worked at the state in the past or in different departments of the state. Basically we cast a really wide net. In our discussions, we also asked around about how to connect with the IT staff. Next slide, please.

So, eventually we were connected to staff at the state who administered the child care subsidy program. We had multiple conversations with a group of program and IT staff to discuss their interests and what questions that we could and could not answer using existing data.

For example, we were very interested in studying cliff effects, meaning that we wanted to understand whether the program rules, specifically income requirements, factored into parents’ employment decisions. We also knew that there was limited research on this topic and the broader group of community organizations and policymakers in Massachusetts were interested in this question.

As it turned out that none of our questions on our research agenda including cliff effects were of interest or answerable with the existing data.

So in all of our conversations with state agency staff, we ended up talking a lot about the administration of the program and the state’s interest in making it more family friendly. As a group, we decided on a research question focused on the impact of recent administrative changes (that changed the location of reassessment from Child Care Resource and Referral agencies to contract providers) and the impact of that on subsidy stability. So to answer this research question, we needed data at the child, family and provider level.

Another important topic of discussion was the state’s requirements for data storage and their data transfer process. We needed to confirm that on our end, we had the appropriate infrastructure to house the administrative data.

So in the process of these initial discussions, we learned that we needed to have a lot more communication with the IT staff about the data system than we had originally planned for, without taking up too much of their time. So our solution was we set up biweekly phone calls with an EEC program staff member and an IT staff member for the first year of our grant. Through these initial conversations, we learned that the state already had a data request process, so we did not have to break new ground. Next slide, please.

So once we agreed on the study questions and the data that we would need, the state sent us a copy of their MOU template that included the general parameters for data elements that we would submit a request for. We did not have to get into too much detail, for example, about the variable names. The MOU was prepared by the EEC legal team and had to be signed by the EEC commissioner. The head of our university’s office of research administration, who is a lawyer, had to approve and sign this agreement on our end. After we were awarded the grant, the MOU was submitted to the university’s Institutional Review Board.

One point to consider is what happens if your project needs additional data that is not covered by the agreement. In our case, we wanted to understand how the characteristics of providers, such as offering nonstandard hours, affected subsidy stability. This data is collected by CCR&Rs [child care resource and referrals] through a system called NACCRAware. The state had a separate agreement for NACCRAware
so the university had to agree to and sign a non-disclosure agreement with Child Care Aware of America in order to keep the data confidential. This required the signature of our Office of Research Administration.

Lastly, we had to extend the MOU for another year which required an amendment to our agreement that had to be signed by the EEC Commissioner and the university’s office of research administration. All of these agreements take time and should be factored into project timelines.

In the end decided not to pursue employment data that is housed in a different agency, which would have required EEC to enter into an inter-agency agreement. Next slide, please.

So the actual MOU is straightforward. The proposed research study’s abstract was included in the MOU’s purpose section.

Based on our proposed study design, we had to specify the time period of the study and a general description of the data elements needed. And again, this all came from our research proposal.

The state specified the timing of the data requests starting from the initial transfer to quarterly transfers after that.

The state also specified that the data transfer process had to use secure data transfer methods to protect confidentiality of participants. Also, it was specified that the MOU covered all partners in the research project.

Therefore, we did not have to obtain an additional MOU for our colleague based at Boston University. Next slide.

So I’m going to talk about some lessons learned.

It is important to understand the landscape of existing data agreements within and between agencies. There may be some data that won’t be available due to lack of data agreements between departments even within the same agency. For example, EEC is within the Department of Elementary and Secondary Education. However, EEC does not link program data to education outcomes.

Another lesson learned is to understand upfront whether a unique identifier is needed to match data across files. It’s important to budget the time and labor costs to do the data matching. Next slide.

If a no cost extension is an option in your grant, if your state partner agrees, it is useful to add an extra year to the data agreement. Usually there is a lag in the data analysis because it takes a while for the data to be released. In order to avoid having to amend the agreement, it is wise to plan for a no cost extension. Next slide, please.

So my tips are more about after you have the data.

The first tip is to formalize a process to obtain input from the IT staff about the administrative data.

It is important to tap into staff knowledge about data quality; in our experience, we also found that the IT staff have a lot of policy and practice knowledge because they have to program the IT system to respond to specific policy changes.
Asking for sample data is useful in order to understand data structure, the data elements and the coding of responses. A challenge is that state systems many times don’t come with codebooks that researchers are used to.

Also, be mindful of staff time, they’re very busy. Try to save up your questions.

Another way to understand administrative data systems before or after obtaining data is watching webinars that are generally made for training purposes. For example, when Massachusetts revamped the IT system, it was very useful to watch the training webinar to understand the front end of the data system and which staff inputted the data.

I’ll stop there and I’m happy to answer questions in the discussion section, thank you.

[Sara] Thank you Pam. Next, we’ll hear from Naneida Lazarte from the Oklahoma Department of Education who will be discussing the state agency perspective and the process for developing a data sharing agreement.

[Naneida Lazarte] Thank you, Sara. Good afternoon everyone. Let me briefly thank Child Trends and the Office of Planning Research and Evaluation and the Administration for Children and Families for having me here today and have the opportunity to talk about my experience on setting up data sharing agreements with researchers from the state agency perspective and some of the approaches and tips I found helpful in developing those agreements. I have worked for years in the Department of Human Services and I’m currently working as a data scientist and researcher at the State Department Of Education. And in all these years, I have had the opportunity to follow up, implement, and review several data sharing agreements with researchers from various universities and other state agencies.

So without further delay, let’s move on to the next slide, please.

And then the next one.

Thank you.

There are a few key things that are extremely important to researcher and the state agency staff should keep in mind during the initial step of the process.

The short-term goal is to have an approved agreement to start the data-sharing process as soon as possible. But, it is good to remember the broad meaning of the tool. We need to always keep in mind that during the agreement development and approval process (until all signatures are included), we want to establish and keep a good working relationship with all partners involved, whether they are internal or external to the organization, because those relationships will be critical during the implementation process, that usually is not as fluid and smooth as we would like. Having the communication channels open and the willingness of partners to help resolve issues are key during implementation. They will come from the experience partners had working with us developing the agreement.

It is also wise to remember all of the resources partners bring to the collaboration. Keeping that in mind will help shape the type of relationship with our partners. For instance, researchers, as we all know, they have the knowledge of field and methodology, resources in the form of staff and software, and expertise in analyzing and interpreting results. But on the other hand, state agency staff bring data to the table, of
course data, but they also have the knowledge of data systems and data collection processes, direct
communication with stakeholders, and the knowledge of local context, needs, and program
administration.

Third, we’ll want to purposely build informal relationships, focusing on the interpersonal and social
aspects of work relationships (as opposed to only task-related). This is true for any work relationship of
course, and it also applies to the development of this type of agreements. For example, it is always a
good idea investing in informal, friendly conversations before and after meetings, or during conferences,
whatever we have the opportunity to reach out to some of the partners who you work with or you want
to know better. These interactions will make things easier for everybody and provide the collaboration
team increased resources to help get the job done and to be more efficient. And this goes both ways, for
the researchers and also for state agency staff.

And finally, it is not uncommon that an initial agreement is the start of a long-term collaboration that
can address additional research and program questions, so it is advisable to keep our eyes on the long
term, especially thinking about multiple-years research agendas that are not uncommon, and the ever-
growing list of questions addressing long-standing and new public policy issues.

So we now move to the next slide please.

At the overall approach level, there are a few key tips and strategies that researchers follow to help
expedite the drafting and approval process of the agreement. For example, learning about the basic
organization structure and key players in the state agency, specially about the divisions or units that
administer and oversee the data target for the agreement, including program administrators or
directors, and data administrators, can be really helpful when it comes to knowing the go-to-person
with general or more specific communication or questions as we develop the agreement. Also, it is
important that researchers learn about key federal and state laws and regulations about privacy and
confidentiality, which govern the data target of the agreement. It can really help to save time and
resources when discussions are in place about the specific data to be accessed, the format, and
management during and at the end of the agreement, having that information beforehand. And, I also
found it very helpful when researchers approach state agency staff with effective and relevant
information. And this can be helpful during the drafting and approval process, for example, whether
researchers have or had in the past similar collaboration projects with other state agencies, or in other
states, and how those collaborations worked. It could be really helpful for state agencies to have that
information and to share that information with the state agency leadership. Let’s move to the next slide
please.

So developing data sharing agreements can be challenging and they can take a long time. Both,
researchers and state agency staff, can greatly benefit during the agreement development if they thrive
at implement a few things. First, facilitating the process as much as possible for all partners. For
eexample, with clear, relevant and timely during the first stages of the collaboration information about
the overall objectives and data to be involved in the agreement. It can take the form of the preparation
and circulation of a summative document very short, not even half page long with that information, we
don’t need to repeat over and over again what the main goals of the agreement and the collaboration is.

Another way in which we can facilitate the process during the development is by sharing any relevant
information about the involvement of an Institutional Review Board, as Pam was mentioning as well for
the approval of the project, whether it is research or not, the type of approval that was received, where that approval is in the process, or whether the state agency as is the case where I worked in the past, has an assigned IRB that will need to review and approve the project. That is the kind of information that is important to have sooner rather than later.

Another example that I found very helpful on how to facilitate the process during the development of the agreement includes scheduling, but most importantly, actively participating in follow up meetings, whether they are in person or on the phone. But reviewing any notes from the previous meeting and reporting on assigned tasks. That will be very helpful for everybody, especially for state agencies that don’t always have the same priorities as researchers.

Second, we always need to remember to involve key individuals in all communications regarding the agreement and collaboration. For example, involving staff from the legal divisions in each organization. It is a good idea to keep them informed even if they are not addressed directly in the ongoing communication or discussion, but at least they are reminded about the project agreement and its “active” status.

And finally, it is important to learn and share information about the entire vetting process in the state agency, and the expected timelines until the agreement is finalized and approved. The vetting process in a state agency, at least in my experience, generally involves three different activities. One it is data availability inquiries. So the state agency really have the data that the researcher needs. Second, data sharing feasibility inquiries (including the actual data transfer options for the data and data storage, data sharing prohibitions that could affect the realization of the agreement. And finally the agency leadership’s willingness and interest in the project, for example, in terms of the relevance of the project to the organization’s strategic plan or need, or any new regulation or reporting requirement.

Can we go to the next slide please?

Here, I have listed a few additional strategies once taking out those data sharing agreement for both researchers and state agency staff. During the data agreement development it is useful to make sure the document is clear and very specific about its purpose, the conditions under which the data will be exchanged, and any prohibitions included. For example, it is the responsibility, always good to remember that it is the responsibility, of the principal investigators and the key officials or program administrators involved in the project to exhaustively review the agreement, especially the content related with the data specifics. The legal staff will advise and add any legal language needed, but ultimately those who will be using the agreement as a framework for the work ahead are those directly involved in the project or collaboration and the ones that are responsible for those final review.

Also, it’s good to remember that the target data elements are jointly reviewed by all partners. During these reviews that you have with both researcher and agency staff together, any doubts or wrong assumptions about the data will be cleaned up, which will be extremely helpful to anticipate any issues or plan accordingly for data cleaning, preparation and analysis. And, finally, it is also wise to review the steps of the project, the head, vis-à-vis, the agreement clauses just to make sure everything is covered and included. Agreements can always be amended, but that takes time. With that, I will turn it back over to Kelly, thank you.
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[Kelly] Thank you Naneida, and thank you Pam, Sara and Van-Kim for all of that great information that you shared with us. I want to open it up now for discussions. And as a reminder, if you have a question or a comment please type it in the questions box. But as you’re thinking about questions and typing away, I hope, I’m going to kick us off. And I think my first question is for you, Pam. As a researcher, what do you wish state agency staff knew that would make it easier to develop data sharing agreement?

[Pam] Thanks Kelly. So, I would say, just based on our experience in Massachusetts, we developed a data sharing agreement actually very quickly and relatively easily in response to an RFP. But, I think just a couple of general things that I think is important for state agency staff to know is that it’s important to recognize that researchers will work with the files at the back end of the data system and I’m going to include myself in here, we don’t necessarily generally have a great understanding of the front end because we don’t see how the data is inputted into the system. And as I mentioned, researchers are looking for codebooks, and in our experience, there isn’t a codebook that we’re used to, so I’d recommend that the IT staff just try to be as explicit as possible about the types of elements that are available in the data system. And really just send as much information about the data system that they’re comfortable sharing so that researchers can try to be as efficient as possible in trying to figure out how their data files will eventually look. I think this helps with making sure that the research question will be answered with the existing data and that the data request and timeline are much more specific. I also think it’s important to be honest about the potential quality of the data and if there are known data issues I think it’s just better to put it on the table earlier rather than later. The second thing that I would say is that most researchers who contact state agencies are wanting to do applied research and they want their research to have impact and they want their research to be useful for the state as well as the field. And so in many ways, I think that even if, staff are busy, I think it’s always useful to listen to researchers’ questions just to see if their mutual interest, even if they don’t have time or feel like they have the data or bandwidth to deal with a researcher know that researchers in general are pretty thoughtful and if we want to work with administrative data, I think hopefully, the researchers are in it for the long haul and are willing to work with sometimes messy data so I think that those are important to keep in mind just when thinking about how to work with researchers.

[Kelly] Thank you. Well, we have questions coming in so I’m going to ask some of the questions that our participants are raising. The first question is “Do we have any guidance about developing data sharing agreement when data from participants living on tribal land is involved? How do you engage the tribal continent?” Naneida and Pam have you ever had to enter into data sharing agreements with tribal government?

[Naneida] I have not worked with that kind of data, Kelly

[Pam] Yeah, unfortunately, I’ve never had that experience.

[Kelly] So I would encourage you to look at the Research Connections website for a range of resources to see if there’s information about working specifically with tribal governments. My guess is that when you identify all the key players who oversee and own data then you would need to have a conversation with the tribal government as well as anybody else with that you were engaging to get access to the data.

[Kelly] The next question, first they give us compliment, I appreciate of all this information. My biggest issue is getting data sharing agreement among agencies, i.e. education and health departments. Any advice how facilitating those cross-agency agreements that might be necessary to do research.
Pam, I know you talked about how you specifically didn’t get some data because it would require going to another agency.

[Pam] That’s right. Mine is more of a story of not pursuing that so I don’t necessarily have any advice on how to make it happen. You know, I think in some cases, it’s personal connections, sometimes some of the grants like, I would say some of the ACF grants would encourage collaboration between agencies are useful to apply for and then therefore encourage collaboration but from a researcher’s point of view I think it’s pretty challenging to convince state agencies to pursue those agreements unless there is a very good reason to do so or really an really interesting question that both agencies are interested in answering. So unfortunately, I don’t have any really good strategies on how to do that but I’m looking for that too.

And in my experience, probably the big take away from my experience is that trying to access data from a non-state agency is pretty much the same process as researcher space in trying to get state data from a state agency. It’s basically the same. But from what I have seen is that what goes better when it is an agreement between state-agencies is leadership is first involved and at that level there’s an agreement about sharing data and what the general agreement about it and then you can start working with researchers and the data people to actually work out the agreement and figure out the next steps. Those are the tips that I would have from my own experience trying to do that.

[Kelly] The thing I would add is that if the two agencies have shared data previously, I think it increases likelihood that they will engage in another data sharing agreement. If the state is developing or has in place an integrated data system (many states are working on or have developed early childhood integrated data system and are pulling data from multiple agencies) you might be able to work with the governance structure that oversees that integrated data system to access some of those data that you are interested in for your research.

Scroll down.

A person asked, “Are there any established standards for who can access the data and for what reason, within or across agencies?”

I mentioned data governance and usually there’s a data governance in place of individuals who has access to the data and what are the procedures in place to decide whether data are going to be shared with another organization. Does anyone else want to add anything from the panelists?

[Pam] I don’t have anything else to add to that, Kelly.

[Naneida] Neither I do.

[Kelly] Somebody asked about resources related to data sharing agreement in other areas beside from early care and education such as public health. We’ve already talked about health education. I would really encourage people who are interested in data sharing agreements and the use of administrative data broadly to look at the Research Connections website on that page that has administrative data resources. Many of the tips and strategies are relevant across content areas so I would encourage you, again, to look at those broad set of resources on using administrative data and research.

[Pam] Kelly, I have something to add to that, this is Pam. So one thing that I’ve done in collaborating with the Department Of Public Health, not in early childhood, is joining advisory committees. So you
can, for certain data, for example, PRAMS data, there is at least in Massachusetts there is an advisory committee and that sort of helps facilitate interacting with state agency members and also hearing about what kind of research questions they’re interested in. So I’ve been very interested in maternity leave and I think over the years we’ve convinced each other that that was an interesting question to pursue. So I do think that there are ways to do it just in terms of trying to get involved if there are opportunities to join these advisory agencies, or more like research councils even. So, I would maybe ask around to see if those are opportunities that are available.


[Van-Kim] This Van-Kim, I just wanted to note that a lot of participants are providing some really helpful resources about data sharing agreements especially in regards to cross-agency data sharing agreements, and I will note that a lot of these resources have been compiled under our research connection page under working with administrative data. And just to affirm that we have a lot of these resources that would be helpful if you checked out the research connection page.

[Kelly] Pam and Naneida, we focused this webinar on tips and steps and developing a data sharing agreement, but I’m wondering if either of you have run into challenges that you couldn’t overcome so you that you didn’t have a data sharing agreement in place and if so, could you tell us briefly about that and whether you were able to eventually overcome those challenges and access the data in some way.

[Pam] Sure, I’ll take that question. I think this might sound obvious, but I think that’s important for researchers to know that they’re not always going to be successful when they approach the state even if they think they’re offering added value by conducting data analysis. I’ve approached a couple of states and had multiple conversations about research questions in the data systems and my experience is that it is not generally the data sharing agreement that might trip up the project from going forward although sometimes some colleagues that this has been the case but I think it’s more around coming to agreement on the question or just not being comfortable with sharing data with a researcher that is not known. I think sometimes data analysts or program staff may be interested in working with a researcher but agency staff and management positions may not be interested in that for a variety of reasons and so I think in this scenario, really a researcher that wants to overcome the challenge, I think it’s just important to keep checking in periodically because what we found is priorities can change, clearly in a fast paced policy environment, or there’s turnover at the management level or so I think it’s just periodically checking in to see if some of the research questions are of interest and you can pursue the data.

[Kelly] Thank you. Another question, do you know how many states make all of their QRIS program data publicly available? No, I don’t know off the top of my head. I think that it is a discussion with each of the agency about what they’re willing to share and under what circumstances they will share the data that they have about the program and families and children that they serve.

One more question, we focused today on the data sharing agreement almost like it’s the end point when it’s really actually the beginning of much of the research work between state agency staff and researcher. Could each of you, Naneida and Pam, talk about what it’s like to do research once the data sharing agreement is in place? Have you had to revise the agreement based on something that came up in the research and how is the data sharing agreement, a quote un-quote a living document?
Once the agreement is in place, I would say that the real work starts in the sense that the data needs to be extracted, files with information needs to be prepared, the actual transfer of the data needs to occur, sometimes it takes several rounds of questions for researchers to have the data and answers, it takes the researchers a couple round of questions and answers between the column and row in the tables, the conversations included what is the meaning of the blanks, what is the data, the consistency of the data, the variables etc. So really once we have the agreement finalized and we have the data, it is a long process until the data that is received is understood and we can clean and get it ready for analysis. So it is a very intense phase with a very close collaboration with the external researchers, and internal researchers if there are some, and the state administrator and data specialist will take place. A solid and comprehensive agreement as we mentioned before where much of the detail about the data are included and have included them in the appendices is extremely helpful and I was fortunate enough not having to make any amendments today in the experience. They are possible, but amendments take time sometimes even for a minor change still, they need to have an additional set of signatures.

Thank you. Pam do you want to add anything?

Sure, I would just add that what we have found is really asking for sample data is so before having the IT staff pull the data for us, we get a sample of the data particularly and how the data is organized and sometimes we don’t even actually have real data in there it’s just because we want to see the structure before we start the long process of filling out a form so in Massachusetts there’s this actual form that you fill out in terms of the variables that you want and it starts getting much more specific after the data sharing agreement comes and you know the data variable names that you’re interested in. So, I can’t say enough how this you know just having more sample data is really helpful cause we don’t want to waste anybody’s time and we know it’s complicated and so we want to get it right but we really have to have a good understanding of the data to get it right so I think sample data is really helpful,. We didn’t revise our MOU at all for the child care subsidy data, but they talked about, in my presentation I did have additional agreement to get provider data.

Thank you. We’ve had a couple of questions about working with smaller agencies whose staff might be a little more nervous about sharing data, particularly child level data, and if we have any advice for that. And I’ll kick us off by just saying that I really think it’s important to develop strong partnerships between the researchers and the program agency staff so that you’re working on a research question that is really critically important to both of you and to think about doing this research in the context of a longer term relationship with them to address a range of questions. I do think that different individuals in different agencies vary in terms of their policies and practices about sharing data, so you will have to navigate that as best you can, but again I think that having a strong collaborative partnership will serve you well in those discussions.

Naneida, or Pam, or Van-Kim, or Sara, do you have anything to add?

This is Naneida thank you Kelly I think I will just reiterate that I found it very helpful from the state agency staff perspectives that if the researchers had in the past done a lot of collaborations with other state agencies or other states something happening similarly at the state level and how those collaboration levels work, it is very helpful for the agency to know about them. So to see if this is happening in other parts and it’s working or things and their outcomes from the collaboration. I think showing that it is happening in other places, it is very helpful to know.
[Kelly] Sara let’s move to the next slide please.

I really appreciate everyone’s questions today and I want to now close the presentation by thanking OPRE again for their support of this work and thanking the presenters, Naneida, Pam, Sara and Van-Kim for sharing their expertise with us today. I’d also like to thank each of you for joining this webinar. We’ve listed on this slide email addresses for each of the individuals from today’s webinar in case you would like to contact one of us. We have also listed again the link in yellow to the landing page on OPRE’s website where you can find all of the CCADAC resources.

Thank you again and I hope you enjoy the rest of your day.