Use of administrative coding in electronic health care record-based research of nonalcoholic fatty liver disease – an expert panel consensus statement

Appendix

Statement	Percent agreement / comment	Implication
1. Should this work focus on ICD-10-coding or also include ICD-8/9 or other coding systems?		Final document included ICD-versions 8-11
Only ICD-10	30%	
Also include ICD-8/9	60%	
Other	Also include ICD-11 (10%)	
2. Which is the main coding system in your setting?		Question considered redundant for next round of the survey
ICD-10	85%	
ICD-9	10%	
ICD-8	0%	
Other	Combination ICD-9/10 (5%)	
3. When using a cohort design to study risk of cirrhosis in persons with NAFLD, if a person defined as having NAFLD at baseline is coded with ALD, or another specific liver disease, after study baseline, should this person be censored at that timepoint?		Question rephrased for next round of the survey
Yes	45%	
No	15%	
Other	40%	
4. Should register-based definition of NASH require coding for liver biopsy? (ie not only K75.8 in ICD-10 but also a procedure code for liver biopsy)		Question rephrased for next round of the survey
Yes	55%	
No	45%	
5. If yes to the previous question, is a 6 month time-window prior to NASH diagnosis sufficient?		Question rephrased for next round of the survey and merged with question #4.
Yes	47%	
No	12%	
Other	41%	

6. In some databases/registers, primary and additional diagnoses are recorded. Should endpoints generally include also additional diagnoses? (e.g. a cohort study examines risk for incident NAFLD, should then hospitalization with diabetes as the primary indication and NAFLD as secondary count as an outcome?)		Question rephrased for next round of the survey
Yes	55%	
No	5%	
Other	45%	
7. Should hospitalization for NAFLD (with no additional coding for cirrhosis-related diagnoses) be counted as a liver-related endpoint when studying risk for cirrhosis?		Question rephrased for next round of the survey
Yes	25%	
No	60%	
Other	15%	
8. In some cases with incident cirrhosis, no etiologic code is made at the time of cirrhosis diagnosis. Is the lack of a specific code for liver disease (e.g. ALD) enough to define cirrhosis-outcomes as due to NAFLD? (e.g. in a population-based study, a person is coded with K74.6 without etiologic coding at that time).		Question rephrased for next round of the survey
Yes	10%	
No	55%	
Other	35%	
9. Regarding the previous question, sometimes an etiologic diagnosis is made a later visit to healthcare (e.g. first a hospitalization event with cirrhosis but no etiologic code, and 30 days later a visit to an outpatient clinic with an etiologic code made). Should cases where		Question removed from next round of survey after discussion among coauthors

an etiologic code exists after the event defining cirrhosis be used?		
Yes, reduces misclassification bias	75%	
No, risks survivor bias	5%	
Other	15%	
10. Should a diagnosis corresponding to a part of the metabolic syndrome (e.g. diabetes) prior or simultanously as the cirrhosis diagnosis, be enough to define a case as having cirrhosis due to NAFLD? (Given that no other liver disease is diagnosed)		Question rephrased for next round of the survey
Yes	60%	
No	15%	
Other	25%	
11. When investigating HCC-related outcomes, should the definition of HCC be restricted to only C22.0 (ICD-10), or should also "liver cancer, unspecified" (C22.9 in ICD-10) be included in the definition?		Question carried over to next round of survey as is.
Only C22.0	70%	
Also include C22.9	30%	
Also use other codes (specify)	0%	
12. It is not uncommon that persons with decompensated cirrhosis are only recieving coding for the primary decompensation, and not cirrhosis per se (e.g. coding for esophageal varices but not cirrhosis). Should we generally aim at using a composite endpoint (inspired by the cardiologists "MACE" composite event) when ascertaining progression to cirrhosis?		Question carried over to next round of survey as is.
Use composite outcome	90%	
Look at separate diagnoses	5%	
Other	5%	

13. Ascites can be found also in persons without liver disease (e.g. gynecological cancers). Should ascites require previous/simultaneous coding also for liver disease (e.g. NAFLD), and/or be used in clinical cohorts where liver disease status is known, to be counted as a decompensation endpoint?		Question carried over to next round of survey as is.
Ascites needs to be combined with a cirrhosis code	30%	
A diagnosis of ascites is enough to count as a liver-related outcome without a diagnosis of cirrhosis	5%	
A diagnosis of ascites is enough to count as a liver-related outcome without a diagnosis of cirrhosis, only if the patient is known to have a chronic liver disease (e.g. NAFLD or cirrhosis)	55%	
Other	10%	
14. There is no specific code for hepatic encephalopaty in ICD10. Is a prescription for lactulose or rifaximin, together with a code for cirrhosis or decompensated cirrhosis ok to define hepatic encephalopathy?		Question carried over to next round of survey as is.
A prescription of lactulose or rifaxmin is enough only when combined with a code for cirrhosis	60%	
A prescription of lactulose or rifaxmin is enough	0%	
A prescription of lactulose or rifaxmin is enough only when combined with a code for chronic liver disease (e.g. NAFLD or cirrhosis)	15%	
Other	25%	
15. There are other examples of codes that might or might not correspond to cirrhosis,		Question carried over to next round of survey as is.

for instance "liver failure". How should "liver failure" coding be considered?		
Include “chronic liver failure” coding in cirrhosis definition	65%	
Include “acute liver failure” in cirrhosis definition	0%	
Do not use any “liver failure” codes, too unspecific	30%	
Other	5%	

eTable 1. Replies from collaborators to the first round of the survey, and the result from these replies on the next round of the survey.