


# The Co-Creation of a Patient Information Leaflet for Patients With the Rare Eye Infection *Acanthamoeba keratitis*

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## Abstract

*Acanthamoeba keratitis* (AK) is a rare but severe eye disease. A research engagement event, “The Cornea Day,” in London, UK in 2013, identified the lack of credible information about AK and a need for practical day to day management strategies. Experiences of 15 AK patients attending The Cornea Day were distilled into a survey that was administered to a wider group of 76 patients, carers, researchers, and clinicians. A Patient Information Leaflet was cocreated and then represented to additional patients for final modification. The AK Patient Leaflet (revised 2019) is available in several languages and used globally.

## Keywords

vision, eye, infection, co-creation, patient engagement, patient perspectives/narratives, quality of life, survey

## Introduction

*Acanthamoeba keratitis* (AK) is a rare but disabling infection of the cornea (front window of the eye) that is very difficult to treat (1). More than 30% of patients with AK lose 25% of vision and nearly 50% require treatment over 12 months (2).

Most AK cases occur in economically active, otherwise healthy contact lens wearers (1) with a dramatic loss of quality of life (3,4). AK incidence is 1 per million adults (5); this rarity is isolating and further disabling.

*Acanthamoeba* exists as an active trophozoite and a hibernating cyst (6). The cyst is highly resistant to antimicrobials; can lie dormant and reactivate disease months after resolution (1). Unlike other corneal infections, severe concurrent inflammatory responses occur in around 30% of patients, often requiring systemic immunosuppressant therapy (1). Around 50% of AK cases is misdiagnosed as Herpes Simplex Keratitis (7,8), which is associated with worse outcomes (7).

At the time of this article, no AK licensed treatments exist; the main treatments, biguanides (polyhexidine biguanide and chlorhexidine) are compounded by licensed pharmacies. Adjunctive therapy with diamidines is frequent, and while these are commercially available (Brolene, May and Baker and Desmodine, Chauvin), they are used off-label. The compounded drops are sterile for 1 month only, manufactured in glass stopper bottles and subject to raw ingredient availability.

The drops are administered hourly, day and night for the first 3 to 5 days, then 2 hourly, and then tapered. In concurrent severe inflammation, the agent prescribed has impactful side effects (1).

The rarity of AK, the severe outcomes, the potential for misdiagnosis, and difficult treatments lead to great stress for patients. The aim of the project was to demonstrate the benefit of co-creation in healthcare by the development of the first AK patient information leaflet.

## Method

Awareness of the need for a comprehensive information leaflet in the patient voice arose from an AK focus group of patients, clinicians, and researchers at the University College London (UCL) and Moorfields/NIHR Biomedical

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Research Centre (BRC) Cornea Day on October 12, 2013. At the time, an outbreak representing a 3-fold increase in AK cases at Moorfields Eye Hospital was occurring (9). The session was facilitated by 2 clinician researchers and a Patient Advocate aligned with the Patient Engagement Team at BRC. Many AK patients in the focus group commented on the lack of credible evidence-based information available during their disease. The AK focus group agreed by consensus to cocreate an AK Patient Information Leaflet, based on their experiences with the support of clinicians and researchers to ensure it was accurate and evidence based.

A non-formal qualitative summary of the AK focus group discussion was incorporated in a quantitative survey that was distributed to a wider group, including AK research participants and clinicians as well as an AK global Facebook support group. The survey data was collected via an online survey software (Qualtrics<sup>SM</sup>) link which was emailed and posted on the AK Facebook page. Survey questions included a Likert scale ranking of the importance of factors identified by the Corneal Patient Day AK focus group and included free text to add other suggestions.

## Results

Fifteen patients, 4 carers, and 2 clinician-researchers attended the 2013 Corneal Patient Day AK focus group. The main topics discussed are shown in Table 1.

For the quantitative survey (76 respondents), most had a diagnosis of AK. However, 12% were clinicians, indicating broad engagement. Most respondents were aged under 53 (74%) and 40% were male. Priority topics in order of importance are shown in Figure 1. The main concerns were

**Table 1.** Points Raised by 21 Participants of AK Cornea Day Focus Group, 2013.

Topic	Details
What is <i>Acanthamoeba</i> keratitis?	What are the symptoms? What causes AK? Background, frequency, progress of the condition, outcomes, etc.
Treatment options	Biguanides (polyhexidine biguanide and chlorhexidine) compounded by licensed hospital pharmacies. Adjunctive therapy: diamidines (Hexamidine and Brolene).
Help for patients	Appropriate contact lens hygiene/compliance. Useful tips for patients and their carers (information on hair washing, driving, working, putting eyedrops in, etc), emotional support, work support, FAQs.
News	Information about cornea days, relevant news at Moorfields.
Further reading	Links to more detailed information, academic papers, any relevant news articles etc.

understanding diagnosis, treatment, time scale for treatment, and long-term possible complications.

The AK Patient Leaflet was drafted by author IE, with clinical information provided by authors NC, MW, and MM. Plain English editing was performed by several patients, including author BR. The draft was presented at a subsequent AK Patient Focus Group in October 2014. Responses were recorded on flip charts. The patient group agreed unanimously that the scope and size of the leaflet was appropriate. Some suggested that an abstract or executive summary could also be used. Clinicians felt that the leaflet might be too long, contrasting with patient opinion, and they varied in their views regarding information to provide about complications and duration of treatment.

Further topics suggested for inclusion:

- emotional support adjusting to changes in facial appearance;
- monocular vision adjustment;
- travel, particularly flying;
- emergency indicators between appointments.

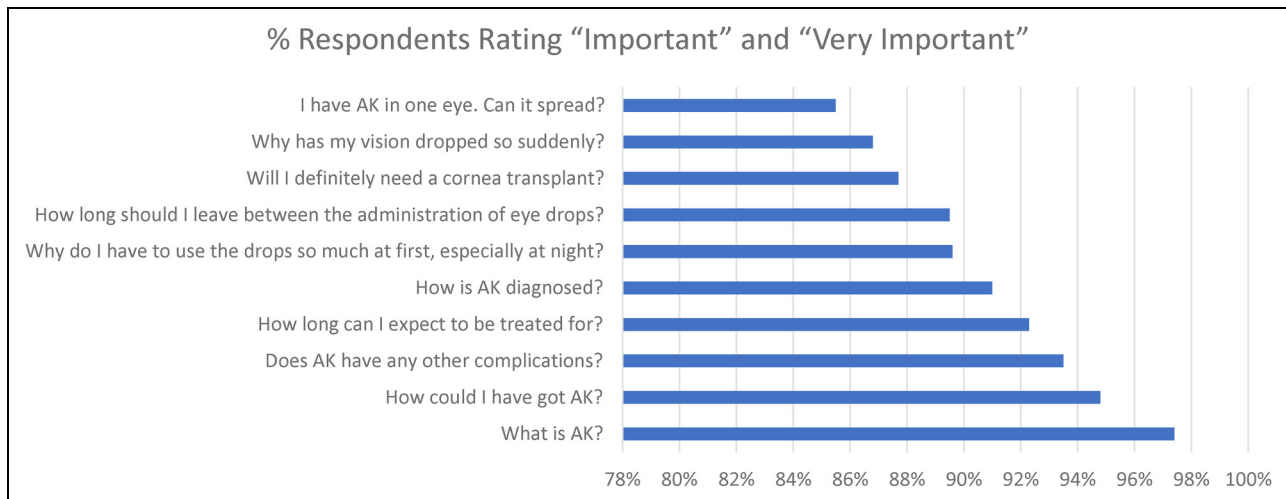
Following minor edits, the AK Leaflet was available on the hospital website (reviewed and updated 2019) (10).

## Discussion

The number of survey respondents is high compared to the rare occurrence of AK (around 5% of corneal infection patients at Moorfields Eye Hospital have AK) (1), providing robust evidence of AK patient needs. Moorfields treats 1 in 3 AK cases in the United Kingdom (5) meaning the findings are relevant broadly. The topics prioritized for inclusion in the patient leaflet demonstrate a lack of knowledge of contact lens wear risks and AK among the patient group. Furthermore, they confirm the lack of resources available to patients at diagnosis and during management.

The most easily accessible online information was questionable, alarming and not scientifically based. Online misinformation is an increasing issue and can cause confusion and concern (11). There are specific issues also around the availability of patient information for rare disease:

- Limited access to and negative information in circulation.
- Well-intentioned attempts by patients to build awareness forums without the context of official information.
- In rare diseases, the lack of opportunities for contact with other patients to share/exchange information is isolating (12,13).
- Because the main anti-*Acanthamoeba* treatments are compounded by licensed pharmacies and adjunctive therapy is off-label, there is limited information about treatments for patients compared with the information leaflets provided with licensed prescriptions—side effects, cautions etc. This further highlights the importance of credible sources of information.



**Figure 1.** The 10 highest rated priorities for the top 2 Likert categories (“important” and “very important”) (n = 76).

The second focus group meeting in October 2014, convened to review the leaflet content, was an opportunity to discuss and agree on inclusion of further topics. These concerns had not initially been voiced by patients who may have been reluctant to ask for information that did not relate to emergency medical treatment but has been proven to have long-term impacts. It was recognized that providing information about emotional support for adjusting to monocular vision, pain management, and cosmetic concerns such as wearing make-up were valid and important. In addition, cosmesis of the affected eye was discussed. James et al (14) have found that in ophthalmic patients, eye appearance is generally well-tolerated; however, there was a substantial number that did not adapt well and exhibited anxiety. Of note, they found that greater appearance-related distress and dysfunction was exhibited by younger patients and women (14), a pattern seen in the general population (15). Psychological strategies to deal with altered facial appearances are effective, particularly in establishing a trust relationship with the counselor (16).

The current version of the patient information leaflet is a downloadable PDF. Various technologies are available to magnify the print as well as assistive technology that can voice PDF text with correct markup for those with visual impairment. However, formats that are easier to navigate with poor vision, include Microsoft word documents and HTML without columns, and consideration will be given to these alternative formats in the next version of the patient leaflet.

## Limitations

A limitation of this study is that the AK Focus Group at the Cornea Day and the follow-up focus group in 2014 may have only represented patients able/willing to share experience and other patients for example too ill or speakers of other languages may have had other opinions/experiences to share.

We did invite family and friends of AK patients and make the survey available via email and on a Facebook page which may have overcome some of this bias. In the future, we could use a hybrid format and potential attendees could use real-time translation software, if required. Also, a recording available for a feedback period would have been more inclusive.

Other identified limitations of this study are that the recorded Patient Cornea Day interviews were not transcribed, and software (such as NVivo) was not used to analyze results. However, field notes were taken, and flip charts were used to record actual time responses from live discussions. These provide evidence for the subsequent quantitative study. Also, the period over which the survey was conducted was relatively short, precluding ethics board approval. However, participants were aware of the research goal and the study was conducted with Good Clinical Practice.

## Conclusion

AK patients attending The Corneal Patient Day identified a clear and urgent need for credible, accurate, and evidence-based patient information. Clinicians and researchers were able to collaborate with a wider identified patient and clinical cohort to support and structure the content of this information via a survey. This resulted in the co-creation of a practical and useful resource to aid understanding and management of the condition that is used globally. This project is a good example of the potential of working in collaboration and partnership and for the value of co-creation in the health-care system.


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