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Perspectives on a North Dakota Data Information Hub

Presented to the North Dakota Data Information Hub Steering Committee

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Center *for* Rural Health
The University of North Dakota
School of Medicine & Health Sciences

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Methodology

- Key informants
  - Suggested by Hub Committee, CRH and MPH discussion, legislative names reviewed by Senator Lee for balance
  - 8 state legislators responded out of 11 identified (House – 6, Senate – 2; Republican – 4, Democrat – 4) 3 not responding were Senators and Republican
  - 6 representatives from state associations, providers, and state agencies
- Institutional Review Board (IRB)
- Anonymity assured
- Content or thematic analysis by 1) legislative and 2) association/agency/provider response

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Questions to Interviewees

1. Would it benefit your work as a legislator to have more data and in a more timely manner? If yes, how?
2. What information do you need at this time or expect that you will need during the next legislative session (or business operations)?
3. Where do you obtain information?
4. Have you needed information in the past session (or past) but were unable to locate it? What kind?
5. Do you feel that the information that you receive currently is timely, accurate, and unbiased?

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Questions to Interviewees

6. What parameters should be considered in designing a Hub?
7. What are the core subjects, areas, types of information that you would like to find in an information hub?
8. How do you view an information hub (necessary and helpful or unnecessary)? Why?
9. How should aggregated health information be shared and who should have access?
10. Would you support continuing the work to develop a North Dakota Information Hub?

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Study Findings

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1. Would it benefit your work as a legislator to have more data and in a more timely manner? If yes, how?

- **Legislative – all yes**
  - **Decision making**
    - **Allocate money correctly (e.g., cost benefit of incarceration vs. prevention)**
    - **Determine the need/access issues (e.g., behavioral health – workforce (number, who they are, what they do), availability of services, location of services, types of services, rural access vs. urban)**
    - **Track trends (opioid)**
    - **Health policy planning – proactive not reactive, plan for the future need, respond to last crisis**
    - **Better understand – is it isolated event (family) or pattern/trend**
  - **Forming an argument**
    - **Advocate for change, credibility in your argument, state numbers not national**
    - **No specifics, speculation, anecdotes – no hard facts make it questionable**
  - **Quality – Positive**
    - **Validity, relevance, reliable, trustworthy, timely, neutral source, understandable**

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1. Would it benefit your work as a legislator to have more data and in a more timely manner? If yes, how?

- **Legislative – all yes**
  - **Quality – Negative**
    - **Agencies sometimes too much data and not relevant**
    - **"get a data dump"**
    - **Agencies can "stack the deck" – what they want you to know**
    - **"not gathered that way" – the way you ask for or hope for**
    - **Don't collect it**
    - **"piece of the picture but not the full picture"**

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1. Would it benefit your work as a legislator to have more data and in a more timely manner? If yes, how?

- **Associations/Agencies/Providers – all yes, but slightly more qualified**
  - **Decision making**
    - **Analysis – link data sets/more comprehensive for analysis**
    - **Track patients via EMR across health care systems**
    - **Have the entire picture for better decisions**
    - **Questions are different now, more complex, "bigger" – need analysis stream**
    - **Respond better to members and to legislators**
  - **Quality – Positive**
    - **Reliable, timely, real time data, have the data "avenue"**
  - **Behavioral health/mental health/population health**
    - **"In the past we did not look at social determinants of health like poverty and housing and how this impacts health care. But health care even for hospitals has moved to population health so being able to find that type of data is useful."**
    - **Opioid data**
    - **Mental health factors a newer concern**
  - **Won't help us**
    - **"When it comes to getting information from this data hub, I just don't see it adding a lot of value to our work."**

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2. What information do you need at this time or expect that you will need during the next legislative session (or business operations)?

- **Legislative**
  - **Opioids and counter acting medication – policy changes and does drug abuse increase or decrease, access to care**
  - **Behavioral health (3 legislators) – coordination, number of providers, # of psych beds**
  - **Demographics and economics shape budget- shapes human services**
  - **Population health – cancer, concern about registries**
  - **General observations: Costs, program and budget decision making**
    - **Tight budgets now, cuts, evidence to show what is important, works**
    - **Information to use to make better decisions**
    - **Does a Hub lead to better health care? –outcomes, better quality**
    - **Better information to determine costs, cost/benefit analysis, what do we invest in (cost to outcome)**
    - **Human services covers multiple agencies and don't get complete picture**
    - **"We are responding to our political demands with no data. It is ridiculous."**

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2. What information do you need at this time or expect that you will need during the next legislative session (or business operations)?

- **Associations/Agencies/Providers**
  - **Medicaid/Medicaid Expansion**
  - **Behavioral health**
  - **Population health (2 people)- social determinants and influence on care and outcomes, prevention**
  - **LTC – resident characteristics, payers, bad debt**
  - **Immunization data**
  - **Care management/care coordination**
  - **Cancer and other screenings**
  - **Workforce**
  - **Health care delivery**
  - **General observations:**
    - **Big picture planning**
    - **ROI**
    - **Real time interactive data base**
    - **"No I don't need information right now…obtain from internal sources…."**

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3. Where do you obtain information?

- **Legislative**
  - **Human Services (3 legislators)**
  - **NCSL (3 legislators)**
  - **Corrections and law enforcement – (2 legislators)**
  - **Associations and providers – NDHA, NDMA, NDLTCA, ND Pharmacy, BCBSND – lobbyists**
  - **Legislative Council (2 legislators)**
  - **Agencies -department heads and testimony**
  - **Other legislators**
  - **General Observations:**
    - **"Reliable. So a group where there is no agenda or at least you understand it. Bu no agenda is what you expect but look for."**
    - **Data from groups but it is in a silo, one perspective**
    - **"There is a tremendous array of groups. They provide information they want us to see, not always our choice. We can set agenda but the interest fill in the information so need to be aware of where it comes from."**

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3. Where do you obtain information?

- **Associations/Agencies/Providers**
  - **Human services**
  - **Providers**
  - **Members (3)**
  - **Center for Rural Health (2)**
  - **National organizations and journals**
  - **Public health**
  - **NDDoH data base**

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4. Have you needed information in the past session (or past) but were unable to locate it? What kind?

- **Legislative – all indicated some level of frustration**
  - **Hinders Policy Making**
    - **Narrow and segmented information does not lend itself to broader policy questions**
    - **Raw data, no interpretation, not forward looking**
    - **Didn't have the data to change policy so funded an autism pilot in 2013 to get understanding**
    - **Looking at an isolated case or a few cases or bigger population need (requiring a policy fix)**
    - **Sometimes forced to guess, if wrong, then try to fix in the next session**
    - **Example, could not project forward to plan for the number of correction officers needed**
  - **Human Services Issues**
    - **Human service needs are not always available – maybe exists but can't locate**
    - **We need DHS to have the definitive answer – to be keeper of HS data but not set up for that**
    - **Behavioral health data (especially early childhood) is lacking, elderly and community based services data is lacking, "we really truly don't know who gets basic interventions."**
  - **Quality Issues**
    - **Data is not always timely**
    - **Scattered locations and hard to find or can be located but not always useable or informative**
    - **The numbers are subjective**
  - **Lobbyists**
    - **Rely more on non-agency information but concern is bias**

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4. Have you needed information in the past session (or past) but were unable to locate it? What kind?

- **Associations/Agencies/Providers**
  - **Satisfied – Self-Generated**
    - **In general, no, we have gotten it. Have a tremendous amount of data**
    - **All information is from membership**
    - **Internal surveys – work on quality to get a better response "but if I knew I had a reliable source at my fingertips I would want to use it, if it was better, faster, and inexpensive."**
  - **Critical**
    - **Worked on opioid overdose deaths and compared local coroner data with state data and it was inconsistent – could locate it but unreliable**
    - **Lack of access to health system data to examine local issues (Hepatitis C)**
    - **State workforce data and health care delivery system data, population health – can't find it, doesn't exist, does exist but is collected incorrectly or you are prevented from accessing it, monetary cost to acquire**

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5. Do you feel that the information that you receive currently is timely, accurate, and unbiased?

- **Legislative - Frustration**
  - **Lack the Big Picture**
    - **If we had a better way to use information for planning the could have systems in place an not be in reactive mode**
    - **Behavioral health and how to think about the system and other areas but data and knowledge not there yet (contrasted this with how much legislators know about roads and bridges)**
    - **Frequently ask the question for which there is no answer, lack the data**
    - **Dash board data "but data below the main metric that is much more of a problem. The easy stuff, yes, but if it is a more complicated question then much harder."**
    - **Limited in scope – not connected to other data sets – "It is just raw data and we lose out on lack of interpretation. It is accurate for the most part but missing the next step which is analysis."**
    - **TANF example – dollars spent, number of clients, number of kids in foster care – yes. But don't try to connect the data, these are very distinct "data dots" but to try to link together to get bigger picture, no**
    - **"Piece of the truth" from the agencies but different agencies have different data "what truth is right?"**
    - **State agencies give what is asked, but only what is asked**
    - **"Hold some information back. They don't deliberately deceive they just don't say everything (laugh) – keep some back as it would likely hurt them. You understand this so it depends on how you phrase the question, the legislator has to ask the right question."**

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5. Do you feel that the information that you receive currently is timely, accurate, and unbiased?

- **Legislative - Frustration**
  - **Timely, accurate, unbiased**
    - **Comments were generally accurate, but not complete information**
    - **Comments were generally unbiased – understand people who testify frame the issue and experienced legislators can detect this**
    - **Comments were generally less likely to view information as timely – old data, hard to get, takes time**
    - **Many comments started out positive (basically accurate or unbiased) but then discussed limitations – lack of analysis, lack of predictive ability, data silos, current data**

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5. Do you feel that the information that you receive currently is timely, accurate, and unbiased?

- **Associations/Agencies/Providers**
  - **Timely – generally not seen as timely**
    - **Sometimes not what you want or need**
    - **No, not timely – real limitations in the time lines**
    - **Not timely during a crisis**
  - **Accuracy – mixed answers**
    - **Private insurers don't share so don't know – "I don't know if I trust the privacy and security of private agencies housing data."**
    - **Behavioral health big problem in obtaining accurate information**
    - **Accuracy is OK**
    - **If our information doesn't look accurate we follow up but it is time consuming**
    - **Accuracy is questionable – asthma data that was available was inaccurate and drilled down and found different findings**
    - **Depends on the source – some yes, some no**
  - **Unbiased –generally seen as unbiased**
    - **Unbiased is OK**
    - **External sources like cost report data is unbiased**
    - **Asthma data was biased**

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6. What parameters should be considered in designing a Hub?

- **Legislative**
  - **Two legislators said not qualified to answer (health providers)**
  - **Specific parameters**
    - **HIPAA and other regulations**
    - **Cost**
    - **Security and privacy**
    - **How is it (data) formatted?**
    - **Determine the type of information first**
    - **Who is the audience? Legislators or legislators and others – that shapes parameters**
  - **Cautionary comments – Privacy – De-identify - Transparency**
    - **Lesson from autism – set up in NDDoH and understood to be aggregated data but recently learned data is not de-identified – shows names, addresses, Social Security numbers – issue is harder to go forward now as feel trust is violated**
    - **Open architecture – use across agencies so to have uniformity for collecting data, storing it, and how to manage it and who has access**
    - **"You need transparency to build creativity. Have to be first transparent, then people trust it to use it."**

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6. What parameters should be considered in designing a Hub?

- **Legislative**
  - **Cautionary comments (continued)**
    - **Hub information must be de-identified and aggregated – if it is unidentifiable then anyone can access it, public information then – universities have access – open records requests should be included and it can be tracked (who requested)**
    - **"The number one area of resistance or opposition to this hub will be privacy and protection concerns. Security. We saw this with HIE. Hub is like that and will have the same things to contend. Who has access? Is data identifiable? What are the guards to my information?"**
    - **"In planning this you have to give people piece of mind. Some legislators do not know any of the details but react to bad stories, bad experiences others have had, and they don't have first hand experience so are cautious. I'm cautious too but open. Some think the worse first."**
    - **"Need effective information hub but also need to be sensitive to concerns regarding the privacy."**

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6. What parameters should be considered in designing a Hub?

- **Associations/Agencies/Providers**
  - **Privacy and De-identified data**
    - **No personal information - no names or personal identification – some code is OK**
    - **Concerned about law enforcement snooping, fishing expeditions**
    - **"Privacy is number one."**
    - **Encrypted, ensure patient confidentiality**
    - **Integrity and security of the data, de-identification**
  - **Structure and organization of the Hub**
    - **Management - Where would the data hub be stationed/managed? – Assume state run by NDDoH – open records, a private group should have access but not manage**
    - **Flexibility – flexibility for the public is good but need rules on usage and access thresholds**
    - **Member data – our data to vendor and aggregated so if to Hub want our safeguards in place**
    - **Quality of data is important**
    - **Cost of data – need some form of a cost/benefit analysis – "The history of the EMR is a low yield on the utility of having EMR and the cost, tremendous cost in getting to where we are now." "We can overestimate the benefit, we just assume technology at all costs produces good results."**

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7. What are the core subjects, areas, types of information that you would like to find in an information hub?

- **Legislative**
  - **Subjects**
    - **Behavioral health (4 legislators)**
      - ✓ **Substance abuse, TBI, providers (location, distribution), private/public and non-profit/for-profit data, services provided, barriers to services and access, psych beds for children (number, what do we need)**
    - **Medicaid (2 legislators)**
      - ✓ **Number of people on Medicaid and in nursing homes, types of health conditions**
    - **Medical (2 legislators)**
      - ✓ **Providers**
      - ✓ **Medical records better connections for the patient**
    - **DOT Crash data**
    - **Conditions – cancer, autism, stroke and then analyze by comorbidities – what does it show?**
    - **Corrections – tracking of inmates, capacity, level and type of coordination between corrections and post-incarceration with human service agencies – what works?**
    - **Department of Health – data on conditions, formularies**

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7. What are the core subjects, areas, types of information that you would like to find in an information hub?

- **Legislative**
  - **General Observations**
    - **Value (what is benefit of the Hub)**
      - ✓ **Comorbidities (multiple registries) – what is the impact on cost and outcomes, research this, not just silo of data for one condition, two conditions, but analyze the cost of patients with comorbidities to the system and what outcomes are effective – policy implications for ND**
      - ✓ **Show how the Hub has value – "Providers need to see value, that is the first thing, they have to have buy-in even more important [for them] than for legislature. The legislator will ask the providers they know do you like this, will it help? If the providers says yes, that sways a number of legislators, but if they say no or seem neutral, than a lot of people on the fence will say no."**
      - ✓ **Need to show how it benefits consumers, not just legislators or agencies**
      - ✓ **Health care delivery system is changing – had been production, number of encounters over patient care now it will be outcomes for the patient "this is an example of a policy problem that could be better addressed using data."**
    - **Quality (outcomes)**
      - ✓ **Duplication – happens when people don't know what others have for data**
      - ✓ **Security and privacy – consumers are interested not just legislators**
      - ✓ **Data that is useable – comprehensive, accurate, reliable, and up-to-date**

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7. What are the core subjects, areas, types of information that you would like to find in an information hub?

- **Associations/Agencies/Providers**
  - **Subjects**
    - **Workforce (2 times)**
    - **Population health**
    - **Health care delivery system**
    - **Public health delivery system**
    - **Prevention**
    - **All hospital and clinical data**
    - **Oral health**
    - **Immunizations**
    - **EMS (Transports)**
    - **Lab data**
    - **Utilization (discharge data, number of births)**
    - **Financial (implication for providers, consumers)**
    - **Clinical (diagnosis, what people are seeking care for)**

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7. What are the core subjects, areas, types of information that you would like to find in an information hub?

- **Associations/Agencies/Providers**
  - **General Observations**
    - **Analytics**
      - ✓ **Analytic is more important than even the repository, necessary even, neutral**
      - ✓ **"Hardest part is to structure data so that we can answer a question that is asked later. I mean to be proactive in our thinking." Do massive data pulls.**
    - **Value**
      - ✓ **People use data to write grants – data that people need for grant development should be in the hub – contain the data people need**

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8. How do you view an information hub (necessary and helpful or unnecessary)? Why?

- **Legislative – all necessary**
  - **Necessary**
    - **"Absolutely necessary and critical as state is in a crisis and we do not have the information we need to make the best decisions for the people. We need empirical evidence."**
    - **"For policy and appropriations having that information from a neutral source would be invaluable."**
    - **"I think it's very necessary because of the lack of data. You look at how much money we've spent on health care, but we have no data to justify the spending."**
    - **"I support it but it doesn't have to happen today, but it is necessary." "The devil is in the details though. Privacy and access."**
    - **"Pretend I am from Missouri, show me, prove it. If all it is, is a data base then no. But if it is a tool for better health, better decisions, and better policy, then OK."**
  - **General Observations**
    - **Analytics**
      - ✓ **Analytics, yes but be careful – too much too soon – providers resist – but if benefit providers than possible**
      - ✓ **Be able to show the trends**
    - **Decision making**
      - ✓ **Use it to make change – not just silos of data – reliable location – less duplication – get policy capability for better outcomes**
      - ✓ **Make better decisions for population health**
      - ✓ **Hoped we could have done more last session**

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8. How do you view an information hub (necessary and helpful or unnecessary)? Why?

- **Associations/Agencies/Providers (3- necessary, 3 – concerned)**
  - **Necessary**
    - **"Definitely necessary. We could do much with it. The impact and benefit could be a number of things." – public health issues, geomapping, unmet mental health needs**
    - **"It is absolutely necessary. Now the discussion is back on the table."**
  - **Concerns**
    - **Need to do a cost benefit analysis as sometimes more information is not equal to the cost of securing it**
    - **Who funds it? State or providers? " I think a big concern, and a lot of my organizations support of this project will depend on who funds it."**
    - **"I don't know, we would have to evaluate it and compare it to what we are doing now ourselves, what would it cost, whether they can do it in a quicker time that would free up resources, or would it draw away resources." "We know what we need and want, we don't have to communicate with a third party."**
    - **"I'm always for more information. Information is power…but the state is looking at conservative resources, and I don't know if it's the best way to spend our resources."**

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9. How should aggregated health information be shared and who should have access?

- **Legislators**
  - **Have Access**
    - **Policy makers (3 legislators)**
    - **Associations/Providers (3 legislators)**
    - **Agencies (2)**
    - **Universities**
    - **Special interests (maybe a fee)**
    - **Family members**
  - **General Thoughts**
    - **Open Access**
      - ✓ **Open to a wide group**
      - ✓ **If truly aggregated then general public**
      - ✓ **Need public access – wide scope – for citizens**
      - ✓ **If aggregated then public information and public access**
      - ✓ **If state pays for it then taxpayers are owed access**
      - ✓ **If broad scope, aggregated, then public access**
      - ✓ **Aggregated data should be transparent and available**

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9. How should aggregated health information be shared and who should have access?

- **Legislators**
  - **General Thoughts**
    - **Closed Access**
      - ✓ **Possibly pay for access for some private groups**
      - ✓ **No individual access needs to be legitimate organization – submit application for data – reviewed and approved – review how many times information accessed by the same group**
    - **Privacy**
      - ✓ **Patients can opt in our opt out**
      - ✓ **Privacy is a concern**
      - ✓ **Privacy concerns, that is where the resistance will come**
    - **Security**
      - ✓ **Need to be confident it is aggregated and secure**
      - ✓ **Parameters are key**
      - ✓ **Assure the public on how information will be used**
      - ✓ **Safeguard the public**
      - ✓ **Criteria on who has access and on what type of information**

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9. How should aggregated health information be shared and who should have access?

- **Associations/Agencies/Providers**
  - **General Thoughts**
    - **Open access**
      - ✓ **Everyone**
      - ✓ **Pretty broad – legislators, state associations, agencies university, community people**
      - ✓ **If security is done right don't have to worry and can be open**
      - ✓ **IRB process then should have access – IRB not just for universities but everyone – assures data used properly – aggregated and de-identified**
      - ✓ **IRB and HIPAA then favor open architecture**
      - ✓ **Big data available for research, policy, and planning**
    - **Caution**
      - ✓ **We (association) make information request to the Hub and get information back and share this with members, "I wasn't envisioning this as a public site" some information we share publicly and some strictly for operations**
      - ✓ **Our members, anyone putting in data should have access "I don't like it that is my initial reaction but if we are using it and our stakeholders use it and let others use it, it is practically public already." "Still my gut tells me that making the data public is a bad idea."**

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10. Would you support continuing the work to develop a North Dakota Information Hub?

- **Legislators – All yes**
  - **"Yes, it is critical for our progress"**
  - **"Yes, absolutely. It is important. I believe we waste a lot of money and time by not having a central data hub."**
  - **"Yes, I am a huge proponent of this effort and I will continue to support it."**
  - **"Absolutely. I has the potential for tremendous value. I am very supportive but that is qualified by this, what is the value to the citizens of North Dakota?"**
  - **"Yes, as long as…here is the thing, you can't guarantee that things are safe online/databases/servers because of the way technology has changed." "The bottom line is that data must not get back to the citizens on an individual basis."**
  - **"Yes over time." "Won't happen in two years." "It will take longer to set up and to fund it gradually, stages." "Show the benefit and the cost to get the benefit."**

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10. Would you support continuing the work to develop a North Dakota Information Hub?

- **Associations/Agencies/Providers**
  - **Yes, but concerns over costs –NDHIN is more important to members and Hub sounds like the same "just another space to report to"**
  - **Yes, could do a lot of planning and policy for the state "In ND we build things light" small steps – grand plan but stages – HIE some states did "big iron" promised too much and could not deliver, but ND did HIE in stages and Hub is the same "build it light."**
  - **"I guess I wouldn't be opposed to it. I don't know how it would benefit us, but I would be open to it. I just don't have sufficient information to know whether I would way yes or no yet."**
  - **"I think we would be interested in supporting it, I just don't know what good it would do our organization at this time. I don't want to say don't do it, I just don't see it having a lot of benefit to us."**
  - **Partially, we need to study other states. How much data and at what cost?**

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Conclusions

- **Legislators support idea and continuation of work**
- **Some caveats related to safety, security, cost – prove it**
- **Generally open access to wide audience**
- **Big picture – legislators see potential for analysis, forecasting, predictive quality, proactive decision making, better policy to be based more on facts and not guesses, less silos**
- **Associations/Agencies/Providers – guardedly supportive, cautious, associations maybe see it as a threat or do not perceive the benefit as readily as do legislators**

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