JDMW Advisors, LLC

Responses to Request for Information

From: Jean D. Moody-Williams, JDMW Advisors, LLC

Jdmwadvisors@gmail.com

Thank you for seeking input. I offer the following comments related to patients and caregivers:

B. Patients and Caregivers

This section is intended for all stakeholders to provide input on questions as they relate to use cases and workflows that involve patients and caregivers. While we certainly want patients and caregivers to answer questions in this section (and in other sections) from the patient/caregiver point of view, we also invite all stakeholders to provide their viewpoints on the patient/caregiver workflows.

1. Patient Needs

PC-1. What health management or care navigation apps would help you understand and manage your (or your loved ones) health needs, as well as the actions you should take?

a. What are the top things you would like to be able to do for your or your loved ones' health that can be enabled by digital health products?

It is essential to have the ability to assess the quality of care provided by healthcare providers, to whom we entrust our health. The data that is generally available is outdated and not specific to the care team that we either have or are called upon to choose. There is always a movement for patient-centered care, which has different definitions depending on who uses the term. For some, it means that consumers should be more responsible for taking care of their health, choosing providers that practice value related to quality and cost, and following their recommendations. It would be much easier to accomplish this with better data on quality and cost.

The development of patient-reported outcome measures must also advance to add value to the information available to patients and caregivers. While some progress has been made in this area, the pace is slow. Collecting information from patients can be resource-intensive and challenging to analyze. Technology can help advance the development of patient-reported data as well as the collection and analysis of the information provided.

Patients, families and caregivers must be involved with developing the measures as well as the policies that govern the use of the information.

b. If you had a personal assistant to support your health needs, what are the top things you would ask them to help with? In your response, please consider tasks that could be supported or facilitated by software solutions in the future.

A personal or virtual assistant would be helpful in care coordination, particularly for those with multiple chronic conditions. It becomes challenging to schedule appointments (partially due to the lack of availability), connect the various patient portals (including pharmacy portals), and ensure that each provider is aware of the patient's status.

Technology can also be used for predictive analytics to provide warnings of potential adverse events based on a series of data points from remote monitors, patient-reported data or other sources of information. The alert would be geared towards proactively providing guidance that could change the course of events if the patient or caregiver followed the advice provided.

PC-2. Do you have easy access to your own and all your loved ones' health information in one location (for example, in a single patient portal or another software system)?

Access to health information has improved; however, it is not all in one place. There are at least three to four different portals that one must access. The insurance company also attempts to track health information and intervene; however, the information is often less helpful than the actual information in the portal. Additionally, some of the electronic health records are not very user-friendly.

a. If so, what are some examples of benefits it has provided?

I have greatly benefited from being able to access the portal to obtain the results of laboratory or other diagnostic tests, download referrals, review discharge instructions, schedule appointments, and track healthcare status, such as lab results going up or down.

b. If not, in what contexts or for what workflows would it be most valuable to use one portal or system to access all such health information?

It would be valuable to connect the history and physical, diagnostic tests, and patient concerns across all the various electronic health records, so that, with permission, the patient's care journey can be viewed by all providers, regardless of the health system for

which they practice.

respondc. Were there particular data types, such as x-rays or specific test results, that were unavailable? What are the obstacles to accessing your own or your loved ones' complete health information electronically and using it for managing health conditions or finding the best care (for example, limitations in functionality, user friendliness, or access to basic technology infrastructure)?

Access to diagnostic tests and imaging results has greatly improved over the past year. The results are generally available within 24 hours and can be viewed even before the healthcare provider has reviewed. It is particularly helpful when the provider sends a follow-up note with their interpretation of the results, ensuring agreement on the path forward based on the results. It would also be helpful for the laboratory results to have a layman's description that may provide information until the clinicians respond or may help to structure follow-up questions.

PC-3. Are you aware of health management, care navigation, or personal health record apps that would be useful to Medicare beneficiaries and their caregivers?

Beneficiaries and caregivers would benefit from access to resources that support their healthcare needs, including transportation, coordination of benefits, and transparency regarding payment.

PC-4. What features are missing from apps you use or that you are aware of today?

It is essential to have the ability to assess the quality of care provided by healthcare providers, for whom we are called upon to entrust our health. The data that is generally available is outdated and not specific to the care team that we either have or are called upon to choose. There is always a movement for patient-centered care, which has different definitions depending on who uses the term. For some, it means that consumers should be more responsible for taking care of their health, choosing providers that practice value related to quality and cost, and following their recommendations. It would be much easier to accomplish this with better data on quality and cost.

a. What apps should exist but do not yet? Why do you believe they do not exist yet?

Real-time or close-to-real-time quality data does not exist for which you can choose your clinician. If you do a search on nearly any site for a clinician, you will find minimal information such as office address, education and possible specialty.

PC-5. What can CMS and its partners do to encourage patient and caregiver interest in these digital health products?

a. What role, if any, should CMS have in reviewing or approving digital health products on the basis of their efficacy, quality or impact or both on health outcomes (not approving in the sense of a coverage determination)? What criteria should be used if there is a review process? What technology solutions, policy changes, or program design changes can increase patient and caregiver adoption of digital health products (for example, enhancements to data access, reimbursement adjustments, or new beneficiary communications)?

CMS, working with other appropriate agencies, should work to ensure the protection of health care information so that it is only used for providing healthcare services, improving quality of care or determining next steps in innovation for activities such as care coordination. There must be caution for using data to inappropriately restrict needed care or limit insurance coverage.

b. What changes would enable timely access to high quality CMS and provider generated data on patients?

Clinical data must be readily available for populating quality information digitally, with minimal to no manual abstraction from clinical records. This will help ensure accuracy and reduce the burden for clinicians, healthcare professionals, and others involved in data collection. AI features should be used to query information without the need for laborious measure specification development and programming. These lengthy processes result in delays in introducing new measures to the public for reporting.