Clinical Research 

## Development of Knowledge, Attitude and Practice Questionnaire for age-related macular degeneration patients

Mohd Harimi Abd Rahman<sup>1</sup>, Prashanti Amirtharatnam<sup>1</sup>, Sharanjeet Sharanjeet–Kaur<sup>1</sup>, Sumithira Narayanasamy<sup>2</sup>, Hanif Farhan Mohd Rasdi<sup>3</sup>, Mae–Lynn Catherine Bastion<sup>4</sup>

<sup>1</sup>Optometry and Vision Science Programme, Center for Rehabilitation and Special Needs Studies (iCaRehab), Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Kuala Lumpur 53000, Malaysia

<sup>2</sup>Optometry and Vision Science Programme, Center for Community Health Studies (Reach), Faculty of Health Sciences, University Kebangsaan Malaysia, Kuala Lumpur 53000, Malaysia

<sup>3</sup>Occupational Therapy Programme, Center for Rehabilitation and Special Needs Studies (iCaRehab), Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Kuala Lumpur 53000, Malaysia

<sup>4</sup>Ophthalmology Department, Faculty of Medicine, Universiti Kebangsaan Malaysia, Kuala Lumpur 56000, Malaysia

**Correspondence to:** Mohd Harimi Abd Rahman. Optometry and Vision Science Programme, Center for Rehabilitation and Special Needs Studies (iCaRehab), Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Kuala Lumpur 53000, Malaysia. harimirahman@gmail.com

Received: 2022-10-01 Accepted: 2023-02-16

## Abstract

• AIM: To develop and validate a questionnaire to evaluate knowledge, attitude and practice of patients diagnosed with age-related macular degeneration (AMD) who have undergone intravitreal injection treatment.

• **METHODS:** This study was conducted among patients diagnosed with AMD in Kuala Lumpur. The generation of the instrument included four phases which included item and domains development, content, face validity and exploratory factor analysis. Content validity and modified Kappa was used for validation of knowledge domain. Exploratory factor analysis was used for validation of both attitude and practice domains. Face validity was conducted in 12 patients, content validity was ascertained in 120 patients and test-retest reliability was determined in 39 patients with AMD.

• RESULTS: Content validity index (CVI) and modified

kappa showed excellent values for most items in the knowledge domain with CVI for item (I-CVI) values between 0.78-1.0 and Kappa values of >0.74. The Kaiser-Meyer-Olkin (KMO) sampling adequacy showed acceptable scores of 0.70 and 0.75 for both attitude and practice domains respectively and Bartlett's Test of sphericity were significant ( $\chi^2$ =0.00, *P*<0.001). Factor analysis resulted in five factors with thirty items for attitude domain and four factors with twenty items for practice domain. The Cronbach's alpha showed acceptable values for all items in knowledge, attitude and practice domain with values >0.70 and good test-retest reliability. The final version of the questionnaire consisted of 93 items from four sections consisting of demographic details, knowledge, attitude and practice.

• **CONCLUSION:** The findings of this validation and reliability study show that the developed questionnaire has a satisfactory psychometric property for measuring KAP of patients diagnosed with AMD undergoing intravitreal injection treatment.

• **KEYWORDS:** knowledge; attitudes; practice; age-related macular degeneration; instrument development

## DOI:10.18240/ijo.2023.04.13

**Citation:** Abd Rahman MH, Amirtharatnam P, Sharanjeet-Kaur S, Narayanasamy S, Mohd Rasdi HF, Catherine Bastion ML. Development of Knowledge, Attitude and Practice Questionnaire for age-related macular degeneration patients. *Int J Ophthalmol* 2023;16(4):589-600

#### **INTRODUCTION**

A ge-related macular degeneration (AMD) is a multifactorial condition that causes progressive damage to the macula, the part of retina responsible for central, and fine vision<sup>[1]</sup>. It is the leading cause of irreversible blindness in the elderly people over 50 years of age with the number of affected individuals predicted to be 288 million by 2040<sup>[2]</sup>. Due to its progressive and irreversible nature, there is an increase in societal cost burden and on the resources of the health care system<sup>[3]</sup>. Global

Burden of Disease Study 2010 highlighted an overwhelming burden of AMD for societies with an exponential increase of 160% in vision-related years lived with disability due to AMD<sup>[4]</sup>.

Patients diagnosed with AMD can present with distortion of vision or loss of sharp, fine-detailed central vision. Activities such as reading, driving, recognizing faces and perceiving color that require fine vision may become more difficult for these patients<sup>[5]</sup>. Vision loss in these patients has been strongly associated with reduction in quality of life as it will limit their ability to perform their daily activities<sup>[6]</sup>.

However, the awareness of AMD is low worldwide and there is also low compliance to treatment. A global survey conducted by AMD Alliance International among 14 countries showed that AMD awareness was alarmingly low. It ranged from 4% to 30% with the highest awareness level in the United States of America<sup>[7]</sup>. In many developing countries, numerous studies have shown low level of knowledge of AMD in the general population<sup>[8-11]</sup>. This may be due to the lack of available information on knowledge, attitude and practice (KAP) of AMD, especially in light of the low number of published studies highlighting this problem in many countries<sup>[12]</sup>.

A KAP survey can provide information on the patient's knowledge and awareness of the disease. The information obtained can be used to develop and implement an educational program for the specific population<sup>[13]</sup>. A KAP study measures knowledge, attitude, and practice of a community<sup>[14]</sup>. It is usually done to collect information on the knowledge (i.e., what is known), attitudes (i.e., what is thought), and practices (*i.e.*, what is done) about specific topics on a targeted population<sup>[15]</sup>. Knowledge refers to their understanding of the AMD, attitudes are their feelings towards AMD and practices is how they demonstrate their knowledge and attitude through their actions. All the information would be useful for healthcare and eyecare providers to develop and implement a targeted preventive action before the disease develops in the general population as well as an educational program in AMD patients. Globally, there is a lack of validated KAP instrument focusing on AMD. KAP towards AMD patients in Malaysia has never been explored. Therefore, the current study aims to develop and validate a KAP questionnaire for patients with AMD undergoing intravitreal injection treatment.

## SUBJECTS AND METHODS

Ethical Approval This study protocol has been approved by the Ethics and Research Committee of Universiti Kebangsaan Malaysia (UKM PPI/111/8/JEP-2020-694). Signed informed consent was obtained from all subjects.

**Questionnaire Development** The questionnaire was developed based on review of published research and modified to meet our objective. A standardized procedure was followed in the



Figure 1 Flow Chart of Knowledge, Attitudes and Practice Study.

process of development and validation of the questionnaire which included four phases. 1) Phase 1: Items and domains development; 2) Phase 2: Assessment of content and face validity; 3) Phase 3: Feasibility study; and 4) Phase 4: Assessment of construct validity, internal consistency and reliability. A flow chart for the research is presented in Figure 1. Phase 1 Items and Domains Development The first step was to determine the content domain which is the content area related to the variables being measured<sup>[16]</sup>. A comprehensive study of literature was done to find available resources on KAP as well to identify items and scales in previously developed questionnaires related to AMD and its measured constructs. The main domains related to KAP were then determined based on extensive reviews and literature search of previous studies done using five databases which were Science Direct, Scopus, PubMed, Cochrane, and Medline. Keywords used for this search were "development and validation, questionnaire, awareness, knowledge, attitude, practice" and "age-related macular degeneration, age related maculopathy, AMD". The first draft of the Knowledge, Attitude and Practice Questionnaire for Patients with Age-Related Macular Degeneration (AMD-KAPQ) was developed based on phase one. The first draft of questionnaire comprised of 140 items that emerged from the literature review search covering the three domains, knowledge, attitude and practice.

**Phase 2 Assessment of Content and Face Validity** Content validity was conducted to determine the ability of the questionnaire to adequately cover all relevant topics of the construct to be measured<sup>[17]</sup>. A group of eight panel experts consisting of two practicing optometrist, four retinal specialists and two optometry academicians who are experts in the field were asked to review the items in the questionnaire. The Delphi technique for two rounds was used by the panel of experts to gain consensus or agreement on the topic<sup>[18]</sup>. The

inclusion criteria for the panel of experts were: 1) engaged in the clinical diagnosis and management of AMD; 2) minimum of five years' experience in the field of ophthalmology as retinal specialist and optometry.

Delphi round one: expert validation The first draft of AMD-KAPQ was modified into a content validation form and sent to the expert panel by email for the first round to review 140 items. These panel of experts reviewed each of the item for relevance, clarity, simplicity, and ambiguity by rating on a four-point scale (1 to 4, where 1=not relevant and not clear, 2=item need some minor revision, 3=item is relevant and clear but need minor revision, and 4=very relevant and very clear)<sup>[19]</sup>. They also provided their feedback and comments for each item. Experts were asked to return the forms within two weeks, and a reminder email was sent if no response had been received after one week. Content validity was then quantified by measuring content validity index (CVI) and modified Kappa for each item. The CVI value can be calculated based on each item (I-CVI) and the overall scale (S-CVI)<sup>[20]</sup>. The comments from the expert panel were tabulated and presented in the Delphi round two focus group discussion.

**Delphi round two: focus group discussion** A focus group discussion was then held *via* online platform (Microsoft Teams) with the same panel of experts to review the comments of the first draft of AMD-KAPQ. The focus group discussion was conducted to achieve an agreement among the panel of experts to retain, remove and modify items in the questionnaire. The expert of panels opinions was taken into consideration in revisions of the wordings and phrasing of the items for better understanding by the patients. The first draft was then corrected and a pre-AMD-KAPQ was prepared.

Phase 3 Feasibility Study Face validity was conducted to evaluate the understanding of a layman towards comprehending the questionnaire and determining how meaningful the questions were to the participants<sup>[21]</sup>. The pre-AMD-KAPQ was presented to seven participants diagnosed with AMD for face validation to check on the readability, feasibility and general formatting. A face validity form was given to the patients for evaluation after they have completed the questionnaire. A similar feasibility study using cognitive interviewing was also conducted among 12 participants (10% of actual sample size) diagnosed with AMD through random sampling. Patients were asked to "think aloud" when they answered each part of the questionnaire<sup>[22]</sup>. They were also asked to comment on the general wording if it was clear and understandable, and whether the content was complete and relevant. After these procedures, the final version of AMD-KAPQ to test validity and reliability was developed.

The overall questionnaire consisted of three main domains namely knowledge, attitude and practice, with a total of 112 items. Knowledge items reflects symptoms, risks factors, treatment and management options, monitoring vision and consequences of AMD. This domain consisted of 30 items with two answer options of "Yes" or "No". All items in knowledge domain were scored as "Yes-1" and "No-0" respectively. A "don't know" response was not included as an option as research has found that there are a variety of reasons an individual might select the midpoint including item characteristics (*e.g.*, items are sensitive, multidimensional or unclear) and individual respondent characteristics (*e.g.*, individual ambivalence or anxiety about responding)<sup>[23]</sup>.

Attitude items defined the patients' opinions and beliefs towards counselling, caregiver, treatment and followup, orientation and mobility, activities of daily living and monitoring vision. This domain comprised of 58 Likert scale items. Patient could indicate their degree of agreement towards the statement given. Likert scale of four points will be used to represent the scores, such as, "Strongly Disagree", "Disagree", "Agree", "Strongly Agree". Numerical scores of 1, 2, 3 and 4 will be given to category "Strongly Disagree", "Disagree", "Agree", "Strongly Agree" respectively. A four-points Likert scale was used as studies have shown that Asians and Asian Americans tend to select the midpoints and avoid extreme responses when given Likert scale<sup>[24]</sup>.

Practice items corresponded towards patients' practice towards management and treatment, clinic appointment, information acquisition and activities of daily living. This domain comprised of 27 items assessed by "Always" (6-7d a week), "Frequently" (5d a week), "Sometimes" (3-4d a week), "Rarely" (2-1d a week, "Never" (0d) category, scored as 5, 4, 3, 2 and 1. The participants were classified after summing up the scores obtained, into two levels of low, high levels using the mean score and standard deviation<sup>[25]</sup>: Good level: score > mean and poor level: score < mean.

# Phase 4 Assessment of Construct Validity, Internal Consistency, and Reliability

**Study design** This is a cross-sectional questionnaire-based study. This study was conducted at an eye specialist center and a primary care clinic of a tertiary hospital from November 2020 to October 2021.

**Participants** The sample size was determined based on Cochran formula;  $n=z^2pq/e^2$  where n is the sample size, z is 1.96 with 95% confidence interval, p is the prevalence of AMD, q=1-p and e are the accuracies ( $e^2=5\%$ ). Based on a study done in Singapore on a multi-ethnic cohort, age-standardized prevalence of AMD was 7% in persons age 40 years and older<sup>[26]</sup>. After calculation using the Cochran formula, the required sample size for this study was 100 patients. A 20% dropout was included if patients were to withdraw from the study. Therefore, the sample size required was 120. Although

the sample size recommended is 5 to 10 participants per item, researches have concluded that sample to variable ratio, N:p showed that there was no minimum level of N to achieve good factor recovery across conditions examined<sup>[27]</sup>. It is widely acknowledged that at least 100 samples are required in order to evaluate exploratory factor analysis (EFA)<sup>[28]</sup>.

The sample size for test-retest reliability was determined based on web-based sample size calculator<sup>[29]</sup>. The calculated size was added with 20% dropout. Hence, the sample size required was 39.

**Procedures** All participants diagnosed with AMD undergoing intravitreal injection treatment by a medical retina or vitreoretinal specialist visiting Oasis Eye Specialists and Hospital Canselor Tuanku Muhriz (HCTM) were included in this study. Patients were recruited at the waiting area outside the consultation rooms while waiting to see the specialists. All patients were approached and those who consented were considered for this study. Patients who fulfilled the following criteria were recruited: 1) aged above 50y diagnosed with AMD, 2) received at least one intravitreal injection in one eye or both eyes, and 3) received past or alternative treatments such as photodynamic therapy. Whereas the exclusion criteria were patients with hearing loss, dementia, debilitating commodities and not received any intravitreal injection.

The purpose and importance of the study was explained to the patients using an information sheet and written consent was obtained if they fulfilled the inclusion criteria. Sociodemographic information such as patients' gender, ethnicity, level of education, working status, smoking status, duration of AMD, type of AMD and eye affected by AMD was collected. Then the AMD-KAPQ questionnaire was administered via face-to-face and one-to-one to patients diagnosed with AMD. The questionnaire was administered by patients with the help of the same researcher and was returned on the same day. Those patients who cannot read or see clearly, the researcher would help the patient to read the questionnaire without additional explanation. All questionnaires were anonymous, and patients independently completed the AMD-KAPQ. To ensure the quality of data, AMD-KAPQ with missing and unreliable responses were eliminated. The AMD-KAPQ was re-administered to the same patients after three weeks for testretest reliability. Three weeks was chosen as it was considered an appropriate time frame to prevent memory as a confounding factor<sup>[30]</sup>.

**Statistical Analysis** All data were analysed using IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp. Descriptive statistics was used to describe the socio-demographic characteristics of the sample.

CVI was used to measure content validity of each item in the domains for knowledge, attitude and practice. Content validity

was quantified by measuring CVI and modified Kappa for each item. The CVI value can be calculated based on each item (I-CVI) and the overall scale (S-CVI). I-CVI is calculated by dividing the number of raters who scored the item as three or four divided the number of experts. Kappa statistics is the consensus index of inter-rater agreement and provides degree of agreement beyond chance<sup>[31]</sup>. I-CVIs were translated into values of a modified kappa statistic to adjust for chance agreement. Chance agreement becomes an issue for inter-rater agreement when it comes to dichotomous choices, as in case when 4-point ratings are reduced into two categories, relevant and non-relevant.

Construct validity of all the items in both attitude and practice section questionnaire was measured using exploratory factor analysis (EFA). EFA was conducted on both attitude and practice domain as it had a larger range of response scale. It was not done on knowledge domain as it had dichotomous response either true or false. Construct validity is extent to which a questionnaire measures the construct that is intended to measure<sup>[32]</sup>. EFA was conducted to identify and organize a large number of items into constructs under specific variables in the questionnaire<sup>[33]</sup>. The Principal Component Analysis (PCA) with varimax rotation was used to determine number of factors influencing the variables and to analyze variables that belong together<sup>[34]</sup>. Barlett's test of sphericity (P < 0.001) and the Kaiser-Meyer-Olkin (KMO) measurement of sampling adequacy (>0.7) were met for a satisfactory factor analysis to proceed<sup>[35-36]</sup>. The number of factors to remain were determined by considering the eigenvalues (>1), scree plot and interpretability of the factor<sup>[37]</sup>. Since the sample size for this research was 120, based on Hair et al<sup>[38]</sup>, the cut-off point of 0.5 was taken into account for factor loading. Items with factor loadings of <0.5 were removed from the questionnaire. For the items that crossed loaded on more than 1 factor, these items were placed with the factor that was most closely related to conceptually<sup>[39]</sup>. All *P*-values were regarded as significant if the *P* value was < 0.05.

Reliability is the degree to which a questionnaire produces similar results each time it is administered<sup>[40]</sup>. To determine internal consistency of the questionnaire, Cronbach's Alpha and intraclass correlation coefficient (ICC) test-retest reliability method was used. Acceptable Alpha levels were determined, and it was considered excellent when Cronbach's Alpha is > $0.70^{[41]}$ . Test-retest reliability test was done using ICC<sup>[42]</sup>. ICC values less than 0.5 shows poor reliability, values between 0.5 and 0.75 show moderate reliability, values between 0.75 and 0.9 show good reliability. Test-retest reliability correlation coefficient with 0.70 was recommended as minimum standard for reliability and indicated good reproducibility of the questionnaire<sup>[42]</sup>. For knowledge domain, items were remained based on internal consistency reliability while for both attitude and practice domain, items were retained from both factor analysis and internal consistency reliability. *P*-values of <0.05 were considered statistically significant.

#### RESULTS

**Results of Item Pool Generation** Comprehensive literature search with the keywords yielded a total number of 106 articles, in which a total of 32 articles were found to be relevant for this study. For the item generation, a total number of items were 140 with 17 of sub-domains and 3 domains. The items in the three domains of knowledge, attitude and practice were analysed by the team and were then grouped and named into 17 subdomains. Few previous studies have focused on awareness on AMD worldwide and only one study was identified on KAP of AMD that was published in Australia in 2020<sup>[43]</sup>. It was done on patients diagnosed with AMD and eye care practitioners. However, there were scarce information on the reliability and validity of the instrument developed.

Expert Characteristics and the Result of Content and Face Validity A total number of eight panel of expert participated in this study. There were altogether four retinal specialist ophthalmologists, two optometrists and two academicians. The average age of the experts was 42.00±7y, which included three males and five females. The average serving time was  $14.5\pm8y$ . In Delphi round one of content validation, the panel of experts reviewed the questionnaire and removed 11 items and modified 12 items. Content validity was then quantified by measuring CVI and modified kappa for each item. The total of 11 items which were removed had low agreement among panel of experts, CVI of <0.78. A total of 12 items with CVI between 0.70-0.78 and were modified. Items with kappa values of >0.79 were retained in the questionnaire as it demonstrated excellent agreement. At the end of the first phase of content validation, 129 items were retained in the pre-AMD-KAPQ.

In the Delphi round two, a total of 18 items were revised and a total of 15 items were removed during the discussion. There was also an additional one item which was under the subdomain, factors that influence outcome for smokers to stop smoking. The panel of experts felt it was an important content for the patients diagnosed with AMD to understand this factor. After content validation was completed, the first draft of the AMD-KAPQ was revised to a pre-AMD-KAPQ consisting of 115 items. **Participant Characteristics and the Result of the Feasibility Study** A total number of seven AMD participants participated in the face validation to check on the readability, feasibility and general formatting. The mean age of the participants was 68.00±6y. From the seven participants, there were six females and one male. They commented on the general wording and phrases for the questionnaire. They stated it was overall good



Figure 2 Scree Plot for attitude domain.

and understandable.

A total number of 12 participants diagnosed with AMD participated in feasibility study. The mean age of the participants was 65.00±8y. From the 12 participants, 10 participants were female and two were males. Overall participants took around 15min to complete the pre-AMD-KAPQ and comment on items with the help of the researcher. At the end of the feasibility study, three items were removed, and four items needed revision producing a total of 112 items in the final version of AMD-KAPQ.

### Participant Characteristics and the Result of the Construct Validity, Internal Consistency, and Reliability

**Participant characteristics** A total of 120 patients completed the final version of AMD-KAPQ (response rate: 100%). Mean age of the participants was 71.00±9y. The self-reported socio-demographics characteristics were summarized in Table 1.

**Result of construct validity** Exploratory factor analysis (EFA) was used to determine the appropriate construct validity of the items in attitude and practice domain in the AMD-KAPQ. The Kaiser-Meyer-Olkin (KMO) and Bartlett's Test of sphericity was used to measure sampling adequacy and to show if the data could factor well prior to analysis. KMO value should be greater than 0.7 and Bartlett's must be significant at P<0.001<sup>[34]</sup>. Items in both attitude and practice domain showed acceptable KMO values of 0.70 and 0.75, with Bartlett's Test of sphericity found to be significant ( $\chi^2$ =0.00, P<0.001). Therefore, exploratory factor analysis could be conducted on this study.

Principal component analysis with varimax rotation were used to determine number of factors influencing the variables and to analyze variables that belong together. To determine the number of factors to be retained for attitude domain, Kaiser's eigenvalue >1 and Cattell's Scree Plot was used. Since eigenvalues were more than one, nine meaningful factors were extracted which explained 75.2% of total variance and the result of Scree Plot also showed that nine factors could be extracted in Figure 2. The validity of the nine factors were

	Table 1	Self-reported	socio-demographic	characteristics of	participants
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%)

Characteristics         Value (n=120)           Gender         71 (59.2)           Male         49 (40.8)           Ethnicity         28 (23.3)           Malay         28 (23.3)           Chinese         88 (73.3)           Indians         3 (2.5)           Others         1 (0.8)           Level of education         71 (59.2)           None         6 (5.0)           Primary         31 (25.8)           Secondary         45 (37.5)           Tertiary         38 (31.7)           Working status         88 (15.5)           Secondary         45 (37.5)           Tertiary         38 (31.7)           Working status         88 (15.5)           Self-employed         5 (4.2)           Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoker         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease         2 (1.7)           <1y         17 (14.2)           1-Sy         55 (45.8)           >Sy         48 (40) <t< th=""><th></th><th>n (</th></t<>		n (
Gender       71 (59.2)         Male       49 (40.8)         Ethnicity       28 (23.3)         Malay       28 (23.3)         Chinese       88 (73.3)         Indians       3 (2.5)         Others       1 (0.8)         Level of education       0         None       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status       10         Employed       18 (15)         Self-employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status       2         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       2         <1y	Characteristics	Value ( <i>n</i> =120)
Female       71 (59.2)         Male       49 (40.8)         Ethnicity	Gender	
Male       49 (40.8)         Ethnicity       88 (23.3)         Malay       28 (23.3)         Chinese       88 (73.3)         Indians       3 (2.5)         Others       1 (0.8)         Level of education       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status       88 (31.7)         Working status       88 (31.7)         Working status       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       11 (9.2)          55 (45.8)         >5y       48 (40)         Type of AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)	Female	71 (59.2)
Ethnicity       28 (23.3)         Malay       28 (23.3)         Chinese       88 (73.3)         Indians       3 (2.5)         Others       1 (0.8)         Level of education          None       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status          Employed       18 (15)         Self-employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease          <1y	Male	49 (40.8)
Malay       28 (23.3)         Chinese       88 (73.3)         Indians       3 (2.5)         Others       1 (0.8)         Level of education          None       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status          Employed       18 (15)         Self-employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status          Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease          <1y	Ethnicity	
Chinese         88 (73.3)           Indians         3 (2.5)           Others         1 (0.8)           Level of education	Malay	28 (23.3)
Indians         3 (2.5)           Others         1 (0.8)           Level of education	Chinese	88 (73.3)
Others       1 (0.8)         Level of education       6 (5.0)         None       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status       18 (15)         Employed       18 (15)         Self-employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       2 (1.7)          48 (40)         Type of AMD       8 (6.7)         Wet AMD       8 (6.7)         Wet AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)	Indians	3 (2.5)
Level of education         None       6 (5.0)         Primary       31 (25.8)         Secondary       45 (37.5)         Tertiary       38 (31.7)         Working status       8 (31.7)         Working status       18 (15)         Employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status       2 (1.7)         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       2         <1y	Others	1 (0.8)
None         6 (5.0)           Primary         31 (25.8)           Secondary         45 (37.5)           Tertiary         38 (31.7)           Working status	Level of education	
Primary         31 (25.8)           Secondary         45 (37.5)           Tertiary         38 (31.7)           Working status         18 (15)           Employed         18 (15)           Self-employed         5 (4.2)           Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoking status         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease         11 (9.2)           Sy         48 (40)         Type of AMD         Sof (45.8)         Sy         48 (6.7)         Wet AMD         65 (54.2)         Both         6 (5.0)         Don't know         41 (34.4)         Eye affected by AMD         Sof (5.0)         Sof (5.0)	None	6 (5.0)
Secondary         45 (37.5)           Tertiary         38 (31.7)           Working status         18 (15)           Employed         5 (4.2)           Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoking status         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease         11 (9.2)           5y         48 (40)           Type of AMD         8 (6.7)           Wet AMD         65 (54.2)           Both         6 (5.0)           Don't know         41 (34.4)	Primary	31 (25.8)
Tertiary       38 (31.7)         Working status       18 (15)         Employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status       2 (1.7)         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease	Secondary	45 (37.5)
Working status         Employed       18 (15)         Self-employed       5 (4.2)         Not working       35 (29.2)         Retiree/pensioner       62 (51.7)         Smoking status       2 (1.7)         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       2         <1y	Tertiary	38 (31.7)
Employed         18 (15)           Self-employed         5 (4.2)           Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoking status         2 (1.7)           Smoker         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease	Working status	
Self-employed         5 (4.2)           Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoking status	Employed	18 (15)
Not working         35 (29.2)           Retiree/pensioner         62 (51.7)           Smoking status            Smoker         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease            <1y	Self-employed	5 (4.2)
Retiree/pensioner         62 (51.7)           Smoking status            Smoker         2 (1.7)           Ex-smoker         18 (15)           Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease            <1y	Not working	35 (29.2)
Smoking status         Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       17 (14.2)         1-5y       55 (45.8)         >5y       48 (40)         Type of AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)	Retiree/pensioner	62 (51.7)
Smoker       2 (1.7)         Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       11 (9.2)         <1y	Smoking status	
Ex-smoker       18 (15)         Non-smoker       89 (74.2)         Passive smoker       11 (9.2)         Duration of disease       17 (14.2)         1-5y       55 (45.8)         >5y       48 (40)         Type of AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)	Smoker	2 (1.7)
Non-smoker         89 (74.2)           Passive smoker         11 (9.2)           Duration of disease         17 (14.2)           1-5y         55 (45.8)           >5y         48 (40)           Type of AMD         8 (6.7)           Wet AMD         65 (54.2)           Both         6 (5.0)           Don't know         41 (34.4)	Ex-smoker	18 (15)
Passive smoker       11 (9.2)         Duration of disease       17 (14.2)         1-5y       55 (45.8)         >5y       48 (40)         Type of AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)         Eye affected by AMD       55 (54.2)	Non-smoker	89 (74.2)
Duration of disease         <1y	Passive smoker	11 (9.2)
<1y	Duration of disease	
1-5y       55 (45.8)         >5y       48 (40)         Type of AMD       8 (6.7)         Dry AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)         Eye affected by AMD       41 (34.4)	<1y	17 (14.2)
>5y       48 (40)         Type of AMD          Dry AMD       8 (6.7)         Wet AMD       65 (54.2)         Both       6 (5.0)         Don't know       41 (34.4)         Eye affected by AMD	1-5y	55 (45.8)
Type of AMDDry AMD8 (6.7)Wet AMD65 (54.2)Both6 (5.0)Don't know41 (34.4)Eye affected by AMD	>5y	48 (40)
Dry AMD         8 (6.7)           Wet AMD         65 (54.2)           Both         6 (5.0)           Don't know         41 (34.4)           Eye affected by AMD	Type of AMD	
Wet AMD         65 (54.2)           Both         6 (5.0)           Don't know         41 (34.4)           Eye affected by AMD	Dry AMD	8 (6.7)
Both6 (5.0)Don't know41 (34.4)Eye affected by AMD	Wet AMD	65 (54.2)
Don't know41 (34.4)Eye affected by AMD	Both	6 (5.0)
Eye affected by AMD	Don't know	41 (34.4)
	Eye affected by AMD	
Right eye only 47 (39.2)	Right eye only	47 (39.2)
Left eye only 29 (24.2)	Left eye only	29 (24.2)
Both eyes 44 (36.7)	Both eyes	44 (36.7)

AMD: Age-related macular degeneration.

then further confirmed by communalities in which those below <0.05 were removed.

Rotated component matrix contains all the loadings for each component. A loading is considered significant (over a certain threshold) depending on the sample size needed for significance. Items with factor loadings of <0.5 were removed from the AMD-KAPQ. Total items to be removed from attitude domain are 27 items and items retained are 30 items resulting in a five-component solution. The five factors were 1) attitude towards counselling, 2) attitude towards caregiver, 3) treatment



Figure 3 Scree Plot for Practice domain.

and follow up, 4) orientation and mobility, and 5) activities of daily living. The five factors with their items are shown in Table 2.

Similarly, seven meaningful factors were extracted for the practice domain which explained 69.4% of total variance and Scree Plot also showed a seven-component solution in Figure 3. To check on factorability, the diagonal values on the anti-image correlation matrix with correlations <0.5 were noted for possible exclusion because they lack sufficient correlation with other variables.

A total of five items were removed and 20 items were retained during construct validity resulting in a four-component solution. The four factors were 1) reasons for missed appointments, 2) social activities, 3) information acquisition, 4) activities of daily living. The four factors with their items are shown in Table 3. At the end of construct validity, a total of 93 items remained in the questionnaire (Table 4).

**Reliability** The Cronbach's Alpha coefficient was >0.70, ranging from 0. 767 to 0.929 which was considered excellent. To evaluate test-retest reliability, 39 participants diagnosed with AMD were remeasured after three weeks, and the intraclass correlation coefficient was 0.85 (95%CI: 0.76-0.91) for knowledge domain, 0.87 (95%CI: 0.79-0.93) for attitude domain and 0.92 (95%CI: 0.87-0.95) for practice domain (Table 5). Overall, the questionnaire showed good test-retest reliability.

#### DISCUSSION

This study produced a 93-item AMD-KAPQ with three domains (knowledge, attitude and practice) and showed that AMD-KAPQ was consistent, reliable and valid. The AMD-KAPQ is the first questionnaire to explore KAP among patients diagnosed with age-related macular degeneration in Malaysia. The knowledge items were developed based on the area of interest the research team wanted to explore. The items were constructed in a consecutive manner from symptoms, risk factors, treatment and management options, tests used for

Table 2 Exploratory factor analysis of items in attitude domain using principle component	t extracti	on with	varima	x rotatio	on	( <i>n</i> =120
Items	Factors					Cronbach
	F1	F2	F3	F4	F5	Alpha
Factor 1: Attitude towards counselling (6 items)						0.929
CD3 Encourage me to monitor my vision regularly at clinic and at home	0.894					
CD4 Educate and motivate my caregiver to be part of my AMD journey	0.869					
CD1 Improve my knowledge on the eye disease and treatment	0.868					
CD2 Motivate me to change my diet and lifestyle habits	0.854					
CD6 Encourage me to continue to receive treatment	0.791					
CD5 Provide me with someone to share my concerns and challenges	0.686					
Factor 2: Attitude towards caregiver (6 items)						0.903
CE6 Help me in orientation and mobility		0.889				
CE9 Help with household chores and errands		0.881				
CE3 Help me with daily activities		0.859				
CE4 Help me attend my social gatherings		0.857				
CE8 Help with personal care		0.783				
CE5 Attend counselling sessions with me		0.688				
Factor 3: Treatment & follow up (7 items)						0.888
CA2 It is important to monitor vision during each clinic visits			0.877			
CA1 It is important to attend scheduled follow ups on time			0.856			
CB6 Promptly receiving treatment when advised by my doctor			0.765			
CA6 It is important not to miss my regular follow up even if my vision is okay			0.746			
CB4 Attending scheduled appointments			0.684			
CA3 It is important to have an OCT scan done during each clinic visit			0.607			
CB1 a healthy diet (dark green leafy vegetables, fish, nuts, whole grains, vegetable and fruits)			0.505			
Factor 4: Orientation and mobility (4 items)						0.767
CC5 Orientation and mobility (e.g. walking, reading, driving) in the evening and at night				0.813		
CC7 Reading small prints (e.g. labels on food products, medications, books, magazine and newspaper)				0.671		
CC4 Orientation and mobility (e.g. climbing stairs, crossing road, walking) during the day				0.638		
CC3 Driving				0.638		
Factor 5: Activities of daily living (6 items)						0.795
CC9 self-care ( <i>e.g.</i> bathing, grooming)					0.777	
CC10 shopping					0.716	
CC11 attending social functions/activities					0.634	
CC12 travelling by public transportation					0.628	
CC6 recognizing people's faces					0.548	
CC8 using electronic devices (e.g. smartphones, computer, tablet, laptop)					0.525	

Items with factor loading  $\geq 0.50$  are shown.

monitoring vision and consequences when no treatment was provided. Cost of intravitreal injections were not discussed as all patients included in this study had the injections. Apprehension of patients to go totally blind was also not addressed as our study was not looking into emotional and psychological status of AMD patients. Curability was not discussed as there is no cure to AMD. The knowledge items were known facts and therefore, not meant for factor analysis as they were not abstract ideas which required operationally defines and grouped into general factors<sup>[42]</sup>. The knowledge domain showed good content validity with most items scoring I-CVI>0.78. From the measurement only two items were removed, which were, B3 Consequences-no further loss of vision and E6 Monitoring vision-measuring intraocular pressure using tonometer. These two items were considered not relevant by the panel of experts as it showed poor content coverage.

Content validity for the attitude domain showed some initial items that were proposed needed to be revised by the experts during validation. These items were modified for patients better understanding. Construct validity for items in the attitude domain showed a 9-factor model in which 27 items were removed from the section. Some of the items removed, such as, C1 Emotional and Social Impact AMD has affected my psychological wellbeing and C2 AMD treatment has a

Table 3 Exploratory factor analysis of items in practice domain using principle component extra	ction wit	h varima	ax rotatio	on ( <i>n</i> =120	)
Items		Factors			Cronbach
	1	2	3	4	Alpha
Factor 1: Reasons for missed appointments (4 items)					0.877
DB11 The reason for missed appointments are natural disasters (e.g. flood)	0.855				
DB9 The reason for missed appointments are forgot about appointment	0.838				
DB8 The reason for missed appointments are appointments are too frequent/inconvenient	0.835				
DB7 The reason for missed appointments are unwell or sick	0.781				
Factor 2: Social activities (4 items)					0.842
DD9 Attend social functions/activities		0.835			
DD8 Shopping		0.799			
DD10 Travel by public transportation		0.771			
DD1 Driving		0.682			
Factor 3: Information acquisition (6 items)					0.835
DC5 I obtain information from newspapers/magazines			0.862		
DC4 I obtain information from pamphlet from clinic			0.823		
DC6 I obtain information from counsellor at eye clinic			0.639		
DC3 I obtain information from social media (e.g. Facebook, WhatsApp etc.)			0.617		
DC7 I obtain information from support group			0.594		
DC2 I obtain information from Internet/online internet resources			0.500		
Factor 4: Activities of daily living (6 items)					0.837
DD7 Self-care ( <i>e.g.</i> bathing, grooming)				0.777	
DD2 Orientation and mobility (e.g. climbing stairs, crossing road, walking etc.) during the day				0.752	
DD4 Recognising people's faces				0.685	
DD6 Using electronic devices (e.g. handphones, tablets, laptop, computer)				0.645	
DD3 Orientation and mobility (e.g. walking, reading and driving etc.) in evening and night				0.643	
DD5 Reading small print on labels (e.g. food products/medications/books/magazines/newspapers)				0.570	

Items with factor loading  $\geq 0.50$  are shown.

#### Table 4 AMD-KAPQ

Domains	No. of items	Measurements	Response choices		
Demographic details	14	Socio-demographic, ethnicity, level of education, duration of eye disease, working status, smoking status, monthly household income, type of AMD, eye affected by AMD, details on caregiver, other comorbidity, satisfaction of their current vision	Open-ended, close-ended, multiple choice questions		
Knowledge	30	Symptoms, risk factors, treatment and management options, monitoring vision and consequences of $AMD$	Yes/No (1-Yes, 0-No)		
Attitude	29	Attitude towards counselling, attitude towards caregiver, treatment and follow up, orientation and mobility, activities of daily living.	1-strongly agree, 2- agree, 3-disagree, 4-strongly disagree		
Practice	20	Appointment practice, social activities, information acquisition, activities of daily living	1-always, 2-frequently, 3-sometimes, 4-rarely, 5-never		

AMD-KAPQ: Age-related Macular Degeneration-Knowledge, Attitude and Practice Questionnaire.

#### Table 5 Test-retest reliability ICC of AMD-KAPQ

Factors	No. of items	ICC	95%Cl lower bound	95%Cl upper bound	F	Р
Knowledge	28	0.85	0.76	0.91	6.53	0.00
Attitude	29	0.87	0.79	0.93	7.77	0.00
Practice	20	0.92	0.87	0.95	12.37	0.00

ICC: Intraclass correlation coefficient; AMD-KAPQ: Age-related Macular Degeneration-Knowledge, Attitude and Practice Questionnaire; CI: Confidence interval.

positive impact on me needed to be removed as there were varying answers from the patients. This is supported by a study done in 2016<sup>[44]</sup> that studied the emotional and physical impact of wet AMD patients which showed that this disease had major emotional and physical impact which was significantly worse in those who had wet AMD in both eyes and a longer duration of the disease. Dry AMD is the initial stage of advanced AMD

which is characterized by development of drusen and alteration across the retinal pigment epithelium cell. It later progresses to wet AMD which involves blood or serum leakage<sup>[45]</sup>. As our study focused on all patients diagnosed with AMD, these items which were removed were not intended to be answered by all patients. Both wet AMD and dry AMD patients would have given contradicting opinions for these items. Some other items in the attitude domain, such as, CB2 Regular exercise, CB3 Consuming nutritional/ dietary supplements, CB7 For smokers, to stop smoking also needed to be removed during construct validity. It has been shown that patients with late AMD engaged in 50% less moderate to vigorous physical activity that those without AMD due to reduced visual acuity<sup>[46]</sup>. It was shown that patients in the early stage of the disease did not benefit from supplement. Furthermore, current literature also shows that AREDS-based supplement is widely used for treatment of dry form of AMD only<sup>[47]</sup>. Most patients were also unaware of the consequences of smoking to the eye. Overall, it was necessary for these items to be removed as we are investigating patients diagnosed with AMD at all stages of the disease and both forms of AMD.

The practice domain showed good psychometric properties for both content validity phases. There were minor modifications and revision of sentences on the items. Construct validity is based on seven factors and only five items were removed from the questionnaire. Two items which were removed, DA2 How often do you use low vision devices in helping you with your daily task (e.g., magnifiers, telescopes) and DA3 How often do you use an Amsler grid to monitor your vision at home. Vision loss at the late stage of the disease is more profound as compared to the early stage of the disease. A low vision device may only be intended to improve vision for those who are at the late stage of the disease to improve reading ability. The Amsler grid is used to monitor vision at early stage of the disease, as patients would not notice subtle changes in their central vision at late stage of the disease. A recent systematic review of 12 studies conducted by Faes et al<sup>[48]</sup>, it was found that the sensitivity of the test ranged from 0.34 to 1.0 and its specificity ranged from 0.85 to 1.0. The reason for test's variable sensitivity is the remarkable capability of the brain to complete missing or out-of-line details, which could cause slight distortions to pass undetected<sup>[49]</sup>. It has been shown that Amsler grids do not provide precise, quantifiable measures of visual field defects, and are therefore not useful as monitoring tools for disease progression<sup>[50]</sup>. Therefore, these items needed to be removed as it is not intended for all patients diagnosed with AMD.

Item DC1 "I obtain information from eye doctor" was also removed from the practice domain. As most of the respondents were older and most of them retired, they may get most of their information on AMD through media or friends/relatives. This is similar to study done on knowledge and awareness in Iran, it showed that the source of information for agerelated eye diseases such as cataracts, glaucoma and diabetic retinopathy were mainly from relatives or close friends followed by media<sup>[51]</sup>. However, this is contradictory to a study done in Australia which has shown that majority of AMD patients (78.3%) learned about AMD primarily from their treating Ophthalmologist and also preferred to receive more information from them as compared to other sources such as internet, pamphlet and videos/DVDs<sup>[52]</sup>. Therefore, it is important to emphasize shared decision making to improve and build trust between the doctors and patients which means that both of them work together to make a reasonable choice after patient has been advised about the effect, risk and benefit of the treatment and after patients have been fully expressed their views and beliefs<sup>[53]</sup>.

The AMD-KAPQ showed good internal consistency reliability. The Cronbach's coefficient was between 0.767 and 0.929 for knowledge, attitude and practice domain which was considered acceptable<sup>[54]</sup>. The calculated ICC for the factors were 0.85 (95%CI: 0.76-0.91) for knowledge domain, 0.87 (95%CI: 0.79-0.93) for attitude domain and 0.92 (95%CI: 0.87-0.95) for practice domain. This result showed that ICC and upper bound of the 95%CI of the AMD-KAPQ met the minimum requirement of >0.90 for the reliability of the instrument to be considered excellent<sup>[55]</sup>.

AMD is a lifelong disease; hence, it is important for patients to be continuously educated every few years of the course of their disease. This study will serve as a purpose to evaluate the level of knowledge that patients with AMD undergoing intravitreal injection treatment have about their disease and whether there is a need for more education. KAP surveys can provide information on the patients' awareness of the disease and guide to a proper implementation of a health education programme which will also increase knowledge, promote effective treatment, and reduce the burden of the eye disease<sup>[56]</sup>. As this is a cross-sectional study, it is important to acknowledge that the change in patient response over time was not evaluated and so the responsiveness/sensitivity of the scale to clinical improvements is unknown.

An instrument, which may be useful as an easy-to-use measure of AMD patients' KAP towards AMD, was developed and tested in our study. The analyses of reliability and validity demonstrated the strong psychometric properties of the AMD-KAPQ. Ophthalmologist, optometrist, nurses, or other healthcare professionals can use the AMD-KAPQ to identify KAP level among AMD patients. AMD-KAPQ would be an excellent tool for a more personalized development of an educational and counseling program for patients with AMD in the future. The educational or counseling program could also increase awareness of modifiable risk factors such as diet and smoking which will help patients to implement preventive actions before the disease progresses further into an advance stage.

To our knowledge, this study is the first to develop and validate a KAP questionnaire for patients diagnosed with AMD in Malaysia. In addition, data collection was collected through face-to-face interviews with the AMD patients which enabled an easy understanding of the questionnaire by the patients, and this allowed them to answer all the questions without any difficulties.

While this protocol aims to produce a validated instrument, there are some limitations in the process of its development. The data collection was done in a single location, Kuala Lumpur, thus, the data collected and analyzed will only reflect urban population of the country. It is suggested that this study should be repeated in the rural population for the results to be a true representation of a national perspective. Another limitation of this study was that content validity was used to assess the validity for knowledge domain, however, it is recommended that a Confirmatory Factor Analysis (CFA) or Rash analysis should be conducted in the future to validate the knowledge domain in the KAP questionnaire for AMD patients. For CFA or Rasch analysis, a larger sample size of 250-500 participants is needed<sup>[57]</sup> and CFA should be run using a data set different from EFA data set. However, there were problems in data collection for the AMD patients as the data was collected during COVID-19 and there were restrictions during this time. In conclusion, a new validated questionnaire for determining KAP of patients diagnosed with AMD who have undergone intravitreal injection treatment was developed. The final AMD-KAPQ questionnaire consisted of 93 items, 14 items for demographic details, 30 items in knowledge domain, 29 items in attitude domain and 20 items in practice domain. AMD-KAPQ can be used for better understanding of KAP among patients with AMD and can be used to evaluate the effectiveness of educational and counselling programmes given to the patients with AMD.

#### ACKNOWLEDGEMENTS

Conflicts of Interest: Abd Rahman MH, None; Amirtharatnam P, None; Sharanjeet-Kaur S, None; Narayanasamy S, None; Mohd Rasdi HF, None; Catherine Bastion ML, None. REFERENCES

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