

What's New in Clinical Preventive Services

An update on Policies, Research and Emerging Paradigms of Parental Engagement

**Adolescent and Young Adult Health
National Resource Center**

SAHM Annual Meeting
Washington, DC
March 8, 2019

To access this slide set, please visit
tinyurl.com/NRC-SAHM2019

AYAH-NRC : Overview & Scope

- **Funder:**
 - Maternal and Child Health Bureau, Health Services and Resources Administration, USDHHS (cooperative agreement U45MC27709)
- **Grant period:**
 - September 1, 2018 – August 31, 2023 (5 years)
- **Purpose:**
 - To improve the health of adolescents and young adults (ages 10-25) by strengthening the capacity of state maternal and child health (MCH) programs and their clinical partners to address the needs of adolescents and young adults.

More info at <http://nahic.ucsf.edu/resource-center/>

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National Resource Center



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS



State Adolescent Health Resource Center

University of Minnesota



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AYAH-NRC: Project Teams & Foci

Adolescent Well Visit Team

- Increase Adolescent Well Visit Rates

Young Adult Team

- Increase State Focus on Young Adult Health

Quality Improvement Project

- Increase screening and follow-up for major depressive episode for adolescents and young adults

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Health Consortium*

Conflict of Interest Statement

The speakers have no commercial relationships to disclose.

The speakers will not be discussing any unapproved uses of pharmaceuticals or devices.

Session Outline

- ✓ **What's new in research and policy:** The latest on the importance of the well visits, the ACA, preventive care.
- ✓ **Engaging parents:** What we thought and what we're learning.
- ✓ **What we can do:** Resources and initiatives around family engaged care

What's New in Research and Policy: The Importance of the Well Visit and the ACA to Adolescents & Young Adults

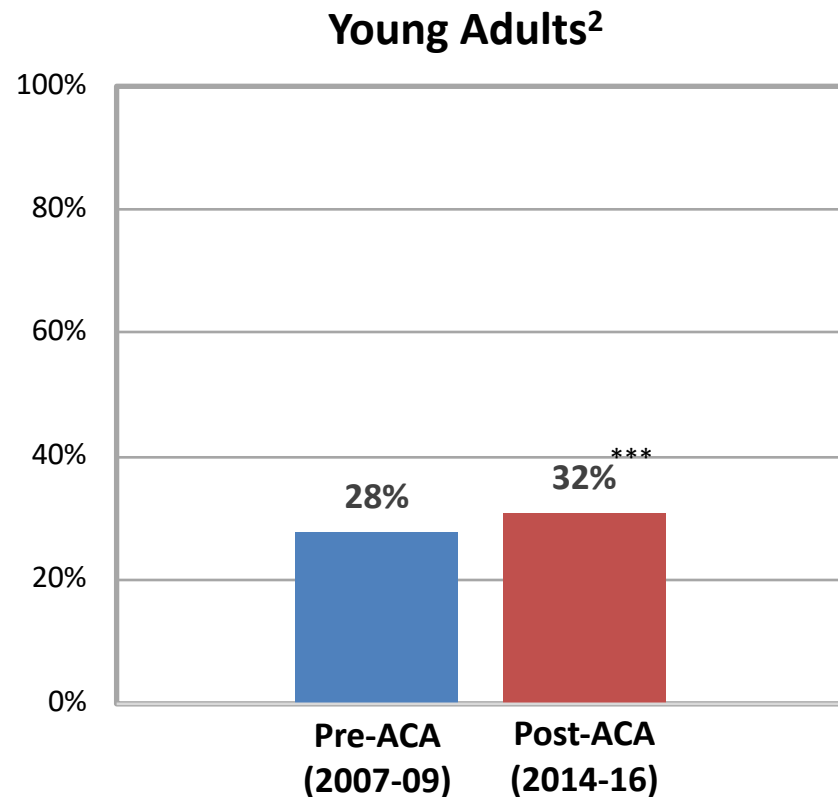
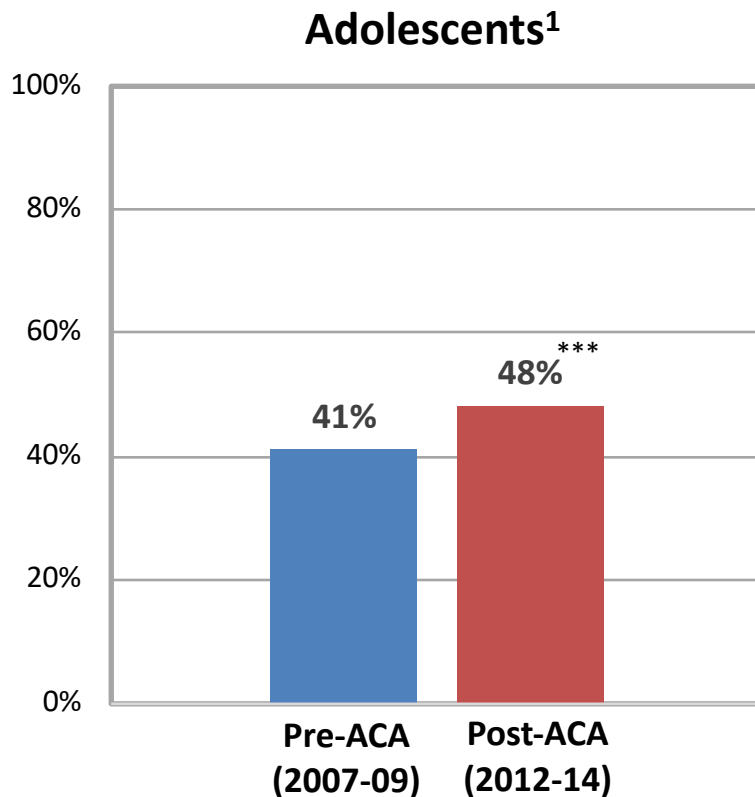
- ✓ The ACA is helping increase well visits and receipt of preventive care
- ✓ The well visit is key to delivery of preventive services
- ✓ Rates are still low

Update on Research and Policy

The ACA is helping increase well visits and receipt of preventive care for Adolescents and Young Adults

- Greatest increases in **adolescent well visit** rates among underserved adolescents (minority, low income, publicly insured)
- **Young adult** rates of receipt of **preventive services** also show greatest increase among underserved

Receipt of Past-Year Well Visit Among AYAs, Pre- and Post-ACA (MEPS)



*** $p < .001$

1-Adams et al., 2018 (<https://www.ncbi.nlm.nih.gov/pubmed/29114725>); 2-Adams et al., In press.

Update on Research and Policy

Services measured in MEPS analyses

- Adolescents

Physical Parameters:

- Blood Pressure
- Weight
- Height

Anticipatory Guidance:

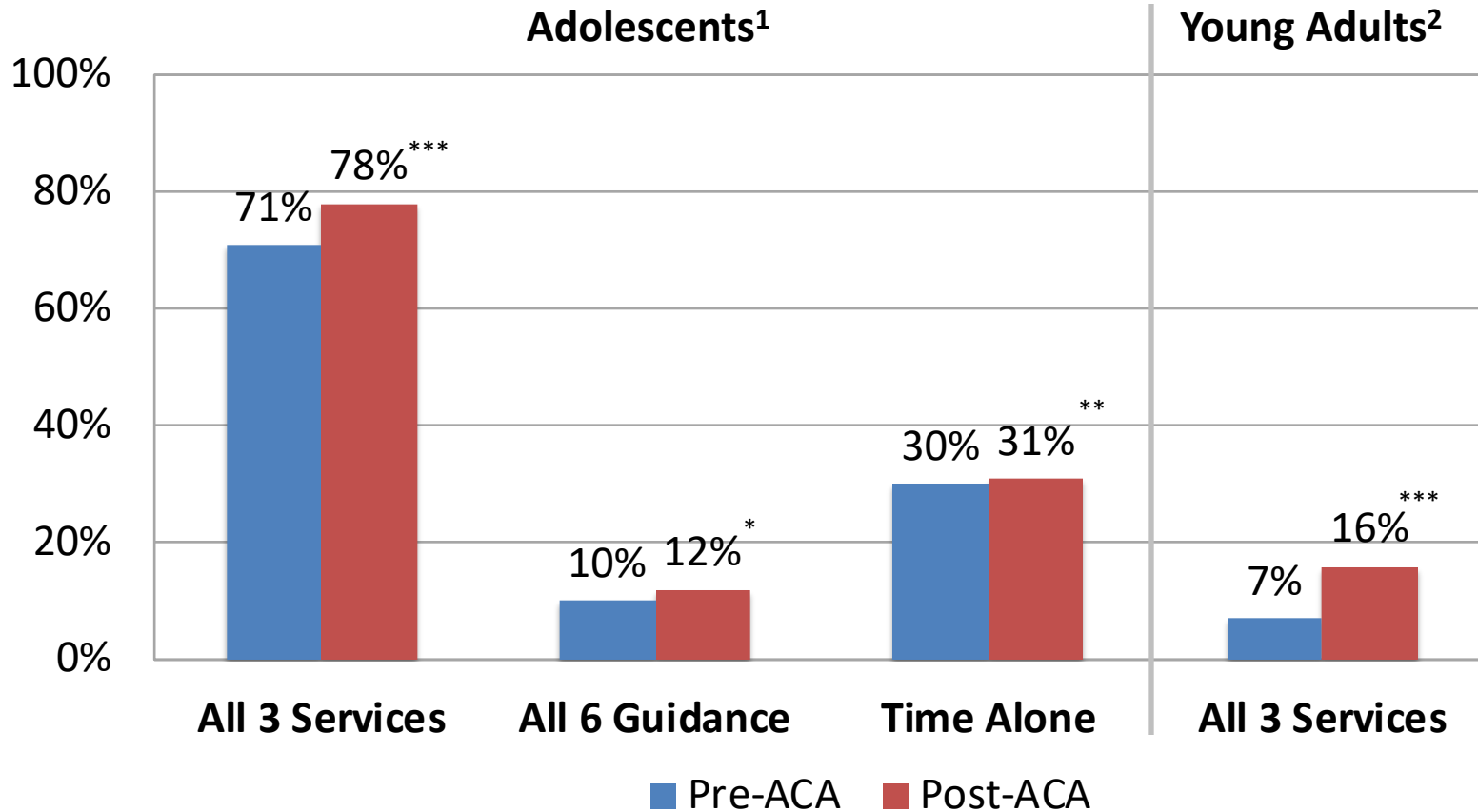
- Physical activity
- Healthy eating
- Seatbelt use
- Helmet use
- Second hand smoke
- Dental visit

- Young adults

Three services assessed:

- Blood pressure checked
- Cholesterol checked
- Flu shot received

Receipt of Preventive Services Among AYAs with Any Healthcare Visit in Last Year, Pre- and Post-ACA (MEPS)



* $p < .05$ in unadjusted model only

** $p < .05$

*** $p < .001$

1-Adams et al., 2018 (<https://www.ncbi.nlm.nih.gov/pubmed/29114725>); 2-Adams et al., In press.

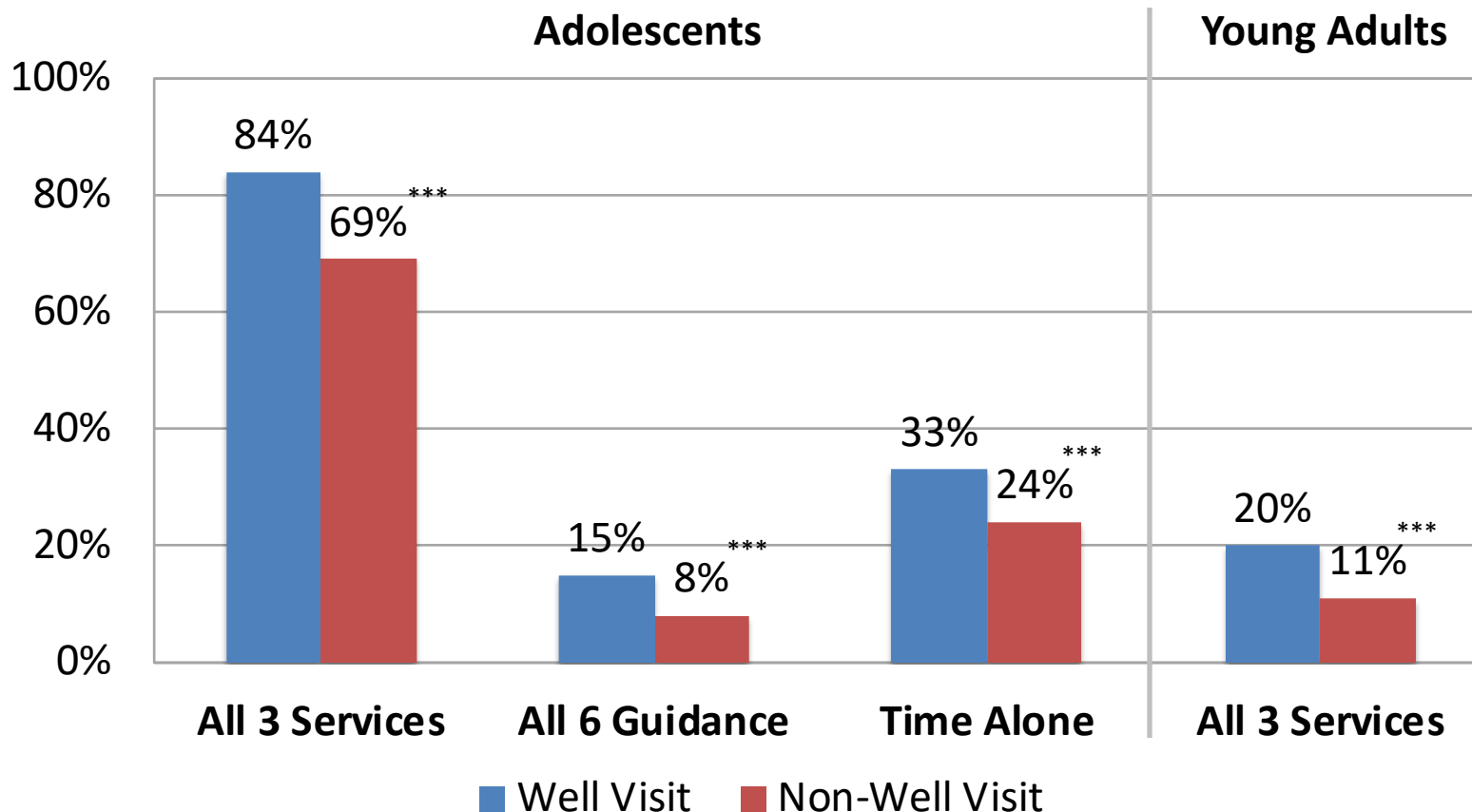
Update on Research and Policy

The well visit is an effective model for delivering preventive services to adolescents and young adults

- Significantly higher rates of preventive services if AYA attended a preventive well visit vs. a non-preventive visit.*

* Adams et al., 2018 (<https://www.ncbi.nlm.nih.gov/pubmed/29929838>)

Receipt of Preventive Services Among AYAs with Any Healthcare Visit in Last Year, Well Visit vs. Non-Well Visit (MEPS)



*** p<.001

Adams et al., 2018 (<https://www.ncbi.nlm.nih.gov/pubmed/29929838>)

Update on Research and Policy

Well Visit Rates are still low

- Rates for AYAs are still low in post-ACA years
- Less than half of As get a well visit
 - Even among full-year insured adolescents, only **half** got a WV
 - Time alone remains low
 - Overall, less than half of As are getting preventive services
- Less than a third of YAs get a well visit
 - Fewer than half got **2 of the 3** preventive services measured

Engaging parents: What we thought and what we're learning

- ✓ From Risk Prevention to Thriving, with supportive relationships and healthy choices
- ✓ Connecting Adolescents and Young Adults to Clinical Preventive Services

Parents: Original Focus - Risk Prevention

- ✓ Consensus recommendations have supported confidential care for adolescents and time alone with a clinician for more than two decades, based on two broad premises:
 - Adolescents **more likely** to seek care and disclose risky behaviors on sensitive topics when confidentiality is assured
 - Adolescents will **gain competence** in managing a relationship with a clinician and navigating the health care system

*Elster AB, Kuznets, 1994 & Hagan et al., 2017

Parents: Original Focus - Risk Prevention

- ✓ Support for time alone and confidential care driven largely by a goal of reducing risky behavior.
- ✓ Subsequent research with adolescents supports premise that adolescents more likely to seek care and disclose risky behaviors on sensitive topics when confidentiality is assured.*
- ✓ Parental perspectives and role in supporting their adolescents' health were rarely addressed in research or programs.

*Ford et al., 1997, Ford et al., 1999 & Ford et al., 2004

New Focus on parents' role in health care

- ✓ Most adolescents want their parents engaged in their health & health care. (*national sample, 2016*)¹
 - 89% of teens feel reassured with a parent in the exam room
 - 87% want their parents' involvement in decisions about their health
- ✓ Research links parent engagement in health care to better outcomes,² including in “sensitive” areas such as helping males who have sex with males make healthy choices.³

Parents generally support time alone

- ✓ Parents report support for time alone
 - 58% said “a lot” important (Urban pediatric clinics, 58% Black/28% White; 2016)¹
 - 89% said adolescents should be able to speak with their providers (national sample, 2012-3)²
 - 67% of parents say time alone is important (national sample, 2016)³
- ✓ Parents willing to waive rights to allow confidential care (university-based adolescent clinic, 2016)⁴

1-Miller et al, 2018; 2-Gilbert et al, 2014; 3-Unity Consortium, 2017;

4-Butler & Middleman, 2018

Parents are ambivalent about their role

- ✓ Parents also want to stay in the room
 - *61% prefer to be in the room the entire visit (national sample, 2012-3)¹*
 - *53% of parents insist on staying the room for the entire visit (national sample, 2016)²*
- ✓ Early qualitative research suggests that ambivalence can be addressed by building on parents' recognition of time alone's benefits in building competence in adult responsibilities.³

Role of parents: Next steps

How do we advance **adolescent-centered, family-engaged** care?

- Support time alone
- Improve “health literacy” around confidentiality & time alone
 - Communicate policy/clinic procedures, etc.
 - Communicate in ways that are meaningful to diverse populations of adolescents and families for whom we provide services

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

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

A collaboration involving:

American Academy
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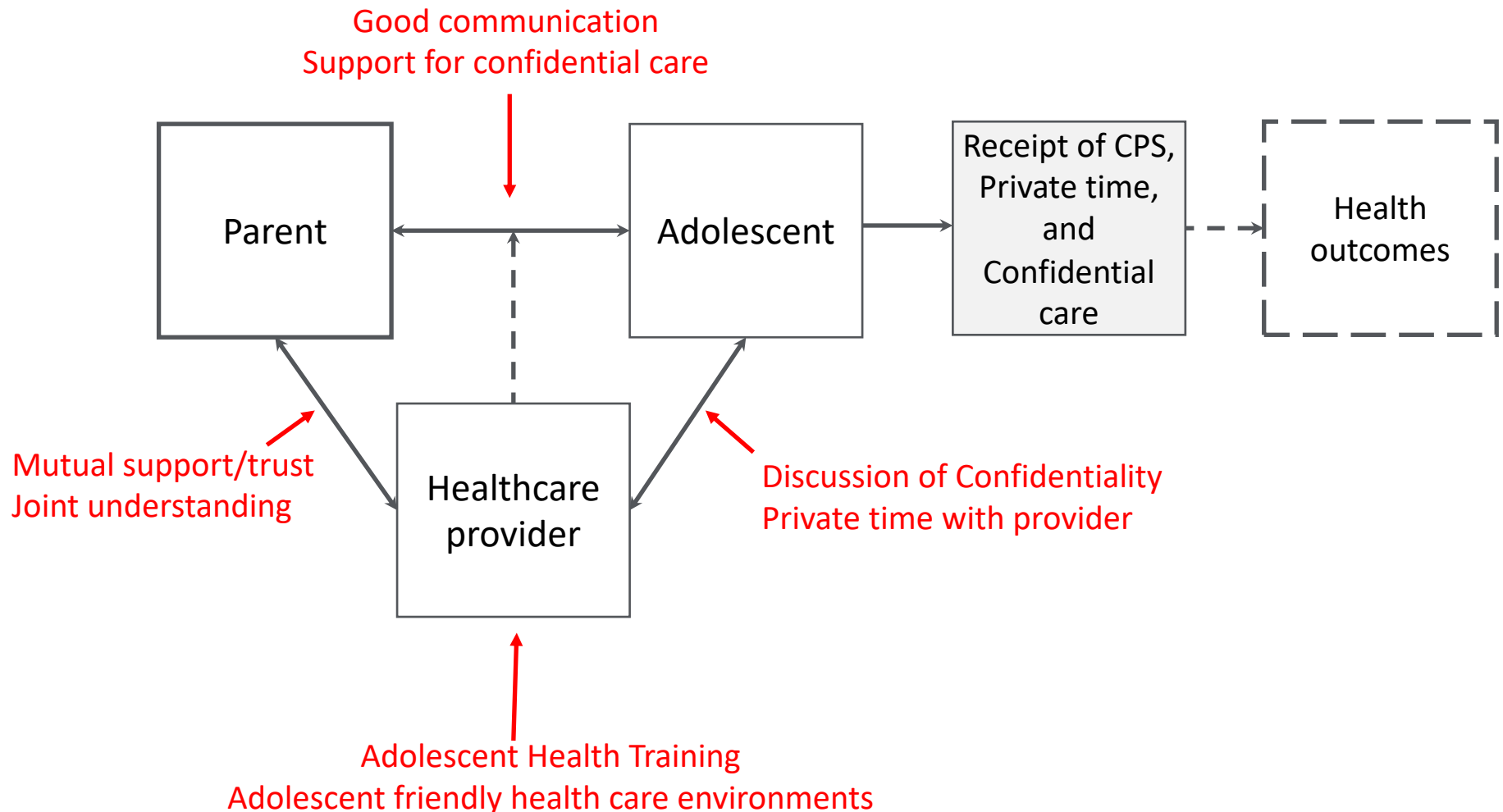
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AND GYNECOLOGISTS

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

Original article

Parent and Adolescent Attitudes Towards Preventive Care and Confidentiality



Xiaoyu Song, Dr.P.H.^{a,b}, Jonathan D. Klein, M.D., M.P.H.^{c,d,*}, Hanying Yan, M.S.^e,
Marina Catallozzi, M.D., M.S.C.E.^{f,g}, Xianling Wang, M.S.^e, Jenifer Heitel, M.P.H.^f,
Kristen Kaseeska, M.P.H.^d, Julie Gorzkowski, M.S.W.^d, and John S. Santelli, M.D., M.P.H.^{f,g}



Original article

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

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

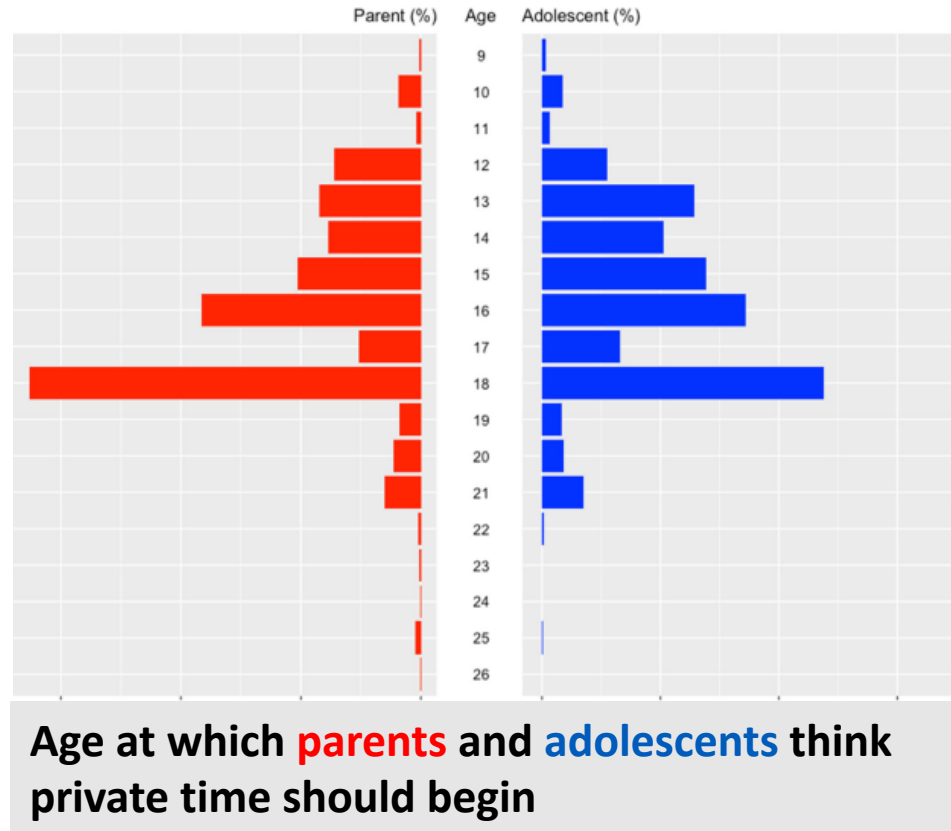
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Discussion of Potentially Sensitive Topics With Young People

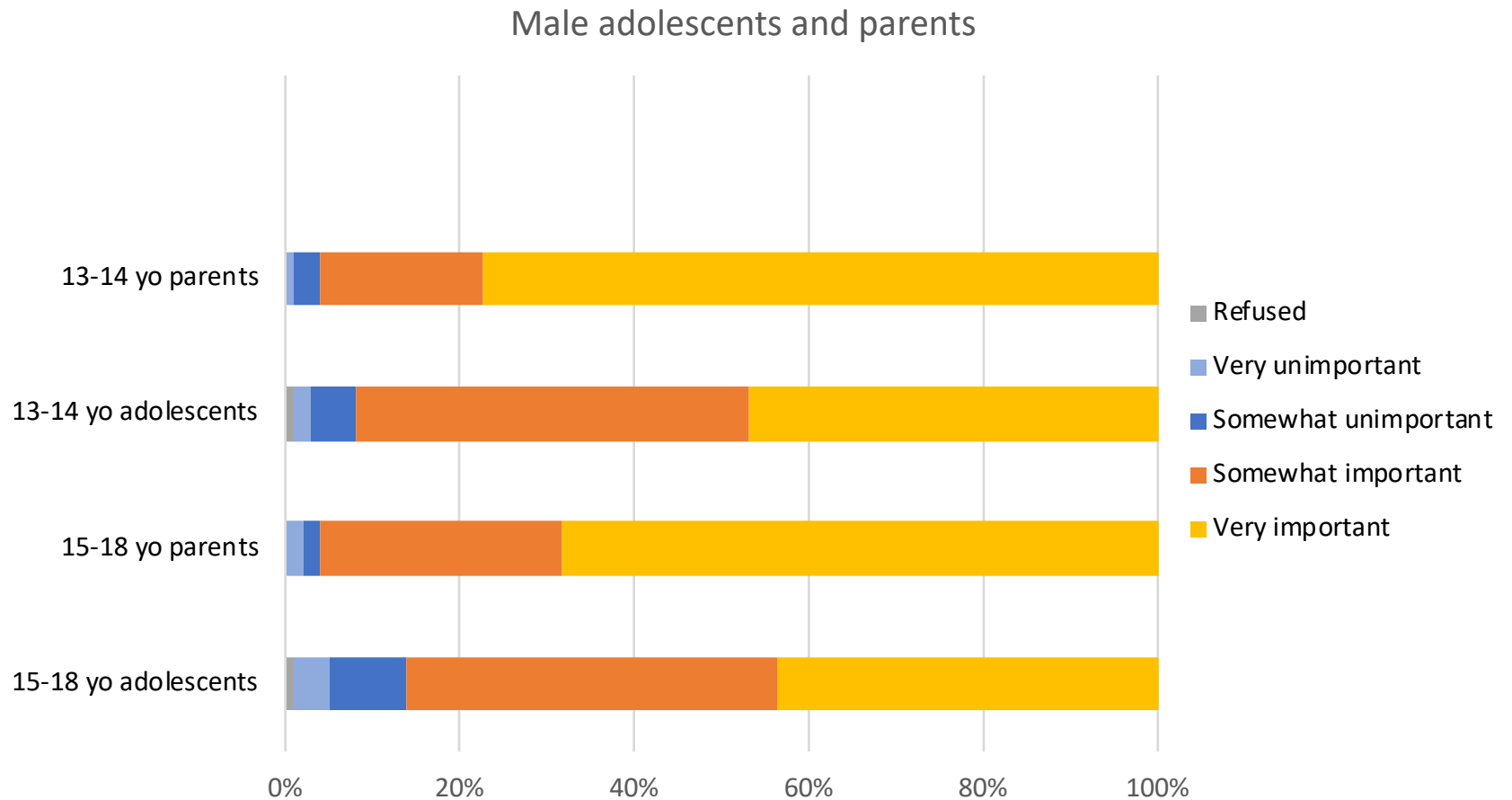
John S. Santelli, Jonathan D. Klein, Xiaoyu Song, Jennifer Heitel, Stephanie Grilo,
Mengru Wang, Hanying Yan, Kristen Kaseeska, Julie Gorzkowski, Madeline
Schneider, Alexandra E. Dereix and Marina Catallozzi

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**)



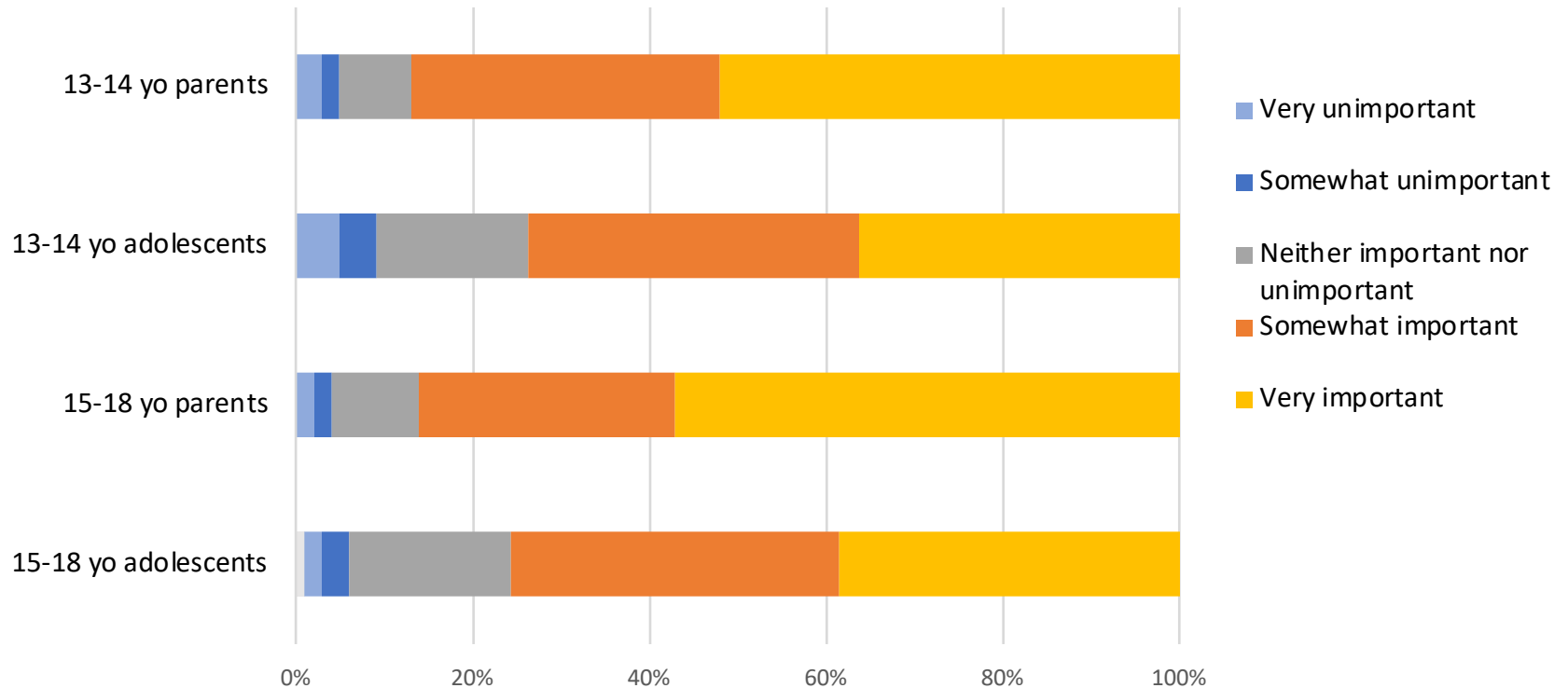
How important is it that adolescents and young adults have preventive visits?



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

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

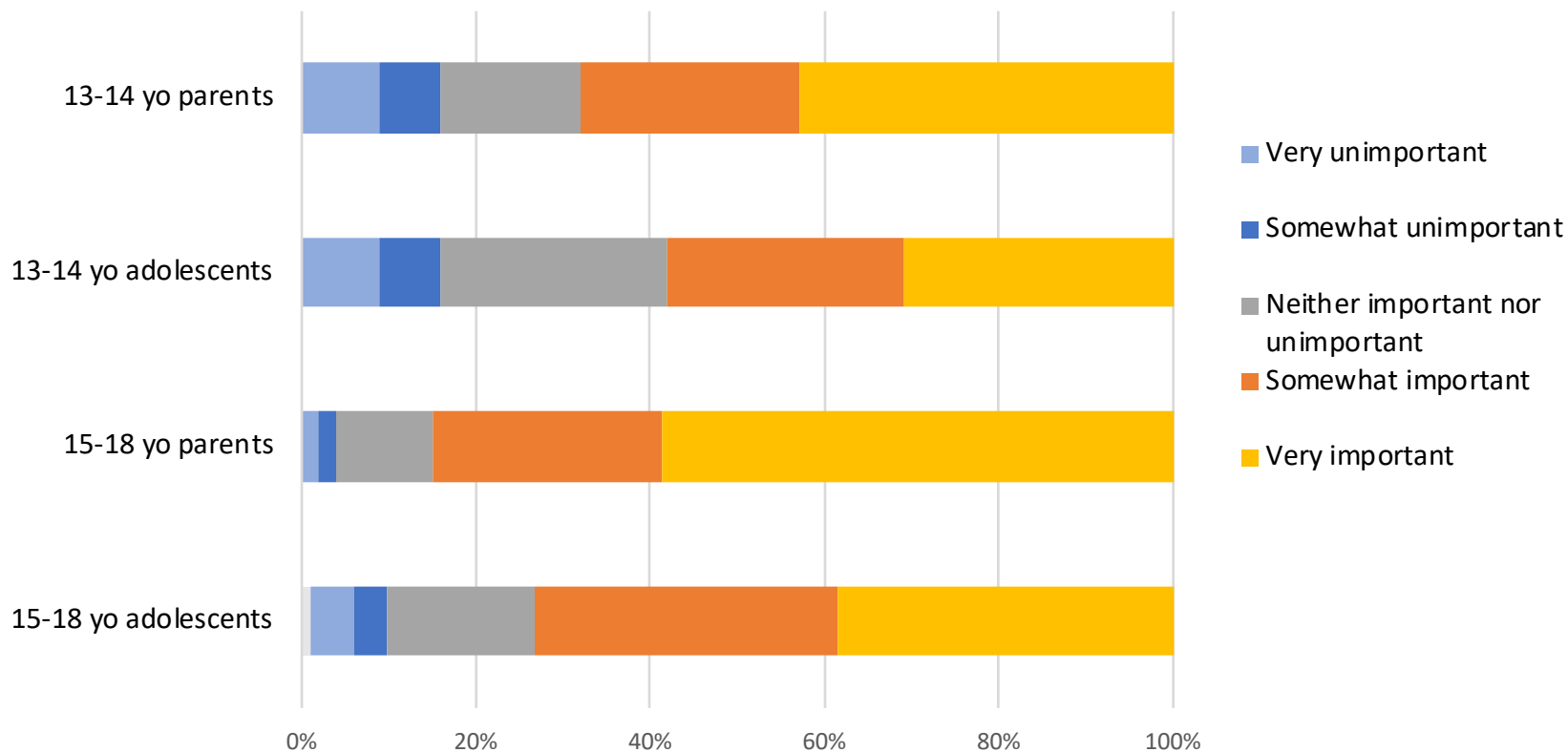
Female adolescents and parents



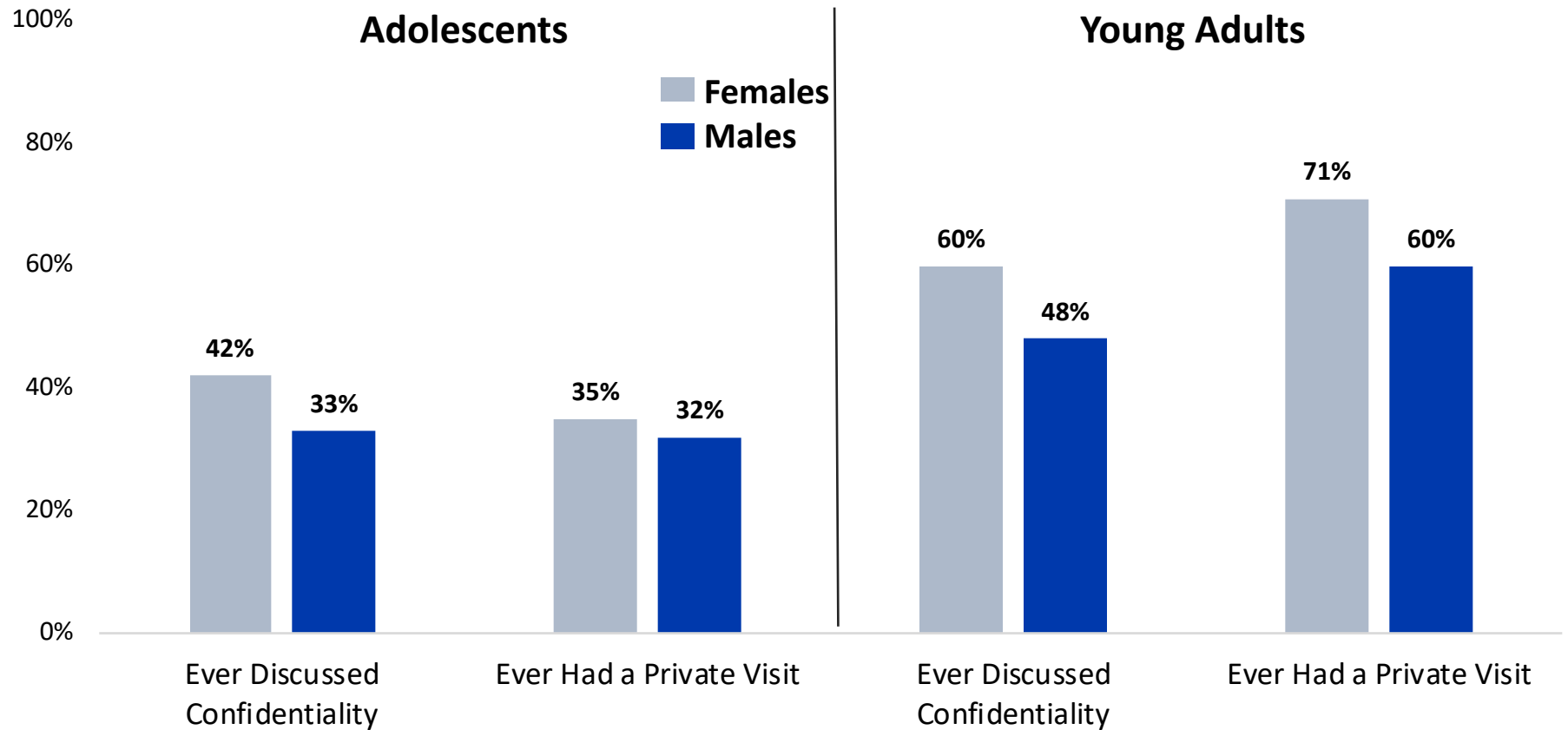
During a preventive visit, how important is it that a health care provider talks about:

STIs and HIV?

Female adolescents and parents



Ever had Private Time and Ever Discussed Confidentiality

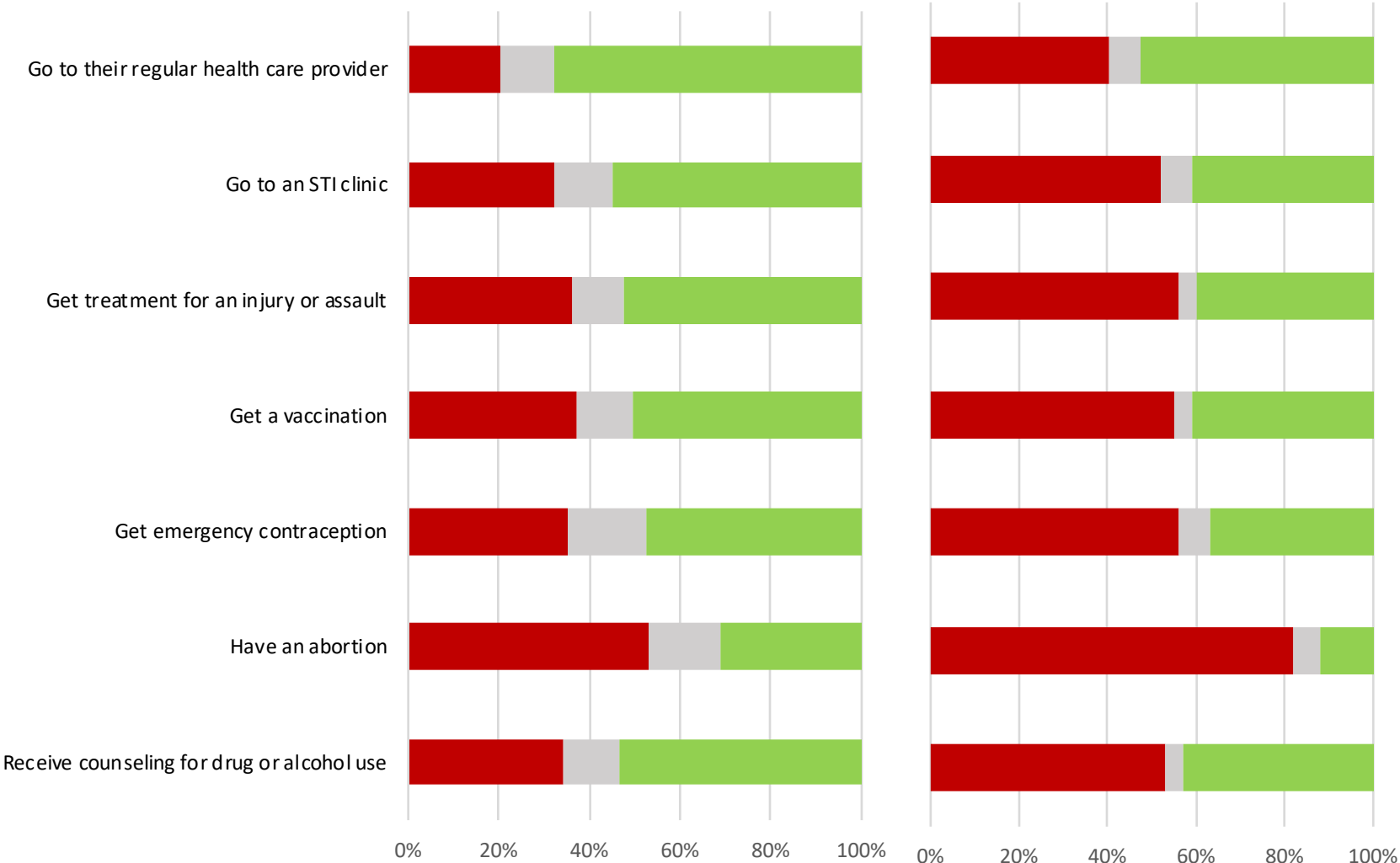


Kinds of healthcare that minor adolescents should be able to receive confidentially, without their parents' permission:

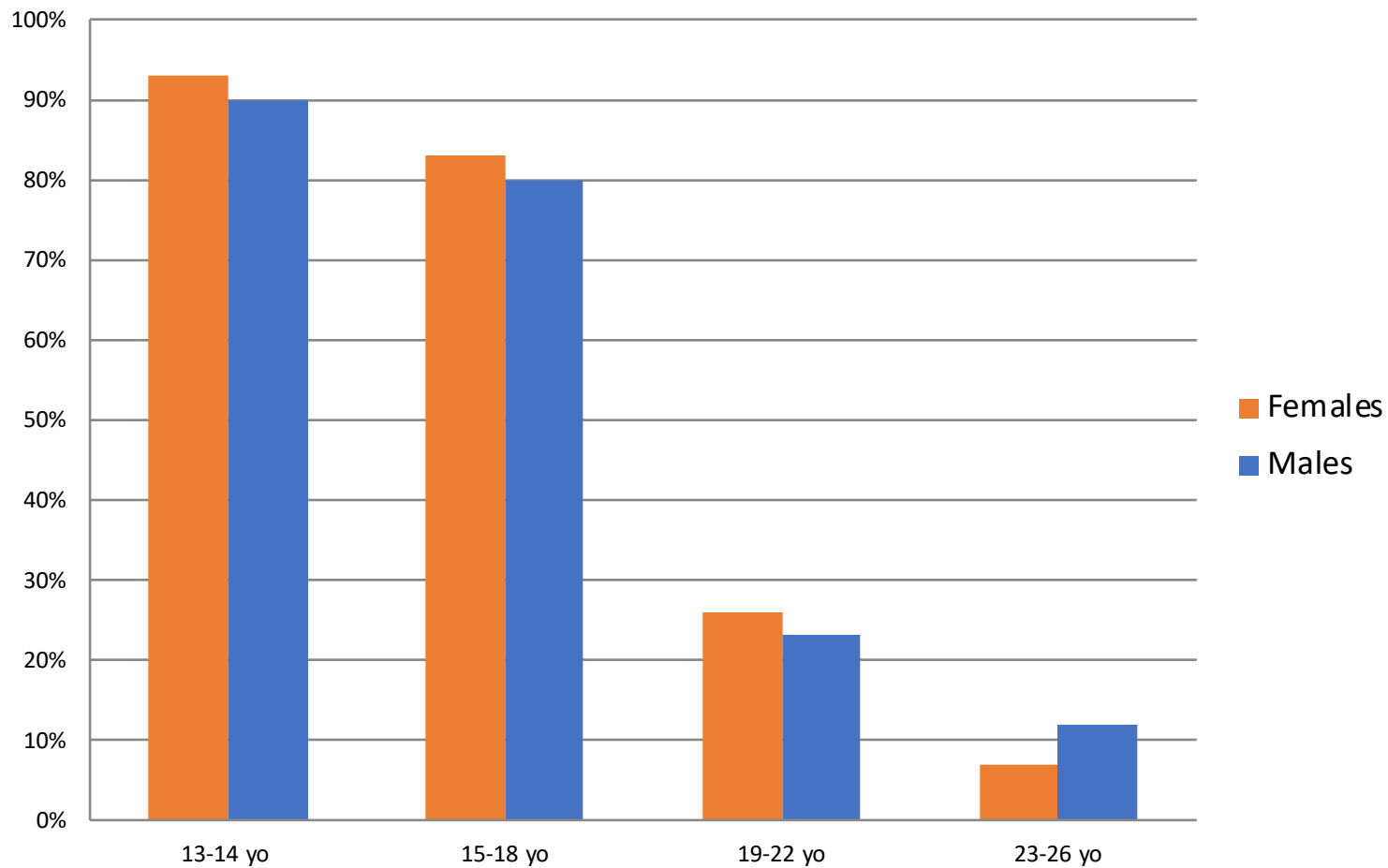
15-18 yo females

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



Acknowledgments



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Marina Catallozzi, MD, MSCE

Stephanie Grilo, PhD Candidate

Xiaoyu Song, DrPH

Yutao Liu, PhD Candidate

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Glenna Urquhart, MPH Candidate

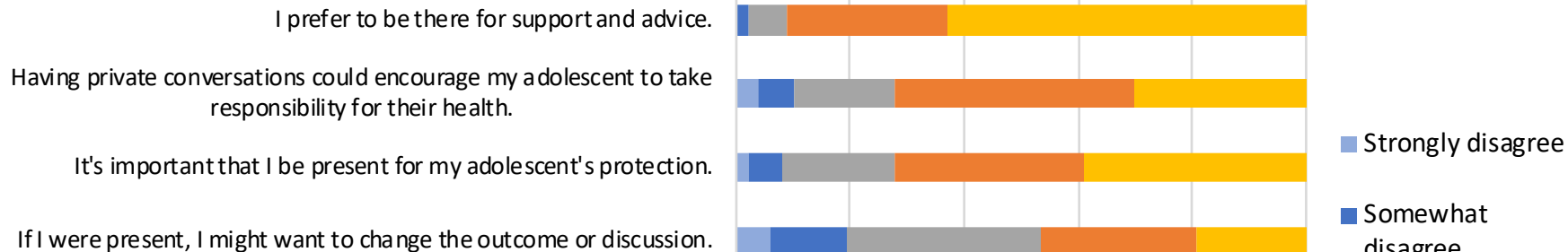
Sam Master, DO

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

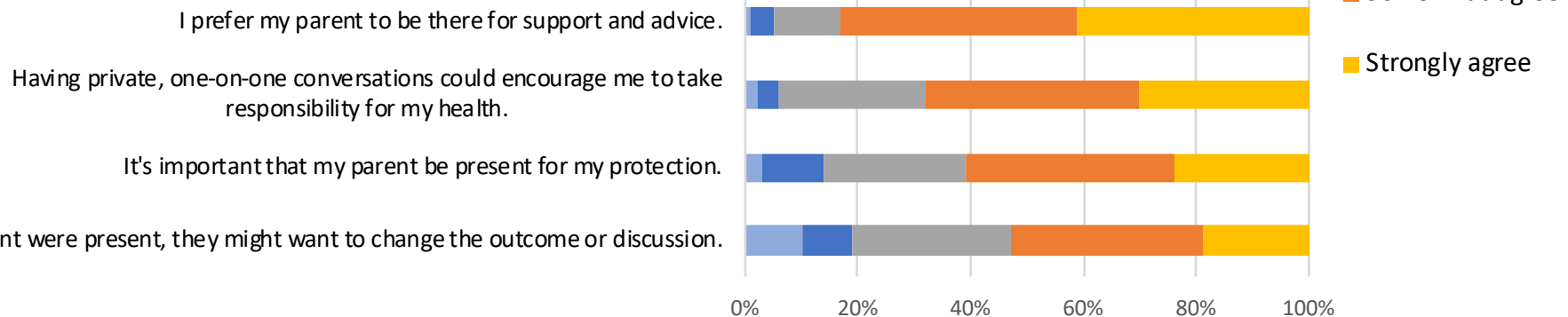
To what extent do you agree or disagree with the following statements about your adolescent seeing his/her health care provider:

Female adolescents and parents

Parents



15-18 yo adolescents



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

What We Can Do

- ✓ **Resources and initiatives around family engaged care**

ADOLESCENT and YOUNG ADULT
HEALTH RESEARCH NETWORK

Engaging Parents Through Research and Intervention

Elizabeth Ozer, PhD

*Division of Adolescent and Young Adult Medicine
University of California, San Francisco*

Principal Investigator

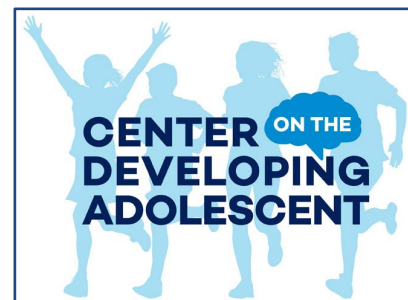
Adolescent and Young Adult Health Research Network

Funded by the Maternal and Child Health Bureau (UA6MC27378)

MCHB Project Officer: Evva Assing-Murray, Ph.D.

ADOLESCENT and
YOUNG ADULT

**HEALTH
RESEARCH NETWORK**



ADOLESCENT AND YOUNG ADULT HEALTH RESEARCH NETWORK

Overall Goals:

To develop and maintain a transdisciplinary multi-site research network that will

- Accelerate the translation of developmental science into MCH Adolescent & Young Adult (AYA) practice
- Promote scientific collaboration
- Develop additional research capacity in the AYA health field

Prioritizing parents in our Research Agenda

- Clinical Preventive Services is a key focus of the Research Network
- Conducted a broad literature review
 - Identified research gaps
 - Made recommendations for future research



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Review article

Research on Clinical Preventive Services for Adolescents and Young Adults: Where Are We and Where Do We Need to Go?



Sion K. Harris, Ph.D.^{a,b}, Matthew C. Aalsma, Ph.D.^c, Elissa R. Weitzman, Sc.D., M.Sc.^{a,b},
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Prioritizing Parents in our Research Agenda

- Parent-focused recommendations:
 - Clarify the role of the health care system, and of parents, in supporting healthy developmental transitions for adolescents and young adults.
 - Implement developmentally and culturally appropriate strategies to engage parents in the clinical encounters of AYAs and evaluate their effects on the receipt of clinical preventive services and health outcomes.

Projects Focused on Parents

- Formative research to inform an intervention for youth with special health care needs
 - Patient-centered, parent-engaged, and developmentally-informed
 - Examine how youths' skills in a variety of "in the home" and "out of home" tasks relate to age, health status and parenting style (*K. Ahrens, University of Washington*)

Projects Focused on Parents

- Assess adolescent technology use
 - *California Health Interview Survey*--state-wide survey
 - Representative adolescent sample (ages 12-17)
(UC San Francisco/UC Berkeley)
 - Household rules about technology use
 - Hours of sleep
 - Clinician discussion of technology use

Projects Focused on Parents

- Preventing Adolescent Opioid Use: website for parents (signs of abuse, prevention tips & links to resources)
 - <http://teen-safe.org/the-course-9/> (*S. Harris, Boston Children's Hospital, Harvard University*)
- Parenting Intervention in Primary Care (*pilot*)
 - Includes adolescent communication, monitoring & conflict
 - Parents (N=99) receptive to intervention
 - Particular interest in mental health and improving relationship with child (*M. Aalsma, Indiana University*)

Next Step: Developing a Parent-Focused Intervention

- AYAH-RN parent engagement workgroup: Developing models for engaging parents in the primary care setting
 - S. Harris, PhD, Boston Children's Hospital, Harvard University
 - M. Aalsma, PhD, Indiana University
 - L. Richardson, MD, MPH & C. McCarty, PhD, Seattle Children's Hospital, University of Washington
 - E. Ozer, PhD & C. Penilla, DrPH, UCSF
 - R. Sieving, PhD, RN & C. Mehus, PhD, University of Minnesota
 - C. Ford, MD, Children's Hospital of Philadelphia, University of Pennsylvania

Next Step: Developing a Parent-Focused Intervention

Parent questionnaire/assessment tool

- Researching existing tools
- Create an on-line module compatible with EHR
 - Provide “actionable” information for clinician providing care to adolescent
 - Identify and respond to parents’ interests and concerns
 - Basic facts/guidance provided within module

Next Step: Developing a parent-focused intervention

Identify and develop tools & interventions for parents

- Linkage from on-line module to existing resources and more intensive interventions
- Identify gaps and develop on-line interventions and resources

Questions for group

- ✓ What does this mean for clinical practice?
- ✓ What research do we need to do now?
- ✓ What tools/resources are needed by clinicians, clinic staff, adolescent and parents?
- ✓ How do recent changes in policy (insurance, etc.) affect clinician, parent & young person's

Time Alone Question: MEPS, 2001 - present

- Asked parents/guardians about adolescent clinical visits 12-17 years of age:
“The last time your son/daughter had a health care visit, did the doctor or other health care provider spend **time alone** with him/her without a parent, relative or guardian in the room”

Time Alone Question: NSCH, 2016 - present

- Asked of parents of adolescents who had a health care visit in the past 12 months:
“At his or her last preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room?”

Citations

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