

September 15, 2026

Dear Colleagues,

Today, on behalf of the National Keratoconus Foundation (NKCF), we presented a proposal to the ICD-10-CM Coordination and Maintenance Committee requesting the creation of a dedicated ICD-10-CM code for keratoconus suspect. We are writing to ask clinicians, researchers, professional associations, patient organizations, and other members of the keratoconus community to consider submitting public comments in support of this proposal.

The public comment period closes November 13, 2026.

Why NKCF is requesting this code

Advances in corneal imaging and biomechanical assessment have made it increasingly possible to identify patients with findings suggestive of early corneal ectatic disease who do not yet meet diagnostic criteria for confirmed keratoconus. These patients are commonly identified in clinical practice as keratoconus suspects and may require longitudinal monitoring for progression. Yet there is currently no unique ICD-10-CM code for this clinically recognized population. As a result, clinicians may use codes for confirmed keratoconus, corneal ectasia, nonspecific corneal disorders, astigmatism, or other conditions.

Coding a keratoconus suspect as having keratoconus can inaccurately imply established disease; using a nonspecific code can obscure clinically important information about the patient's findings, surveillance needs, and potential for progression. The absence of a dedicated code also means this patient population cannot be reliably identified in administrative databases, electronic health records, clinical registries, or public health surveillance systems. This limits the ability to study the prevalence, natural history, progression patterns, clinical outcomes, and potential disparities associated with keratoconus suspect populations.

What this proposal is (and what it is not)

To keep public comments focused on the issue currently under consideration, we encourage commenters to distinguish the proposed code from broader issues surrounding keratoconus detection and treatment.

This proposal is specifically intended to create an accurate means of identifying patients who have clinical or imaging findings suggestive of early ectatic disease but who do not yet meet diagnostic criteria for confirmed keratoconus.

It is not a proposal to redefine confirmed keratoconus, establish screening recommendations, determine treatment eligibility, or establish reimbursement or coverage policy.

Points to consider including in your comment

To help keep comments focused on the specific issue under consideration, NKCF encourages commenters to consider incorporating the following points, as relevant to their organization, clinical experience, research, or patient community:

- *Keratoconus suspect is a clinically recognized and distinct patient population.* These patients have clinical or imaging findings suggestive of early corneal ectatic disease but do not yet meet diagnostic criteria for confirmed keratoconus.
- *Existing ICD-10-CM codes do not adequately distinguish keratoconus suspect from confirmed keratoconus.* Using an existing keratoconus code may inaccurately imply established disease, while using a nonspecific corneal or refractive code may fail to capture clinically important information about disease risk, surveillance needs, and progression potential.
- *Keratoconus suspects require clinical management that differs from both healthy individuals and patients with confirmed keratoconus.* Management may include periodic follow-up examinations, repeat corneal imaging, counseling regarding modifiable risk factors, monitoring for progression, and referral to a corneal specialist when appropriate.
- *The absence of a dedicated ICD-10-CM code creates an important clinical and public health information gap.* Keratoconus suspects cannot currently be reliably identified within administrative databases, electronic health records, clinical registries, or public health surveillance systems.
- *A dedicated code would improve the ability to study keratoconus suspect populations.* Accurate identification would support research into prevalence, natural history, progression patterns, clinical outcomes, populations at greatest risk for progression, and potential disparities in diagnosis, monitoring, and treatment.
- *Accurate identification may be particularly important in children and adolescents.* Keratoconus diagnosed in pediatric populations is frequently more aggressive and progresses more rapidly than disease diagnosed later in life, increasing the importance of identifying patients who require appropriate surveillance.
- *A dedicated keratoconus suspect code would align ICD-10-CM with terminology already used in contemporary eye care.* “Keratoconus suspect” and related terminology are already used in clinical practice, scientific literature, corneal imaging reports, and electronic health records to describe patients with findings suggestive of early ectatic disease who do not yet meet criteria for confirmed keratoconus.

How to submit a comment

Comments must be submitted no later than November 13, 2026. Please send comments to the CMS ICD-10 Coordination and Maintenance Committee mailbox at: nchsicd10CM@cdc.gov



We encourage commenters to clearly identify that their comments relate to the ICD-10-CM proposal for Keratoconus Suspect and to state whether they support creation of a dedicated code. The strength of the public comment process comes from hearing independently from clinicians, researchers, professional societies, patient organizations, and others who encounter this issue from different perspectives. We therefore encourage you to share your own experience.

Thank you for helping ensure that the ICD-10-CM system can accurately represent this clinically important patient population.

Sincerely,

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