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Title: Patient experiences of treatment for diabetic retinopathy: development of a retinopathy-specific treatment satisfaction questionnaire.

Aims: To design a measure of satisfaction with treatments for diabetic retinopathy, incorporating patient views.

Methods: An iterative approach incorporated qualitative and quantitative methods. In 44 semi-structured interviews (11 in each of 2 UK and 2 German hospitals) respondents described experiences of retinopathy treatments and reactions to possible new treatments. They completed and commented on the latest draft Retinopathy Treatment Satisfaction Questionnaire (RetTSQ), which was revised and translated between centres to incorporate patient views. Interviews were content analysed.

Interviewees: 44 people with varying levels of diabetic retinopathy, 31 having macular oedema. 26 men, 18 women. Median age 60.8 (range: 28-82); median visual acuity best eye 0.80 (range: detect hand motion at 1 metre (0.0025) – 6/5 vision (1.20). Laser photocoagulation sessions ranged 0-20; vitrectomies ranged 0-2.

Results: Dimensions of satisfaction were similar in UK and Germany and included satisfaction with treatment effectiveness, emotional and physical experiences (before, during and after treatment), information provision and influence over treatment. Content and layout of the resulting 13-item RetTSQ are appropriate for people with diabetic retinopathy.

Conclusions: There is considerable scope for improving patient experience of

diabetic retinopathy treatments. The RetTSQ will be useful in evaluating current and future treatments in research and clinical contexts.