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

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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
Exploration phase
Six explorative interviews with patient representatives

Consultation phase
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)

Prioritization phase
Two questionnaires amongst people with a visual impairment or ophthalmological disease; on medical and societal issues (respondents > 1000)

Integration phase
Dialogue meeting with stakeholders from the field of eye care and eye research and selection of patients from previous phases

Dialogue Model – Results

Top 3 Medical Research Agenda
1. Food & lifestyle to avoid, slow down or stop ophthalmological disorders
2. Heredity research on ophthalmological disorders
3. Stemcell therapy

Top 3 Socio-Psychological Research Agenda
1. Adjustment technologies
2. Accessible productinformation on packages
3. Adjust printed and written texts

High prioritized research wishes are homogeneous with respect to the Socio-psychological Research Agenda and to a lesser extent to the Medical Research Agenda

Functional difference between low vision and blindness

Variety of ophthalmological diseases

Dependence on remaining vision as long as possible

“Unclear about definitions of blindness and visual impairment”

Some disease-specific research priorities for medical research agenda (don’t occur in Top-3)

“Fatigue”

“I don’t sleep well, my biorhythm is disturbed because I don’t see day and night” [blind]

“It’s two aspects. I am tired because of the side-effects of medication, and because of looking. The chaos, filling in the gaps” [low-vision]

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.

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