Act 1: Privacy Vs. Transparency – A View from Washington

Act 2: Data Privacy and HCCI

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HCCI is a non-profit, independent, non-partisan research institute dedicated to creating the United States’ most comprehensive source of information on health care activity and promoting research on the drivers of escalating health care costs and utilization.

• Non-profit - Incorporated as a 501(c)(3)
• Public mission - improving US health system by creating comprehensive data infrastructure and analytics
• Non-partisan - HCCI does not advocate policy
• Independent - Board comprised principally of academic health economists
• Research - We hold roughly 9 billion claim lines from national sources, all with allowed amounts, for more than 50 million Americans, from 2007 onward which we make available for independent, non-commercial research
Act 1: Washington and Price Transparency

Don’t look now but we are making sausages –

- Two unconnected efforts going on in Washington – one in Congress and one at CMS
  - the one in Congress is more visible but you can ask Niall tomorrow about the one within CMS
  - By 2013, make available to the public provider/supplier–level Medicare claims and payment data through a database searchable by location, type of provider/supplier/specialty, type of item/service;
  - no quality information;
  - uses NPIs
Wyden-Grassley-Sensenbrenner

Data
- The bill does not liberate the data since the data would remain locked in a website database
- The bill is not specific as to what data will be available. Broad language in Section (1) coupled with limiting language later in the bill
- Not clear that one could extract utilization rates from the database since it would be possible to comply with Section (2)(B)(I) without the ability to calculate utilization rates
- No requirement that CMS couple the release of these data with consumer information or how data might need to be adjusted for delay in releases and updates

Website
- Ambiguous language; how the data is "organized" vs. how it is "searchable"; is the goal to compartmentalize the data by specialty or type of provider?
- Unclear if this site is for consumers, purchasers, researchers, or marketers? Medicare prices are a function of formulas – so no secrets here
- Concern that companies might use the data to market to providers, suppliers, or consumers
- Finally, consumers do not consume CPT codes, they consume bundles of services – how will this be dealt with?
Peripheral Bills

Burgess (TX)/Green (TX) HR 1326

- Public release and access to hospital charge information
- Require insurers to provide an estimate of out-of-pocket costs for health care services
- AHRQ to study what information would be useful to consumers

HR 2810 (Energy and Commerce Committee initial SGR Fix Bill)

- Effort to expand how qualified entities can use data
- Non-public purposes
- May provide or sell data to providers of services or suppliers – not limited to purposes of improvement activities
- Perhaps superseded by bipartisan finance/ways and means bill

Lipinski (Illinois)/Mullen (OK) Bill – HR 2853 –

- Would expand access to hospital and ambulatory care prices
Two Issues/One Effort Remains

The two issues that really get to the heart of the matter, whether QE access and sustainability trump greater transparency and data access or vice-versa

• In Washington, these two issues are at odds in the political process and interests are aligned in different corners on this question
• Can some compromise between the two be reached?
  – While there are a number of bills still being introduced, including by Baldwin (WI)/Thune (SD) as late as 11/21/13, the action to watch is around the SGR fix – December 12th is the markup. All new players and all new interests.
  – Full Disclosure: HCCI has an interest in obtaining Medicare data but we have no objections to others also obtaining the data – we favor broad access for analysis, sustainability, and transparency
Act 2: How Does HCCI Deal with Privacy? (1)

For licensing purposes, we start with a statistically de-identified dataset.

- We currently maintain two data views (age rich vs. geography rich)
- We do not license data to individuals
  - our license agreements run to universities as responsible parties
  - Require everyone gaining access to the data to be a party to the contract and agree to terms
Act 2: How Does HCCI Deal with Privacy? (2)

- License agreements:
  - Project specific
  - Require a data security plan
  - Provide for as limited a set of variables as needed
  - Prohibit merges or re-identification of individuals or providers
  - Incorporate data masking rules that incorporate HIPAA, antitrust, and other requirements
  - Provide for a right of review prior to public release of results
Where is HCCI Going with Data Security

HCCI believes that licensing and distributing data through either cartridges or electronic transfers is problematic.

• HCCI is building out a **data enclave**

• A data enclave is a “secure computing environment, firewalled from outside intrusion, accessible only by authorized users, that allows for remote access to microdata where the inflow and outflow is controlled and monitored by either experienced confidentiality officers or by algorithms, where users have access to analytic tools and only those data they are licensed to use.”
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