

# Developing Quality Measures for Adolescent Care: Validity of Adolescents' Self-Reported Receipt of Preventive Services

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**Objective.** To demonstrate the feasibility of directly surveying adolescents about the content of preventive health services they have received and to assess the validity of adolescent self-reported recall.

**Data Sources/Setting.** Audiotaped encounters, telephone interviews, and chart reviews with 14–21 year olds being seen for preventive care visits at 15 pediatric and family medicine private practices, teaching hospital clinics, and health centers.

**Design.** 537 adolescents presenting for well visits were approached, 400 (75 percent) consented, 374 (94 percent) were audiotaped, and 354 (89 percent) completed telephone interviews either two to four weeks or five to seven months after their visits. Audiotapes were coded for screening and counseling across 34 preventive service content areas. Intraobserver reliability (Cohen's kappa) ranged from 0.45 for talking about peers to 0.94 for discussing tobacco. The sensitivity and specificity of the adolescent self-reports were assessed using the audiotape coding as the gold standard.

**Results.** Almost all adolescents surveyed (94 percent) remembered having had a preventive care visit, 93 percent identified the site of care, and most (84 percent) identified the clinician they had seen. There was wide variation in the prevalence of screening, based on the tape coding. Adolescent self-report was moderately or highly sensitive and specific at two weeks and six months for 24 of 34 screening and counseling items, including having discussed: weight, diet, body image, exercise, seatbelts, bike helmet use, cigarettes/smoking, smokeless tobacco, alcohol, drugs, steroids, sex, sexual orientation, birth control, condoms, HIV, STDs, school, family, future plans, emotions, suicidality, and abuse. Self-report was least accurate for blood pressure/cholesterol screening, immunizations, or for having discussed fighting, violence, weapon carrying, sleep, dental care, friends, or over-the-counter drug use.

**Conclusion.** Adolescents' self-report of the care they have received is a valid method of determining the content of preventive health service delivery. Although recall of screening and counseling is more accurate within two to four weeks after preventive care visits, adolescents can report accurately on the care they had received five to seven months after the preventive health care visits occurred.

**Key Words.** Adolescents, quality measurement, validity, self-report

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## BACKGROUND

Adolescent preventive services guidelines recommend confidential, comprehensive health screening and preventive counseling (Elster and Kuznets 1994; U.S. Preventive Services Task Force 1996; Green 1994). Current public health surveillance and managed care quality assurance methods have relied on parents' report of the care adolescents receive, on chart reviews, or on administrative databases (Centers for Disease Control and Prevention [CDC] 1995; Department of Health, Education, and Welfare [DHEW] 1974; Vistnes and Monheit 1997). However, adolescent care often includes confidential discussions between teenagers and their clinicians about sensitive issues, including sexuality, reproductive health, substance use, mental health, or abuse. These confidential encounters may not be accurately reflected in either parent or guardian reports. Additionally, chart documentation of preventive counseling service content may not reflect the actual care delivered. Physicians tend to overestimate their delivery of preventive services, and often do not document all of their interactions (Lewis 1991; Gemson and Elinson 1986). In contrast, preventive visits may be of high salience to adolescents, and thus may be more accurately remembered by youth than by providers. To know if recommended services have been delivered, and to improve preventive services for youth, accurate surveillance tools for assessing the content and quality of health services are needed. This study assesses the validity of self-reported recall of the content of preventive health services received by adolescents compared to chart reviews and audiotaped records of their encounters.

## METHODS

A convenience sample of 14–21 year old adolescents were recruited at the

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time of their preventive care visits. Adolescents were recruited from 15 community-based primary care practices in Monroe County, New York, including seven pediatric and three family medicine private practices, two teaching hospital clinics, and three community health centers. Clinical sessions were monitored for eligible patients, with systematic rotation of days to allow for sampling from all sessions of each provider's practice.

A research assistant approached each adolescent in the clinician's waiting room to determine eligibility, explain the study and obtain informed consent. Both parent and adolescent consent were obtained for adolescents who were younger than 16 years of age; 17 year olds were allowed to consent to their own participation in the study if they were seeking care as mature minors. The study protocol was approved by the University of Rochester Research Subjects Review Board and the Institutional Review Board at CDC.

To audiotape the visits, a research assistant accompanied the adolescents to the exam room with the recorder, and then left the room. The adolescent was instructed to start the audiotape when the provider entered the exam room. Discussion that occurred outside the room may not have been captured on tape. Occasionally, a clinician or an adolescent chose to stop the tape for part or all of an interview. These visits were excluded from the analysis. Adolescents were randomly assigned to early and late follow-up groups, and were surveyed by phone either two to four weeks after their visit, or five to seven months after their visit, respectively. Interviewer-administered surveys assessed the adolescents' use of and access to care as well as the content of their most recent preventive visit (the "index visit," for the purposes of this study).

Audiotapes were coded to assess delivery of 33 specific preventive service content areas identified by the CDC/AMA Guidelines for Adolescent Preventive Services (GAPS) (Table 1). Two trained research staff listened independently to each tape, coding for discussion of each of the content areas. Intraobserver reliability was assessed using Cohen's kappa, which accounts for the agreement between observations due to chance (Landis and Koch 1977).

The audiotape coding for whether the topic was discussed was used as the gold standard for defining if the counseling or screening service had been provided. Chart reviews were used as the gold standard for determining whether a physical examination and testing had been provided during the visit, since these procedures were less likely to have been captured on the audiotape.

Of 561 eligible adolescents seen for preventive care visits during monitored sessions, 537 (96 percent) were approached, and 401 (75 percent) consented and enrolled in the study. After completing the initial questionnaire

Table 1: Interrater Reliability (Cohen's kappa)/Percent Disagreement for Content Coding of Audiotaped Visit

<i>Topic</i>	<i>kappa</i>	<i>% Disagreement</i>
Weight	0.85	6.1
Blood pressure	0.67	15.7
Cholesterol	0.82	2.7
Immunizations	0.84	5.6
Diet	0.81	8.0
Body image	0.62	14.9
Exercise	0.74	12.8
Sleep	0.85	6.7
Teeth	0.82	8.8
Seatbelt	0.90	4.8
Bike helmet	0.89	5.3
Fighting	0.73	6.9
Violence	0.73	6.9
Weapons	0.83	3.2
Cigarettes/Smoking	0.94	1.6
Chewing tobacco	0.72	4.0
Alcohol	0.89	3.7
Drugs	0.81	8.0
Steroids	0.74	1.1
OTC drugs	0.38	20.3
Sex	0.80	5.3
Sexual orientation	0.20	23.5
Birth control	0.75	12.0
Condoms	0.91	4.5
HIV	0.83	7.5
STDs	0.81	9.1
Friends	0.45	27.5
School	0.77	8.3
Family	0.73	13.6
Future plans	0.75	12.5
Suicide	0.79	4.0
Abuse	0.70	3.2
Confidentiality	0.91	4.3

and having their visit audiotaped, one participant dropped out of the study. Complete audiotapes were successfully obtained from 374 of the adolescent health care visits (94 percent of enrollees), and a total of 354 subjects (89 percent) completed subsequent telephone interviews. Half (180) of the final sample were interviewed between two and four weeks of their visit (90 percent completion rate), and the other half (174) were interviewed five to seven months after their visit (87 percent completion rate). Chart review data was obtained for all 400 of the adolescents who completed their enrollment into the

study. Each chart was reviewed by two coders, and consensus interpretations were assigned with a third coder mediating any remaining disagreements.

If both of the audiotape coders agreed that a topic was or was not addressed during the visit, the content area was coded as discussed. Disagreements were coded as missing. The proportion of disagreements between the two raters ranged from 1.1 percent for having discussed anabolic steroids, to 25 percent for having discussed an adolescent's friends (Table 1). Recoding disagreements between raters to either "yes" or "no" codes for whether a topic was discussed, or treating disagreements as missing data had little or no effect on the sensitivity and specificity of the audiotaped gold standard when compared to adolescent telephone interviews (data not shown). Because there were virtually no differences in the magnitude of agreement regardless of the method for treating discordant coding, in the interest of space results are presented only for data in which unresolved cases are treated as missing and excluded from the analysis.

## RESULTS

Seventy-five percent of the adolescents who participated were white, and 59 percent were female. The mean age of participants was 16 years (s.d. = 1.67 years). There were no differences in gender, age, or ethnicity between the adolescents who chose to enroll in the study and those who refused participation.

Intraobserver reliability (Cohen's kappa) between raters ranged from 0.20 for discussing sexual orientation to 0.94 for discussing tobacco (Table 1), reflecting fair to excellent agreement for most items (Landis and Koch 1977). Three items, over-the-counter (OTC) drug use, sexual orientation, and friends, had kappas of 0.45 or less.

### *Visits and Utilization*

Almost all adolescents surveyed (94 percent) remembered having had a preventive care visit on or near the index visit date. Adolescents who were interviewed two to four weeks after their visit were more likely than adolescents interviewed at five to seven months to remember the exact date of their visit (20 percent versus 3 percent;  $p < .0000$ ), and gave a smaller range of possible visit dates (within 78 and 502 days.). Adolescents who were interviewed two to four weeks after their visit were also more likely than adolescents interviewed at five to seven months to note the date of their visit

within a week (76 percent versus 24 percent;  $p < .0000$ ). Most adolescents (94 percent) accurately identified the site of care delivery, and 84 percent identified the clinician they had seen. There were no differences between those interviewed earlier and those spoken with later in their ability to identify their clinicians and their site of care.

### *Screening and Counseling Validity*

The prevalence of preventive screening and counseling during these preventive health care visits, based on coding of all tapes (early and late), ranged from 2 percent for discussing anabolic steroids to 86 percent for discussing sex (Table 2). Other topics discussed with low prevalence included suicide (9 percent), sexual orientation (8 percent), cholesterol (7 percent), chewing tobacco (6 percent), and abuse (4 percent). In addition to sex, diet (71 percent), weight (72 percent), drugs (73 percent), school (79 percent), alcohol (79 percent), immunizations (79 percent), and cigarettes and smoking (85 percent) were most often discussed.

Adolescents in both the earlier and later interview groups were most likely to report that they had received counseling about cigarettes/smoking, physician-patient confidentiality, exercise, and school performance. Weight, sex, family issues, and alcohol use were also among the topics that were often discussed. Both early and late interview groups were least likely to report having received counseling about or having discussed violence, abuse, cholesterol, teeth or dental care, weapons, steroid use, fighting, and suicide.

The sensitivity of adolescents' recall of the services they received for the two-to-four week follow-up group ranged from a low of 12 percent for having discussed over-the-counter drugs to 100 percent for having discussed steroids (Table 3). Sensitivities for the five-to-seven month group ranged from 0 percent for discussing cholesterol, to 90 percent for discussing physician-patient confidentiality. Adolescents had the highest sensitivities for anabolic steroid use, family issues, cigarettes and smoking, exercise, school performance, and physician-patient confidentiality. For items with the highest sensitivity by self-report, the two-to-four week group was slightly more accurate than the five-to-seven month group in each category. However, this difference was relatively small ( $< 10$  percent) for each topic.

Specificity for the two-to-four week follow-up group ranged from a low of 25 percent for having discussed exercise to a high of 93 percent for having discussed weapons (Table 3). Specificity at five to seven months also ranged widely, from 17 percent for having discussed confidentiality to 96 percent for having discussed violence. Both early and late groups reported

Table 2: Frequencies of Reported/Documented Discussion Between Adolescent and Health Care Provider

Discussion of	Early Interview		Late Interview		Early and Late Combined	
	Phone %	Tape %	Phone %	Tape %	Phone %	Tape %
Exercise	84	49	84	51	84	50
School	84	76	81	81	83	79
Confidentiality	81	30	86	36	83	33
Cigarettes/Smoking	78	86	76	85	77	85
Diet	76	68	67	75	72	71
Sex	73	84	67	88	70	86
Family	71	46	64	58	67	52
Future plans	71	57	58	56	64	56
Weight	69	69	70	75	70	72
Body image	62	20	56	25	59	23
Alcohol	62	81	61	78	61	79
Condoms	57	49	49	50	53	49
Immunizations	56	76	41	82	49	79
Friends	49	45	44	43	46	44
HIV	48	31	52	32	50	31
Drugs	43	71	44	74	44	73
Birth control	41	38	36	37	38	37
Bike helmet	39	41	29	33	34	37
STDs	37	35	40	36	38	36
Sleep	34	33	33	32	32	32
Seatbelt	31	40	21	33	26	36
Blood pressure	31	38	26	40	29	39
Chewing tobacco	27	5	39	7	33	6
Sexual orientation	24	8	21	9	22	8
OTC drugs	22	12	26	14	24	13
Teeth	19	48	12	54	16	51
Suicide	19	7	17	10	18	9
Fighting	17	10	17	15	17	12
Weapons	16	24	14	25	15	25
Cholesterol	14	6	10	8	12	7
Steroids	11	1	14	3	12	2
Abuse	11	4	9	4	10	4
Violence	10	10	8	15	9	12
Overall median	41	38	40	36	38	37

discussing weapons, violence, bicycle helmet use, abuse, and cholesterol with the highest specificity. The early group also reported discussing steroids with high specificity, while the late follow-up group reported discussing teeth or dental care with high specificity. As with sensitivity, there were relatively few and only minimal differences between early and late specificity for each topic (< 4 percent).

**Table 3: Sensitivity/Specificity: Adolescent Self-Report of Discussion with Health Care Provider Compared to Audiotape of the Encounter**

<i>Discussion of</i>	<i>Early Interview</i>		<i>Late Interview</i>	
	<i>Sensitivity %</i>	<i>Specificity %</i>	<i>Sensitivity %</i>	<i>Specificity %</i>
Exercise	91	25	85	19
School	93	42	87	46
Confidentiality	94	28	90	17
Cigarettes/Smoking	86	55	80	42
Diet	83	35	74	60
Sex	84	78	73	58
Family	91	48	78	48
Future plans	84	48	67	57
Weight	72	42	72	35
Body image	84	46	70	50
Alcohol	69	62	70	65
Condoms	82	68	65	67
Immunizations	57	49	46	69
Friends	55	59	49	64
HIV	66	61	64	56
Drugs	50	73	50	73
Birth control	80	83	57	75
Bike helmet	83	91	59	89
STDs	66	80	63	71
Sleep	62	83	59	75
Seatbelt	43	80	41	88
Blood pressure	38	74	36	79
Chewing tobacco	67	74	75	64
Sexual orientation	60	79	67	82
OTC drugs	12	86	47	80
Teeth	22	87	15	93
Suicide	67	85	50	87
Fighting	29	85	15	84
Weapons	48	93	32	94
Cholesterol	30	87	0	89
Steroids	100	89	75	87
Abuse	50	90	40	92
Violence	35	92	10	96
Overall median	67	74	63	71

### *Examination Validity*

Based on chart review data, considered our gold standard for the physical examination and lab procedures, the most often documented examination items included heart (84 percent), ears (85 percent), height (86 percent), and weight (96 percent). HIV testing (5 percent), MMR immunizations



**Table 4: Frequencies of Adolescent Self-Reported Receipt of a Physical Examination or Procedure Compared to Chart Documentation**

<i>Examination of</i>	<i>Early Interview</i>		<i>Late Interview</i>	
	<i>Phone %</i>	<i>Chart %</i>	<i>Phone %</i>	<i>Chart %</i>
<i>Exam</i>				
Weight	99	97	97	95
Blood pressure	98	34	94	29
Height	97	86	94	87
Testes	94	33	96	34
Heart/Lungs	92	84	93	84
Ears	90	86	89	85
Breast	29	35	26	40
Pelvic	24	13	13	11
<i>Lab Tests</i>				
Blood test	33	31	19	33
Pregnancy test	20	6	14	5
Pap smear	13	4	9	9
Cholesterol test	13	6	12	5
HIV test	12	6	3	3
TB test	12	7	20	8
Gonorrhea test	11	8	10	8
Chlamydia test	9	8	9	8
Urinalysis	2	63	1	58
Drug test	1	0	2	0
Urine culture	0	3	2	4
<i>Immunizations</i>				
Hepatitis-B	70	49	72	49
Immunizations	62	57	45	56
Tetanus	38	19	33	16
MMR	10	6	9	3
Overall median	24	19	19	16

(4 percent), urine culture (3 percent), and drug testing (0 percent) were least often provided (Table 4). Adolescents also were most likely to report having had their height, weight, and blood pressure measured; having received an immunization (usually a hepatitis B and/or a tetanus shot), and having had their ears, heart, lungs, or testes examined.

Among the two-to-four week follow-up group, the sensitivity ranged from a low of 5 percent for having a urinalysis to 100 percent for having height and weight measurements, and for having either a pap smear or an HIV test (Table 5). Sensitivity for the five-to-seven month follow-up group ranged

Table 5: Sensitivity/Specificity (Adolescent Self-Report of Discussion with Health Care Provider Compared to Chart Data from the Encounter)

<i>Did Your Doctor Examine/Order:</i>	<i>Early Interview</i>		<i>Late Interview</i>	
	<i>Sensitivity %</i>	<i>Specificity %</i>	<i>Sensitivity %</i>	<i>Specificity %</i>
<i>Exam</i>				
Weight	100	50	97	*
Blood pressure	95	1	98	5
Height	100	30	98	40
Testes	95	11	95	*
Heart/Lungs	97	40	98	33
Ears	99	57	99	52
Breast	36	72	38	79
Pelvic	52	84	62	94
<i>Lab Tests</i>				
Blood test	78	88	42	93
Pregnancy test	78	98	75	94
Pap smear	100	92	71	96
Cholesterol test	88	95	100	95
HIV test	100	96	*	96
TB test	85	93	77	85
Gonorrhea test	89	92	100	92
Chlamydia test	89	95	100	93
Urinalysis	5	89	4	100
Drug test	*	99	*	98
Urine culture	*	100	*	94
<i>Immunizations</i>				
Hepatitis-B	94	88	87	65
Immunizations	94	86	68	86
Tetanus	97	87	84	83
MMR	73	97	50	92
Overall median	24	19	19	16

\*Cell size too small to calculate.

from 4 percent for a urinalysis to 100 percent for chlamydia, gonorrhea, and cholesterol testing.

For the two-to-four week follow-up group, the specificity of self-report ranged from a low of one percent for having had blood pressure measured to 100 percent for having had a urine culture (Table 5). Specificity for the five-to-seven month follow-up group ranged from 5 percent for having blood pressure measured to 100 percent for a urinalysis. Both early and late groups were least specific at reporting whether they had heart and lung exams or

height and blood pressure measurements. The early-interview group also was not very specific at reporting for testicular examinations. For the early group, reports of procedures such as urine cultures, drug testing, pregnancy testing, MMR immunizations, and HIV testing had the highest specificity.

## DISCUSSION

These data suggest that adolescents' self-report of the care they have received may be a valid method of determining the content of preventive health service delivery. In reporting about the care they had received five to seven months earlier during preventive care visits, most adolescents remembered having preventive care visits, and identified their doctor and site of care.

Previous field tests of the National Health Information Survey examining the validity of self-reported medical care use by a household sample of adults found an underreporting of health care encounters by 20 percent, and as many as 39 percent of adults incorrectly classifying their usual source of health care (Jobe et al. 1990; Perloff and Morris 1989). Our sample, however, was drawn from clinical sources, and not from the general population. Thus, our subjects' responses about care use, while substantially better in accuracy, are not directly comparable to those of randomly selected respondents.

Adolescents recall discussing steroids, confidentiality, school, exercise, family, and cigarettes/smoking with highest sensitivity and specificity. Other important issues such as alcohol use, sex, and condoms were also accurately recalled most of the time. Adolescents also were able to report with reasonable accuracy about those topics that were not discussed at their visits, including weapons, violence, abuse, bicycle helmets, and cholesterol.

Although we found chart documentation to be a good source of information about immunizations and some laboratory procedures, our data suggest that charts may result in both over- and underreporting of the quality of screening and counseling services actually delivered. While we had trained clinicians review the charts in our study, we did not attempt to further validate our interpretation. Additionally, in a study examining the use of office records as a source of ambulatory care information, 20 percent of records contained illegible terms and abbreviations that precluded their use to anyone but the recording physician (DHEW 1974).

These measures of adolescent clinical preventive services might serve as proxy measures to assess the quality of annual adolescent preventive health care visits. For example, recent data suggest that just over half of

all adolescents had the opportunity to talk alone with their provider during health care encounters (Klein 1998); and adolescents are known to avoid care for sensitive issues unless their confidentiality is assured (Malus et al. 1987). The Health Plan Employer Data and Information Set (HEDIS) version 3.0 also includes several measures for clinical preventive services, including one for annual preventive care visits for adolescents (National Committee for Quality Assurance 1996). This is similar to the periodicity of visits recommended by many of the guidelines for adolescent preventive care, including the Guidelines for Adolescent Preventive Services, Bright Futures, and the American Academy of Pediatrics (Elster and Kuznets 1994; Green 1994; American Academy of Pediatrics [AAP] 1996; U.S. Preventive Services Task Force 1996). However, to assess the quality of care provided, it is important to look at the content of care delivered, and not just utilization measures. Each of the guidelines referenced above also calls for specific screening and counseling interventions, most of which are endorsed and recommended by the American Academy of Family Practitioners ([AAFP] 1994) and by the U.S. Preventive Services Task Force ([USPSTF] 1996).

These measures may be useful for assessing the receipt of specific clinical preventive services in public health surveillance systems and medical care quality assurance systems, and in health services research. The various guidelines for adolescent care all call for specific screening and counseling interventions, which were discussed at the preventive care visits we audiotaped. However, the recommended screening and counseling services that were provided in these visits fall short of the content of care recommended for adolescents.

Our study is limited by the representativeness of the sample of providers, since both the clinicians and the adolescents who agreed to participate may be subject to selection bias, and may not be representative of either clinicians' performance or adolescents' recall. Additionally, we are limited by the accuracy of the audiotape coding, both by not being able to see nonverbal communication between providers and patients, and by not being able to capture all of the patient and provider interactions (e.g., discussions on the way to the room or in the hall). Thus, the tapes may underestimate the true rates of counseling or screening that went on. The presence of the tape itself also may have affected both adolescents' recall and the content of the discussion. However, these effects likely would have resulted in increased delivery of recommended preventive services; thus, our observations may have inflated the true performance of these clinicians.

This study provides evidence that adolescent self-report may be a reasonably accurate source of information for public health surveillance and quality assurance systems about the content of the health services that adolescents have been provided. In fact, as many of the discussions during adolescents' visits are conducted privately between adolescents and their clinicians, adolescents in some cases may be a much better source of information than either their parents or their charts. Additionally, interviewing adolescents is the only way to assess the preferences of youth with regard to the care they receive. This study adds support to quality measurement strategies that seek to obtain data directly from youth.

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