**Template information to share with cystic fibrosis patients via CF clinical teams**

I am contacting you as part of a communication to all of our patients with cystic fibrosis (CF) following information issued by the UK Health Security Agency (UKHSA), who are investigating a small number of cases of the bacterial infection *Burkholderia cenocepacia* in the UK. Preliminary investigations suggest these cases may be linked to carbomer containing lubricating eye gels used to soothe dry eyes, though this link has not yet been proven.

So far, only a small number of people have been affected across the UK and the risk to most members of the public is considered to be very low. Even if a product is contaminated, only a small proportion of people using it would go on to develop infection. We are writing to you because people with CF are more likely to become seriously unwell with this infection.

As a precautionary measure, and until further information is available, we recommend that individuals with CF avoid using carbomer containing lubricating eye gels where possible. If you have CF and are currently using eye lubricating gel and are unsure if this is carbomer containing or have any questions concerning this, please speak to your CF clinical team. UKHSA and partners are working to confirm the source of the infections and will provide more information on their investigations as soon as possible.

**Q&A**

* What has happened?

The UK Health Security Agency (UKHSA) has identified a small number of cases of *Burkholderia cenocepacia (B. cenocepacia)* in the UK. The majority of these people did not have CF. Preliminary findings from the UKHSA investigation suggest a potential link to carbomer containing lubricating eye gels. However, at this time, there is not enough evidence to point to a particular manufacturer or specific product, or to trigger a recall. While UKHSA works with partners to investigate further, as a precautionary measure they are advising people with Cystic Fibrosis (CF) to stop using these products. This is because people with CF are susceptible to *B. cenocepacia* infection.

* What is *B. cenocepacia*?

*B. cenocepacia* is a bacteria that is found naturally in the environment but the risk of acquiring this from the general environment is low. Rarely it can cause infection in people with CF.

* How does it affect people with CF? What are the symptoms of infection?

*B. cenocepacia* can occasionally cause infections of the respiratory tract in those with CF. People with CF more likely to get seriously unwell if they have an infection, although serious illness hasn’t been observed among CF patients in relation to this situation to date.

* What brand/type of eye drops are affected?

There isn’t enough evidence to be able to conclude that one particular brand is affected, but preliminary evidence suggests that carbomer containing lubricating eye gels might be impacted. Further investigations continue.

* What should I do?

As a precautionary measure, UKHSA advise that people with CF avoid using carbomer containing lubricating eye gels while the investigation continues. If you are currently using eye lubricating gel and are unsure if this is carbomer containing or have any questions concerning this, please speak to your CF clinical team.

* How should I manage any impacts of stopping using eye drops?

If you have dry eyes or soreness and need an alternative, there are multiple other non-carbomer containing lubricating eye gels available, although UKHSA is unable to recommend a specific alternative. Please liaise with your treating CF clinician/Treatment Centre for further advice.

* Can I meet people who are using eye drops – is there a risk of cross infection?

This communication is precautionary, there is no need to change your normal interactions with people. We are advising all people with cystic fibrosis to stop using carbomer containing eye lubricating gels whilst the investigation is ongoing.

* Who should I talk to if I have questions or concerns?

Please speak to your CF clinical team.