A 3D perspective view of a grid of light gray, glossy cubes. One cube in the upper right quadrant is a vibrant red color, standing out from the rest of the grid. The lighting creates soft shadows and highlights on the surfaces of the cubes.

# Ethical Questions to Consider When Preparing to Share Data

VEI Group Three Presentation, June 7, 2019



# Spring 2019 VEI Team Three



**Christopher Hall**  
District Engineer  
Hampton Roads District  
VDOT



**Stuart Goodpasture**  
Manager  
Cash and Banking  
TRS



**Dan Wolf**  
Interim Director  
Legal & Legislative Services  
VITA



**Kristin Zagar**  
Assistant Director  
Division of Family Services  
VDSS



**Sharon Brown**  
Director  
Driver Services  
Virginia DMV

# Agenda

What is Data Sharing

01

So Far In Virginia

02

Exploring Ethics in  
Data Sharing

03

Recommendations and  
Next Steps

04

# Data Sharing

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## What is Data Sharing?

A formal process by which state agencies that collect and manage records grant other government agencies and outside researchers access to microdata within those records to support authorized activities.

## Why is it Important?

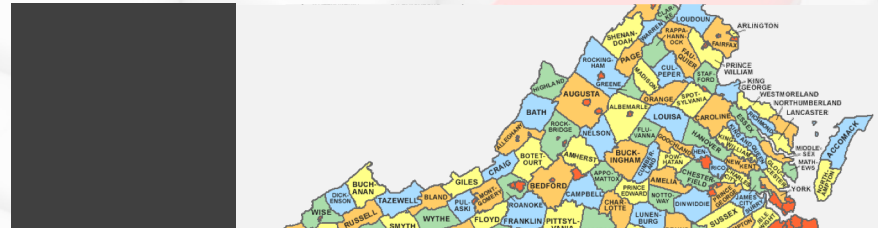
Offers potential to improve services to citizens, break down silos, and create efficiencies.

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# Who Should Share Data?



Between Virginia State Agencies



Between Virginia Regions and Localities



Between State Agencies and Federal Government



Between State Agencies and Universities

# Data Sharing In Virginia

## Limited Sharing Between Agencies

Mainly via ad hoc agreements

2011

## Mandatory Health Agency Sharing

Legislation required health agencies to share data with the goal of improving services to citizens

2018

## New Initiative to Fight Opioid Epidemic

DCJS awarded contract to create a data-sharing and analysis platform to help address opioid addiction trend

2019

Prior to 2010

Secretarial Committee on Data Sharing Established

2017

Chief Data Officer (CDO) Created

Legislation created CDO and Data Sharing and Analytics Advisory Committee

2018

Data Sharing Exploration Continues

# Asking the Right Questions

## Valid Consent

Privacy/Confidentiality

Secondary Uses

## How

Collecting, Managing,  
and Storing  
Expectations

## Social Justice

Stigma

Discrimination

## Decision Making

Who Gets Access

Levels of Access

## Monitoring

What Should be  
Shared

Policies/ Procedures

## Why Share Data

Who Benefits

Cautions

## Protecting Data

Large/ Diverse  
Enough

Data Principals

## Organizational Culture

Code of Ethics

Data Stewards

# Suggested Best Practices





# Recommendations and Next Steps

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Establish a Data Ethics WorkGroup to Create Formal Structure to Address Ethical Questions

Identify Data Stewards in Each Agency to Address Business Ethical Implications

Follow Recommendations from the Data Sharing and Analytics Advisory Committee



Develop Best Practices Regarding Data Sharing Ethics





Questions



**Thank You**

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