

# Essential Requirements for Uveal Melanoma Guidelines-learnings from the first MPNE patient consensus meeting.

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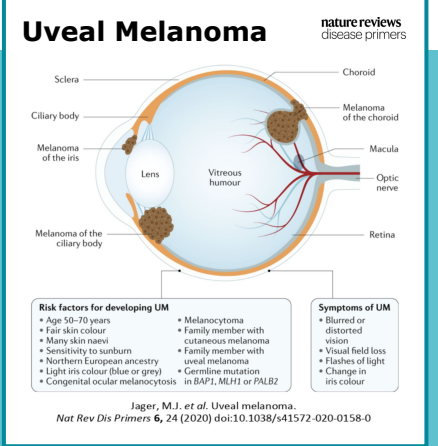


## A patient consensus on essential requirements for guidelines

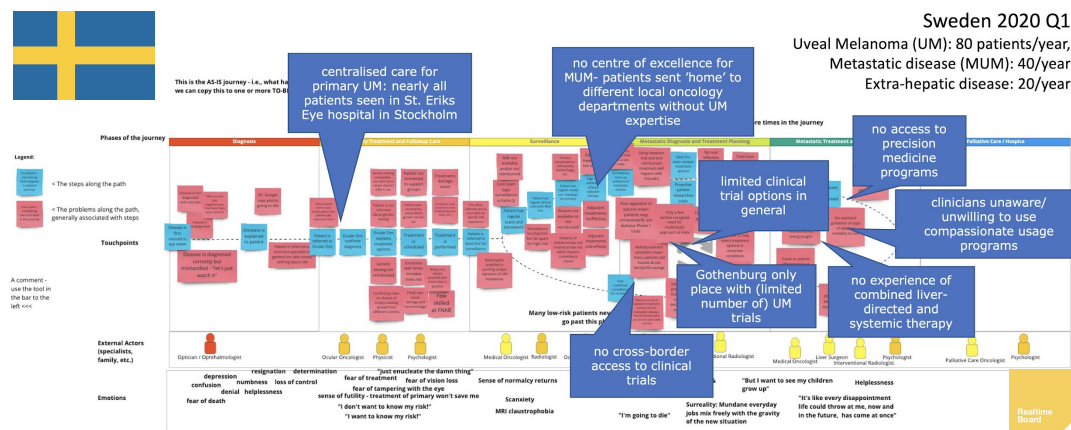
**Uveal Melanoma** is a rare form of Melanoma starting in the eye and affecting 6-8 out of 1 Million people. Currently, several guidelines are in preparation to improve care and outcomes in Uveal Melanoma. To ensure constructive, high-quality and consistent patient input into these guidelines, our community 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



**Uveal Melanoma patient pathways** were mapped repeatedly in face-to-face and virtual sessions for consistency. We generated both general and country-specific maps, shown here is the Swedish example.

### 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!



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