

Privacy, Transparency, and Quality Improvement in the Era of Big Data and Health Care Reform

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ABSTRACT

The era of big data and health care reform is an exciting and challenging time for anyone whose work involves data security, analytics, data visualization, or health services research. This presentation examines important aspects of current approaches to quality improvement in health care based on data transparency and patient choice. We will look at specific initiatives related to the Affordable Care Act (e.g. the qualified entity program of section 10332 which allows the Centers for Medicare and Medicaid Services (CMS) to provide Medicare claims data to organizations for multi-payer quality measurement and reporting, the open payments program, State-level all-payer claims databases to inform improvement and public reporting) within the context of a core issue in the era of big data: security and privacy versus transparency and openness. In addition we will examine an assumption that underlies many of these initiatives: data transparency leads to improved choices by health care consumers and increased accountability of providers.

For example, recent studies of one component of data transparency, price transparency, show that, although health plans generally offer consumers an easy-to-use cost calculator tool, only about 2 percent of plan members use it. Similarly, even patients with high-deductible plans (presumably those with an increased incentive to do comparative shopping) only seek prices for about 10 percent of their services. Anyone who has worked in analytics, reporting, or data visualization recognizes the importance of understanding the intended audience, and that methodological transparency is as important as the public reporting of the output of the calculation of cost or quality metrics. Although widespread use of publicly reported health care data may not be a realistic goal, data transparency does offer a number of potential benefits: data-driven policy making, informed management of cost and use of services, as well as public health benefits through, for example, the recognition of patterns of disease prevalence and immunization use.

Looking at this from a system perspective we can distinguish 5 main activities: data collection, data storage, data processing, data analysis, and data reporting. Each of these activities has important components (such as database design for data storage, de-identification and aggregation for data reporting) as well as overarching requirements such as data security and quality assurance that are applicable to all activities. A recent Health Affairs article by CMS leaders noted that, "The big-data revolution could not have come at a better time..." but it also recognizes that challenges remain. Although CMS is the largest single payer for health care in the U.S., the challenges it faces are shared by all organizations that collect, store, analyze, or report health care data. In turn these challenges are opportunities for database developers, systems analysts, programmers, statisticians, data analysts, and those who provide the tools for public reporting to work together to design comprehensive solutions that inform evidence-based improvement efforts.

INTRODUCTION

There is so much current activity and research on data transparency and quality improvement that it would be almost impossible to do an exhaustive survey of current initiatives or research. This paper on focus on the main issues at a fairly high level, but will relate these issues to the interests of the SAS® community. The organizers of SAS Global Forum should be commended for recognizing that there are important connections between formal systems, the content and purpose of those systems, and the intended users of systems and system output.

A number of years ago, in a paper on quality control (Gorrell 2004) I used the term *content-based programming* to refer to the need for SAS programmers to be aware of the content and uses of the data they were working with. This observation is applicable to the current context. Below I will discuss some findings from a 2014 GAO report on health care transparency that concludes, among others things, that it is important for information to be understandable to

the intended audience. This may seem like a trivial observation but it is a crucial fact when one considers, for example, the complexities of how health care charges and cost or specific quality measures are formulated and communicated. To take just one example, consider publicly reporting the cost of a procedure like an MRI. Is that number really sufficient in isolation? Doesn't the patient really only care about the current cost at the facility where they will have the MRI? And of course the specific cost of, for example, a lower back MRI? Presumably most consumers only really care about the out-of-pocket cost and not the total cost or the cost to their insurer.

Below we will discuss these specific issues within the larger context of the current health care landscape in the United States. We will begin with the Department of Health & Human Services (HHS) National Quality Strategy.

THE NATIONAL QUALITY STRATEGY

In March 2011, HHS first published its National Strategy for Quality Improvement in Health Care (the National Quality Strategy), as required by the Patient Protection and Affordable Care Act (PPACA).

The National Quality Strategy builds on priorities HHS previously identified in its strategic plan for fiscal years 2010-2015, which emphasize the need for transparent information to give consumers the means to make more informed choices about their health care. Two of the National Quality Strategy's overarching goals—better care and affordable care—relate to health care cost and quality transparency. According to the strategy, to achieve better care, patients must be given access to understandable information and decision support tools that help them manage their health and navigate the health care delivery system. We can add an emphasis to *understandable information* that includes plain language, standardization across systems, providers, and payers, as well as clear formatting and graphics. As I discuss below I am skeptical of the view of the patient as consumer for a number of reasons, but this in no way obviates the need to present information in a way that is understandable to the intended audience.

The National Quality Strategy is based on the belief that to achieve affordable care, systems must be created to make health care cost and quality more transparent to consumers and providers, so they can make better choices and decisions. The strategy also focuses on coordinating and aligning efforts across the public and private sectors, for example by establishing an aligned set of common cost and quality measures by which to assess how well providers and programs support effective care. This is crucial if meaningful comparisons are to be made.

Many States are engaged in transparency and public-reporting initiatives such as all-payer databases (discussed below) that promise to provide researchers and consumers with comprehensive information about health care cost and quality for a wide array of procedures and services across providers and payers (e.g. private insurance, Medicare, Medicaid).

Commenting on legislation that would create a publicly-available all-payer database, this past January Governor Jay Inslee of Washington noted that, "We all want a top-notch health care system that improves our families' health at an affordable cost. Better information will result in a better system. I appreciate the hard work of our health care and insurance providers in helping us develop a database that will ultimately make our system more efficient and effective for everyone."

Cassie Saurer, Senior Vice President of the Washington State Hospital Association stated that, "Washington's hospitals and physicians will use the data to improve our quality and better serve our patients. For example, hospitals can identify what types of post-discharge services help keep patients from being re-admitted to the hospital. Rural providers can examine which services patients are traveling long distances for and make plans to provide those services closer to home."

Washington is just one of numerous States that have moved toward establishment of an all-payer database. As is well known the Federal government, in particular the Centers for Medicare & Medicaid Services (CMS) is increasing its public reporting of data. But the public release of healthcare data, unlike data about other consumer products or services, raises significant privacy and interpretation concerns. The President of the American Medical Association, Ardis Dee Hoven, has noted that, "The disclosure of payment data from government health care programs must be balanced against the confidentiality and personal privacy interests of physicians and patients who may be unfairly impacted by disclosures. The unfettered release of raw data will result in inaccurate and misleading information. Because of this, the AMA strongly urges HHS (the U.S. Department of Health and Human Services) to ensure that

physician payment information is released only for efforts aimed at improving the quality of healthcare services and with appropriate safeguards.”

COST AND QUALITY TRANSPARENCY

Although the U.S. health care system is enormously large and complex, the twin peaks of discussion topics are cost and quality. Studies or initiatives that seek to contain or lower costs must pay particular attention to quality measurement since it is obviously easier to lower costs if you ignore quality than if you strive to maintain high quality.

Although the reasons are fiercely debated there is a near consensus that U.S. health spending is too high and that quality is too low. Some analysts believe high prices for medical care lie at the heart of the spending problem. But privately insured patients traditionally have had little reason to worry about prices because they were shielded by generous insurance coverage. Historically, even if they wanted to comparison shop, patients seeking price information would have had to navigate a bewildering array of information sources and technical terms (e.g. charges v. costs) to get even incomplete price information. As private health coverage becomes less comprehensive and patients shoulder more of the cost of their care directly through increased cost sharing, consumer awareness of pricing practices becomes more important.

Today, questions of cost and quality are at the center of the health spending discussion. A growing body of research makes clear that prices paid to providers by private health plans vary widely within and across markets. But wide differences in unit prices for specific services are just the tip of the iceberg—physicians practice differently and recommend different courses of treatment for the same clinical condition. Visiting a physician who tends to recommend an aggressive course of care, above and beyond accepted guidelines, can significantly raise a patient’s out-of-pocket costs.

White *et al* (2014) note that price transparency generally refers to the ready availability of price data for the purpose of comparison shopping. The same can be said for transparency of healthcare quality. White *et al* note that transparency discussions focus on patients, and on providing them with more information on, for example, out-of-pocket costs. But that focus is insufficient. The healthcare purchase process is complex and includes, according to White *et al*, five key audiences

1. Patient
2. Physicians
3. Employers
4. Health plans
5. Policymakers

Each audience has distinct needs and uses for cost and quality information.

Berwick *et al* (2003) distinguish two general methods (pathways) by which the public reporting of data might lead to improved quality performance:

1. **Selection:** consumers (broadly construed as patients, regulators, purchasers, referring physicians, etc.) use available information to evaluate choices and make value-based purchases. Providers and/or plan respond to consumer behavior by improving performance
2. **Change:** providers or plans use available data to inform improvement efforts in order to avoid being identified as a poor quality provider or plan

White *et al* (2014) note that, “A 2012-13 survey of health plans found that ‘while 98 percent of responding plans said they offer a price calculator tool, just two percent of their patient members use these tools.’” Further, “... even patients using healthcare services and enrolled in a high-deductible plan only sought price data for about 10 percent of the services they used. Presumably having a high-deductible plan increases the incentive for seeking cost information. There are two main points that stem from these observations. The first is that the selection method or pathway depends on consumer engagement with the available information, but the virtual non-use of price calculators and related information argue that value-based purchasing, and by extension, quality improvements they

motivate, is not widespread. The second point is that, as noted, consumers are concerned about their out-of-pocket costs, not total costs or charges (which often seem as fanciful as the “list price” for certain consumer goods) or the cost to the payer or provider. It may well be that, for many consumers, the cost differences among providers for particular services or procedures isn’t meaningful because they do not affect out-of-pocket costs. For example, if you have a \$5,000 deductible it probably doesn’t matter to you if the cost for a procedure under Plan A is \$20,000 and \$22,000 under Plan B.

The change method, because it does not depend on direct consumer use of information they often find confusing, appears to be a more viable path toward quality improvement and cost effectiveness. This is especially true when combined with financial incentives to lower costs (e.g. through bundled-payment models) or improve quality.

If the selection method is to become more widespread and successful, relevant information must be made easily accessible and understandable. To date this is only the case sporadically. If patients are going to become informed consumers in a position to make valid value-based purchases, then organizations with responsibility for the processing and display of health care information should pay particular attention to the points made in a recent Government Accountability (GAO) report, which we discuss in the next section.

GAO REPORT

The October 2014 GAO report on health care transparency addresses many of the main issues we’ve noted with respect to cost and quality transparency to inform improvement, as well as issues related to consumer engagement and understandability. As the report notes, “The cost and quality of health care services can vary significantly, with high cost not necessarily indicating high quality. As consumers pay for a growing proportion of their care, they have an increased need for cost and quality information before they receive care, so they can plan and make informed decisions.”

With respect to relevancy of information for consumers GAO identified eight important areas:

1. Range of services
2. Range of providers
3. Key differences in quality of care
4. Key differences in patient’s experience of care
5. Key differences in cost (especially out-of-pocket cost)
6. Inclusion of additional quality information
7. Use of timely data
8. Description of the strengths and limitations of the data

The *range of services* should be as broad as possible so that publicly-available information is applicable to the maximum number of consumers. In particular services and procedures related to chronic conditions or non-urgent care, since those are most likely to allow time for evaluation and comparison, should be included.

Similarly, the *range of providers* should be as extensive as possible for specified geographic areas. This range should include all applicable settings (e.g. hospital or outpatient clinic) and be independent of network status. It is often useful for consumers to be aware of choices that exist outside their particular plan options or network.

The display of information should highlight *key differences* in quality of care and patient’s experience of care. In general the information display should facilitate comparisons and minimize the need to navigate multiple screens and dropdown menus in order to get relevant information to make informed choices.

With respect to *key differences in cost*, it is important to provide information that is directly relevant to consumers. For example, a national, or even regional, average is less useful than information that takes into account out-of-pocket costs for particular plans.

Including *additional quality information* requires knowing the particular audience. For example, it might be appropriate to include quality information for specific settings (e.g. nursing home or long term care facilities) or consumers with particular conditions (e.g. diabetes).

It is of course crucial that information not only be relevant, but also *timely*, i.e. as current as possible. This is often a challenge because of the results of, for example, patient satisfaction surveys may not be available with the immediacy consumers would need. In any event clear data information is important, and well as standardization of data ranges to allow valid comparisons.

Whenever data, or outcomes based on particular data, are presented, it is important to indicate the *strengths and limitations* of the data. For consumers this is particularly important because they, unlike researchers, are not experienced with evaluating the data which underlie claims or summary output. An additional dimension of data transparency is methodological transparency. That is, clearly communicating relevant properties of the data that an informed consumer should know. This is especially important for overall results such as star ratings which have numerous components.

From the perspective of the SAS community these eight areas clearly relate to familiar issues such as documentation (necessary for transparency and accuracy), data visualization, dynamic display so that updates are not labor intensive, and efficiency to ensure that the use of timely data is not delayed by system issues.

In addition to these areas focused on relevance, the GAO also addressed seven areas related to understandability:

1. Use of plain language and clear graphics
2. Explanation of ratings, e.g. star ratings
3. Identify patterns and provide summary information
4. Include functionality to allow customization
5. Include functionality to allow comparisons on a single view (screen)
6. Include functionality to allow both cost and quality comparisons
7. Ensure that access and navigation are consumer friendly

The use of *plain language and clear graphics* is intuitively clear, and close to the heart of those in the SAS community concerned about data visualization and the display of information for different audiences, but often quite difficult to achieve in practice. This is one reason that detailed usability testing is important. In addition it's often difficult to strike the right balance between clarity of presentation and the presentation of information about the strengths and limitations of the data.

Ratings, whether for individual or composite, measures, provide a handy summary of a plan's or provider's performance, but it is important to relate ratings to usefulness and to explain what is behind the rating and guidelines for interpretation. This relates to the use of plain language because terms, such as *access-to-care*, may be familiar to researchers but not to patients who are just learning about quality information. The functionality of web-based displays, if they are designed well, can allow for both clear summary displays, as well as links to more-detailed information and explanations behind the summaries.

Another aspect of summary data that can facilitate understanding and meaningful comparisons is the display of *patterns* within the data, e.g. rankings of providers according to overall quality scores or other metrics. As noted above, where possible it is best to minimize the need to navigate among screens in order to access information needed to compare plans or providers.

Web-based displays can also be designed to facilitate customization, e.g. sub-setting the information displayed or available for download to what's of particular relevance to the user. This might be a particular procedure or geographic area, or even particular quality measures. The overall goal is to get patients to access the data made available to them, and allowing them to easily target information directly relevant to their location or condition is a powerful incentive to use the system.

A theme that runs through all of these points is that ease of use is crucial if patients are going to take the time to go to a particular web site or portal in order to access quality or cost information. Being able to display information to compare plans or providers on a *single view* is one way to increase usability. Health care information is confusing for most patients, so any added confusion introduced by the technology for information display may cause users to simply give up rather than put up with the added confusion.

This last point also applies to *cost and quality comparisons*. Many consumers make an intuitive connection between high cost and high quality. This may lead them to assume, for example, that a high- or low-cost plan has a comparable quality rating. Displaying cost and quality information together can give consumers a more-complete picture of the relationship between cost and quality, and allow them to identify high-quality, cost-effective, options.

As discussed a number of times, ease of navigation is crucial if patients are going to be comfortable accessing information and taking the time to locate information of particular relevance to them. Data transparency and public reporting are empty exercises if the target audience is not accessing the information they need to make informed choices.

Above we distinguished between the “selection” pathway and the “change” pathway by which data transparency might lead to quality improvement or greater cost effectiveness. To date, as noted, there is little evidence of widespread consumer use of publicly-available information to inform choices about health care services or procedures. But if we are to move toward a system of consumer driven value-based purchasing, the GAO focus areas discussed above must be implemented across the board.

But consumer-focused efforts are only of part of the current landscape. Consider the Open Payments program. Through this program CMS is required to collect and display information reported by applicable manufacturers and group purchasing organizations (GPOs) about the payments and other transfers of value these organizations have made to physicians and teaching hospitals. Between when the data are collected and publically displayed, registered physicians and teaching hospitals can review and, if needed, dispute payments reported about them. Data are then displayed on the public Open Payments website.

The first Open Payments reporting period covers transactions from the last 5 months of 2013. Future reports will be published every year and will include a full 12 months of payment data. Data collected for each calendar year will be published in June of the following calendar year. For example, data that is submitted by applicable manufacturers and GPOs for the 2014 calendar year will be published in June 2015.

Open Payments gives the public more information about the financial relationships between physicians and teaching hospitals and applicable manufacturers and GPOs. Specifically, the program:

- Encourages transparency about these financial ties
- Provides information on the nature and extent of the relationships
- Helps to identify relationships that can both lead to the development of beneficial new technologies and wasteful healthcare spending
- Helps to prevent inappropriate influence on research, education and clinical decision making

For patients, consumers, and the public, Open Payments can be used to learn about the relationships between physicians and applicable manufacturers and GPOs. For physicians and teaching hospital representatives, reviewing the data reported in the Open Payments system can ensure that this information is accurate and, most importantly, inform improvement efforts. Open Payments is a good example of a data transparency initiative consistent with the Change pathway.

A related effort at the State level is aimed at creating publicly-available databases which include information from all payment sources (Medicare, Medicaid, State, private, etc.). Over the past 10 years, a growing number of states have established state-sponsored all-payer claims database (APCD) systems to fill critical information gaps for state agencies, to support health care and payment reform initiatives, and to address the need for transparency in health care at the state-level to support consumer, purchaser, and state agency reform efforts. States with APCDs are responding to a need for comprehensive, multi-payer data that allows states and other stakeholders to understand the cost, quality, and utilization of health care for their citizens.

APCDs are large-scale databases that systematically collect medical claims, pharmacy claims, dental claims (typically, but not always), and eligibility and provider files from private and public payers. As noted in a 2014 report from the Robert Wood Johnson Foundation, the first statewide APCD system was established in Maine in 2003. By 2008, five states (Kansas, Maine, Maryland, Massachusetts, and New Hampshire) had passed legislation and established APCDs. By the end of 2010, four additional states (Minnesota, Tennessee, Utah, and Vermont) did the same. Since 2010, state interest in APCDs has grown at a steady pace. Currently, more than 30 states have, are implementing, or have strong interest in APCDs.

Though data drives performance improvement in many sectors of the economy, it can be maddeningly difficult to acquire in health care. Information on the cost and quality of health care services is mostly disaggregated among payers and providers, making benchmarking and other forms of performance measurement a challenge. One goal of APCDs, which aggregate medical, dental, and/or pharmacy claims from public and private payers, is to create a more-complete picture of quality and resource use that can inform not only consumer choice, but also policy decisions.

Current APCDs demonstrate that aggregated data has tremendous potential to inform health care decision making. Some combine data contributed by legislative mandate from private insurers with state Medicaid programs and hospital discharge data, while others depend on voluntary contributions. Among their many benefits, the APCDs have helped to assess the prevalence of chronic conditions in different communities to allocate public health dollars, populate public reporting sites for consumers, inform rate-setting by state regulators, and identify opportunities for policy reform. To date many APCDs have lacked timely access to Medicare claims data for inclusion and comparison.

In the next section we look at one particular program aimed at making more Medicare data more available to plans, providers, and the public. This is the Qualified Entity Program which seeks to make Medicare claims information available to “qualified entities” in order to inform improvement efforts.

CMS QUALIFIED ENTITY PROGRAM

Beginning January 2012 section 10332 of the Affordable Care Act 9QE program) required that standardized extracts of Medicare claims data (Parts A, B, and D) be made available to “qualified entities” for the evaluation of the performance of providers of services and suppliers. The motivation for this was that,

- There were numerous emerging local and regional provider performance measurement efforts
- Despite National Quality Forum efforts, there was a lack of common measurement and reporting standards
- There was limited availability of Medicare data for performance measurement
- Many existing reports on provider performance were produced without an opportunity for provider review

Specifically the QE program authorized CMS to make Medicare data available for the purpose of provider performance measurement. This is one instance of a Federal government initiative to increase transparency and data availability, as well as timeliness of data.

Qualified entities (QEs) may use the data they receive through this program for the sole purpose of evaluating the performance of providers of services and suppliers, and to generate specified public reports. Qualified entities may receive data for one or more specified geographic areas and must pay a fee equal to the cost of making the data available. Congress also required that qualified entities combine the Medicare claims data from at least one other claims data source to evaluate the performance of providers of services and suppliers.

But what qualifies an organization to become a “qualified entity”? Any organization that will report provider performance data is eligible. Additional requirements include:

- Demonstrated experience calculating and reporting on performance measures
- Demonstrated ability to ensure the privacy and security of Medicare claims data
- Access to additional (non-Medicare) claims data

The last requirement relates to the fact that qualified entities must combine Medicare claims data with other claims data. In addition QEs must allow providers an opportunity to review results and make corrections before publicly reporting the information. One of the real benefits of participating in the QE program is timely access to Medicare data. In addition to State-level data for matching with other claims data, a 5% national sample file of Medicare claims is made available for benchmarking.

As with the National Quality Strategy the belief is that the sharing of Medicare data with QEs, and the resulting reports, will be an important driver of improving quality and reducing costs in Medicare, as well as for the healthcare system in general. Additionally, CMS believes this program will increase the transparency of provider and supplier performance, while ensuring beneficiary privacy.

The APCDs discussed above enable, among other things, providers to compare their performance with their peers. They have also increased the transparency of price and quality information for consumers. But APCD data can be incomplete without timely access to outpatient and pharmacy claims from Medicare's fee-for-service program, which together with inpatient services accounted for about 20 percent of all health care spending. That is now changing. The QE program addresses this need by making this Medicare claims data available to QEs for reporting.

The information on outpatient and pharmacy claims supplements inpatient claims data since most states mandate reporting of hospital discharge data for all patients. The new claims will allow those that receive them to explore the quality, costs, and resource use in ambulatory care settings, increasing the reliability of reporting on primary care or specialty care practices. This is because many chronic and expensive-to-treat conditions are more prevalent among the elderly and, without access to large volumes of data on Medicare beneficiaries, denominators are not large enough to accurately rate provider performance.

"We are quite excited because the program will make our reporting much more robust," says Mylia Christensen, executive director of the Oregon Health Care Quality Corp., one of the first set of QEs to receive provisional approval from CMS to participate in the program. The nonprofit will use the data to enhance its reporting on the quality and utilization of health care services, which had been based only on claims data from commercial health plans and the state's Medicaid program.

The Health Improvement Collaborative of Greater Cincinnati, another QE, uses Medicare data to explore the cost and utilization of ambulatory care in its region, with the ultimate goal of combining the claims information with clinical data. That "will let us see whether improvements made on the clinical side result in reduced costs—[and] see if we're meeting our goal of working toward the Triple Aim of improved care, improved health, and reduced costs," says Tim Salvage, the Collaborative's project manager for performance measures.

And while the qualified entities are required to use the data for public reporting on provider performance, there are limitations on the use of data for purposes other than public reporting. For example, physicians cannot drill down into the data to compare performance or inform their improvement efforts. Despite these limitations the QE program is an important step in an evolving effort to increase transparency while maintaining privacy and confidentiality. "With the Medicare data we can begin to look across the health system and raise questions about variation in care delivery—this is a first step in engaging physicians," says Denise Love, executive director of the National Association of Health Data Organizations (NAHDO).

The QE program, although important for the reasons discussed above, is just one of numerous Federal, State, and private initiatives aimed at further data transparency and public reporting with the goal of informing quality improvement and cost effectiveness efforts. We are well past the tipping point on the road to greater transparency, despite concerns about privacy and valid interpretations of the data. Continued efforts will involve patients both

directly, as consumers of health care services, and indirectly as providers and plans seek improvements in order to build or maintain a reputation for high-quality health care delivery. Although beyond the scope of this paper, financial incentives will also play a role in this as quality measures are used in pay-for-performance programs.

CONCLUSION

At the beginning of this paper we note that data transparency and its relation to quality and cost improvement can be viewed from a system perspective; one familiar to member of the SAS community. With this perspective we can distinguish 5 main activities: data collection, data storage, data processing, data analysis, and data reporting. Each of these activities has important components (such as database design for data storage, de-identification and aggregation for data reporting) as well as overarching requirements such as data security and quality assurance that are applicable to all activities. When we consider the different focus areas of the GAO report discussed above, the actual implementation of these guidelines (such as clarity of graphics and figures and ability to combine views of cost and quality data across providers), requires expertise in data processing and merging of different data sources, directing output to different destinations and formats, including dynamic Web pages to display up-to-date information. Again, all of these are familiar activities to the SAS community.

A basic principle of information accessibility is that the more important information is, the easier it should be to access and understand. As discussed above this will be crucial if patients really are going to become informed consumers of health care services. But the same is also true internally for organizations; the information required to inform quality improvement and cost effectiveness should be an integral part of each organization's business intelligence portfolio.

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