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## VALUING PATIENT EXPERTISE IN DRUG DEVELOPMENT

A fair market value calculator for patient engagement rolled out this week by the National Health Council aims to clear up concerns over pay for patients that may have limited their engagement in drug development. NHC hopes **the tool** will help set an industry benchmark for pharmas to fairly compensate patients, caregivers and patient advocacy group representatives for their expertise.

Patient-focused drug development has been a priority of FDA's since the agency held its first workshop on the topic in 2012. One of the barriers to realizing this goal, NHC's Elisabeth Oehrlein told BioCentury, has been determining how to properly compensate patients for their role in drug development. Oehrlein is senior director of research and programs for NHC, an umbrella group comprising more than 140 healthcare organizations and businesses that include patient advocacy groups, biopharmas and payers.

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*Elisabeth Oehrlein, National Health Council*

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"Companies didn't know how to pay patients, and so there was confusion," said Oehrlein. "But more broadly, the concern was inconsistency across companies. You don't want to have the perception that you're overpaying and maybe having a patient participate because you're paying a lot, or underpaying in terms of being a good partner."

What's more, Oehrlein said, the patient community didn't know how much they should be asking for. In addition to encouraging companies to pay advocates consistently, the calculator is also a tool to help patients determine the value of their expertise.

In the past, some pharmas would use fair market value calculators developed with clinicians or researchers in mind that took into account higher degrees and clinical trial expertise -- criteria that aren't as applicable to patients.

A patient who advises a pharma is a KOL just like any other medical KOL, and should be paid as such for their service and wisdom, said Susan Schaeffer, president and CEO of the non-profit Patients' Academy for Research Advocacy Inc. She was Editor of BioCentury in 2012-18.

"But there's been no benchmark for that," Schaeffer told BioCentury. "How much do you pay for that expertise? How do you figure out what's fair?"

NHC members asked the organization to create a calculator a couple years ago, Oehrlein said. The organization established a steering committee comprising patient representatives, members of industry

and patient engagement researchers. The committee first discussed the range of activities patients are being asked to engage on, such as participating in a roundtable, or being shadowed in their daily life. The group then identified standard rates for the different types of engagement, and how those base rates would vary for patients or caregivers based on their experience.

The calculator takes into account variables such as travel expenses, lost wages and child or elderly care incurred because of a patient's participation.

"Irrespective of the value the calculator spits out, it delineates the variables that should be considered when deciding what patient compensation is," Schaeffer said. "Having a tool like this, whether it's used to calculate the rate that someone gets paid for their time or expertise or whether it's used to inform that discussion, should make it even clearer that this is a professional activity that patients engage in and should be considered as such."

Oehrlein called the calculator an opportunity equalizer.

"The idea is we want to make sure we're able to engage folks and do a better job of being representative," she said. "If you're not getting paid for your time, that may mean some wealthier patients can participate when others can't."

Taken together, the calculator proposes a pay range the patient community thinks is appropriate, and Oehrlein hopes standardizes the field. "I expect that it will definitely be a facilitator of more patient engagement in drug development."

The calculator is the first of a pair of patient compensation tools NHC plans to launch. Oehrlein said that this summer, NHC will make available sample, plain-language contracting templates that can be used by companies engaging with patient organizations.

Another barrier to patient-focused drug development are small patient groups that lack the resources to handle tasks such as reviewing a contract, she said. "They might hire an attorney for \$1,000 to look at a contract that was for \$1,000 in the first place."

The templates were originally developed by the Patient Focused Medicines Development (PFMD) group and the Workgroup of European Cancer Patient Advocacy Network, and adapted for U.S. use by NHC. PFMD will add other countries to the calculator.

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