

WG5 - Implications and Implementation of Standardized Terminology - Public Comments February 13, 2012 – February 17, 2012

| Practice Type | | |
|-----------------------|---|-----|
| Clinician | 2 | 22% |
| Pathologist | 4 | 45% |
| Other, please specify | 3 | 33% |

| Years of Experience | | |
|------------------------------|---|-----|
| More than 20 years | 9 | 90% |
| 11-20 years | 0 | 0% |
| 10 years or less | 1 | 10% |
| Currently a resident/student | 0 | 0% |

| Practice Setting | | |
|----------------------------|---|-----|
| Academic | 3 | 30% |
| Community/Private Practice | 3 | 30% |
| Government | 2 | 20% |
| Industry | 1 | 10% |
| Insurance/Payers | 0 | 0% |
| *Other, please specify | 1 | 10% |
| * COMMERCIAL LAB | | |

Clinician Public Comments

Question 1: What are the potential implications of standardizing histopathology terminology for lower anogenital lesions? Are there any potential benefits and/or harms not previously discussed in the prior Work Group recommendations which should be considered?

No responses received

Question 2: Are there any additional recommendations for strategies to inform clinicians of clinical implications of this new standardized terminology:

No responses received

Question 3: What else is needed for successful implementation and dissemination of this terminology? (examples: (a) how best to facilitate adoption among various affected organizations, providers/labs, insurance companies, and industry? (b) what tools should be developed to facilitate dissemination? (c) what metrics are needed to assess the uptake and impact of this terminology?)

No responses received

Question 4: Other comments:

No responses received

Pathologist Public Comments

Question 1: What are the potential implications of standardizing histopathology terminology for lower anogenital lesions? Are there any potential benefits and/or harms not previously discussed in the prior Work Group recommendations which should be considered?

Harms include lack of agreement with terminology used for most recent ASCCP treatment guidelines incorporating HPV testing. National Program of Cancer Registries will not be able to collect data on precursor lesions if link to CIS lost and the burden will be greatly increased if CIN2 lesions are merged into the category. Impact of recommending p16 to arbitrate CIN2 lesions is unknown.

Question 2: Are there any additional recommendations for strategies to inform clinicians of clinical implications of this new standardized terminology:

Hopefully the wisdom of not introducing new terminology will prevail.

Question 3: What else is needed for successful implementation and dissemination of this terminology? (examples: (a) how best to facilitate adoption among various affected organizations, providers/labs, insurance companies, and industry? (b) what tools should be developed to facilitate dissemination? (c) what metrics are needed to assess the uptake and impact of this terminology?)

No responses received

Question 4: Other comments:

Terminology should not be for the ease of pathologists. Clinical and public health considerations are equally important.

Other

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|---|
| Practice Type |
| Epidemiologist (Population-based Cancer Surveillance) Cancer Registrar |

Question 1: What are the potential implications of standardizing histopathology terminology for lower anogenital lesions? Are there any potential benefits and/or harms not previously discussed in the prior Work Group recommendations which should be considered?

1. The combining of VIN II with VIN III, VAIN II with VAIN III, AIN II with AIN III would cause problems for the cancer control and epidemiology community and the population-based cancer registries who currently collect the information on III: a. Temporal trends would be immediately affected since IIs would suddenly be combined with the IIIs. b. The number of additional cases of IIs is unknown and the additional collection of this information would be an added financial burden c. Standard setters such as NCI's Surveillance, Epidemiology and End Results (SEER) Program and population-based cancer registries would need decide whether to drop the collection of VIN, VAIN, and AIN for III or add the collection of IIs to their already stressed workload. d. Some registries could start surveillance for the new categories immediately. Others would need to obtain new legal authorization before changing their list of reportable diseases. 2. The combining of CIN II with CIN III would cause problems for the cancer control and epidemiology community and the cancer registries who currently collect CIN III: a. Most cancer registries no longer collect CIN III after cervix in situ was combined with CIN III. Combining of CIN II and III could be an additional hurdle to moves to reinstate CIN III reporting. b. Temporal trends would be immediately affected since IIs would suddenly be combined with the IIIs. c. The number of additional cases of IIs is unknown and the additional collection of this information would be an added financial burden d. Some registries could start surveillance for the new categories immediately. Others would need to obtain new legal authorization before changing their list of reportable diseases. 3. PIN III should not be used for penile intraepithelial neoplasia since PIN III is recognized in the US and internationally as prostatic intraepithelial neoplasia, grade III in such publications as the International Classification of Diseases for Oncology 3rd edition, ICD-10CM, & ICD-9CM. 4. Some definitions of minimally invasive cancers (i.e. T1a) introduce new parameters that are not part of the AJCC staging criteria. For example, completely excised margins are a newly proposed parameter in the LAST report definition of "superficially invasive penile squamous cell carcinoma." Changes and additions to T1a definitions would need approval by AJCC and UICC before they could be adopted.

Collection in cancer registries could be an issue since this is governed by state and federal law. If new terminology is added, these laws would all have to be changed or the cases cannot be collected.

Question 2: Are there any additional recommendations for strategies to inform clinicians of clinical implications of this new standardized terminology:

No responses received

Question 3: What else is needed for successful implementation and dissemination of this terminology? (examples: (a) how best to facilitate adoption among various affected organizations, providers/labs, insurance companies, and industry? (b) what tools should be developed to facilitate dissemination? (c) what metrics are needed to assess the uptake and impact of this terminology?)

need to involve the standard-setters for the cancer registry world: American College of Surgeons Commission on Cancer, NCI/SEER program, CDC/NPCR, and others it also needs to be changed in future staging editions of the AJCC

Question 4: Other comments:

No responses received