

# More on What We are Learning about Parents: Dyad Research from the Adolescent Health Consortium

# What's New in Clinical Preventive Services

## A Focus on Parents: Formative Research from the Adolescent Health Consortium

**John Santelli, MD, MPH**

SAHM Annual Meeting  
Washington, DC  
March 8, 2019

# Adolescent Health Consortium Project: Connecting Adolescents and Young Adults to Clinical Preventive Services

A collaboration involving:

American Academy  
of Pediatrics



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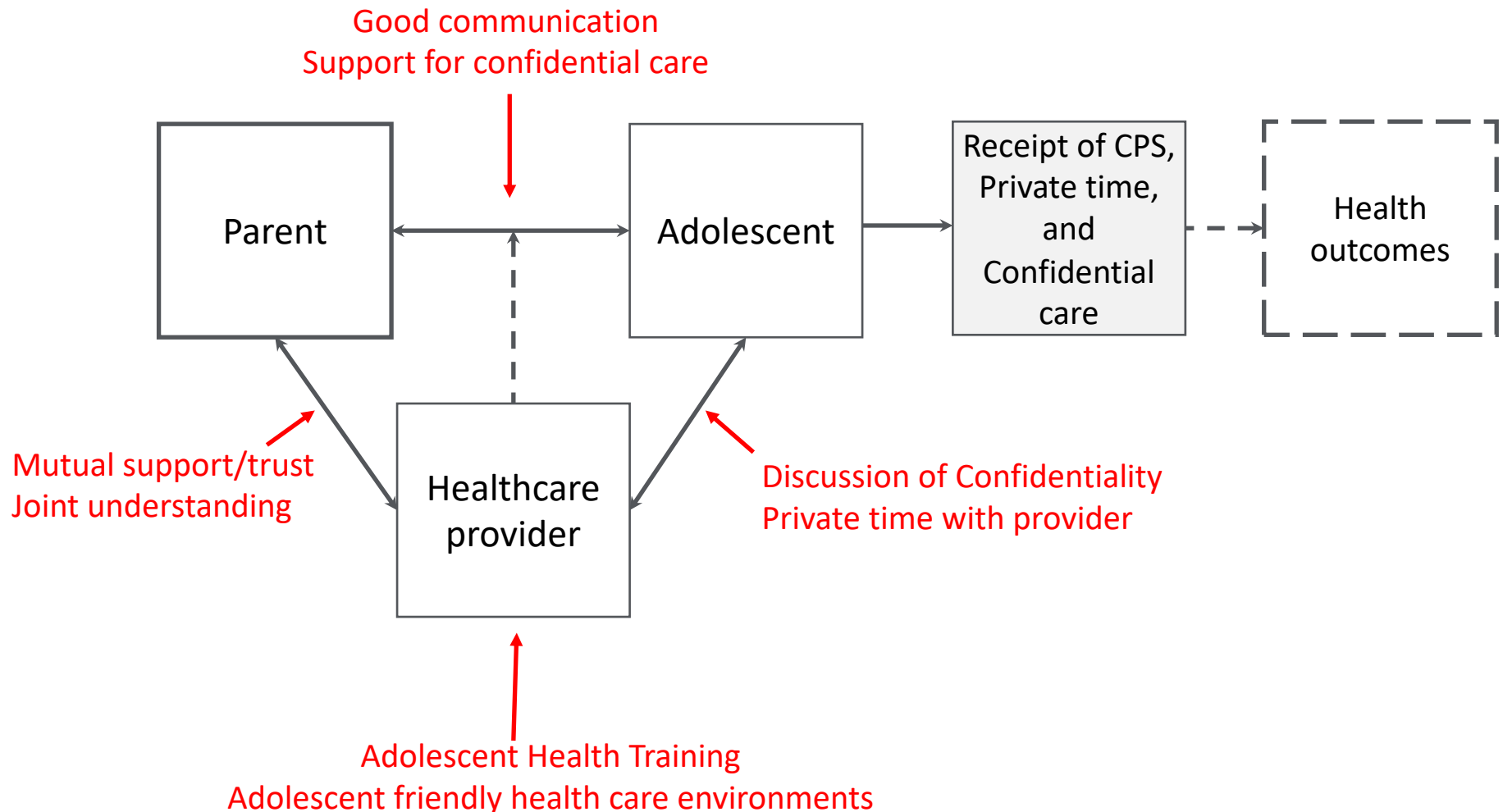
**SAHM**  
SOCIETY FOR ADOLESCENT  
HEALTH AND MEDICINE



**ACOG**  
THE AMERICAN CONGRESS  
of OBSTETRICIANS  
AND GYNECOLOGISTS

Funded by an unrestricted research grant from Merck

# Triadic Logic Model for Improving Adolescent Receipt of Clinical Preventive Services



# Formative Research Design

**Focus group discussions** (FGDs) in 2015 with:

- Adolescents (16 FGDs/n=139 adolescents)
- Young adults (4 FGDs/n=32)
- Parents of AYA (4 FGDs/n=33)
- Healthcare providers (12 FGDs/n=95)

**National Internet Survey** (NIS) in 2016

- National probability survey, online panel, address-based sampling, response rate=65%
- Adolescent parent dyads (n=1209)
- Young adults (n=709)

# National Internet Survey Domains

Access to  
care and  
health  
insurance

Receipt of  
clinical  
preventive  
services

Attitudes  
towards CPS,  
healthcare  
system &  
providers

Confidentiality  
and private  
time with  
providers

Risk  
behaviors

Access to  
health  
information

# Prior Research on Parents and Adolescent Health Services and Confidentiality

- The parent “voice” is often absent in research on AYA health services
- Parents attitudes/interest: want information about adolescent health but discussions with providers not so common
- Support and concern about confidentiality (key factors: perceived role as parents and their trust in healthcare provider)
- Reporters on adolescent receipt of clinical preventive services in U.S. surveys (MEPS, NHIS, NSCH)

Sasse 2013, Ford 2016, Akers 2014, Aalsma 2016

# FGDs: Understandings of CPS and Confidential Care

- Parents strongly support CPS, private time, confidential care
- Private time and confidentiality understood as transition to independence
- Considerable confusion about the “ground rules”





# FGDs: Understandings of CPS and Confidential Care

- Parents (and clinicians) want clarity in laws and policies designed to support teen healthcare
- Parents want a better understanding of the benefits of confidentiality and clear expectations for their role
- Parents forceful about their perceived rights and responsibilities
- Parents supportive of CPS, private time, and confidential care – but want to know what's happening during private time

# FGDs: Parents Want More Information on CPS

*“I think it’d be good if the doctor and the child and the parent had just a discussion initially and the doctor would explain here’s as far as he can go and how far the parents....*

*But let the parent and the child know that their best health care and their best well-being is the whole purpose for why we’re having this relationship.*

*Let everybody know they’re on the same page...”*

Parent of 18-26 year old



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[www.jahonline.org](http://www.jahonline.org)

Original article

## Parent and Adolescent Attitudes Towards Preventive Care and Confidentiality



Xiaoyu Song, Dr.P.H.<sup>a,b</sup>, Jonathan D. Klein, M.D., M.P.H.<sup>c,d,\*</sup>, Hanying Yan, M.S.<sup>e</sup>,  
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Original article

## Confidentiality Discussions and Private Time With a Health-Care Provider for Youth, United States, 2016

Stephanie A. Grilo, M.A., M.Phil.<sup>a,\*</sup>, Marina Catallozzi, M.D., M.S.C.E.<sup>b,c,d</sup>,  
John S. Santelli, M.D., M.P.H.<sup>b</sup>, Hanying Yan, M.P.H.<sup>e</sup>, Xiaoyu Song, Dr.P.H.<sup>f,g</sup>, Jennifer Heitel, M.P.H.<sup>b</sup>,  
Kristen Kaseeska, M.P.H.<sup>h</sup>, Julie Gorzkowski, M.S.W.<sup>h</sup>, Alexandra E. Dereix, M.P.H.<sup>b</sup>, and  
Jonathan D. Klein, M.D., M.P.H.<sup>i</sup>

# PEDIATRICS®

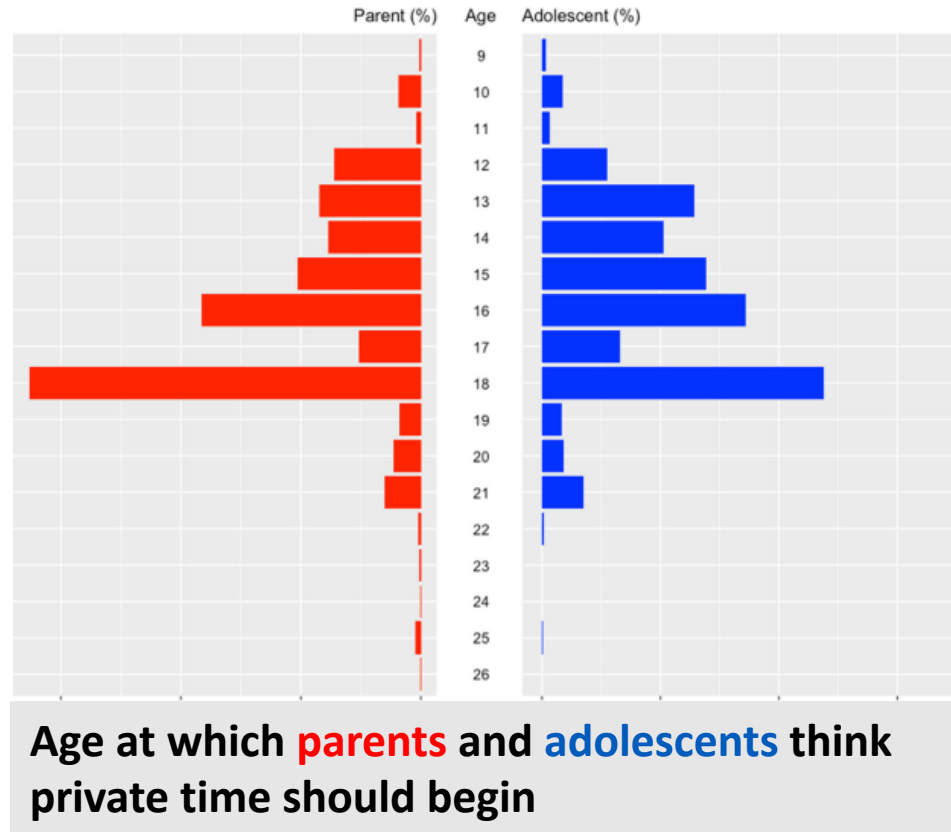
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

### Discussion of Potentially Sensitive Topics With Young People

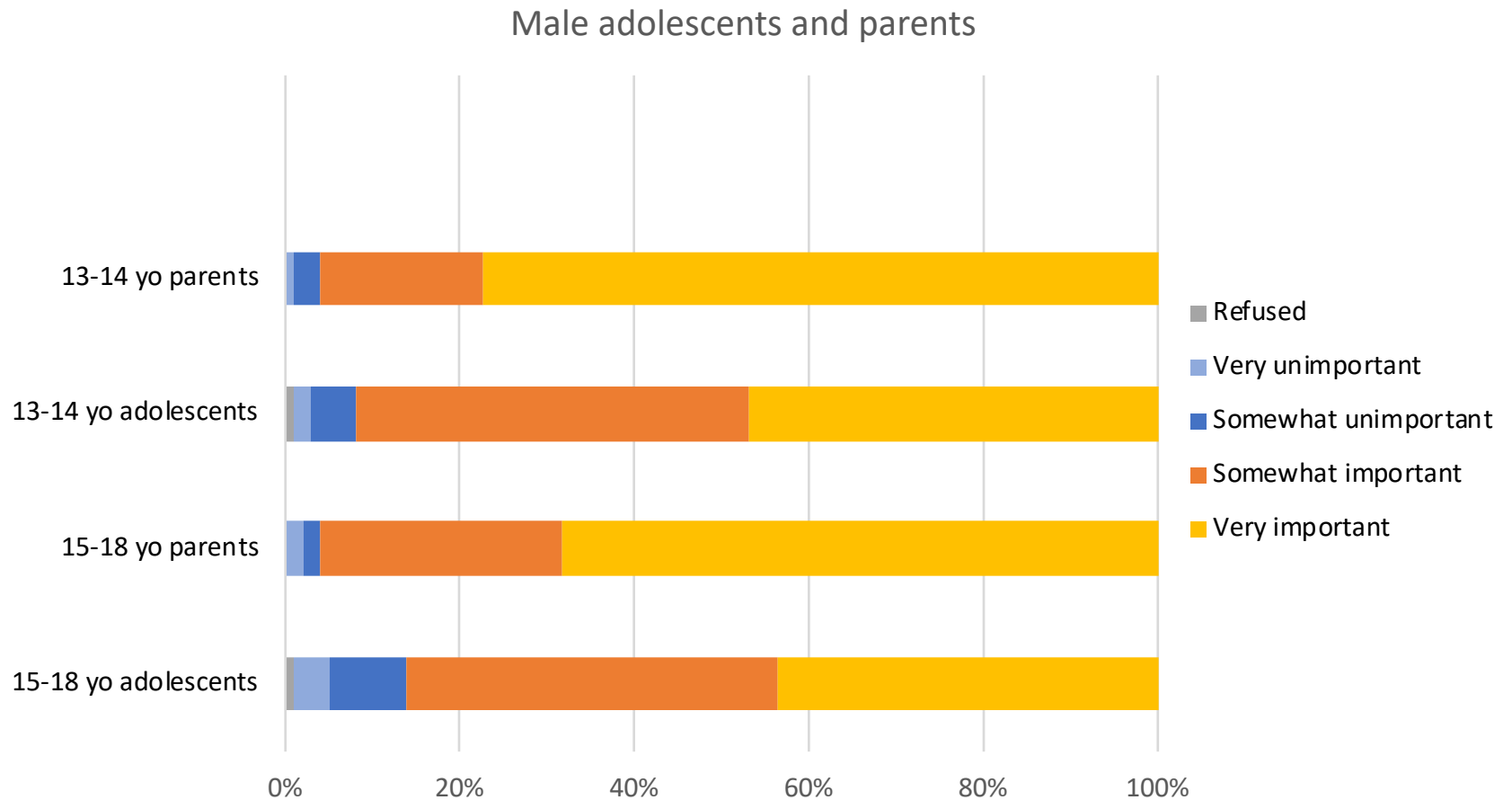
John S. Santelli, Jonathan D. Klein, Xiaoyu Song, Jennifer Heitel, Stephanie Grilo,  
Mengru Wang, Hanying Yan, Kristen Kaseeska, Julie Gorzkowski, Madeline  
Schneider, Alexandra E. Dereix and Marina Catallozzi

# Parent and Adolescent Attitudes toward CPS

- Adolescents and parents often agree about **importance of preventive services**, private time and confidentiality
- Parents value **clinical preventive services** somewhat more than youth
- Youth value **confidentiality** somewhat more than parents
- Both parents and adolescents think private conversations should start later (mode=age 18) than recommended guidelines (**age 13**)



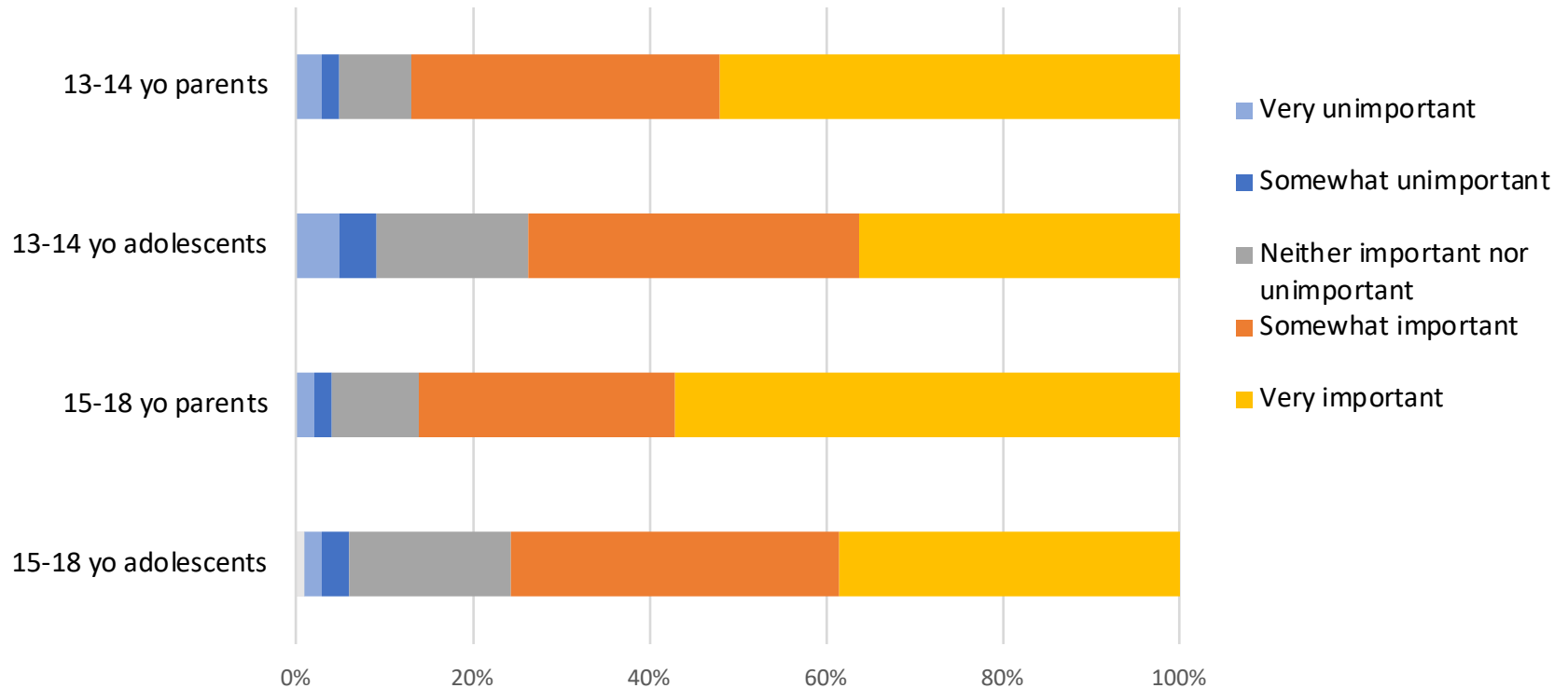
# How important is it that adolescents and young adults have preventive visits?



During a preventive visit, how important is it that a health care provider talks about:

Mental health and emotional issues (e.g. stress, anxiety)?

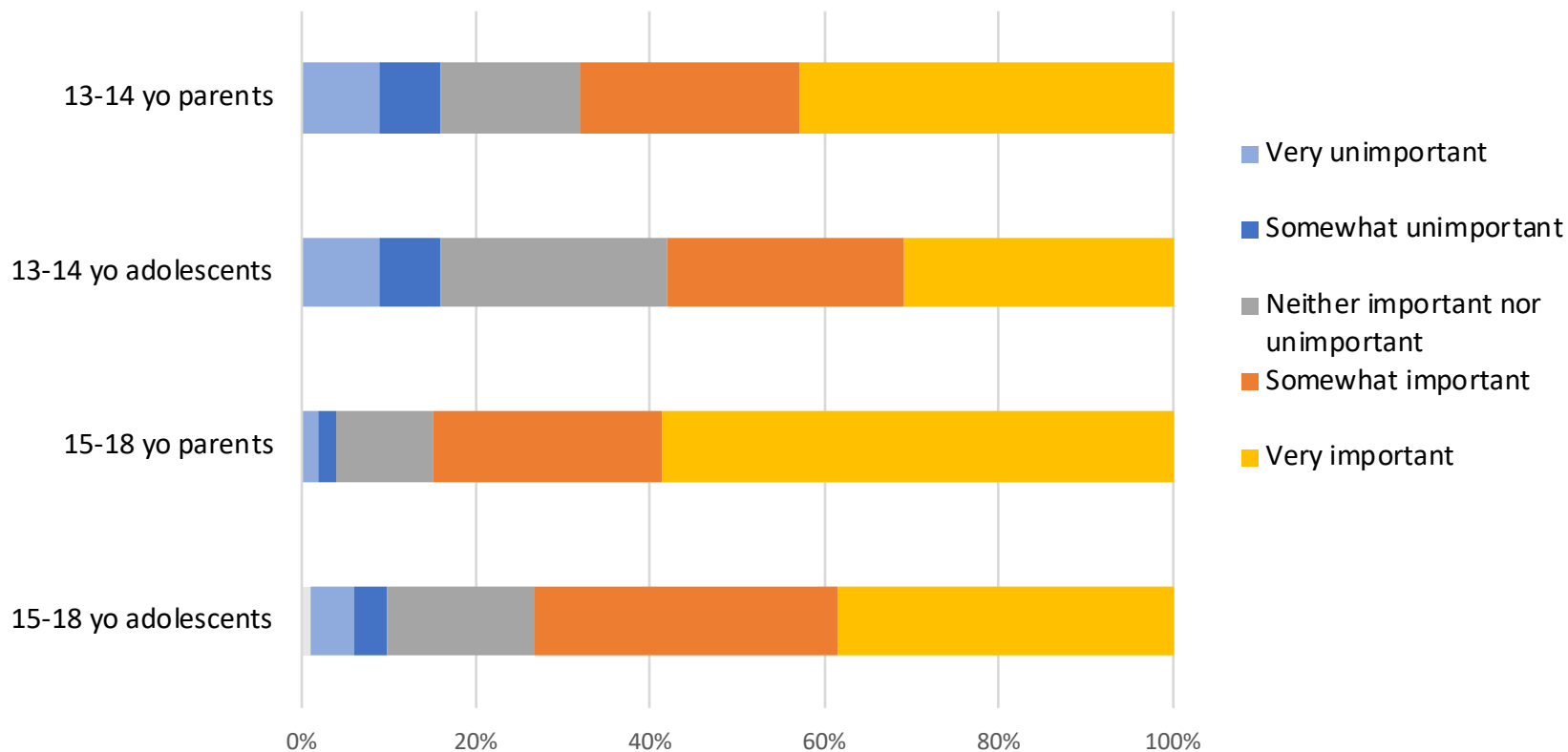
Female adolescents and parents



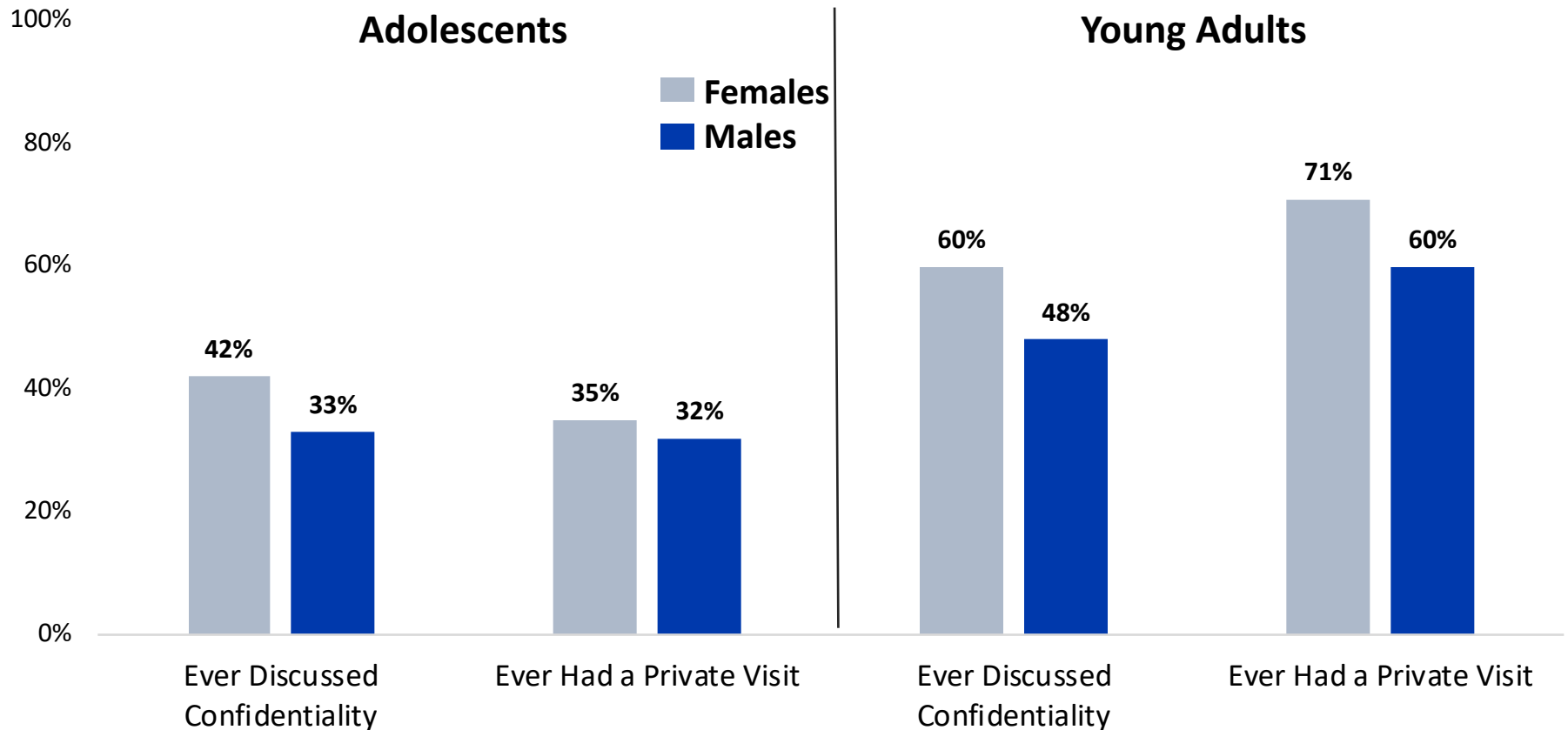
During a preventive visit, how important is it that a health care provider talks about:

### STIs and HIV?

#### Female adolescents and parents



# Ever had Private Time and Ever Discussed Confidentiality



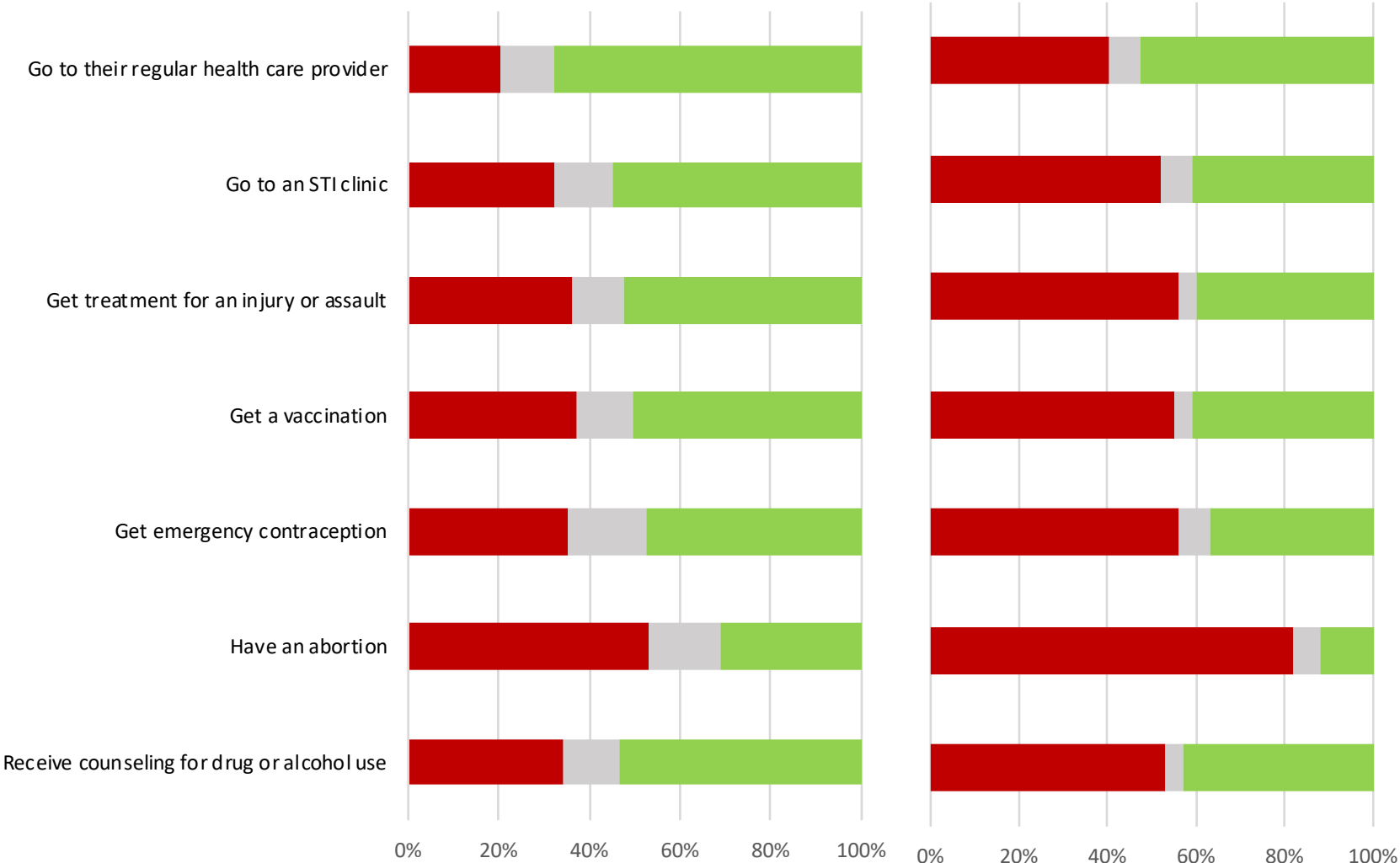


# Kinds of healthcare that minor adolescents should be able to receive confidentially, without their parents' permission:

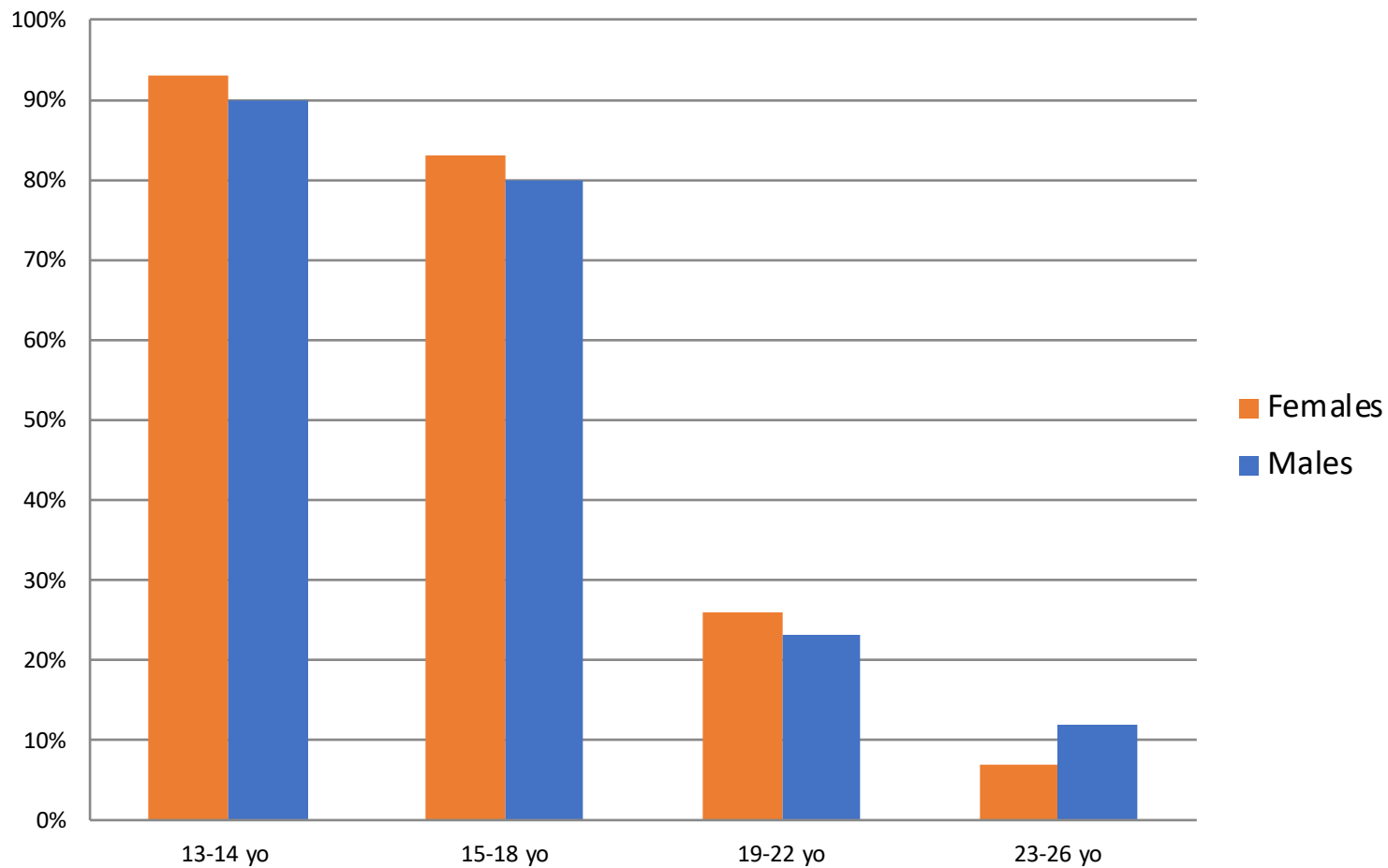
15-18 yo females

Parents of 15-18 yo females

No  
Don't Know  
Yes



## Parent was in the room during last visit to provider



# Parental Involvement in Young Adult Health

Many young adults reported continued parental involvement in accessing health care (19-22 & 23-26 years) :

- Remaining on parents' health insurance (65% & 33%)
- Parents helping to schedule appointments (32% & 12%)
- Parents attending office visits (32% & 12%)
- Parents accessing information/results from visits (33% & 16%)



# Summary: Parents Perspectives

- Support preventive care, private time and confidentiality for their adolescents
- Parent and adolescent attitudes often very similar
- Parents conflicted over confidentiality and private time
- Want clear guidance on laws and office practice, particularly for private time and confidentiality
- Support private time but want to know what happened!
- Remain involved in facilitating healthcare for young adults
- Strong protective impulse remains



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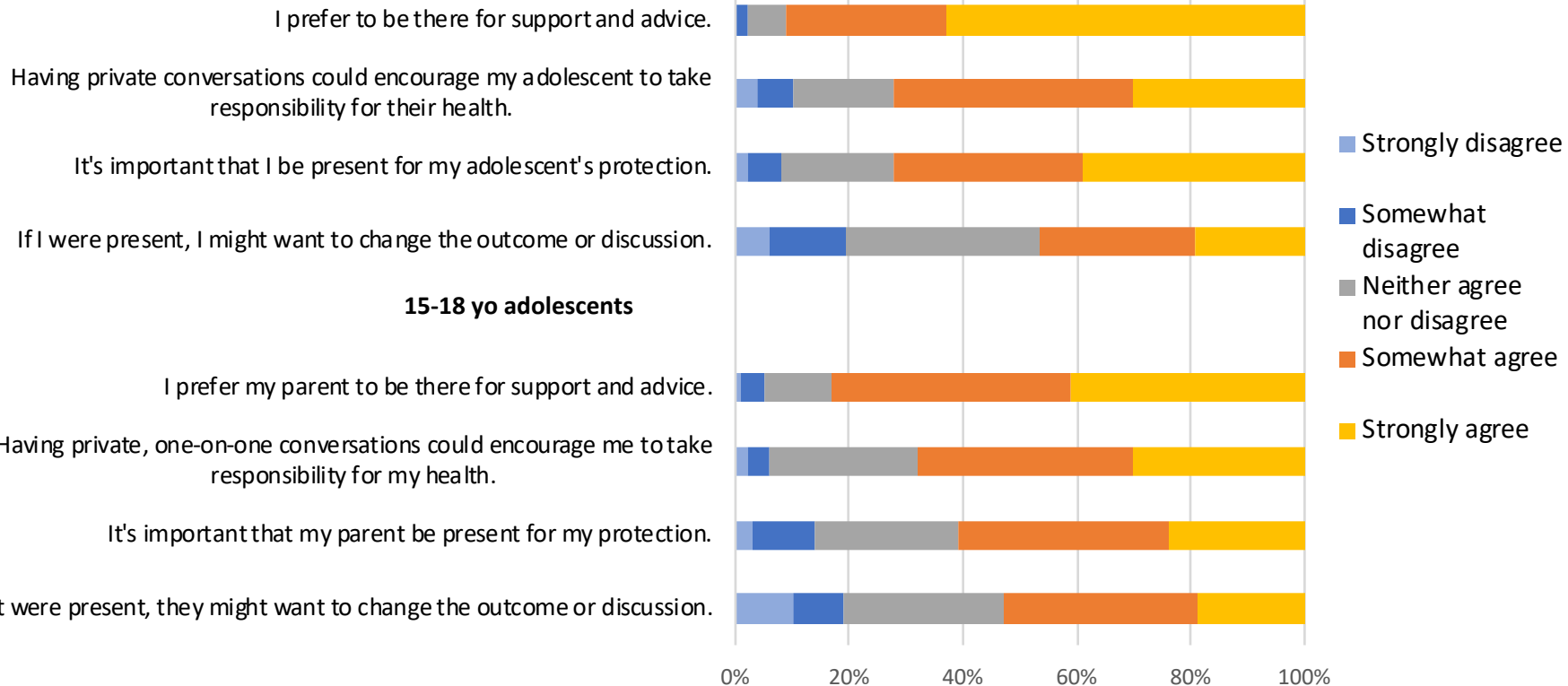
Sam Master, DO

**And thank you to all of the members of the Adolescent Health Consortium from our partner organizations (AAP, AAFP, ACOG and SAHM)**

To what extent do you agree or disagree with the following statements about your adolescent seeing his/her health care provider:

Female adolescents and parents

Parents



# Summary: Adolescents and Young Adults Perspectives

- Value discussions with their provider, but also value alternate sources for health information
- Want to know what to expect at preventive visits
- Younger adolescents expressed anxiety about receiving care without parental involvement

Ever having had a talk about confidentiality and ever experiencing private time are:

- Important facilitators of AYA-provider communication
- BUT only a third of adolescents and two thirds of young adults have experienced these!

# Summary: Provider Perspectives

Many providers:

- Have developed strategies for preserving adolescent confidentiality and negotiating private time
- Expressed concern about the ambiguity between parent and clinician roles in adolescent care
- Identified a need for clear professional guidance regarding office practice and emphasized the role of laws and policy in provision of care to adolescents
- Experienced time constraints as a major barrier to providing preventive care