**A patient consensus on essential requirements for guidelines**

**Uveal Melanoma** is a rare form of Melanoma starting in the eye and affecting 6-8 out of 1 Million people. Currently, several guidelines are in preparation to improve care and outcomes in Uveal Melanoma. To ensure constructive, high-quality and consistent patient input into these guidelines, our community decided to proactively formulate a patient consensus on the essential requirements for Uveal Melanoma guidelines. Here we report on the methodology and progress of MPNE’s first consensus process.

### Desired outcomes of MPNE’s first consensus process

- Define essential aspects any uveal Melanoma guideline needs to cover
- Define essential criteria for successful guideline implementation
- Develop an accompanying advocacy and educational strategy

---

**Identifying problematic decision points in the UM patient pathway**

**Sweden 2020 Q1**

- **Uveal Melanoma (UM):** 80 patients/year, Metastatic disease (MUM): 40/year
- Extra-hepatic disease: 20/year

**Findings**

- Well-structured care for primary Uveal Melanoma
- No structured pathway for metastatic UM
- Poor access to experimental medicine (clinical trials, precision medicine programs, compassionate usage)

**Progress and learnings**

**Progress**

The COVID-19 outbreak forced us to postpone the March 13th-15th F2F meeting, so we altered our methodology, starting with a virtual kick-off meeting.

1. Map UM patient journeys, identify problematic decision points ✔
2. Facilitators and barriers to guideline implementation ✔
3. Establish a joint Zotero literature repository for UM ✔
4. Review existing evidence in those areas of concern

**Next**

Classification of action points- to be covered by guideline? Research need? Advocacy concern? Other? Problem statement (executive summary style)

**Learnings so far**

- Appropriate methodology critical for effective consensus-finding
- Allow for sufficient time for training on the tools
- Group size of 11 ensured productive work
- Extended periods of online work problematic
- Literature search and management surprisingly time-consuming
- Feedback from other stakeholders so far very positive

**Thank you**

To the UM consensus faculty for their dedication and continuing hard work!