Louisiana Cancer and Lung Trust Board

Louisiana Tumor Registry Legislative Rule Changes

September 4, 2018

Board Members Present: Jay Brooks, Steve Cantrell, Renea Duffin, John Rainey, Kristi Rapp, Oliver Sartor.

Others Present: Lauren Maniscalco, Aubrey Thelen, Donna Williams, and Xiao-Cheng Wu.

Providing Written Comments: Elizabeth Fontham and Robert Newsome

After introductions, Dr. Wu reviewed the legislative rules changes previously provided to the Board and allowed for discussion.

* Screen both in-patient and out-patient records (Page 2, Column 2, 8507.A.1.ii.)
  + Board members expressed agreement.
* Request full SSN (Page 2, Column 2, 8505.A)
  + Dr. Sartor expressed concerns regarding the legality which was echoed by others. Dr. Wu assured the board that after their comments were incorporated, the proposed rule changes would go to LSUHSC-New Orleans legal for review. Members expressed agreement if approved by legal.
* Include clinically diagnosed cases (Page 2, Column 2, 8507.A.1.i.)
  + agreed
* Include molecular labs as reporting facilities (Page 2, Column 1, 8505.A.)
  + agreed
* Clarify charges for abstracting cases for facilities (Page 2, Column 2, 8507.F.)
  + Dr. Rainey suggested that the amount proposed might not cover all costs and that contract companies charge much more. Others agreed. After discussion, the Board agreed on $65 per case.
* Contacting next of kin if LTR only receives a death certificate on a case (Page 6, Column 1, 8512.B.)
  + Ms Duffin pointed out that death certificates list “informants” rather than next of kin. It was suggested that this change be made to allow contacting the informant rather than next of kin.
* Resubmission for hospitals at 15 months (Page 3, Column 1, 8507.E.1.i.)
  + Clarification was requested and Dr. Wu explained that was to ensure completeness of cases before submission to NCI and CDC.
* Requiring hospital cancer registries to participate in the LTR follow-up data exchange (Page 3, Column 1, 8507.E.1.ii.)
  + Clarification was asked for and Dr. Wu explained that this was a two-way exchange of information on date of last contact and vital status.
* Addition of genetic and genomic testing companies in external linkages. (Page 4, Column 1, 8507.I.)
  + Agreed.

Regarding section 8507.D.1, variables to be reported, a change is proposed to allow for reporting of screening data. Ms Maniscalco clarified that no one would be expected to seek out screening data, but would only be expected to report data available to them. The Board agreed to add the word “available” prior to “screening data.”

Ms Thelen discussed next steps. The draft will be reviewed by legal. Then it will go to the state for rule-making that includes a public comment period prior to promulgation.