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The Leading Edge

## Crowdsourcing healthcare costs: Opportunities and challenges for patient centered price transparency

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## ARTICLE INFO

## Article history:

Received 2 September 2014

Received in revised form

15 June 2015

Accepted 16 June 2015

Available online 2 July 2015

## Keywords:

Crowdsourcing

Price transparency

Out-of-pocket cost

Hospital charge data

## ABSTRACT

Efforts to improve health care price transparency have garnered significant attention from patients, policy makers, and health insurers. In response to increasing consumer demand, state governments, insurance plans, and health care providers are reporting health care prices. However, such data often do not provide consumers with the most salient information: their own actual out-of-pocket cost for medical care. Although untested, crowdsourcing, a mechanism for the public to help answer complex questions, represents a potential solution to the problem of opaque hospital costs. This article explores, the challenges and potential opportunities for crowdsourcing out-of-pocket costs for healthcare consumers.

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Earlier last year, an upset patient took to the internet to post a picture of his \$55,000 hospital bill after an appendectomy for acute, uncomplicated appendicitis<sup>1</sup>. The post went viral, receiving over 700,000 views on Reddit, over 10,000 comments, and garnered significant media attention from various websites and news outlets. Many people from the general public responded by posting their own bills, or relaying personal stories about exorbitant fees and bills<sup>2,3</sup>. For those familiar with hospital charge practices, the contents of the bill (which included anesthesia, imaging, surgical and inpatient fees) may not be that surprising. However, as demonstrated by the widespread attention to both the “appendicitis bill” post and to high profile news stories that have used specific hospital bills to characterize variations in pricing, publicly shared contents of hospital bills are touching the public’s nerve. The significant interest in the shared hospital bill suggests additional uses beyond its shock value. In this perspective, we outline why shared hospital bills could become part of a patient-driven approach to cost transparency.

Nationwide, there are multiple ongoing efforts to make hospital costs more available to patients. However, most of these initiatives involve the release of hospital charge data. Hospital representatives and others have repeatedly stated that public charge data does not reflect reality or provide patients with useful

information. These figures represent Chargemaster level data – not the actual price many patients are asked to pay once prices for services are negotiated between insurance companies and providers<sup>4,5</sup>. Yet, despite criticism, many states have already initiated price transparency plans based on the release of hospital charges, and others will likely follow to open up charge data for public use<sup>6,7</sup>.

Despite the increased push to make charge data public, current transparency policies often fail to answer the most critical question for the patient seeking a hospital-based procedure or test: what will be my actual, out-of-pocket costs? To answer this question, some insurance companies such as Cigna and United Healthcare, have begun to provide cost estimates to their customers via online calculators. However, this information is limited to those with specific health plans and does not benefit others without private insurance. Additionally, these tools do not disclose the underlying financial agreements with providers and do not provide information about the rates other insurance companies have agreed on with the same providers. Entrepreneurial efforts, such as Castlight and Change Healthcare share cost and charge information services to corporate employers and health plans, but are not open to the general public.<sup>8</sup> These closed transparency services obtain pricing data through collaborative ventures with health insurers that can be fed back to employers and employees seeking cost information. Legislators have proposed policy changes such as the Health Care Price Transparency Promotion Act (H. R. 1326) of 2013 to encourage transparency, but uncertainty remains when such policies would be enacted or how well the policy

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changes would address the question of consumer out-of-pocket cost<sup>9</sup>.

Given this gap between charges and out-of-pocket costs, innovative methods in transparency are likely to emerge. Crowdsourcing is one, largely untested, mechanism that could bypass some of the challenges with hospital charge data that has confounded experts and consumers alike. Crowdsourcing is the portmanteau of “crowd” and “outsourcing” and involves an open call to the public to help collect information or solve a problem. The science of crowdsourcing suggests that because the request for information is offered to an undefined large group of individuals, it engages those who are, (1) interested, (2) likely to complete the task, and (3) able to contribute interesting ideas and perspectives. Crowdsourcing is particularly useful when the truth or real answer to a problem is unknown or difficult to verify. Crowdsourcing provides a potential platform to obtain information about real costs from patients themselves. Individuals already share a range of information with others online (including demographics, location, and health status) and they are beginning to share their healthcare costs<sup>10</sup>. Importantly, crowdsourcing has already been successfully used in healthcare to track influenza, find emergency equipment, and provide training for malaria detection<sup>11</sup>. Crowdsourcing has also been used to successfully solicit individual feedback on public health promotional materials. Currently, patients and families use crowdsourced applications to share information about medical treatments and options (through the lens of their own experiences) on popular platforms such as “Patients Like Me”<sup>12</sup>. Complex scientific problems, such as protein folding, have been addressed through crowdsource applications like “Fold-It”<sup>13</sup>. These previous accomplishments and the attention the general public is paying to healthcare prices have set the stage for a crowdsourcing in health care costs and prices.

Given the challenges associated with top-down approaches to cost transparency, the potential demand for a consumer driven effort to share costs exists. But how could crowdsourcing bills work to be comprehensive, analyzable, and usable? As a model, patients upload their final bills, which include both the “amount due” and the “amount allowed” figures. These bills—while perhaps difficult to match directly to any specific consumer—would, on the most basic level, provide richer information than hospital charges alone. These data would also live in a repository and be incorporated into apps and other tools that sort them based on procedure, payer type, and other filters, with the option of keeping their bills anonymous. To strengthen this crowdsourcing initiative, patients would also have the option of entering their unique insurance plan information such as insurer, specific plan type, start and end dates, deductible amount, co-insurance requirement, and out-of-pocket maximum. All of this information could aid in the creation of a tool that funnels the current labyrinthine system of charges and costs, into something understandable and usable.

Preliminary forays into crowdsourcing healthcare costs are underway, suggesting that such efforts may be feasible. One example is [www.clearhealthcosts.com](http://www.clearhealthcosts.com) – a journalist led crowdsourcing initiative, funded by the Knight Foundation. It uses a combination of news reporting, batch data, and anonymously supplied healthcare cost data to compile a list of out-of-pocket costs for services in 7 cities. Another site [www.pricinghealthcare.com](http://www.pricinghealthcare.com) has very similar aims. In California, two public media stations have launched Pricecheck, a crowdsourced initiative that asks consumers from the San Francisco and Los Angeles regions to upload their health care bills (for MRI scans and mammograms) along with additional insurance information. Their stated goal is to host a “community-created guide to health costs”<sup>14</sup>. The preliminary results of this experiment were described in January 2015 in *JAMA Internal Medicine*, noting that patients were willing to share and eager to use the site to learn about costs<sup>10</sup>.

The reasons why crowdsourced health costs could help consumers extend beyond pure price transparency. Crowdsourcing efforts have the potential to address other problems related to health care cost, access and delivery. For example, crowdsourced bills can serve as a bargaining tool for health care consumers. Patients have demonstrated a willingness to turn to the internet to find cost estimates or agree on a price directly with a provider<sup>15,16</sup>. Consumers, upon receiving a large bill from a hospital for emergent services, often look to medical-billing advocates to work with hospitals to decrease their overall cost<sup>6</sup>. The availability of patient bills from a crowdsourced website—which could include the site of care—would provide substantiated information for patient-consumers as they are trying to navigate the cost of an upcoming surgery or challenge a large bill following an unexpected hospital visit. Shared experiences with medical treatments represent alternative consumer empowerment opportunities for crowdsourcing in general, and specifically could be linked to projects focused on cost<sup>17</sup>. Employers have in turn used the entrepreneurial cost transparency services, such as Castlight, to negotiate fixed fees for certain medical services. But unlike these services, which use health plan provided data and are available only to employees of companies who subscribe to the service, crowdsourced data comes from the general public and could be used by anyone.

Personalizing and scaling-up a crowdsourcing hospital costs initiative will not be without its challenges. Legal concerns, related to privacy and proprietary information, will likely be raised. Technically, it may be difficult to combine data derived from a variety of sources, as many out-of-pocket costs are often plan-specific and may be further complicated by geographic region and type of facility in which the service was rendered. Initial crowdsourcing approaches to cost transparency may initially work best for planned care and certain preventive services such as non-emergent surgeries, and diagnostic imaging, and colonoscopies (particularly for people that are without health insurance or who have high deductible health plans where). Initially limiting the crowdsourced material to these procedures reduces variability in the sample, making the data easier to analyze. Despite anticipated challenges, interest from the participating crowd in other crowdsourcing efforts has been shown to drive innovation for overcoming difficulties specific to the task<sup>18</sup>.

What would motivate enough citizens to participate in healthcare cost crowdsourcing efforts to overcome sample biases and the outsized influence of “shock bill” type outliers? Crowdsourcing initiatives typically engage individuals through a combination of intrinsic and extrinsic motivating techniques. Extrinsic techniques typically involve the receipt of some award such as prize money, increased exposure, or fame. Intrinsic motivational techniques often play to a participant’s desire to contribute to a cause or help others. This enterprise would primarily use intrinsic motivational factors to gain participants. Participants would be urged to share their bills to help others gain more equitable health costs as well as contribute to collective knowledge. Proven techniques to increase engagement, such as framing the question as a problem, creating a user friendly interface, and having low barriers to entry, may all lead to increased participation. Placing a new initiative on a well-known website that manages other popular crowdsourcing efforts is a useful technique to increase participation as such platforms have a well-established set of users who may be more apt to participate<sup>18</sup>. Potential extrinsic motivation could be harnessed in various ways as well: perhaps providing free access to the information if you post a bill or refer a friend. All of these techniques can be utilized to overcome some of the challenges and limitations of a crowdsourcing effort.

Doubtless, for some, posted online bills may be unhelpful. The extent to which individuals will be able to leverage the data to make better decisions or negotiate better prices, remains to be

seen. Clearly, such innovations will need to be rigorously studied once they are in use. However, much of the recent attention to price transparency originated with reports that used single patients' bills to highlight the problem. Crowdsourcing creates an opportunity for the same bills to be part of a potential solution, as opposed to merely a source of outrage.

## Acknowledgments

The authors gratefully acknowledge the input of Daniel Polsky, Ph.D who reviewed an earlier version of this manuscript.

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## Conflict of interest disclosure statement

This statement accompanies the article "Crowdsourcing healthcare costs: Opportunities and challenges for patient centered price transparency" authored by Zachary F. Meisel and co-authored by Lauren A. Houdek VonHoltz, and Raina M. Merchant and submitted to Healthcare as an original article. Below all authors have disclosed relevant commercial associations that might pose a conflict of interest:

Consultant arrangements: None.  
 Stock/other equity ownership: None.  
 Patent licensing arrangements: None.  
 Grants/research support: None.  
 Employment: None.  
 Speakers' bureau: None.  
 Expert witness: None.  
 Other: None.