

# Supplementary Material cover page

**Article title:**

Living well with keratoconus: implications for person-centred eye care

**Journal name:** Quality of Life Research

**Authors:**

Eilin Lundanes University of South-Eastern Norway 1, ORCID iD: 0009-0000-3872-5531

Espen Andreas Brembo University of South-Eastern Norway 2, ORCID iD: 0000-0002-6738-0445

Lena Leren University of South-Eastern Norway 1&2, ORCID iD: 0000-0001-9083-5615

Vibeke Sundling University of South-Eastern Norway 1, ORCID iD: 0000-0002-9567-239X

**Institutional addresses:**

1. National Centre for Optics, Vision and Eye Care, Department of Optometry, Radiography and Lighting Design, Faculty of Health and Social Sciences, University of South-Eastern Norway, Hasbergsvei 36, 3616 Kongsberg, Norway
2. Centre for Health and Technology, Department of Nursing and Health Sciences, Faculty of Health and Social Sciences, University of South-Eastern Norway, Grønland 58, 3045 Drammen, Norway

**Corresponding author:** Eilin Lundanes, [eilin.lundanes@usn.no](mailto:eilin.lundanes@usn.no), +4731008603

## Supplementary file 1

# Interview guide

## Aim and research questions

The aim of the study is to explore experiences living with keratoconus in Norway. The research questions are how are the experiences living with keratoconus, and how do persons with keratoconus experience different optical corrections?

## Introduction and formalities

- Introducing myself and the PhD project
- Talking through the information and written consent form
  - o Aim of the study
  - o How the interview will be used
  - o Recording, transcription, and secure storage of data
  - o Anonymity
  - o The right to withdraw the consent
- Estimating the length of the interview (approximately 30-60 minutes)

| Theme                  | Questions                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Background information | <ul style="list-style-type: none"><li>- How old are you?</li><li>- What do you do for a living—are you currently working or studying?</li><li>- Do you have any hobbies or leisure activities you enjoy?</li><li>- Do you live alone or with someone? (e.g., partner, family, roommates)</li><li>- Where in Norway do you live?<ul style="list-style-type: none"><li>o How far do you travel to see your optometrist?</li><li>o How far do you travel to see your ophthalmologist?</li></ul></li><li>- How long has it been since you were diagnosed with keratoconus?</li><li>- Have you undergone any surgical treatment for keratoconus, such as collagen cross-linking, Intacs, or corneal transplantation? If so, when was your most recent procedure?</li></ul> |
| Introduction           | <ul style="list-style-type: none"><li>- To begin, could you describe what it's like for you to live with keratoconus?</li><li>- How does keratoconus affect your everyday life?<ul style="list-style-type: none"><li>o What feels different now compared to before you were diagnosed with keratoconus?</li></ul></li></ul>                                                                                                                                                                                                                                                                                                                                                                                                                                           |

|                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|--------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                            | <ul style="list-style-type: none"> <li>- Can you describe specific situations where keratoconus impacts your daily life?</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Visual function                            | <ul style="list-style-type: none"> <li>- Can you describe how you currently experience your vision in everyday life?</li> <li>- In what ways has your vision changed since being diagnosed with keratoconus?</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Symptoms                                   | <ul style="list-style-type: none"> <li>- Would you like to describe any specific eye-related symptoms or difficulties, and how these affect your daily life?</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Emotional well-being                       | <ul style="list-style-type: none"> <li>- Do you feel that keratoconus has affected you emotionally? If so, could you describe in what ways? <ul style="list-style-type: none"> <li>o How have your emotional responses changed over time, compared to when you were first diagnosed?</li> </ul> </li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Social relationships and life consequences | <ul style="list-style-type: none"> <li>- How has keratoconus affected your work or studies?</li> <li>- Could you tell me about any choices you've made that were influenced by keratoconus?</li> <li>- How has keratoconus influenced your choices related to hobbies, interests, or leisure activities?</li> <li>- Do you feel that keratoconus affects your social life? If so, in what ways? <ul style="list-style-type: none"> <li>o How do you experience understanding and support from those around you, such as friends and family?</li> </ul> </li> </ul>                                                                                                                                                                             |
| Worries                                    | <ul style="list-style-type: none"> <li>- Has keratoconus led to any new worries that you didn't have before? If so, could you share a bit about them?</li> <li>- How do you feel these worries are acknowledged or addressed by your, family, friends, ophthalmologist and optometrist?</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Optical correction                         | <ul style="list-style-type: none"> <li>- Do you currently use spectacles or contact lenses? If contact lenses, what type do you use? <ul style="list-style-type: none"> <li>o How well do your glasses or contact lenses work for you?</li> <li>o Are there any aspects that don't work as well as you would like?</li> </ul> </li> <li>- Have you previously tried other types of glasses or contact lenses <ul style="list-style-type: none"> <li>o Do you have any thoughts on why these worked or didn't work for you?</li> </ul> </li> <li>- What motivates you to try new forms of vision correction? <ul style="list-style-type: none"> <li>o Are there any factors that discourage you from trying new options?</li> </ul> </li> </ul> |
| Follow-up by eye care professionals        | <ul style="list-style-type: none"> <li>- How do you experience the follow-up you receive from your ophthalmologist? <ul style="list-style-type: none"> <li>o In what ways do you feel your ophthalmologist contributes—positively or negatively—to your experience of living with keratoconus?</li> </ul> </li> <li>- How do you experience the follow-up you receive from your optometrist? <ul style="list-style-type: none"> <li>o In what ways do you feel your optometrist contributes—positively or negatively—to your experience of living with keratoconus?</li> </ul> </li> </ul>                                                                                                                                                     |

|                           |                                                                                                                                                                                                                                                          |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Closing questions         | <ul style="list-style-type: none"> <li>- Before we wrap up, is there anything else you'd like to share about your experiences living with keratoconus?</li> </ul>                                                                                        |
| General follow-up prompts | <ul style="list-style-type: none"> <li>- Could you tell me more about that?</li> <li>- Do you have any additional examples you'd like to share?</li> <li>- How did you experience that situation?</li> <li>- In what ways did that affect you</li> </ul> |