



## Meeting #4

**Date: Wednesday, December 21, 2016 9:00 AM-12:00PM**

**Location: University at Albany – East Campus, 5 University Place, Rensselaer NY 12144**

### Attendees:



PC Workgroup  
Attendance\_meeting

### Overview

This was the fourth and final meeting of the Value Based Payment (VBP) Patient Confidentiality workgroup. The purpose of Meeting #4 was to finalize consensus recommendations on as many topics relevant to the role of patient confidentiality in a VBP context.

The Agenda for this meeting included:

1. Welcome and Introductions
2. Policy Framework
3. Review and Finalization Draft Recommendations
4. Conclusions

**Key Discussion Points** (reference the slide deck “Patient Confidentiality Workgroup #4.pdf”)

#### 1. Welcome and Introductions

The Patient Confidentiality workgroup co-chairs commenced the meeting with a roundtable introduction of participants. Participants were given an overview of the scope of the meeting, which includes the finalization of draft recommendations developed by stakeholders in prior meetings.

#### 2. Policy Framework

Participants were briefed on the transition to VBP and the anticipated changes in the way services will be delivered to the Medicaid population. Those changes raised key policy questions linked to one fundamental theme—with increased integration through VBP, more effective data exchange between entities within the system is a precondition to deliver integrated care while patient confidentiality considerations must nevertheless be protected.

Participants were asked to pay specific attention to implementation mechanisms (e.g., state legislation, model contract, DOH policy, regulatory changes, other modes, or a potential for no changes) for each of the recommendations under consideration.

#### 3. Review & Finalization of Draft Recommendations

Throughout the remainder of the meeting, the discussion revolved around each potential policy recommendation. Participants discussed the feasibility and limitations of each recommendation. The central theme, balancing increased data dissemination against patient confidentiality protections, was observed to drive impassioned debate throughout the whole of the discussion.



**Recommendation #5:** *Step One: Ongoing, robust educational curriculum is required (jointly developed with state and public stakeholders including consumers). All education will include:*

- *patient rights,*
- *meaning of consent,*
- *as well as the opt out process.*

*All materials will address special populations of concerns (E.g., Mental Health, HIV, and Substance Use Disorders). This information will be provided at variety of appropriate environments.*

*Step Two: Align state laws with HIPAA laws (without the need for affirmative consent required).*

*Step Three: Subject to technological capacity, a centralized consent repository should be created to track consent data. (this may require financial assistance from NYS). The creation of this reposition shall be done with input from stakeholders including providers.*

*Step Four: Subject to technological capacity, create an opt-in process for SUD population in accordance with 42 CFR Part 2 and any other required opt-in populations; as well as create an Opt-Out process for those whom elect.*

The workgroup noted that since the last workgroup meeting, many discussions had taken place regarding the issue of how a consensus could be achieved on the topic of how best to share health information, specifically focusing on the contentious matter of whether an opt-in or opt-out regulatory approach would pose a threat to patient rights. Since the previous meeting, interim discussions concluded that so long as patients were fully educated on the uses and purposes of data sharing, the resounding majority of patients will consent to its utilization for healthcare-related purposes.

As part of these discussions, DOH jointly developed language with the stakeholders group. This was used to revise and formulate a proposed consensus recommendation:

**“Only** after a multi-faceted patient education curriculum which covers patient rights, consent for data-sharing and the Medicaid PHI opt-out process has been developed and approved by a diverse group of stakeholders, NYS should work to align its consent and data-sharing regulations to federal HIPAA regulations. In certain situations, this recommend will require the State to take legislative action to remove more restrictive state regulations related to privacy and consent for both mainstream and special populations. Once NYS consent and data sharing regulations are aligned with federal HIPAA regulations, NYS should alter Medicaid policy so as to allow for data sharing, between providers in a care system, which serve a Medicaid member even when a provider in the system is not the provider directly responsible for delivering care to the member. However, at multiple points within a member’s interaction with the health system, there would be instances to continually initiate patient consent education and provide the member with the ability to opt-out of data sharing their health data. At these points of consent education, Medicaid members who do not opt-out of sharing their PHI, will continue to allow for their data to be shared between provider partnerships. However, at any time including these educational touch points, Medicaid members would have the ability to opt-out or opt-back into sharing their data. Finally, a Medicaid member’s eligibility or access to services for which the member qualifies for will never be impacted if they so choose to opt-out of sharing his/her health data.”

Through such education, the workgroup noted that additional education materials would be necessary for various special populations (e.g., HIV/AIDS, mental health, substance abuse), in order to ensure that no population became inadvertently marginalized.

Certain workgroup members noted that delivery of patient rights education must occur as an inter-personal, one-on-one dialogue between a patient and his or her provider. This goes against the idea of education via webinar or online tutorial, which was not believed by certain workgroup members to impart the ability for the patient to make properly informed decisions. With these considerations met, the workgroup would ultimately be comfortable with endorsing the opt-out approach outlined so long as the educational concerns are addressed and real patient education is the requirement.

As a whole, the workgroup agreed that robust language should be added to the educational requirements in order to ensure that patients are receiving this important new information through a one-on-one conversation with their physician. This was noted in particular as a clear area of need for special populations.

A total of three attendees voted against this approach even with the augmented educational requirements.

**Consensus Recommendation:** New York State should implement the following process to ensure education and consent rights for all patients including all Medicaid beneficiaries are protected while permitting appropriate data sharing to enhance care coordination:<sup>1</sup>

1. An ongoing, robust educational curriculum is required (jointly developed with state and public stakeholders including consumers through a new committee formed by the State). All education shall include:
  - a. Patient rights,
  - b. Meaning of consent,
  - c. As well as an opt-out process (only after the education process is in place).
2. All materials shall address special populations of concern (e.g., mental health, HIV, and substance use disorder). This information shall be provided at a variety of appropriate settings, including one-on-one interactions at the time of consent/enrollment on an ongoing basis. Create consistency between state/federal law so that NYS law is no more restrictive than federal law (without the need for affirmative consent)
3. Subject to technological capacity, a centralized consent repository should be created to track consent data (this may require financial assistance from NYS). The creation of this repository shall be done with input from stakeholders including providers.
4. Subject to technological capacity, create an opt-in process for SUD population in accordance with 42 CFR Part 2 and any other required opt-in populations; as well as create an opt-out process for those whom so elect.

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<sup>1</sup> Recommendation 5 was accepted by the larger group, however, a small number voted against this approach even with the augmented educational requirements. The logic provided for that position was that an opt-out approach would imbue upon the patient an impression that if he or she were to opt-out that they would be made ineligible for something valuable in the future that is reserved only for those that have opted in. If true, the concern was put forth that such an approach could leave patients less incentivized to act in their own self-interest.



**Recommendation #6:** *New York State should prioritize and incentivize the development of the technical capabilities required to facilitate recommendation five (5) or any other recommendation where technical capacities are in issue.*

**Consensus recommendation:** The workgroup reached consensus that this recommendation is acceptable in its current form.

**Recommendation #7:** *Ensure that mature minors have the right to both consent to their own medical care, including care coordination, and to consent to the sharing of medical information, or to decline to share such information without the consent of their parents.*

A number of participants made the case that this recommendation had little to no applicability to the mission of the Patient Confidentiality workgroup, which had been designed to deal specifically with matters relevant to the development and implementation of VBP. As such, no additional language was offered as it was deemed more prudent to have it removed from the list final recommendations altogether. The majority decided to move forward with this recommendation but amended it slightly.

**Consensus recommendation:** New York State should ensure that mature minors who do not currently have the legal right to consent to their own care (including care coordination and the sharing of medical information) have such rights and should identify and explore solutions for those mature minors whom are experiencing barriers to care because of such inability. New York State should take the immediate action of studying existing laws related to when mature minors can consent to their own medical care (including care coordination and the sharing of medical information), identify gaps to achieving Recommendation #7, and explore options to fulfill Recommendation #7, including seeking legislative or regulatory change.

**Recommendation #8:** *Create the mechanisms to allow individuals the ability to exercise their right to suppress sharing of sensitive health information (i.e. mental health, HIV etc.) between providers via an opt-out.*

The workgroup felt that currently in New York State within the EHR, if there was a piece of information of a particular person that he or she wanted to suppress from sharing, there is no technical functionality that can accommodate such request if such person has opted-in to data-sharing. Due to the fact that there is no segmentation of data within EHRs, if any component of an EHR is shared it is done so along with every other piece of information that has ever been attached to that particular medical record.

Recommendation 8 was adjusted and accepted by the workgroup as amended.

**Consensus Recommendation:** The State should support the creation of mechanisms to allow for the ability of patients to exercise their right to suppress sharing of sensitive health information (e.g., mental health, HIV) between providers via an opt-out approach.

An objection was made to the idea of patients being able to suppress a piece of their medical record altogether, based on a belief that it is a concept that stands in contradiction to the basic goals of patient care

coordination, which would eventually impact risk stratifications and ultimately the allocation of care. Per the objection, the issue of patient data suppression should be addressed rather through an additional educational outreach effort that could be focused specifically on communicating to patients that there is no risk to them inherent in the sharing of complete medical records among health professionals, and such a system would actually benefit them through a better-informed basis for determining the allocation of care.

**Recommendation #9:** *New York State and New York City Offices of Vital Statistics should grant access to a limited set of individuals and/or organizations to review vital statistics<sup>2</sup> for:*

- *Purposes of health care operations as defined through HIPAA’s healthcare operations part 1 and 2 definitions*
- *To facilitate VBP bundles, including the maternity bundle*
- *Ascertain the death of enrollees*

This recommendation was agreed upon by the workgroup participants but amended.

**Consensus Recommendation:** New York State and New York City Offices of Vital Statistics should grant access to a limited set of individuals and/or organizations to review vital statistics for:

- To facilitate VBP bundles, including the maternity bundle
- Ascertain the death of enrollees

**Recommendation #10:** *All payers should be required to send explanations of benefits only to the patient for whom the claim is made, at the address and in the manner the patient directs.*

Consensus could not be reached on this recommendation, and thus this turned down by the workgroup participants.

#### 4. Conclusions

The workgroup agreed that further follow up will be conducted to solicit input on the finalized versions of recommendations 5- 10.

#### Materials distributed during the meeting:

Document	Description
Patient Confidentiality Workgroup – Meeting #4  Patient Confidentiality Worl	A presentation deck of draft recommendations for consideration as they relate to VBP patient confidentiality.

<sup>2</sup> Vital Statistics (VS) currently have unique restrictions which render them unusable with Medicaid members. New York state regulation 10 NYCRR 400.22 suggests that only state employees may access VS. There are no exceptions or consent processes available to providers, PPSs, and NYS contractors (there are limited exceptions for non-Medicaid members). VS include information on pregnancies, births, deaths, marriages and dissolutions, including trends over time and state population demographics.



## **Key Decisions**

The Workgroup made decisions on the following key points during meeting #4:

- ✓ Recommendation 5: revised to reflect a more concise scope.
- ✓ Recommendation 6: accepted in its current form.
- ✓ Recommendation 7: revised to make more applicable to the mission of the Patient Confidentiality workgroup.
- ✓ Recommendation 8: accepted without the majority's support but revised the language.
- ✓ Recommendation 9: accepted but amended to remove language around HIPAA.
- ✓ Recommendation 10: determined that is no longer relevant.

## **Action Items:**

- Further input will be solicited from workgroup members in January 2017 on the finalized recommendations.

## **Conclusion**

This meeting concluded with all ten recommendations put forth to-date included in the final recommendation report. The ten recommendations were grouped into: (a) unanimously approved recommendations, (b) recommendations approved via consensus, (c) unapproved, non-consensus recommendations. These recommendations will be aggregated and finalized by the meeting co-chairs, and a comment period will be opened for the VBP workgroup committee to provide final feedback. Thereafter, a formalized recommendation report will be posted for public comment.