

# The Patient Voice in Neovascular Age-Related Macular Degeneration: Findings from a Qualitative Patient Study

S. James Talks,<sup>1</sup> Vincent Daien,<sup>2</sup> Paul Mitchell,<sup>3</sup> Tariq Aslam,<sup>4</sup> Jane Barratt,<sup>5</sup> Anna Biberger,<sup>6</sup> Ecosse L. Lamoureux,<sup>7</sup> Ceri Hirst,<sup>8</sup> Michelle Sylvanowicz,<sup>8</sup> Robert P. Finger<sup>9</sup>

<sup>1</sup>Newcastle Eye Centre, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>2</sup>Department of Ophthalmology, University Hospital of Montpellier, Montpellier, France

<sup>3</sup>University of Sydney (Westmead Institute for Medical Research), Sydney, NSW, Australia

<sup>4</sup>Manchester Royal Eye Hospital, Manchester, UK, and University of Manchester, Manchester, UK

<sup>5</sup>International Federation on Ageing, Toronto, ON, Canada

<sup>6</sup>Cerner Enviza, Munich, Germany

<sup>7</sup>Singapore Eye Research Institute, Singapore and Duke-NUS Medical School, Singapore

<sup>8</sup>Bayer Consumer Care AG, Basel, Switzerland

<sup>9</sup>Department of Ophthalmology, University of Bonn, Bonn, Germany



# Disclosures

**S. James Talks:** Advisory board member, speaker fees, and research support: Bayer, Novartis; Research grants: Roche, Boehringer Ingelheim

**Vincent Daïen:** Consultant: Bayer, Horus Pharma, Novartis, Théa

**Paul Mitchell:** Consultant: Allergan, Bayer, Novartis; Steering committee member: Bayer

**Tariq Aslam:** Consultant: Bayer, Bausch & Lomb, Novartis, Oraya, Théa

**Jane Barratt:** Consultant: Bayer

**Anna Biberger:** Employee: Cerner Enviza (formerly Kantar)

**Ecosse L. Lamoureux:** Nothing to disclose

**Ceri Hirst:** Employee: Bayer Consumer Care AG

**Michelle Sylvanowicz:** Employee: Bayer Consumer Care AG

**Robert P. Finger:** Research grants: CentreVue, Heidelberg Engineering, Novartis, Zeiss; Consultant: Alimera, Allergan, Bayer, Ellex, Inositec, Novartis, Opthea, Roche/Genentech, Santhera; Support for travel: Novartis



The gold standard treatment for nAMD is intravitreal anti-VEGF therapy; however, treatment outcomes in routine clinical practice do not match those seen in clinical trials, partly due to patients receiving **fewer injections in a real-world setting**<sup>1,2</sup>



**Visual impairment** resulting from diseases such as nAMD may cause **behavioral, environmental, psychological, and logistical challenges** that could act as barriers to effective treatment with anti-VEGFs; a cycle of worsening vision that further exacerbates these challenges may begin<sup>3-6</sup>



At a more severe level, **clinical depression** is strongly associated with nAMD, as well as poor adherence to treatment, lower physical activity, and poor diet<sup>3,7,8</sup>



**Dissatisfaction with nAMD treatment or care** is associated with a greater likelihood of non-adherence to therapy and poorer outcomes<sup>5,9,10</sup>

nAMD, neovascular age-related macular degeneration; VEGF, vascular endothelial growth factor.

1. Holz FG, et al. *Retina*. 2020;40(9):1673-85. 2. Eter N, et al. *Graefes Arch Clin Exp Ophthalmol*. 2021;259(8):2213-23. 3. Zheng Y, et al. *Sci Rep*. 2017;7:46453. 4. E JY, et al. *Cochrane Database Syst Rev*. 2020;9:CD009233. 5. Okada M, et al. *Ophthalmology*. 2021;128:234-47. 6. Okada M, et al. *JAMA Ophthalmol*. 2021;139(7):769-76. 7. Cimarolli VR, et al. *Clin Ophthalmol*. 2016;10:55-63. 8. Park M, Unutzer J. *Psychiatr Clin North Am*. 2011;34(2):469-87. 9. Droege KM, et al. *Graefes Arch Clin Exp Ophthalmol*. 2013;251(5):1281-4. 10. Polat O, et al. *Turk J Ophthalmol*. 2017;47(4):205-10

# Rationale, challenge and aim



**Rationale:** A **patient-focused approach to care for nAMD**, which relies on understanding and considering the challenges and emotions of patients at every stage of their journey, could improve and optimize the treatment experience and, in turn, visual outcomes and patient quality of life



**Aim:** To gain a **deeper understanding of the emotions and experiences related to nAMD** to understand determinants of adherence, and to identify where meaningful interventions to support improved outcomes can be developed

# Methodology and analysis<sup>1</sup>

Study centers:  
France, Germany, UK



- The study was conducted between 26 October 2020 and 29 March 2021
- No treatment decisions were impacted by inclusion in the study

HCP online survey



- HCPs<sup>a</sup> recruited patients, and provided patient characteristics, treatment history, and health and adherence

Patient questionnaires  
and interviews<sup>b</sup>



- Patients completed NEI VFQ-25 and health status scale questionnaires
- Patients had a telephone interview, including questions about practical and emotional effects of nAMD on their lives, their treatment expectations

Data and  
transcript analysis



- Patient questionnaire data were analyzed descriptively
- Patient interview data were analyzed according to qualitative thematic analysis methodology<sup>2</sup> modified where appropriate to align with research in ophthalmology<sup>3,4</sup>

Insights generation



- Insights into patient emotions and experiences were generated through interpretation of the results by the authors

<sup>a</sup>Retinal specialists with ≥5 years' experience, ≥100 patients with nAMD within their clinic, and regularly initiate anti-VEGF treatments and personally manage patients; <sup>b</sup>Although caregiver interviews were planned, only one of the five caregivers recruited was interviewed; the others could not take part owing to personal and/or medical reasons. Recruitment targets were relaxed due to disruption of usual services caused by the COVID-19 pandemic.

HCP, healthcare professional; nAMD, neovascular age-related macular degeneration; NEI VFQ-25, National Eye Institute Visual Function Questionnaire; UK, United Kingdom.

1. Talks SJ, et al. *Ophthalmol Ther.* 2023;12:561–75. 2. Braun V, Clarke V. *Qual Res Psych.* 2006;3(2):77–101; 3. Taylor DJ et al. *Eye.* 2020;34(3):461–73; 4. Patrick DL et al. *Value Health.* 2011;14(8):967–77.

# Aspects of the nAMD journey covered in patient interviews



Vision concerns and  
diagnosis



Initiation of treatment



Treatment:  
Injections, regimens  
and satisfaction



Treatment:  
Patient–HCP interactions  
and relationships



Clinical management:  
Experiences in the clinic



Clinical management:  
Missing and  
stopping treatment



Impact of nAMD:  
Overall health and  
independence



Impact of nAMD:  
Coping strategies,  
caregivers and PSOs

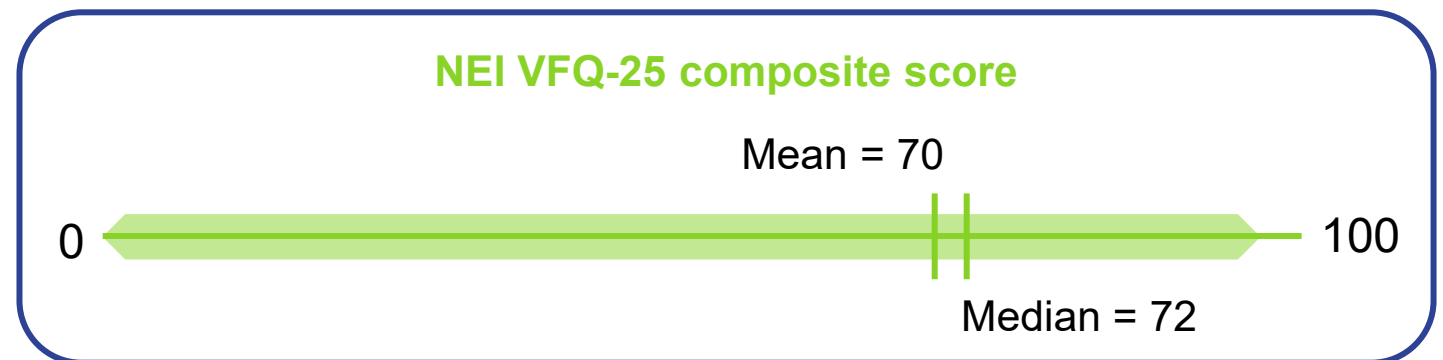
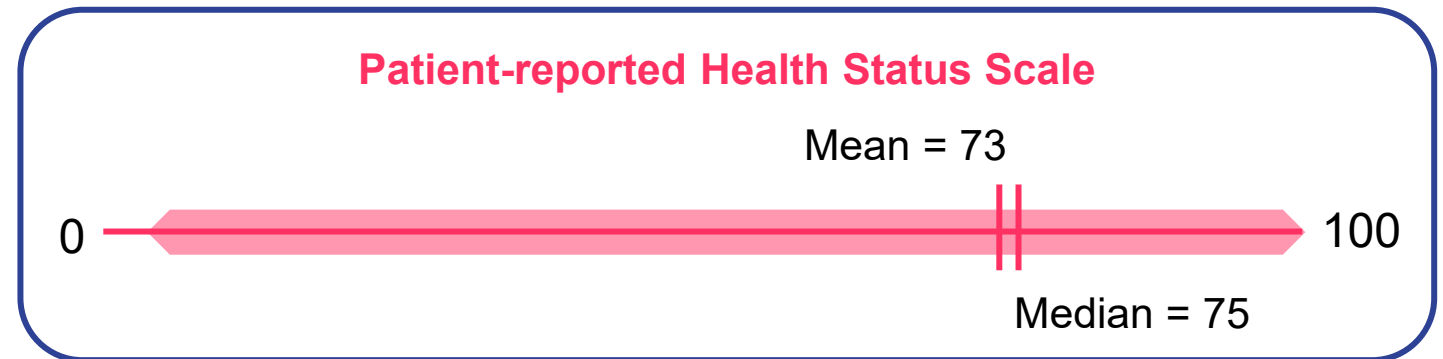
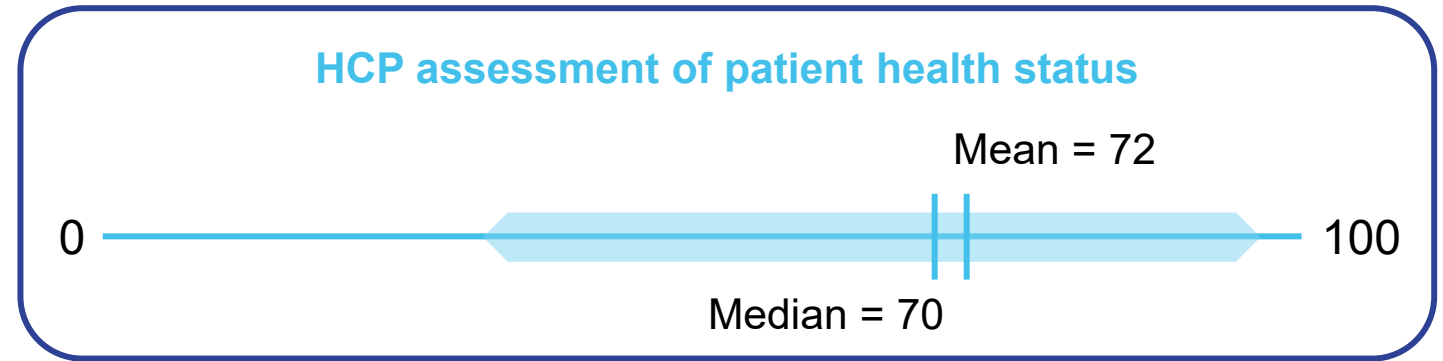
# Patient characteristics and quality of life assessments<sup>1</sup>

Patient characteristics	Overall cohort (n=17)
<b>Age</b>	
Mean, years (median; range)	77 (77; 65–90)
<b>Sex</b>	
Female	9 (53)
<b>Marital status</b>	
Married/living with partner	9 (53)
Divorced	3 (18)
Widowed	3 (18)
<b>Employment status</b>	
Employed	5 (29)
Retired	12 (71)
<b>Duration since nAMD diagnosis</b>	
≤6 months	7 (41)
≥12–<24 months	6 (35)
>24 months	4 (24)
<b>Adherence<sup>2</sup></b>	
Fully adherent	9 (53)
Adherent	4 (24)
Non-adherent	4 (24)
<b>Caregiver support</b>	
Yes	5 (29)
<b>Patient report of other chronic diseases</b>	
	12 (71)

Data in table reported as n (%) unless otherwise indicated.

Arrows visualize reported range for quality of life assessments.

1. Talks SJ, et al. *Ophthalmol Ther.* 2023;12:561–75. 2. Okada M, et al. *Ophthalmology.* 2021;128:234–247.



# Patient experiences and emotions

## Diagnosis and treatment



### Vision concerns and diagnosis

Many patients reported not fully understanding nAMD at diagnosis

“  
*In the beginning, you're lost, you wait for [nAMD] to go away*  
”



### Initiation of treatment

Most patients reported no discussion of treatment options, outcomes, or long-term plans

“  
*He only said it was an AMD, “I prescribe you 3 IVT.” That's it [...]. What else do you expect him to tell me?*  
”



### Treatment: Injections, regimens and satisfaction

After several injections, many understood that treatment was long term and were satisfied with their outcomes

“  
*I want it to maintain the good vision I have [...] I can only see with one eye; it's particularly important to me.*  
”



### Treatment: Patient–HCP interactions and relationships

Many patients described their relationship as good and personable

“  
*Oh, yes, he is willing to actually answer your questions and he's got a very nice manner with him*  
”



# Patient experiences and emotions

## Clinical management and impact of nAMD



### Clinical management: Experiences in the clinic

Waiting room experiences differed by country, but most tolerated some waiting time as an aspect of treatment

“Short time sometimes, and then other times I'm probably waiting 10 or 15 minutes, but it doesn't bother me”



### Clinical management: Missing and stopping treatment

Most patients (82%, n=14) would not want to stop their treatment and had not considered doing so

“As long as the doctor doesn't tell me to stop, I'll keep going until it gets back to normal or it stops. I will never stop by myself”



### Impact of nAMD: Overall health and independence

Patients learned to deal with their nAMD, but many had difficulties with daily activities

“I've knitted for years for charity, and I've had to stop it, just because I don't want to push the eye into more”



### Impact of nAMD: Coping strategies, caregivers and PSOs

Patients had diverse coping strategies to help with their nAMD

“I had to notify my bank and say, “I can't read [my statements], is there anything you can do for me” now I get great big sheets of paper”

# Vision concerns and diagnosis

Many patients reported initially suspecting an issue with vision other than nAMD.

**An ophthalmologist or optician subsequently diagnosed nAMD**

nAMD was usually explained by the diagnosing HCP. Some HCPs gave leaflets and brochures to aid in explanation; however, **many patients reported not fully understanding nAMD at diagnosis**

**A reluctance to ask for further information** was often mentioned, despite some patients feeling underinformed and doing their own research to understand nAMD

Many patients reported that **HCPs did not discuss treatment options at diagnosis**

## Patient quotes

“ I noticed while reading that something was wrong. I became active quickly [...] I thought maybe the eye was inflamed, conjunctivitis. But by a lucky circumstance, I got an appointment with the ophthalmologist. ”

“ In the beginning, you're lost, you wait for [nAMD] to go away. ”

“ I was terrified. ”

“ *Answering: Did you feel you were fully informed at [diagnosis]?*  
What is fully informed? If I knew what fully informed was, then I could say that. ”

“ He told me that I'd got dry macular and he said there's not an awful lot we can do for dry macular, we can just give you a prescription as and when. So, I thought well if that's the case (that's the case as it was then). ”

# Initiation of treatment

When learning about anti-VEGF treatment, patients feelings ranged from **happiness** that a treatment existed, to **anxiety, apprehension, and terror** about the injection process and long-term outcomes

Most patients reported **no immediate discussion of treatment options, outcomes, or long-term plans**. Initial expectations of treatment varied across respondents

Many patients reported **wanting to get the injection over with**

Patients reported **discomfort and sometimes pain**, while some patients were **surprised at side effects of the injections**

## Patient quotes

“ No great expectations were raised. I was told it was not curable. You can only delay it by taking certain measures. And the professor also said, ‘I can only tell you that you will not go blind. But there is no improvement or cure at the moment.”

“ He only said it was an AMD, “I prescribe you 3 IVT.” That’s it [...]. What else do you expect him to tell me? [...] He’s got bigger fish to fry than explaining to the patient details about his pathology.”

“ I felt bad, I was apprehensive about the injection..”

“ And the more injections I receive, the more anxious I am.”

# Treatment: Injections, regimens and satisfaction

Some patients felt the need for life-long injections had not been discussed at time of diagnosis. After receiving several injections, many **understood that treatment would likely continue for the rest of their lives**

Most patients reported initial concern about injections into their eye, but **treatment became routine for a majority of patients** (likened to visiting the shops or the dentist; not necessarily pleasant, but important)

Most patients were **satisfied with their treatment**, understood that stability was a measure of treatment success, and understood the need for life-long treatment

Patients were generally **not aware of the treatment regimen they were receiving**, and were happy to follow their HCP's advice

## Patient quotes

“ It's a bit like going to the dentist: you have a filling, you have this, you have that, and I'm always glad when it's over. ”

“ To have my vision maintained. I want it to maintain the good vision I have [...] I can only see with one eye; it's particularly important to me. ”

“ I expect the frequencies [of injections] to increase. It would be nice when I only had to go there every 3 months or 4 times a year, or when the doctor said, 'The drug has had such a good effect.' I cannot see any difference the last three times: no bleeding, no incrustation. I have never asked. ”

“ I just thought it was long-term, you know, ongoing, I thought I would go every eight weeks perhaps for the rest of my life. I didn't know. ”

# Treatment: Patient–HCP interactions and relationships

Patients largely reported feeling able to **ask their HCP questions during appointments**

Many patients described their **relationship with their HCP as good and personable**

Concerns were raised about **not seeing the main doctor treating their nAMD frequently enough**

**Patients who often saw other doctors instead of their main doctor felt anonymous** and that they were missing the opportunity to build a patient–HCP relationship

## Patient quotes

“ To my main ophthalmologist, [our relationship] is good. I am very satisfied with it. But with the others not. I simply get too little information. In terms of treatment, it may be good. But I just don't get enough information. ”

“ Oh, yes, he is willing to actually answer your questions and he's got a very nice manner with him, he's got a very soft manner. And I think as long as you're asking questions around your eyesight. ”

“ I think there were about 50 consultations that day and all the patients were queuing to receive an injection. I can understand that the intern gets bored when he sees the last patients. ”

# Clinical management: Experiences in the clinic

Patients mentioned **long waiting times** and would actively **request the first appointment of the day**

Experience of waiting rooms differed by country, but **most were happy to tolerate some waiting time as an aspect of treatment**

Changes in hospital set-up due to COVID-19 were frustrating but the **reduced number of patients in waiting rooms was pleasant**

Patients reported frequently **not knowing if the next visit would be for monitoring or injection**

## Patient quotes

“ I had to wait longer there before. They didn't register me when I came in. They had completely lost track of me. ”

“ Well, I can be sat for a short time sometimes, and then other times I'm probably waiting 10 or 15 minutes, but it doesn't bother me because I'm watching what's going on. ”

“ *Answering about changes due to COVID-19:*  
I mean it is strange; I mean you're very much aware that you must try and keep your distance from folk, and if you're forming a queue to go in, maybe two or three people in front of you, there may not be, or there could be two or three people behind you, you know, I try and keep my distance. ”

# Clinical management: Missing and stopping treatment

## Patient quotes

Patients generally **understood the requirement to keep appointments**, but did express frustration that they had to live their lives around these visits

**Missed appointments were infrequent in this cohort**

Three patients missed appointments to prioritize other conditions, and two due to clerical errors

**Difficulties in making appointments were highlighted**, such as not being able to schedule far enough in advance and difficulties with clinic staff members

Most patients would **not want to stop their treatment** and had never yet considered doing so

“ I always try to be there. I prefer to skip other appointments ”

“ As long as the doctor doesn't tell me to stop [receiving anti-VEGF injections], I'll keep going until it gets back to normal or it stops. I will never stop by myself. ”

“ From what I have understood, there are two secretaries: one for the injections and another one for the follow-up consultations. For me, it's a bit peculiar. ”

“ *Answering: Is there anything that might make you want to stop [treatment]?*  
Not being reimbursed for my expenses. I found out that these injections cost a fortune. ”

# Impact of nAMD: Overall health and independence

Patients learned to deal with their nAMD and **developed ways to manage tasks**, but many had difficulties with daily activities such as cooking, cleaning, knitting, and driving

Patients generally reported nAMD having no impact on their lives, other than often requiring assistance attending injection appointments, with many expressing that their **difficulties were typical of their stage of life**

Patients able to drive reported **valuing the independence and control** this gave them

Patients were generally **conscious of their overall health** and reported taking steps to improve their nAMD (e.g., changing their diet)

## Patient quotes

“ I've stopped knitting. I've knitted for years for charity, and I've had to stop it, just because I don't want to push the eye into more ”

“ It's eyesight, for my age, I think it's probably near perfect. ”

“ In the past, I fell down several times when I was running after the bus because of this eye that no longer sees. One must know that I don't have three-dimensional vision since my other eye doesn't work anymore. I don't see the difference in height anymore, I stumble.” ”

“ Carrots, lentils, that's classical. Blueberries ... good for vision. And the intern in the ER prescribed me a treatment to cure vision, not to cure AMD, [but] vision. It is a food supplement with omega 3, lutein, zinc... ”



# Impact of nAMD: Coping strategies, caregivers and PSOs

Patients had diverse coping strategies to help with their nAMD, such as wearing sunglasses or dimming lights after injections, larger font post, and devices to help around the house

Support at home was primarily provided by spouses, with children also mentioned

Most patients reported not using, or having never considered using, PSOs

One patient reported thinking they might be negatively stimulated by attending a PSO

## Patient quotes

“ My son drives me, or my husband. ”

“ I had to notify my bank and say, ‘look, it’s no good you sending me a bank statement, I can’t read it [...], is there anything you can do for me’ [...] Now I get great big sheets of paper. ”

“ I don’t need any support. Only when I come down the stairs at the doctor’s because I can’t see very well. When my husband is standing there, he helps me.... ”

“ I think that I am not the normal AMD patient. I don’t have a problem with my vision, and I don’t need any help. I can do everything by myself, do everything by myself, and get along well by myself. ”

“ I wouldn’t go to a support group. I think I’m so stable that I would be more negatively stimulated there if everyone told me their misery. ”

# Overall themes



Interview responses were varied, indicating **the need for a personalized approach when treating nAMD**



**Information gaps were reported during patient diagnosis and initial treatment**, including patients not fully understanding that treatment for nAMD was likely life-long



**Treatment itself was often approached pragmatically**, and most patients understood that disease stability was a measure of treatment success. The **importance of treatment adherence and persistence** was also generally understood



Patients generally **learnt to deal with their nAMD**, developed **coping strategies**, and framed their vision difficulties in the **context of other adults of a similar age**

# Strengths and limitations of the study



This study provides a **wealth of information directly from patients about their emotions and experiences of nAMD** at every stage



**Challenges during recruitment**, including recruiting non-adherent or non-persistent patients and further COVID-19-related complications, **may have led to a biased study sample**



**This study cohort has a European focus**, and the findings must be taken in context with **the heterogeneity of people with nAMD and the unique health systems in France, Germany, and the UK**



Further comparisons between patients receiving **unilateral injections and bilateral injections** (including those with same and different schedules per eye) would be beneficial



**Non-adherent patients may have been unwilling to participate** due to a lack of engagement with their disease or treatment, or comorbidities

# Conclusions and recommendations



This multi-country, cross-sectional study of patients with nAMD provides unique insights to highlight the **importance of the patient voice when considering approaches to patient care and management**



This study identified **key areas for improving the patient's overall experience**, including:

- A personalized approach to communication and support from HCPs
- A comprehensive approach to tackling logistical challenges



These insights will **assist in the development of meaningful and relevant interventions** that support improved outcomes for patients with nAMD



With these findings, we hope to encourage continued efforts within the retinal community to undertake **patient-focused studies**, considering patient experiences and emotions, **to inform clinical practice and policy**

# Thank you to all study participants and sites



## Acknowledgements

The survey was conducted by Kantar (now Cerner Enviza), and was funded by Bayer Consumer Care AG, Basel, Switzerland.

Medical writing support was provided by ApotheCom, under the direction of the authors, and was funded by Bayer Consumer Care AG, Basel, Switzerland, in accordance with Good Publication Practice (GPP3) guidelines (*Ann Intern Med* 2015;163:461–464).