July 3, 2014

To Integrating the Healthcare Enterprise Quality, Research and Public Health Technical Committee:

We applaud Integrating the Healthcare Enterprise’s (IHE) efforts, in conjunction with the Office of Population Affairs, to develop a method for collecting and exchanging important family planning data in a systemic and structured way, and we are grateful for the opportunity to comment on IHE’s proposed Family Planning Profile. Health information technology (health IT) is a foundational component of a more patient-centered, effective and efficient health care system in which individuals and their health care providers have access to the information they need anytime, anywhere. Standardized data collection is critical for family planning service sites to be able to demonstrate and improve the quality of family planning services they deliver to women and men across the nation.

As we build a nationwide infrastructure for electronic health information exchange, we must ensure that every provider in the country has health IT that is capable of communicating with other providers and facilitating the safe and secure measurement of care quality. This is especially important for Title X family planning service sites and other providers of family planning services given that family planning is basic health care for women – more than 99 percent of women will use contraception at some point in their lives. Given the high demand for family planning services and the widespread applicability of the Family Planning Profile, IHE’s efforts to define for vendors and providers the basic data elements of family planning and a format to facilitate exchange of those data elements are critical to building the next generation of electronic health record systems.

Title X service sites alone serve nearly five million women and men every year, and demand for family planning services from Title X service sites is expected to remain high even in the wake of implementation of the Affordable Care Act. A study of family planning service sites in Massachusetts, which passed its health reform law in 2006, found that demand for publicly funded family planning services remained high among both insured and uninsured patients despite an increase in the overall insurance rate. This will likely be the case nationally given that many women will remain uninsured because of immigration status or certain states’ decision not to expand Medicaid, while others will continue to rely on Title X service sites for confidential care that may not be available to them through their insurance if they are not the primary beneficiary.

The Electronic Health Record (EHR) “Meaningful Use” Incentive Program has already facilitated the development of standardized data elements and transmission methods, which are critical for health information to be more uniformly collected and shared. Where feasible we encourage IHE to align the Family Planning profile with established Meaningful Use standards and processes. For example, we encourage IHE to consider patients as relevant actors in Family Planning Profile transactions with the ability to not only view their own medical record, but to eventually contribute their own health information. In future iterations of the Family Planning Profile, IHE should enable family planning clients to electronically access their health information in a way that is aligned with the “View/Download/Transmit” criteria in Stage 2 of the EHR Incentive Program. Individuals can be true partners in their health care if they have access to the comprehensive and accurate information they need to be engaged. Furthermore, as
data elements and transmission methods are evaluated, potential quality metrics should be carefully considered during this process to facilitate reporting for providers and pave the way for incorporating patient-reported measures into future versions of the Family Planning Annual Report.

Additionally, we appreciate the opportunity to comment on the Generic Family Planning Encounter Form and offer the following recommendations:

- **“Pregnancy Intention Next 12 Months”** – We applaud the inclusion of pregnancy intention on the encounter form, but request clarification of the significance of a 12 month period. We believe that a period of two to three years, or even longer, would be a valuable period of time to inquire about pregnancy intention in order to have a meaningful conversation about preconception health and contraceptive options. We also believe that the options in this box are too limited, and that it would be useful to delineate between women who are currently trying to become pregnant and those who are not currently trying to achieve pregnancy, but intend to try within the designated time period. Additional options could include “Never” and “ Unsure.” These additional responses could better help the provider and the woman choose the best contraceptive method to meet the woman’s needs and prompt providers to initiate conversations about fertility, preconception and prenatal health, and provide any necessary referrals.

- **“Race (check all that apply)”** – With regard to demographic data collection on the encounter form, we encourage IHE to transition from the current Office of Management and Budget (OMB) standards for race and ethnicity data collection to the Department of Health and Human Services (HHS) standards. The HHS standards build upon the OMB standards but add more granularity for Asian and Latino populations (as is currently offered by the American Community Survey (ACS) and Decennial Census). Proper identification of important characteristics of sub-populations is necessary because different ethnic groups often have vastly different health profiles. For example, Indian-American adults are nearly three times more likely to have diabetes than Japanese-American adults, but are less likely to have hypertension.

  - Collecting more granular race and ethnicity data enhances the potential of clinics to stratify or filter quality measures by one or a combination of patient demographic characteristics, including age, sex, preferred language, and/or race and ethnicity data. This functionality is critical to identifying patterns among a patient population, which may in turn be helpful in distinguishing previously unidentified disparities in care delivery or health outcomes.
  - Moreover, a requirement to use the HHS data collection standards is consistent with the requirements of section 4302 of the Patient Protection and Affordable Care Act for data collection standards for race, ethnicity, sex, language, and disability status. We believe such alignment is desirable and consistent with HHS’s interest in avoiding duplicative and unnecessarily burdensome requirements.

- **“Contraceptive Method – Intake”** & **“Contraceptive Method – Exit”** – We recommend adding an additional box within these sections to indicate whether the
selected contraceptive method is the patient’s preferred method. A simple “Preferred Method” box with responses for “Yes” and “No” will help better assess whether a patient is actually receiving the health care he or she wants and needs, rather than just assessing whether a patient receives any contraceptive method.

- “Reason for None” within the “Contraceptive Method – Intake” and “Contraceptive Method – Exit” boxes – We believe that the options listed for not using a contraceptive method are too limited and that additional options would allow for a more meaningful conversation between the patient and provider and generate valuable information for the family planning and public health communities. We also believe that the option “Declined all Methods” should be deleted since it does not provide any insight into why a woman is not using contraception; it just merely restates that she is not. Additionally, reflective of our previous recommendation to indicate whether the “Intake” and “Exit” methods are the preferred method, we recommend that the box read “Reason for None/Not Preferred Method.” Specifically, we recommend including the following additional options:
  
  o Cost Prohibitive  
  o Disagreed with Provider Recommendation  
  o Presumed Infertility  
  o Requires Hard to Detect Method  
  o Prefers Not to Use Contraception

- “Limited Language Proficiency” – We strongly support capturing information about language preferences and proficiency in the encounter form. Identification of a patient’s preferred language will enable providers to better support patients by providing them meaningful and useful information about their health and care in languages they understand and are comfortable using, thereby improving patient safety and care quality. We recommend, however, that this section title be changed to "Limited English Proficiency" (vs. Limited Language Proficiency). The existing check-boxes should be used to capture information on listening, reading, writing, and speaking proficiency in English. We also suggest modifying the write-in option to "Preferred Language" (vs. Other) to capture non-English language preferences.

- Additional Data Collection – We also encourage IHE to collect information on a patient’s sexual orientation and gender identity (SO/GI) on the family planning encounter form. Patients’ SO/GI health information has clinical relevance and is vital for improving health outcomes. For example, transgender individuals have increased risk for certain health conditions, such as depression, suicide, and HIV, and frequently do not receive appropriate “gendered” preventive screenings such as Pap tests, mammograms, and prostate exams. Additionally, studies have shown that lesbians and bisexual women are less likely to receive Pap tests and cervical cancer screenings than heterosexual women, and that gay and bisexual men have a higher prevalence of sexually transmitted infections. Allowing providers to collect and store patients’ SO/GI data in their EHRs, including these elements in the profile, would help ensure that patients receive appropriate care specific to their individual needs. We recommend that IHE look to the
work of organizations such as The Fenway Institute and Center for American Progress, which have published extensive studies on successful methods for SO/GI data collection.¹

Thank you for the opportunity to comment on IHE’s proposed Family Planning Profile. Please contact Melissa Safford (msafford@nationalpartnership.org; 202-238-4846) or Erin Mackay (emackay@nationalpartnership.org; 202-238-4845) at the National Partnership for Women & Families if you have any questions or would like to discuss the comments further.

Sincerely,

Advocates for Youth
AIDS Alliance for Women, Infants, Children, Youth and Families
American Association of Birth Centers
American College of Nurse-Midwives (ACNM)
Association of Reproductive Health Professionals (ARHP)
Black Women’s Health Imperative
Catholics for Choice
Institute for Science and Human Values, Inc.
NARAL Pro-Choice America
National Council of Jewish Women
National Family Planning & Reproductive Health Association
National Health Law Program (NHeLP)
National Latina Institute for Reproductive Health
National Partnership for Women & Families
National Women’s Health Network
Physicians for Reproductive Health