

# How to set a research agenda for a diverse and divided patient population

A qualitative study to assess the research needs of  
PEOPLE WITH A VISUAL IMPAIRMENT OR OPHTHALMOLOGICAL DISEASE

Anne-Floor Schölvinc MSc, Carina Pittens PhD and prof. Jacqueline Broerse

Athena Institute, VU University, de Boelelaan 1085, 1081HV Amsterdam, the Netherlands

## Introduction

### Aim & Background

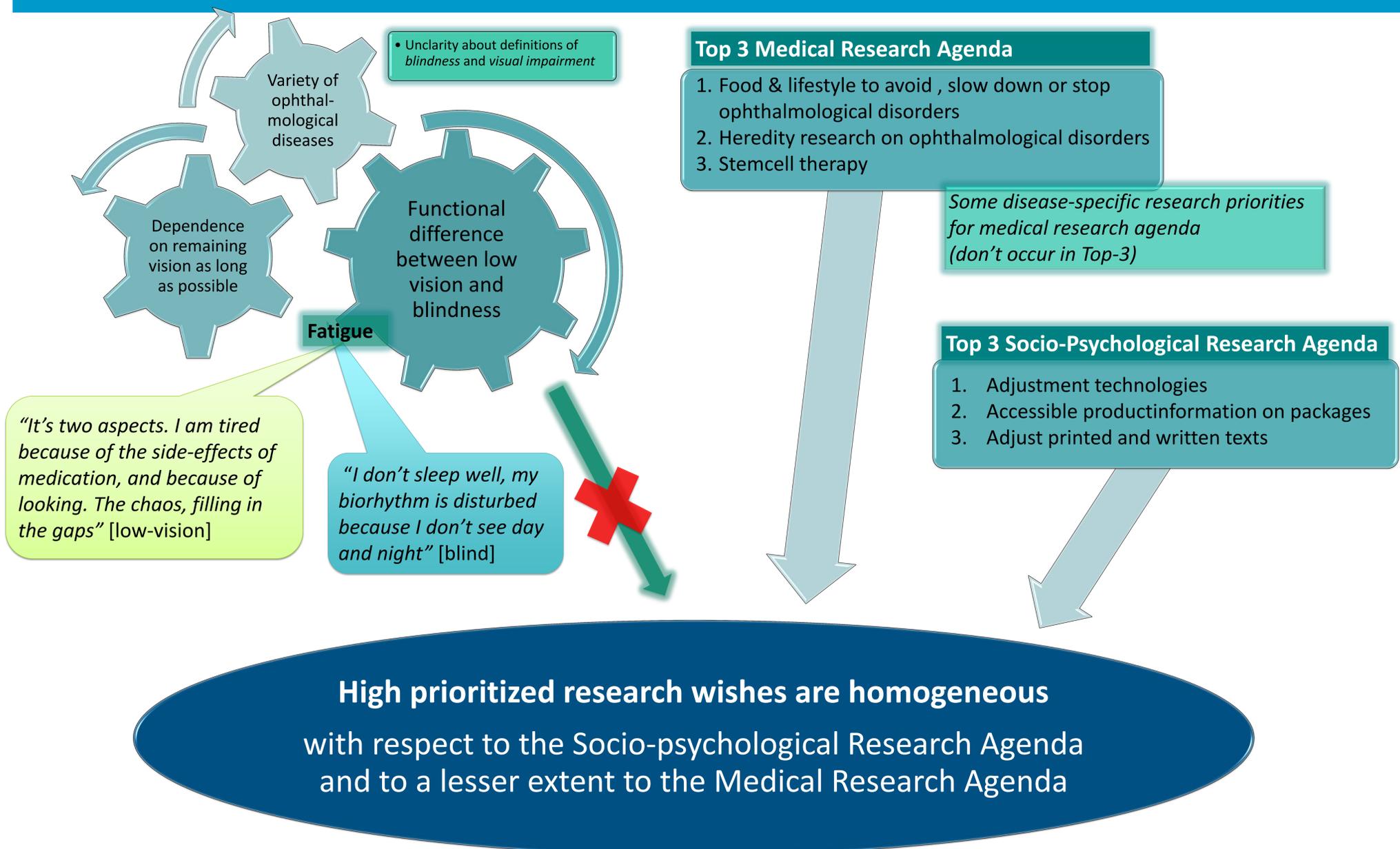
Patient involvement in research agenda setting has been studied in various initiatives. However, little insight is available on **effective involvement strategies** for **highly diverse and divided patient populations**. The heterogeneous nature of people with various ophthalmological diseases or a varying severity of visual impairment is characterized by functional and perceived differences between low vision, blindness and deaf-blindness. This limits the patients' shared advocacy role in policy-making and research agenda setting.

By developing a **shared research agenda**, patients (representatives) can act as a well-equipped and well-informed interlocutor for policymakers and researchers, thereby connecting policy and/or research better to meet the patients' needs.

## Dialogue Model - Methods

<b>Exploration phase</b>	Six explorative interviews with patient representatives
<b>Consultation phase</b>	Eight focus group discussions, four additional interviews and seven feedback sessions with people with a visual impairment or ophthalmological disease (n = 64, 7, 18 respectively)
<b>Prioritization phase</b>	Two questionnaires amongst people with a visual impairment or ophthalmological disease; on medical and societal issues (respondents > 1000)
<b>Integration phase</b>	Dialogue meeting with stakeholders from the field of eye care and eye research and selection of patients from previous phases

## Dialogue Model – Results



## Conclusion

Setting a research agenda for a diverse and divided patient population requires both **efforts to unify the target audience** and **to acknowledge differences in their needs and wishes**. For people with an ophthalmological disease or visual impairment a research agenda has been set in which substantial overlap between different stakeholder groups has been identified, but in which differences have been acknowledged too. The agenda will serve as a starting point to defend the interests of the target audience to policymakers and research organizations.