1. Received Comments on Segment Two of the Exposure Draft

Ms. Amann said written comments were received on Segment Two from the American Council of Life Insurers (ACLI); the Coalition of Health Carriers; the American Property Casualty Insurance Association (APCIA); the Medical Professional Liability Association (MPLA); and NAIC consumer representative, Harry Ting (Healthcare Consumer Advocate). She said comments received by the deadline are posted to the Working Group’s web page. She said comments received after the deadline would be posted soon. She said all comments received would be considered by the Working Group for incorporation into the exposure draft as it goes through the segments to complete its charges. She said the discussion at this meeting would be on comments received on Segment Two – the right to opt in to data sharing, as addressed in Pages 29–32.

Shelby Schoensee (ACLI) said her comments are on behalf of Kristin Abbott (ACLI) as well. Ms. Schoensee said certain situations regarding opt-in need to balance current laws with risk-based review. She said the consumer initiates transactions, so it is an opt-in under the NAIC Insurance Information and Privacy Protection Model Act (#670) and the Privacy of Consumer Financial and Health Information Regulation (#672) under the Gramm-Leach-Bliley Act (GLBA). She said there should not be just one choice for all situations, but it should be flexible, such that opt-out should be maintained in accordance with the GLBA.

Bob Ridgeway (America’s Health Insurance Plans—AHIP) said the Coalition of Health Carriers covered its comments. Chris Petersen (Arbor Strategies LLC), speaking on behalf of the Coalition of Health Carriers, objected to the use of the word “right” when used with opt-in/opt-out because it refers to the ability to place restrictions on data use, whereas the GLBA under Model #672 just refers to nonaffiliates and applies to joint marketing only. He suggested that the definition of opt-in/opt-out be tightened up going forward.

Angela Gleason (APCIA) said the exposure document lumped opt-in and opt-out together. She said a balanced, risk-based approach like that created in the past should be used, and what applies to the technology industry does not apply to the insurance industry. She said applying that type of privacy requirement could perpetuate fraud and hinder underwriting.

Dr. Ting said included with his comments was the Bessemer Venture Partners report on data privacy engineering. He said this report encouraged companies: 1) to not sell or share data unless the consumer consents to it, but it also indicated that most consumers would consent; 2) to allow the consumer’s choice; 3) that internet disclosure or privacy notice should not be allowed, as most consumers do not understand what happens once cookies are allowed; and 4) to allow opt-out through future or prospective data, not for retrospective data. He said regarding the right to opt out: 1) a notice should be provided; 2) there should be a method for tracking; 3) companies should take steps to ensure that consumers know what has been shared, with whom, for what purpose, and how it will be used, much like the California Consumer Privacy Act (CCPA) does. He said there are cases where Health Insurance Portability and Accountability Act of 1996 (HIPAA) rules should go beyond what HIPAA requires because his personal experience as a secret shopper has shown that his personal data that was gathered by a health insurance lead generator resulted in the sharing of that data with 1,722 companies that had nothing to do with insurance.

Mr. Aufenthie asked Dr. Ting what parts of his personal data were shared or sold following his secret shopper experience. Dr. Ting said because he lives in California, the CCPA made it possible for him to obtain information about the companies that received his data and how those companies were using it. He said during an online search for individual health insurance that took him three rounds of inquiries before he was even allowed to get to any type of health insurance plan, the company asked for his name, address, health conditions, health status, age, and income. He said his information was sold but only to companies he would be completely comfortable with receiving his information. He said some of the companies on the list as having received his data were companies that sold windows and pet food, from whom he received lots of calls and emails trying to sell their products to him. He said lead generators pay lots of money to get listed at the top of search results, so those companies must sell consumers’ data to accomplish that listing. He said companies have a choice of who they work with, so they should
Birny Birnbaum (Center for Economic Justice—CEJ) said there is a need for balance; consumer consent should be required for any action and be limited to only that which is necessary. He said industry should understand just how limited a consumer’s understanding of privacy really is, and there should be best practices like those in the CCPA. He said telematic companies that harvest data from phones, geo, and vocations also sell marketing programs based on the telematics being collected. He said he is sure that consumers do not know this is being done, and they have not consented to their data being shared or sold, so it is unreasonable for companies to expect consumers to be knowledgeable or responsible for their own data privacy decisions. However, he said he disagrees with opt-in because the notices are too long, and the consumer does not understand what all the wording means. Mr. Petersen said such notices are required to attain a Flesch score of a high school level reader. Erica Eversman (Automotive Education & Policy Institute—AEPI) said consumer understanding does not have the level necessary. She said most readers are at a fourth- or fifth-grade level, as evidenced by a 1992 survey by the federal government, which indicated most readers were at a sixth-grade level.

Mr. Diederich said it is hard to know what companies will do, but he asked if allowing a consumer to opt in for marketing would help. Dr. Ting said yes, that is an appropriate approach. He suggested that the Working Group give examples in the privacy policy statement of how it would be used; otherwise, the default should be to not allow the sharing or selling of consumer data at all. Mr. Diederich asked if some type of nondiscrimination or nonretaliation disclosure needs to exist. Dr. Ting said yes, if limited to need certain information, but only if it were limited to what is really needed. Ms. Eversman said the concept is good, but her experience with lawyers is that it is impossible to obtain retaliatory evidence that leads to prosecution. Peter Kochenburger (University of Connecticut School of Law) said people do not read them, so the federal government puts most personal information as opt-in because opt-out pretty much guarantees that consumers will not do it. Mr. Diederich said opt-in should not hinder sales or legal compliance. He asked if, given state insurance regulator concerns, consumers should have to opt in for companies to share data for marketing to external parties.

Mr. Petersen said HIPAA does not allow the sharing of non-personal health information (PHI) data, but it has a safe harbor for sharing PHI. He also said HIPAA has a more stringent definition of PHI. Ms. Gleason said opt-in has spots to opt out of marketing.

Ms. Amann said this type of information is sort of in the exposure document, but it needs to be streamlined because people just click through privacy notices and disclosures; but insurance is not retail, so it needs to be considered more carefully. She said the selling of information is the crux of the problem, and the question is if there is a doable fix, perhaps some overt statement that a consumer cannot be retaliated against for their refusal to opt in. Dr. Brenda J. Cude (University of Georgia) said consumers need a reason to read a disclosure. She said consumers feel they have no power because they cannot get service without agreeing, so there is no real or perceived need to read any notices or disclosures.

Ms. Amann said during the next call on Oct. 11, the Working Group will discuss comments received by Oct. 4 on Segment Three – the right to correct information, as addressed in Pages 32–36, would be discussed at the Oct. 11 meeting.

She said:

- Comments received by Oct. 18 on Segment Four – the right to delete information, as addressed in pages 36–39, would be discussed at the Oct. 25 meeting.
- Comments received by Nov. 1 on Segment Five – the right of data portability, as addressed in pages 39–46, would be discussed at the Nov. 8 meeting.
- Comments received by Nov. 15 on Segment Six – the right to restrict the use of data, as addressed in pages 46–50, would be discussed at the Nov. 22 meeting.

Ms. Amann said this schedule had been posted to the web page.

Ms. Amann said the next Working Group meeting is scheduled for Oct. 11.

Having no further business, the Privacy Protections (D) Working Group adjourned.