OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
October 27, 2023
Conference Call

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Introduction

The Holistic Data Review Workgroup (the Workgroup) met via WebEx teleconference on 10/27/2023 to discuss the following agenda items:

1. Source of Payment Update
2. Member Questions – Current State
3. Data Definition Clarification Workgroup Discussion

The following is a summary of the Workgroup's discussions.

1. Source of Payment Update

The OPTN Contractor presented the Workgroup with a few updates regarding their previous discussions related to source of payment. The Workgroup had last discussed the topic during their 9/22/2023 meeting.

Presentation summary:

A discussion regarding the source of payment took place with Pediatric Committee leadership on September 25, 2023. The result of that discussion is reflected in the table below:

FROM	CHANGE TO (Adults)	CHANGE TO (Pediatrics)
Private Insurance	Private Insurance (Commercial Health Insurance)	Same
Public insurance – Medicare & Choice	Public insurance – Medicare Part C or Medicare Advantage	Same
Self	Self-pay	Same
Free Care	Free Care (Charity Care)	Same
Public insurance – Other government	• Public insurance – TRICARE • Public insurance – Indian Health Service	• Public insurance – TRICARE • Public insurance – Indian Health Service • Public insurance – State program
Unknown	Remove unknown	Same
Public insurance - CHIP (Children's Health Insurance Program)	N/A	Keep As Is

Summary of discussion:

> The workgroup further discussed source of payment.

A member raised a concern about the redundancy of the term "Public Insurance – Medicare Part C or Medicare Advantage," asserting that Medicare Part C and Medicare Advantage are essentially the same.

The member pointed out that presenting it as an either/or choice might cause confusion due to the similarity of the two terms. Another member echoed this sentiment, expressing agreement with the potential for confusion. To address this, a suggestion was made to eliminate the word "or" and replace it with a slash, a modification believed to enhance clarity for individuals navigating the information. The OPTN contractor staff supported this proposed change and agreed to consider the member's suggestion as a viable alternative.

Additionally, a member highlighted potential confusion surrounding the option "Public insurance – State Program," noting that many individuals might perceive this as the same as Medicaid. The member emphasized that, despite some states, like California, offering additional programs, users may not be aware of these distinctions. To alleviate confusion, the suggestion was made to include a few examples of states where the option is applicable, providing clarity on its broader scope.

Next Steps:

The suggestions from the Workgroup members will be incorporated in source of payment language.

2. Member Questions – Current State

The Workgroup was provided with an overview of the current process that member questions follow, as well as updates to ServiceNow.

Presentation summary:

OPTN contractor staff provided an overview of the process for handling member questions. The outlined process involves receiving member questions, some aimed at clarifying form instructions. If a question cannot be immediately answered, input is sought from policy analysts. Successful responses are directly communicated to the member, but for more complex issues, additional steps include consulting the source committee for feedback on the data collection form's intent and how to respond. A proposed change is then created and presented to the Data Advisory Committee (DAC) for endorsement. If approved, the technical writer is updated, and the OPTN member is informed.

In the absence of a dedicated work group for reviewing non-substantive changes, the suggestion is to seek input from the DAC or the Transplant Coordinators Committee (TCC) members. In addition, it had been proposed to send email notifications to the affected organ committee chair, as there are no data owners but rather organ committees overseeing the forms. The purpose of these notifications is to inform committee chairs about changes in the forms under their purview.

Currently, Enterprise Data Management (EDM) manages two queues dedicated to handling member questions. To enhance both external and internal user experiences, there is an ongoing initiative to consolidate these queues. The consolidation aims to provide more accurate metrics and simplify the tracking of questions spanning multiple organs and forms. Additionally, improvements to the OPTN member portal layout are being implemented to optimize user interaction. The consolidation is anticipated to contribute to a more efficient internal workflow. As part of this improvement strategy, a new queue is scheduled to be launched in 2023.

Summary of discussion:

The Workgroup did not make any decisions about this agenda item.

3. Data Definition Clarification Workgroup Discussion

Considering the points outlined earlier, the Workgroup engaged in a discussion to assess the Committee's needs for obtaining additional support in the review and resolution of member questions.

Summary of discussion:

> The Workgroup further discussed how to approach member questions.

A member proposed the creation of a database containing previously asked and answered questions, accessible to members. This suggestion aimed at saving time for member organizations and enhancing overall process efficiency. The OPTN contractor staff acknowledged the value of this feedback, particularly in light of plans to implement a Frequently Asked Questions (FAQ) section with questions from members and guidance from the OPTN. While currently internal to the OPTN, there is a future goal to make it externally accessible once it is cleaned up. The members also expressed satisfaction with the timing of presenting member questions and recommendations to the DAC.

Additionally, a member suggested that for non-substantive changes, sharing such questions with the committee could be beneficial, providing insights into community needs. The OPTN contractor staff supported this idea and proposed tracking the frequency of questions by form and field, allowing for prioritized content updates based on community needs. The member further endorsed this notion, suggesting the inclusion of a graphical representation of when questions were asked to aid in educational efforts. The OPTN contractor staff expressed confidence in the member questions tracking system's ability to provide such information and capabilities, facilitating improved tracking and analysis for future enhancements.

A member emphasized the necessity for a concerted effort towards standardization and the establishment of a clear pathway for standardizing procedures across various committees. The member proposed that addressing this matter might require engagement with HRSA (Health Resources and Services Administration) as they progress in reviewing and considering contractual arrangements. The underlying idea is that standardization could significantly contribute to resolving the current challenges and issues at hand within the committees, enhancing efficiency, consistency, and overall effectiveness in their operations.

Regarding the presentation of an initial version of a solution or recommendation from the OPTN Contractor to DAC/TCC, a Workgroup member expressed support for such involvement in this process, highlighting the potential operational expertise of members of those committees. However, it was emphasized that individuals from DAC and TCC may not be subject matter experts on the specific forms in question, as these committees have organ-specific representatives. Thus, directing specific questions to the appropriate individuals was considered crucial. Another member voiced support for the idea but cautioned against potential challenges, noting that involving additional stakeholders might lead to debates and an overflow of opinions, potentially hindering the decision-making process.

OPTN contractor staff sought guidance from the Committee on the approach to the endorsement stage from DAC, specifically in terms of communication about recommendations or text updates. A member suggested that instead of identifying a few volunteers, it might be more beneficial to communicate with the entire Committee. This approach would enhance the Committee's awareness of the types of questions being raised and how they are being addressed.

Drawing from the rotational review board structure employed by heart, lung, and liver committees, which involves a percentage-based participation requirement, a member proposed that a similar structure might be applicable to DAC. This could involve experts outside of DAC membership, preventing potential overburdening of the committee. An individual also noted that SharePoint contains a resource that lists DAC expertise to appropriately direct questions.

The concept of rotational volunteering was emphasized, with a call to assess the level of burden and gather information on frequency by form and field, as well as resources utilized by DAC in each month. The members highlighted that expertise is readily available within the transplant professional community, making it feasible to find several individuals with the necessary knowledge and experience.

The OPTN Contractor thanked the Workgroup members for their feedback related to the data definition clarifications that were addressed throughout the year, as well as their participation in the clinical data standards assessment. The OPTN Contractor stated that as a result of the earlier work, the Workgroup would no longer meet after today. Instead, the normal DAC data definition clarification process will be re-started to update or implement a non-substantive change to data collection. Substantive changes will continue to be addressed through the policy development process. The OPTN Contractor reminded everyone to reach out if they have questions or comments.

Next Steps:

These suggestions will be considered for incorporation to improve the member questions process. As a result of completing their work, the Workgroup will no longer meet.

Upcoming Meeting

- No upcoming meetings scheduled

Attendance

- **Workgroup Members**
  - Rebecca Baranoff
  - Ashley Cardenas
  - Christine Maxmeister
  - Karl Neumann
  - Jennifer Peattie
  - Julie Prigoff
- **HRSA Representatives**
  - None
- **SRTR Staff**
  - Avery Cook
- **UNOS Staff**
  - Eric Messick
  - Jonathan Chiep
  - Cole Fox
  - Gabrielle Hibbert
  - Nadine Hoffman
  - Sevgin Hunt
  - Lauren Mooney
  - Divya Yalgoori