Eastman Dental Institute

Patient Education in Oral Epithelial Dysplasia

The EDUCAT-ED Study

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DECLARATION

I, Waleed Abdullah Alamoudi confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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ABSTRACT

Oral epithelial dysplasia (OED) is a chronic, potentially malignant disorder that can progress to oral squamous cell carcinoma (OSCC). Despite the clinical significance of OED, research into the educational needs of affected individuals remains scarce. This thesis aimed to investigate the scope, quality, and effectiveness of patient education (PE) in OED through a four-part mixed-methods approach: (1) a systematic evaluation of existing online resources, (2) a qualitative exploration of patient experiences, (3) a cross-sectional quantitative assessment of patient knowledge, and (4) a psychometric validation of the oral epithelial dysplasia informational needs questionnaire (ODIN-Q).

In the first phase, a systematic review revealed that most publicly available online OED educational materials were limited in accuracy, comprehensiveness, and readability, with minimal coverage of key domains such as risk factors, treatment options, and psychosocial support. The second phase involved qualitative interviews with patients living with OED. Thematic analysis revealed four main challenges: informational gaps at diagnosis, emotional distress, poor care continuity, and inconsistent delivery of PE. In the third phase, a quantitative study involving 102 individuals assessed disease-specific knowledge using the ODIN-Q. Approximately half of the cohort demonstrated insufficient knowledge, particularly in areas such as human papilloma virus, lifestyle adjustments, psychological support, and navigating healthcare services. Most participants preferred one-on-one meetings with OED specialists as their primary mode of receiving information.

The final phase evaluated the structural validity and responsiveness of the ODIN-Q. Confirmatory factor analysis supported a six-domain model—general knowledge,

investigative procedures, treatments, physical and psychosocial aspects, and access to information—despite some suboptimal fit indices. Responsiveness testing, following an educational intervention using a patient leaflet, revealed small to moderate improvements in informational scores across several domains, affirming the ODIN-Q's utility in measuring dynamic patient information needs.

Collectively, this thesis confirms that individuals with OED experience considerable unmet educational needs and demonstrates that patient-centred tools like the ODIN-Q can identify and track those needs. The findings support the integration of targeted, multimodal PE strategies—anchored in validated measurement tools—into the clinical management of OED. These efforts are essential for improving patient understanding, engagement, psychological well-being, and long-term outcomes. Future research should focus on longitudinal validation of the ODIN-Q, comparative analyses of educational delivery methods, and adaptation for culturally diverse populations.

IMPACT STATEMENT

This thesis is an in-depth exploration of the informational needs of individuals living with oral epithelial dysplasia (OED), bridging key gaps in patient information for more effective patient-centred care models. It comprises four peer-reviewed, published chapters that collectively evaluate the quality of existing patient information sources, capture patient perspectives, quantify informational needs using the oral epithelial dysplasia informational needs questionnaire (ODIN-Q), and test the tool's psychometric properties.

Findings from this research demonstrated that current online audio-visual educational resources on OED are inadequate in quality, clarity, and practical usefulness, leaving patients vulnerable to misinformation and heightened anxiety. Using qualitative methods, we recorded the experiences of individuals with OED, which revealed persistent psychosocial distress and dissatisfaction with existing communication and support. Quantitative assessment using the ODIN-Q confirmed that patient needs are diverse and extend beyond biomedical knowledge to include psychosocial, behavioural, and system-related domains. Advanced psychometric testing established the ODIN-Q as a valid and reliable instrument capable of systematically identifying these needs in clinical practice.

This research has immediate implications for clinical practice, equipping healthcare professionals with validated tools to personalise patient education and support shared decision-making. It also establishes a replicable model for future development of condition-specific educational tools across other chronic and potentially malignant oral conditions. The full publication of all chapters ensures the wider dissemination and impact of the research within academic, clinical, and patient communities.

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LIST OF ABBREVIATIONS

AV	Audiovisual
CIS	Carcinoma in situ
CFA	Confirmatory factor analysis
CNQ-SF	Cancer Needs Questionnaire Short Form
COM-B	Capability, Opportunity, Motivation - Behaviour
COSMIN	Consensus-based Standard for the Selection of Health Measurement Instruments
EDUCAT-ED	Patient education in oral epithelial dysplasia
EMT	Epithelial-mesenchymal transition
GP	General practitioner
GVHD	Graft-versus-host disease
HCRW	Health and Care Research Wales
HPV	Human papillomavirus
HRA	Health Research Authority
IN	Information needs
JAMA	*Journal of the American Medical Association*
JRO	Joint Research Office
LOH	Loss of heterozygosity
MT	Malignant transformation
NHS	National Health Service
OPMD	Oral potentially malignant disorders
OC	Oral cancer
OED	Oral epithelial dysplasia
ODIN-Q	Oral epithelial dysplasia informational needs questionnaire
OL	Oral leukoplakia
OLP	Oral lichen planus
OSCC	Oral squamous cell carcinoma
OSF	Oral submucous fibrosis
PE	Patient education
PEMAT	Patient education material assessment tool
PIL	Patient information leaflet

PROM	Patient-reported outcome measures
QoL	Quality of life
PVL	Proliferative verrucous leukoplakia
SRQR	Standards for Reporting Qualitative Research
UCL	University College London
UCLH	University College London Hospitals
UK	United Kingdom
WHO	World Health Organization

PUBLICATIONS FROM THE PRESENT THESIS

Journal articles

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INTRODUCTION

Oral epithelial dysplasia (OED) is a histopathological condition linked to a higher risk of oral epithelial malignancy transformation (Ho et al., 2012, Sarode et al., 2014, Iocca et al., 2020). OED is defined by the World Health Organization as “a spectrum of architectural and cytological epithelial alterations resulting from accumulated genetic mutations, frequently occurring in a variety of oral potentially malignant disorders (OPMD), that are linked to an elevated risk of transformation to oral squamous cell carcinoma (OSCC) (El Nagar et al., 2017).

OED is often clinically connected to OPMD (Warnakulasuriya et al., 2007, Warnakulasuriya et al., 2021, Muller and Tilakaratne, 2022), which include oral leukoplakia, proliferative verrucous leukoplakia, erythroplakia, oral submucous fibrosis, oral lichen planus, oral lichenoid disease (e.g., graft-versus-host disease, lupus erythematosus), and various familial cancer syndromes such as dyskeratosis congenita and Fanconi anaemia.

Early detection of OED plays a pivotal role in improving clinical outcomes. Head and neck cancers—which include OSCC—are frequently diagnosed at advanced stages (III and IV), where therapeutic options may be expensive, give rise to morbidity and lead to early death (González-Ruiz et al., 2023). Conversely, early-stage OSCC, which often arise from OED, are associated with significantly higher five-year survival rates (60–80%) compared to advanced stages (Bernard et al., 2023). Cancer Research UK reports that in England, stage I oral cancers have a five-year survival rate of 85% or higher, decreasing to approximately 35% for stage 4 cancers (CancerResearchUK, 2016). Similarly, the U.S. National Cancer Institute reports that the five-year relative survival rate for localised (early-stage) oral cancers—most likely preceded by dysplasia—is 88%**,** whereas the survival rate drops to 70% for regional spread, and plummets further to 39% for distant metastases (AmericanCancerSociety, 2021). These findings strongly suggest that timely identification and intervention for OED could lead to earlier OSCC diagnosis and better patient survival.

BACKGROUND AND RATIONALE

Numerous studies have demonstrated the crucial nature of patient education and information availability in the shared decision and treatment of life long and precancerous diseases (Lim et al., 2007, Ankem, 2015, Grilo et al., 2017), including OED (Alsoghier et al., 2022). However, despite the broad information provided by healthcare experts, patients with suspected cervical malignancy may be dissatisfied with the relevant resources available (Palmer et al., 1993, Hellsten et al., 2008). Likewise, insufficient patient information or inappropriate education methods were associated with increased anxiety levels in those with OPMD (Lin et al., 2015), which may impact the individual's welfare and adherence with their management plan (DiMatteo et al., 2000).

Elevated anxiety levels can significantly undermine adherence to follow-up and treatment plans in patients managing chronic or potentially serious illnesses such as OED. A meta-analysis by DiMatteo et al. (2000) demonstrated that anxiety and depression were consistently associated with poorer treatment compliance across diverse medical populations. Similarly, early psychological distress, particularly anxiety and depression, can have a substantial impact on a patient's ability to adhere to treatment and follow-up recommendations in oncology settings, with clear relevance to those diagnosed with OPMD or OED (Pitman et al., 2018). Pitman et al. (2018) reported that approximately 20% of patients with cancer experience depression and approximately 10% experience anxiety, which is significantly higher than that in the general population. These findings indicate that when anxiety and depressive symptoms are not identified and managed, they may add to the emotional burden of living with a potentially serious oral condition and compromise engagement with essential surveillance and intervention plans.

Additionally, research has shown that following a diagnosis of OED, poor provision of health information and inadequate doctor–patient communication adds to the patient's overall psychological burden and can lead to the development of anxiety and depression (Lauver et al., 1999). Therefore, it has been recommended that the provision of appropriate and timely information, when tailored to the medical condition and patients' needs and preferences, increases patients' ability to cope with their disease, supports participation in decision-making (Davis et al., 1999, Farnill and Inglis, 1994, Degner et al., 1997, Pinquart and Duberstein, 2004), reduces anxiety and distress (Kitamura, 2005), and improves adherence to therapy (Braddock et al., 1999, Larson et al., 1996, Stavropoulou, 2012).

Health literacy critically influences the way patients effectively act on the information provided to them regarding their condition. It is defined as the degree to which individuals can obtain, process, and understand basic health information and services needed to make appropriate health decisions (Nutbeam, 2000). Health literacy directly affects patient engagement and outcomes across a range of chronic and acute illnesses. In oncology settings, limited health literacy is associated with poor comprehension of diagnosis and treatment options, low adherence to medical recommendations, and increased decisional conflict (Oldach and Katz, 2014). For individuals with OPMD or OED, adequate health literacy may be essential for interpreting information about disease risk, understanding surveillance protocols, and adopting risk-reducing behaviours. Therefore, ensuring that educational interventions are accessible to patients with varying levels of health literacy could play a pivotal role in improving psychological well-being and clinical outcomes.

An assessment OED informational needs can be established using the Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) (Alsoghier et al., 2020). This 33-item instrument, which was developed in the United Kingdom, includes domains such as general information, investigative tools, treatment options, physical and psychological perspectives, medical system, and information access. It has demonstrated good preliminary validity and reliability. Once patient information needs have been established, it is then necessary to deliver timely, comprehensive, and easily understandable patient education for those with OED. However, studies have revealed the poor efficacy of written and spoken information while audio-visual and digital tools have shown some promise (Armstrong et al., 2011a, Trinh et al., 2014b).

Thus, this study aimed to (1) evaluate online audio-visual information on OED, (2) explore patient experience and clinical challenges of individuals with OED using qualitative methods such as semi-structured interviews, (3) assess informational needs of individuals with OED using quantitative methods with tools such as the ODIN-Q, (4) evaluate additional aspects of the psychometric properties of the ODIN-Q, namely structural validity and responsiveness.

Chapter I. Literature review

A narrative review of the present literature was carried out on oral epithelial dysplasia, patient information, and patient educational materials. Several biomedical search engines, including the University College London libraries, Google Scholar, Scopus, Cochrane library, and PubMed were used to search English publications from 1900 to 2024. The following search terms were employed:

1. Oral dysplasia OR oral epithelial dysplasia, oral premalignancy OR mouth precancer.
2. Oral epithelial dysplasia AND (patient education OR patient information OR health information).
3. Patient* information OR patient* information material OR patient* education tool.

Oral epithelial dysplasia

Background

Oral epithelial dysplasia (OED) is a histopathological condition that relates to a higher risk of oral epithelial malignant transformation (MT) (Ho et al., 2012, Sarode et al., 2014, Iocca et al., 2020). The World Health Organization (WHO) defines OED as "an array of architectural and cytological epithelial alterations resulting from accumulated genetic mutations, frequently occurring in a variety of oral potentially malignant disorders (OPMD), that are linked to an elevated risk of transformation to oral cancer" (El Nagar et al., 2017). Research has shown that OED raises the risk of oral squamous cell carcinoma (OSCC) by 6% to 36% (Field et al., 2015).

Early identification and monitoring of OED is important because a proportion of dysplastic lesions have the potential to progress to OSCC, particularly those with moderate or severe dysplasia. Population-based cancer registry data demonstrates that the five-year relative survival rate for localised oral cavity and oropharyngeal cancers can be as high as 85–90%; however, this decreases sharply to approximately 70% for regional spread and less than 40% for distant metastases (CancerResearchUK, 2016, AmericanCancerSociety, 2021). These figures highlight the clinical urgency to identify OED at a stage when intervention is most effective. For clinicians, this underscores the need for vigilant screening, patient education, and targeted risk-reduction strategies in those with identifiable lesions.

As noted above, OED is suspected to be found in the setting of a group of diseases called potentially premalignant oral epithelial lesions (Porter et al., 2018) or OPMD (Warnakulasuriya et al., 2007, Warnakulasuriya et al., 2021, Muller and Tilakaratne, 2022), which include oral leukoplakia (OL), proliferative verrucous leukoplakia (PVL), erythroplakia, oral submucous fibrosis (OSF), oral lichen planus (OLP), oral lichenoid disease (e.g., graft-versus-host disease [GVHD], lupus erythematosus), and various familial cancer syndromes such as dyskeratosis congenita and Fanconi anemia.

The term “precancer” was initially used to describe the lesions associated with these conditions; however, “potentially malignant” is now preferred since it suggests the possibility instead of the inevitability of transformation (Warnakulasuriya et al., 2007). Additionally, given MT may occur at distinct locations from where the original lesion originates or presents, a phenomenon known as “field cancerization”, the term “disorder” has been substituted for “lesion” (Johnson, 2017, Johnson, 2020).

Epidemiology

OED is expected to impact 2.5 to 5 individuals out of every 1,000 people (Mehanna et al., 2009). It precedes OSCC, which is one of the top 15 malignancies in the United Kingdom (UK), with roughly 6,000 new cases diagnosed each year (Cancer Research UK, 2017). Although most epidemiological data on OED and other OPMD are obtained from high-income countries, the global burden of these conditions is unevenly distributed and closely linked to regional risk exposures. The highest prevalence rates are observed in South and Southeast Asia, where cultural practices such as betel nut (areca nut) chewing, reverse smoking, and use of smokeless tobacco products are widespread (Gupta and Warnakulasuriya, 2002, Petersen, 2009). For example, in parts of India, the prevalence of OL has been reported to range from 0.2% to 5% in the general population, while OSF affects up to 6% of adults in certain high-risk groups (Mehrotra and Gupta, 2011). OLP, another common OPMD, has a reported prevalence of 1–2% in the general population globally, with some regional surveys showing rates as high as 2.6% in South Asia (McCartan and Healy, 2008, González-Moles et al., 2021).

Conversely, in many Western countries, OED is more commonly associated with cigarette smoking, alcohol consumption, and, increasingly, human papillomavirus (HPV) infection. In European populations, prevalence estimates for OL generally range from 0.2% to 1.2%, while OLP prevalence is typically between 1.0% and 1.5% (González-Moles et al., 2021). In the United States, OPMD such as OL are estimated to affect approximately 0.1–0.5% of adults, with higher rates observed in older populations and those with histories of tobacco and alcohol use (Markopoulos, 2012, Warnakulasuriya et al., 2021). Prevalence estimates for OLP in the United States are generally in the range of 0.5–2%, with a slight female predominance and peak incidence in middle-age persons (Eisen, 2002). These figures are markedly lower than those in many Asian countries but still represent a significant burden given the potential for MT (González-Moles et al., 2021).

The WHO’s Global Oral Health Programme highlights these striking geographic variations, emphasising the need for tailored prevention strategies that address both local cultural habits and broader socioeconomic determinants of health (Organization, 2022). Understanding these regional patterns is essential for designing context-specific screening programmes and patient education initiatives.

Clinical presentation of OED and its relationship to OPMD

Given that OED is a histopathological diagnosis, it cannot be identified clinically. Therefore, the focus of this section is on the clinical presentation of OPMD, which are the clinical entities that may or may not harbour dysplasia. OED and OPMD are related but not synonymous: OED represents microscopic architectural and cytological changes, whereas OPMD refer to clinical lesions associated with an increased risk of MT (Warnakulasuriya, 2020). Some OPMD may progress to malignancy without showing dysplasia at the initial stage, while in other cases dysplasia is found only on biopsy. Thus, OPMD constitute the clinical context in which OED may occur, but the presence or absence of dysplasia must be confirmed histologically.

OPMD display a wide variety of clinical characteristics, including differences in colour (white, red, or mixed red-and-white lesions) and surface topography (atrophic, smooth, plaque-like, flat, corrugated, or verrucous) (Williams et al., 2008; Speight et al., 2018).

They can be focal or widespread and may involve any anatomical region of the oral cavity (Farah et al., 2014). Their clinical course is unpredictable: some lesions remain stable over time, others regress, and a proportion will progress to more severe disease or MT (Holmstrup et al., 2006; Speight et al., 2018; Farah et al., 2019).

Most OPMD are identified in middle-aged or older individuals, primarily men (Napier and Speight, 2008, Speight et al., 2018). In the West, however, older women with persistent leukoplakia with no clear risk factors have a considerable risk of developing cancer (Warnakulasuriya et al., 2021). Instead of being impacted by a lifestyle risk factor, these individuals may have an internal risk factor. The variety and patterns of OPMD observed in particular groups have been altered by ethnicity and the dominance of unique sociocultural habits. For instance, the widespread betel and areca nut chewing among South Asian communities has contributed to the higher prevalence of OPMD in this population (Lee et al., 2012, Mello et al., 2018). Moreover, clinically, dysplasia is not typically correlated with pain, hence several possible causes should be considered when pain is present, such as an OLP flare-up or progression to OSCC.

Oral leukoplakia is the most common OPMD encountered in clinical settings, affecting 4.1% of people worldwide (Mello et al., 2018). The MT rate ranged from 0.13% to 34.0% (Warnakulasuriya and Ariyawardana, 2016), with an estimated transformation proportion of 9.8% (Aguirre-Urizar et al., 2021). The MT potential ranges from 0.1% to 14% in the absence of dysplasia and from 6% to 36% in the presence of dysplasia (Brouns et al., 2014). The MT rate of OL, particularly the verrucous subtype, is even higher, ranging from 9% to 49% (Iocca et al., 2020). The recurrence rate ranges from

4% to 30% (Holmstrup et al., 2006). Erythroleukoplakia, a mixed red-and-white variant, carries one of the highest transformation risks among leukoplakia subtypes, with reported MT rates commonly between 20% and 50%, owing to its strong association with high-grade dysplasia (Iocca et al., 2020). The recurrence rate of leukoplakia ranges from 4% to 30% (Holmstrup et al., 2006). Oral erythroplakia is a less frequently encountered condition compared with OL and has a MT rate of 33% (Iocca et al., 2020).

Oral submucous fibrosis is a chronic inflammatory condition driven by smokeless tobacco use and characterised by progressive submucosal tissue fibrosis (Warnakulasuriya et al., 2017). In a recent systematic review, (Iocca et al., 2020) found that the overall MT rate of OSF is approximately 5%, whereas (Kujan et al., 2021) reported in their systematic review that nearly 4% of patients with OSF had a risk of developing OSCC , with a higher risk linked to those with OED.

Oral lichen planus is an immune-mediated condition of unclear cause that affects 1% of individuals worldwide (González-Moles et al., 2021). According to recent systematic reviews and meta-analyses, the MT rate of OLP is extremely low at 0.44% to 1.4% (Iocca et al., 2020, Idrees et al., 2021b). Recent research results suggest that use of topical medications for the treatment of oral disease may lead to the development of OSCC (Kierce et al., 2021). Incorrect administration of topical corticosteroids in cases of hyperkeratosis or dysplasia that have been misdiagnosed as OLP because of overlapping histopathological features may result in cancer progression (Kierce et al., 2021).

Risk factors and aetiopathogenesis of OED/OPMD

It is important to note that there is still no consensus in terms of the nomenclature or descriptions of OED/OPMD. Thus, explaining or defining the aetiology and development of such diseases is complicated, and sometimes evidence is conflicting and/or deceptive (Porter et al., 2018, Warnakulasuriya et al., 2021). Nevertheless, oral carcinogenesis is characterised by a cascade of reversible cellular and molecular changes, some of which eventually become irreversible and lead to malignancy; therefore, certain contributory factors for OED/OPMDs overlap with those for OSCC (Porter et al., 2018).

There is strong evidence that the majority of OSCC cases are caused by social habits, such as the use of tobacco (in its various forms), alcohol consumption, the chewing of betel nut and similar items, and oncogenic types of HPV. Therefore, at present, relatively good evidence shows that these factors, in addition to HPV infection, may also cause or be connected with the development of OED and OPMD (Porter et al., 2018).

While individual risk factors such as tobacco use, alcohol consumption, betel nut chewing, and high-risk HPV infection are well established in the pathogenesis of OPMD and OED, there is evidence indicating that these exposures often act synergistically rather than independently. Case–control and cohort studies have demonstrated that the combined use of tobacco and alcohol confers a multiplicative effect on the risk of developing oral cancer, exceeding the sum of their individual risks (Blot et al., 1988, Hashibe et al., 2009).

Human papilloma virus infection—particularly with high-risk genotypes such as HPV-16 and, to a lesser extent, HPV-18 (Gillison et al., 2008)—has been proposed as a potential cofactor in oral carcinogenesis. While HPV-16 is the predominant type associated with oropharyngeal squamous cell carcinoma, both types 16 and 18 are biologically capable of contributing to epithelial dysregulation. Evidence relating specifically to the oral cavity suggests that HPV alone carries a lower malignant potential compared with the oropharynx; however, concurrent exposure to traditional risk factors such as smoking or heavy alcohol consumption may potentiate carcinogenic pathways (Gillison et al., 2008). In regions where areca nut chewing is prevalent, the addition of tobacco or alcohol further elevates the likelihood of dysplastic changes and progression to carcinoma (Gupta and Warnakulasuriya, 2002). Understanding these synergistic relationships is crucial for risk stratification, patient education, and the development of multifactorial prevention strategies targeting high-risk individuals.

Diagnosis and histopathological features of OED

A vigilant visual inspection of the oral cavity and clinical examination of both the lesion and head and neck lymph nodes are crucial in making an initial diagnosis of any clinically apparent OMPD (Warnakulasuriya, 2020). However, to establish a definitive diagnosis of OED, performing a biopsy for histopathological assessment at areas likely representing dysplasia is essential (Odell et al., 2021). Hence, biopsy is considered the gold standard for diagnostic investigation, and ideally, both cellular (atypia) and architectural changes must be evident to establish a reliable diagnosis (Dost et al., 2014, Edwards, 2014, Giovannacci et al., 2016, Warnakulasuriya, 2018).

Once an OED diagnosis is made, grading the disease on the basis of the degree of dysplastic alterations in the epithelial layers is necessary, and numerous histology-based classification systems have been used (Odell et al., 2021). A three-tier categorisation was proposed by (Smith and Pindborg, 1969), which included no, minor, and marked dysplastic changes. However, the 2005 WHO grading system identifies five histopathological stages of precursor lesions in the epithelium, encompassing squamous hyperplasia, mild dysplasia, moderate dysplasia, severe dysplasia, and carcinoma in situ (CIS) (Barnes et al., 2005). The terms “squamous hyperplasia” and “CIS” were removed from the 2017 WHO classification, which includes 3 grades of dysplasia: mild, moderate, and severe (Reibel et al., 2017).

The grading is based on the degree of dysplastic changes across the epithelial layers as follows: less than 1/3, “mild dysplasia”; between 1/3 and 2/3,“moderate dysplasia”; and more than 2/3 (but not the entire thickness), “severe dysplasia” (Reibel et al., 2017). Mild dysplasia has always been difficult to diagnose because of the immense subjectivity between pathologists, whereas moderate and severe dysplasia frequently have a better inter-examiner agreement (Kujan et al., 2007). As such, (Kujan et al., 2006) proposed a binary system that divides lesions into low-risk dysplasia (no, questionable, or mild) or high-risk dysplasia (moderate or severe). However, the binary system remains unvalidated against MT (Nankivell et al., 2013).

In addition to the aforementioned well-established histopathological criteria of OED (Kujan et al., 2006, Reibel et al., 2017), other features have been proposed (Woo, 2019, Li et al., 2021, Odell et al., 2021) and must be considered, especially if cytologic alterations are minimal or absent. These features include (1) verrucous and papillary surface morphology, (2) bulky epithelial hyperplasia, (3) epithelial atrophy with hyperkeratosis, and (4) “skip segments”, described as areas of dense keratosis alternated with patches of normal-appearing non-keratinised epithelium. Table 1-1 summarises the 2017 WHO diagnostic criteria based on histopathological examination findings, as well as the additional features included in 2022.

Table 1-1 OED diagnostic criteria indicated by the WHO in 2017, along with the additional stated in 2022. Adopted from (Muller and Tilakaratne, 2022).

Architectural features	**Cytological features**
Irregular stratification of the epithelium	Abnormal variation in nuclear size
Loss of polarity / disorganisation of basal cells	Anormal variation in nuclear shape
Drop-shaped rete processes	Abnormal variation in cell size
Increased mitotic activity *(moved to cytological features)*	Abnormal variation in cell shape
Abnormally superficial mitoses *(now: mitosis high in epithelium)*	Increased nuclear-to-cytoplasmic ratio
Premature keratinisation in single cells *(now: generalized premature keratinisation)*	Atypical mitotic figures
Keratin pearls in rete processes	Increased number and size of nucleoli
Reduced epithelial cell cohesion	Hyperchromasia
Additional features included in 2022	
Altered keratin pattern for oral sub-site	Single cell keratinisation
Verrucous or papillary architecture	Apoptotic mitosis
Extension along minor gland ducts	Increased nuclear size
Sharply defined margins to changes	

Multiple different patterns to dysplasia	
Multifocal or skip lesions	
Basal cell clustering/nesting	
Expanded proliferative component	

After the 2022 additions, several considerations should be taken into account when diagnosing OED (Odell et al., 2021). These considerations include (1) categorising dysplasia by thirds oversimplifies OED complexity, (2) judging the number of thirds affected is one factor in assigning a grade, (3) OED may only affect the basal third in some cases but due to presence of cytological and architectural alterations, it may still be classified as severe dysplasia.

Progression of OED to OSCC

For better understanding of cancer progression associated with OED, it is cardinal to determine if research should concentrate on characterising diseases at a molecular, cellular, tissue, or clinical level (Porter et al., 2018). For example, remarkably extensive research has been conducted on clinically observable leukoplakic lesions, which, in most instances, will only show thickening of tissues (hyperkeratosis), while abnormalities concerning histopathological alterations, namely cellular atypia or epithelial dysplasia, are not predominantly evident in such lesions. Thus, research based predominantly on the clinical characteristics of OPMD, which has contributed to uncertainty and contradictions in the current literature, is unjustifiable.

The MT and risk of OSCC development are typically connected to the grade of dysplasia. The 5-year MT risks of severe, moderate, and mild dysplasia are 39%, 18%, and 6%, respectively (Sperandio et al., 2013). In their systematic review, (Mehanna et al., 2009) reported that severe OED was associated with higher MT rates (24.1%) than mild and moderate OED (10.3%) and that OED preceded 12.1% of cases that progressed into OSCC in 4.3 years.

These findings are in line with recent research that found an elevated annual risk of MT in patients with severe OED than in those with mild OED (3.57% vs. 1.7%) (Iocca et al., 2020). The MT rate differs between studies and is subject to multiple variables such as sample size, histopathological evaluation, risk factors, and follow-up duration. Therefore, the MT rate ranges from 6.6% to 36.4% with a follow-up period of 15 years approximately (Field et al., 2015).

Although histopathological evaluation remains paramount for OED detection, considering the subjectivity of pathologist interpretation and that OSCC may be preceded by either mildly dysplastic or non-dysplastic lesions, histopathological examination alone is insufficient, and other clinical and biological factors should be considered to anticipate the risk of MT (Van der Waal, 2014).

Histopathological considerations and mimics of OED

Histopathological grading according to the WHO 2017 classification (mild, moderate, severe) is the cornerstone of OED assessment. However, variability in interpretation continues to challenge reliability and prognostication. Multi-centre and survey studies have shown substantial inter- and intra-observer variability in dysplasia grading, reinforcing the need for standardised criteria and decision support tools such as structured feature checklists and consensus training (Kujan et al., 2007, Ng et al., 2025).

Histological grade alone does not fully predict clinical outcomes, as some lower-grade lesions progress to carcinoma while some higher-grade lesions remain stable over time (Woo, 2019). Notably, evidence has shown that some lesions may show hyperkeratosis only and no or minimal atypical alterations but can progress to dysplasia or OSCC over a long period (Bagan et al., 2011, Pentenero et al., 2014, Li et al., 2021). This is especially evident in the case of large multifocal lesions found in PVL, where 70–100% of cases eventually progress to cancer. Therefore, the significance of clinical correlations cannot be overemphasised.

Moreover, studies have reported that some solitary benign leukoplakic lesions that demonstrate hyperkeratosis without OED may advance to OSCC in 0.1% to 14% of cases (Brouns et al., 2014, Chaturvedi et al., 2020). As a result, (Woo, 2019) proposed that in the absence of dysplastic changes and if the histopathological findings are not inflammatory, the phrase “hyperkeratosis, not reactive” should be used instead of “hyperkeratosis, no dysplasia”.

In addition, histopathological findings in numerous conditions comprise epithelial atypia (Li et al., 2021). This atypical presentation could be reactive and benign, and may not necessarily be a dysplastic phenotype (Woo, 2019). For example, cellular changes (atypia) may be observed in multiple settings such as trauma, ulceration, regeneration, and inflammatory reactions from OLP or candidiasis (Neville et al., 2015, Li et al., 2021).

HPV-associated OED can be identified by its distinctive histopathological features and affirmed by in situ hybridisation. It appears to be a rare lesion, as it accounts for only a very small percentage of oral biopsies that show dysplasia (McCord et al., 2014). However, the cytologic and architectural criteria for assessing dysplasia in non-HPV-associated OED (Reibel et al., 2017) should not be used for HPV-associated OED, which has a characteristic morphology that involves the entire thickness of the epithelium but does not always represent severe dysplasia undergoing a malignant transformation (Odell et al., 2021). In a previous study, the p16 test result was positive in almost all high-risk HPV-associated lesions (Lerman et al., 2017).

Importantly, clinicians must realise that OED can elicit a host inflammatory response at the epithelial basement membrane that mimics an OLP band-like lymphocytic infiltrate also known as 'interface mucositis' and can impose a difficult clinical challenge for practitioners to reach a definitive diagnosis in many occasions (Fitzpatrick et al., 2014, Odell et al., 2021). However, the distinction between the two conditions is based on multiple characteristics such as clinical appearance, location, duration, and response to topical therapy (Shearston et al., 2019, Idrees et al., 2021a). The evidence of both the architectural and cytologic histopathological alterations in OED must also be conspicuous (Reibel et al., 2017).

The early lesions of PVL may also exhibit interface mucositis, which has been reportedly misdiagnosed as OLP (Warnakulasuriya et al., 2021). Thus, the importance of clinical context (female sex, presence of gingival lesions, and no history of tobacco/alcohol use) plays a significant role in PVL differentiation from OED. In addition, the histopathological demonstration of surface projections, or "verrucous morphology", premature keratinisation, increased keratin, skip lesions, and sharp lateral margins can be associated with PVL (Li et al., 2021, Odell et al., 2021). Interface mucositis can also be observed in cases of OSCC (Fitzpatrick et al., 2014), and current research has revealed that this robust lymphocyte host response may be related to better prognostic outcomes (Spector et al., 2019) and may provide the foundation for developing of a novel immune checkpoint inhibitor therapy (Kujan et al., 2020).

These considerations have accelerated interest in digital pathology and artificial intelligence-assisted approaches that analyse whole-slide images to improve reproducibility, quantify diagnostically relevant features, and enhance risk stratification beyond grade. Recent studies have demonstrated deep-learning models capable of detecting and grading OED at the whole-slide level, and emerging computational biomarkers, such as peri-epithelial lymphocytic activity, have been shown to predict malignancy (Bashir et al., 2023, Peng et al., 2024). State-of-the-art reviews have summarised these advances and outlined practical considerations for integrating artificial intelligence into OED workflows alongside WHO criteria (Alajaji et al., 2024).

Adjunctive diagnostic tools for the diagnosis of OED

The definitive diagnosis and grading of OED relies on tissue diagnosis through histopathological examination of a surgical biopsy specimen (incisional or excisional), which remains the gold standard. Auxiliary diagnostic methods can be useful adjuncts for initial assessment and lesion mapping, but it is important to note that none of these methods provide a definitive tissue diagnosis, as their output—whether cytological smears (brush test), vital dye retention (toluidine blue), or real-time imaging (light/laser systems)—is insufficient for the comprehensive assessment of cellular architecture and invasion required for grading dysplasia (Sridharan and Shankar, 2012, Yang et al., 2018, Tiwari et al., 2020). Several diagnostic aids have been tested in clinical investigations, including cytology or brush test, toluidine blue stain, and light or laser-based imaging systems.

Oral brush cytology analysis is a useful tool for detecting OED, especially when scalpel biopsy is not feasible or is an aggressive approach. It is a quick, non-invasive, and tolerable testing technique that has the highest accuracy among adjunctive diagnostic techniques (Lingen et al., 2017). However, a significant limitation—often considered the "Achilles' heel" of the system—lies in its sampling variability: the brush yields only shed superficial and full-thickness cells with no guarantee of capturing sufficient numbers of cells from the critical basal and parabasal layers of the epithelium (Walsh et al., 2021). This issue is compounded by the potential for sample degradation and artifacts from thick smears, blood, or saliva contamination, which can compromise the quality of preparation and lead to false-negative results (Çelebi et al., 2025). Consequently, other systematic reviews highlight that the overall diagnostic accuracy remains questionable due to these inherent sampling flaws (Omar, 2015). Although moderate sensitivity has been reported (74.1%), its specificity was only at 32% for detecting OED or OSCC (Poate et al., 2004).

The toluidine blue stain is an inexpensive and convenient tool for diagnosis (Chhabra et al., 2015). Regardless of its reduced reliability with mild dysplasia lesions, it demonstrated elevated sensitivity for detecting moderate or severe dysplasia (Martin et al., 1998, Omar, 2015, Lingen et al., 2017).

Autofluorescence imaging devices function by helping to visualize the loss of tissue fluorescence (L-AF), which is strongly associated with the biochemical and structural alterations that occur during the progression to dysplasia and malignancy (Farah and McCullough, 2008). This capability is highly valued for potentially aiding in lesion margin delineation, especially for lesions that are poorly defined under white light, though their specificity remains limited (Farah and McCullough, 2008). . Optical coherence tomography offers non-invasive, high-resolution cross-sectional imaging of oral mucosa, enabling visualisation of epithelial thickness and architectural changes suggestive of dysplasia (Kim et al., 2023). While these technologies are not yet replacements for biopsy, they may serve as complementary tools to improve lesion detection, guide biopsy site selection, and monitor high-risk patients over time.

Clinical and molecular characteristics correlated with progression of OED

Given the documented interobserver variability in grading and the observation that some low-grade lesions progress while some high-grade lesions remain static, histopathology alone is insufficient for precise prediction of MT. Multivariate risk models that integrate clinical, histological, and molecular factors have shown promise in improving prognostic accuracy. Clinical factors encompass lesion characteristics (e.g., appearance, site, size, and multifocality), patient characteristics, and OPMD type. A meta-analysis highlighted the clinical characteristics that increase the risk of MT in OPMD (e.g., red, speckling, non-homogenous appearance, a lesion size larger than 200 mm^2, and lesions at the lateral borders of the tongue or floor of the mouth) (Narayan and Shilpashree, 2016). Patient characteristics, including female sex, age above 50 years, and dysplasia in non-smokers, have also been correlated with a higher risk for OED or MT (Speight et al., 2018).

While histopathological grading remains the gold standard for OED diagnosis, advances in molecular oncology have revealed a complex cascade of genetic and epigenetic events underlying disease progression. Abnormal DNA contents are a characteristic sign of malignancy, and numerous biological markers have been investigated to determine their roles in the molecular pathogeneses of OED and OSCC (Leemans et al., 2011, Speight et al., 2018). Alterations such as TP53 mutations, loss of heterozygosity (LOH) at chromosomal regions, DNA ploidy, epithelial–mesenchymal transition (EMT) changes, and dysregulation of cell cycle control pathways have all been implicated in the transformation of dysplasia into invasive carcinoma (Califano et al., 1996, Tilakaratne et al., 2019). Understanding these molecular drivers aids in refining prognostic assessment and opens avenues for personalised patient education—allowing clinicians to better communicate individual risk profiles and the rationale for surveillance or intervention.

Tumour protein p53 expression level was reported as the most critical biological sign of OSCC formation (Whyte et al., 2002). LOH at specific chromosomes (3p, 9p, and 17p) has been observed in OED, especially in mild degree cases (Pathare et al., 2009, Leemans et al., 2011, Zhang et al., 2012). DNA ploidy has been investigated as a useful biological marker (Sperandio et al., 2013, Sathasivam et al., 2021) and a meta-analysis reported that aneuploidy was a feasible predictor of MT in individuals with OPMD (Alaizari et al., 2018). Recent expert reviews have advocated incorporating LOH and, where available, DNA ploidy testing into clinical workflows to augment traditional grading and guide personalised surveillance and intervention strategies (Kerr and Lodi, 2021). EMT is a process where the epithelial cells are converted into mesenchymal cells during the normal development and regeneration of tissues. This process is often disrupted in malignancy (Guarino et al., 2007, Zeisberg and Neilson, 2009, Speight et al., 2018), and its potential role in the transformation of OED has been reported in several studies (de Freitas Silva et al., 2014, Abdalla et al., 2017, Lopes et al., 2018). Table 1-2 highlights the risk factors associated with the MT of OED (Warnakulasuriya et al., 2011, Ho et al., 2012, Dost et al., 2014, Van der Waal, 2014, Thomson, 2015, Speight et al., 2018, Kierce et al., 2021).

Table 1-2 Risk factors associated with higher risk for MT of OED.

Patient characteristics	-Age: older individuals -Sex: female -Habits: strong and excessive addiction to smoking, non-smoking with lesions showing OED, excessive alcohol intake, and use of betel quid -Status: low socioeconomic status and material deprivation
Clinical characteristics	-Colour: erythroplakia and erythroleukoplakia -Time: longer duration -Presentation: multiple lesions, associated with ulceration or erosion, lichenoid features, and proliferative verrucous leucoplakia -Texture: Non-homogeneous lesions -Size: >200 mm² -Site: tongue, retromolar area, floor of mouth, and gingiva -History of OSCC in the past 5 years but not within the previous 6 months -Immunosuppression: local and systemic medicines and systemic disease
Histopathological characteristics	-Dysplasia: higher OED grade -Aetiology: human papilloma virus and chronic hyperplastic candidiasis

Molecular characteristics	-DNA contents: P53, loss of heterozygosity, DNA ploidy, disruption of the epithelial-mesenchymal transition

Overall, risk factors for MT of OED can be usefully grouped according to the strength of current evidence supporting their role in pathogenesis (Porter et al., 2018). Well-established risk factors include tobacco use (both smoke and smokeless forms), heavy alcohol consumption, betel nut (areca nut) chewing, and chronic mechanical irritation. These exposures have repeatedly been shown in large-scale epidemiological studies to significantly increase the risk of OED and oral cancer, often with dose–response relationships (Gupta and Warnakulasuriya, 2002, Hashibe et al., 2009). High-risk HPV infection is a probable risk factor (de la Cour et al., 2020). Although HPV's role in oropharyngeal carcinogenesis is well documented, its contribution to OED development in the oral cavity appears variable and may be more pronounced in combination with other exposures (Gillison et al., 2008).

Suggested risk factors are those indicated in research, with less convincing evidence (Porter et al., 2018). These factors encompass conditions such as OLP, oral lichenoid disease in lupus erythematosus (Warnakulasuriya et al., 2007) and GVHD (Mawardi et al., 2011), candida infection (McCullough et al., 2002), genetic diseases (dyskeratosis congenita and Fanconi anaemia), scleroderma, haematinic deficiency (iron, vitamin B_{12}, and folate) (Porter et al., 2018), and low dietary intake of fruits and vegetables (Morse et al., 2000). Poor oral hygiene (Irani, 2020) and immunosuppression (Müller, 2018) have also been suggested, although their relevance as independent risk factors is highly uncertain, and current evidence does not support a strong causal role in OED progression. Recent research has also examined the role of the oral microbiome in carcinogenesis, with studies showing altered microbial composition and increased abundance of periodontopathogens in OPMD lesions compared to healthy mucosa, suggesting a potential role in disease initiation and progression (La Rosa et al., 2020). Other proposed emerging factors include systemic inflammation and metabolic disorders such as diabetes mellitus (Ramos-Garcia et al., 2021). Table 1-3 summarises the risk factors associated with OED development.

Table 1-3 Risk factors linked to the development of OED

Well-established risk factors	Tobacco use (both smoke and smokeless forms) Heavy alcohol consumption Betel nut (areca nut) chewing
Probable risk factors*	Oncogenic HPV types
Other suggested factors	Oral lichen planus and lichenoid diseases (e.g., lupus erythematosus and GVHD) Genetic diseases (dyskeratosis congenita and Fanconi anaemia) Haematinic deficiency Chronic mucocutaneous candidiasis Systemic inflammation Immunosuppression Low dietary intake of fruits and vegetables Poor oral hygiene

GVHD: Graft-versus-host disease; HPV: Human papilloma virus

*This is likely to be only relevant to the posterior tongue

Management of patients with OED/OPMD

Despite decades of research on OED and OPMD, there remains a notable absence of large, randomised controlled trials directly comparing management strategies. No substantial evidence has proposed any consensus on the preferred management approach for OED. Most available data come from retrospective case series, prospective observational cohorts, or small interventional studies with limited follow-up (Mehanna et al., 2009, Iocca et al., 2020). This reliance on non-randomised evidence limits the ability to draw definitive conclusions regarding optimal treatment or surveillance intervals. In this context, well-designed prospective studies—particularly those incorporating modern risk stratification tools—are essential to refine current practice and improve patient outcomes, providing the rationale for the present investigation.

In most cases, the intervention is determined through the assessment of the correlated clinical, histopathological, and molecular risk factors and characteristics (Field et al., 2015). Overall, most patients with OMPD will only necessitate routine monitoring by an oral health specialist. However, when dysplasia is present, the goal of treatment is to reduce or prevent the possibility of progression to OSCC, which, according to available evidence, is difficult to achieve with any of the therapeutic regimens applied so far in clinical practice (Tilakaratne et al., 2019).

Treatment plans must include the mitigation and control of lifestyle risk factors such as alcohol and tobacco use. Clinically, OED is currently managed with either surveillance or surgical excision (with a scalpel or laser) (Field et al., 2015). Some evidence suggests that surgical excision lowers the risk of MT compared with regular surveillance, which is why surgical procedures are commonly performed (Arnaoutakis et al., 2013). A systematic review that analysed 992 patients with OED indicated that resected lesions were associated with considerably higher MT rates than non-resected lesions (Mehanna et al., 2009). This seemingly paradoxical finding warrants critical discussion, as the overall result likely masked substantial heterogeneity in the surgical techniques employed. The studies included likely aggregated data from sharp scalpel dissection and various laser modalities (excision vs. vaporisation). Unlike scalpel excision, which provides a clean margin for histopathology, laser techniques can induce thermal damage at the excision boundary, leading to an indeterminate or positive surgical margin. The resulting residual dysplasia significantly increases the risk of recurrence and malignant transformation, which artificially elevates the MT rate in the surgical group (Deuerling et al., 2019, Walsh et al., 2021).

Surgeries are usually performed in cases of moderate and severe dysplasia, regular surveillance is considered for patients with mild dysplasia (Field et al., 2015). Considering that the recurrence rate of OED after treatment is approximately 30% (Tilakaratne et al., 2019) and regardless of the severity or degree of dysplasia, lifelong follow-up examinations are recommended, with the frequency of visits determined according to clinical judgement (Van der Waal, 2009). If concerning clinical changes are observed by the patient or clinician, re-biopsy is usually performed for further histopathological analysis (Epstein et al., 2007).

Management of OPMD varies according to the disease. Management may vary within the treatment of the same disease according to the presence of dysplasia. However, previous studies have not distinguished between lesions with and without dysplasia while examining various treatments for OPMD (Lodi et al., 2016). Hence, the following paragraphs elucidate the management of the most prevalent OPMD encountered in clinical settings, namely OL, oral erythroplakia, OLP, and OSF (Speight et al., 2018).

The treatment options for OL might range from risk counselling and watchful monitoring to surgical intervention, depending on the factors associated with the lesion and patient (Kumar et al., 2013). However, whether avoiding risk factors such as smoking cigarettes and alcohol consumption is sufficient to prevent the MT of oral leukoplakic lesions is uncertain (Lodi et al., 2016). Routine surveillance is advisable in cases where dysplasia is not detected or when mild dysplastic changes are demonstrated (Ribeiro et al., 2010). In addition, the non-surgical approach can be considered in patients with widespread OL lesions to preclude serious side effects or accommodate patients contraindicated for surgical procedures.

Nevertheless, considering the unpredictable progressive behaviour of OL, which entails oral malignancy preceded by non-dysplastic or mildly dysplastic lesions, surveillance alone can be risky, and obtaining a biopsy sample at regular intervals may be needed, particularly if the clinical presentation changes or worrisome symptoms appear (Kerr and Lodi, 2021). The surgical treatment often performed for OL is excision with a cold knife, CO2/Nd:YAG/KTP laser ablation, or a combination of both (Kerr and Lodi, 2021). In non-randomised clinical trials, surgical interventions have been found to be effective in reducing recurrence and possibly prevent the advancement of lesions with non-homogeneous appearance or lesions with dysplastic features (Jerjes et al., 2012, Mogedas-Vegara et al., 2016). This positive clinical outcome appears to conflict with the finding of Mehanna et al. (2009), who reported that resected lesions were paradoxically associated with a higher MT rate than non-resected lesions.

Oral erythroplakia is a less frequently encountered condition compared with OL, with a MT rate of 33% (Iocca et al., 2020). It typically requires immediate surgical treatment, and long-term surveillance is strongly recommended (Rhodus et al., 2014, Awadallah et al., 2018).

Although OLP possess a MT potential of only 1%, regular vigilant surveillance is required (Iocca et al., 2020). Topical corticosteroids are the preferred type of intervention for the management of symptomatic OLP (Lodi et al., 2020). Evidence suggests that topical calcineurin inhibitors such as tacrolimus may be slightly more potent in managing pain than topical corticosteroids, despite the former's potential side effects (Lodi et al., 2012, Lodi et al., 2020).

The management of OSF typically involves non-surgical treatments such as cessation of the causative agent (e.g. betal nut with or without tobacco), professional physical therapy, mouth guards, collagenase and hyaluronidase intralesional injection, and the use of topical corticosteroids, pentoxifylline, and interferon-gamma (Warnakulasuriya and Kerr, 2016, Rao et al., 2020). Surgical management may involve the use of extra- or intra-oral flaps or allografts (Arakeri et al., 2017). However, at present the strategies to manage OSF are not well detailed and have not been shown to be notably effective. Emerging evidence suggests there may be value in considering fat stem cell transfer, which has demonstrated benefit in the management of orofacial fibrosis associated with scleroderma (Jeon et al., 2020).

A recent systematic review (Kujan et al., 2020) explored the therapeutic use of immune checkpoint inhibitors for the management of OPMD and OSCC. It is an emerging therapy that targets checkpoint receptors such as the programmed death-1 receptor (PD-1) of T-cells, allowing T-cells to fight and restrict the proliferation of cancer cells and ultimately improve the immunological response of the host against tumours (Almokadem, 2016). Pembrolizumab and nivolumab therapies targeting PD-1 have shown to enhance disease outcomes and increase patient survival rates, particularly when combined with chemotherapy or radiotherapy (Barbee et al., 2015).

The relevance of checkpoint therapy in the management of OPMD has been investigated, and the over-expression of PD-1 on infiltrating T lymphocytes has been demonstrated in patients with OLP (Du et al., 2011) and actinic cheilitis (de Souza Malaspina et al., 2011). Thus, blocking the expression of PD-1 receptors may inhibit the MT of some OPMD (Yagyuu et al., 2017). However, additional research is necessary to comprehend the connection between immune checkpoint inhibitors and the MT of OPMD. Of note, immune checkpoint inhibitors (including anti-PD-1) have themselves been associated with T-cell mediated immune attacks in the oral mucosa that clinically and histologically mimic OLP (e.g., oral lichenoid reactions in patients treated with pembrolizumab and nivolumab) (Sibaud et al., 2017; Goveris et al., 2022; Jiang et al., 2024).

Anxiety and distress in patients with OED/OPMD

Knowledge regarding the psychological impact and incidence of disorders such as anxiety and distress in patients with oral malignancy or pre-malignancy is limited, largely underappreciated, and not supported by scientific evidence (Scott et al., 2006, Brocken et al., 2012, Noonan, 2014). Generally, the quality of life (QoL) may be impacted after the diagnosis of OED (Morse et al., 2010), as indicated in studies on pre-cancers involving disparate regions of the body such as the lungs (Brocken et al., 2015), breasts (Brocken et al., 2012), and colorectal tissues (Ndukwe et al., 2012).

The vast majority of patients undergoing cancer screening are found to be clear, whereas a small percentage is reported to have cancer (Renzi et al., 2015). In addition, this associated psychological burden has been demonstrated to impact cancer patients' ability to cope with medical therapy (Manne et al., 2010). In the same line, psychological disorders were found in 19% to 50% of patients with OC (Reisine et al., 2005) and may even last for 10 years after the initial diagnosis in 22% to 32% of cases (Espie et al., 1989).

Psychological disorders such as distress, anxiety, and depression among patients with OED can originate from various reasons, starting from the initial diagnosis and emergence of symptoms to the physician's incompetency, referral process, financial burdens, and possible side effects of the surgical intervention. During this time, the patient may experience greater anxiety, stress, and mood swings, and decreased immune cell activity (Witek-Janusek et al., 2007, Ndukwe et al., 2012, Renzi et al., 2015). Anxiety secondary to the oral and systemic manifestations of OPMD can also impact patients' QoL. For example, increased levels of anxiety and depression have been reported in patients with OLP compared with general population (Vallejo et al., 2001, Gavic et al., 2014, Pippi et al., 2016, Wiriyakijja et al., 2020).

Effective risk communication is central to mitigating avoidable anxiety and decisional conflict in patients with OED/OPMD. Message framing influences perceptions and emotions: presenting identical information in gain versus loss terms can shift preferences and heighten worry; therefore, balanced, transparent framing is recommended (Akl et al., 2011). In decision making in oncology, patient decision helps to increase knowledge, improve accuracy of risk perceptions, and help people make choices aligned with their values possibly reducing decisional conflict and associated distress (Stacey et al., 2017, Smith et al., 2024).

Communication techniques that check understanding, such as teach-back, which are associated with better comprehension and downstream outcomes are advisable when discussing prognosis, surveillance schedules, and symptom monitoring (Yen and Leasure, 2019). For OED/OPMD—where prognostic uncertainty and long surveillance horizons are common—combining balanced framing with absolute risk formats, clear visuals, explicit uncertainty, and teach-back provides a practical, evidence-based approach to inform patients while minimising unnecessary anxiety.

Information needs for patients with OED

Before initiating an information needs (IN) exploration, it is necessary to distinguish between information and knowledge. Information is the externally gained organised data, which converts into knowledge when undergoes processing and synthesis (Greer and Fowler, 2013). The combination of informational seeking, demand, and needs comprises the “information behaviour”, described by (Wilson, 2000) as *“the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use”.*

IN broadly refers to *"a state or process started when one perceives that there is a gap between the information and knowledge available to solve a problem and the actual solution of the problem"*, (Miranda and Tarapanoff, 2008). Ormandy (Ormandy, 2011) described the IN of patients as *"recognition that their knowledge is inadequate to satisfy a goal, within thecontext/situation that they find themselves at a specific point in the time"*. Evidence has shown that higher satisfaction levels of patients are associated with the volume of information delivered by their healthcare providers (Kenny, 1995).

Considering that clinicians generally spend less time to educate their patients (Stirling et al., 2001), evaluating patients' IN may improve the effectiveness of their educational experience during clinic visits and potentially enhance their overall satisfaction. Furthermore, meeting patients' IN may promote their overall disease management experience and coping strategies, enhance their compliance with medical treatments, lower their anxiety and stress levels, improve their QoL , and achieve focused and cost-effective healthcare services (Ankem, 2015, Christalle et al., 2019, Pian et al., 2020).

Patient information instrument specifically used in OED

The assessment of the IN of patients with OED can be established using the ODIN-Q, a 33-item instrument developed in the UK, with domains including general information, investigative tools, treatment options, physical and psychological perspectives, medical systems, and information access. The theoretical framework used to develop the tool was the Lazarus and Folkman stress and coping theory. It has demonstrated good preliminary validity and reliability based on its psychometric properties (Alsoghier et al., 2020).

Information provision role and locus of control in patients with OED

In the UK, the incidence of OC has increased by 92% since the 1970s, accounting for 31 cases each day (Cancer Research UK, 2017). One obstacle in the dentist-patient relationship is the absence of knowledge (Brouha et al., 2005, Scott et al., 2006, Pati et al., 2013, Renzi et al., 2015, Lee et al., 2016) and panic from unnecessary anxiety stimulated by discussions about OC (Awojobi et al., 2015), which could ultimately lead to delayed diagnosis of OED or OC. On the other hand, supplying patients with tailored and reliable information through educational tools may likely enhance their understanding of the disease, engagement, self-control and autonomy, and decision-making, which ultimately contributes to desirable outcomes and management results (Ali et al., 2014).

Anecdotal evidence suggests that the interpretation of early symptoms may also aid in the timely identification and improved prognosis of OED or OC. This has been demonstrated by the locus of control (LOC) theory that consists of 2 types (internal and external). The internal LOC indicates self-control over health and welfare, whereas external LOC outlines that health is impacted by variables beyond the individual's control (Rotter, 1966, Wallston et al., 1978, Syx, 2008). Individuals with a greater degree of control over their long-term health outcomes are likely to be those whose beliefs are guided by their internal LOC (Härkäpää et al., 1991, Syx, 2008, Trento et al., 2008).

A comprehensive understanding of patients' information needs in OED can be enhanced by situating patient education strategies within established health behaviour change frameworks. The Health Belief Model (HBM) remains one of the most widely applied theories in preventive health; it suggests that engagement in protective behaviour is influenced by perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rosenstock et al., 1988). In OED, perceived susceptibility (likelihood of MT) and perceived severity (anticipated impact of OC) may directly influence willingness to attend regular surveillance, adopt risk-reducing behaviours, and comply with clinician recommendations.

The Capability, Opportunity, Motivation - Behaviour (COM-B) model offers a complementary systems perspective, conceptualising behaviour as the result of the interaction between psychological and physical capability, social and environmental opportunity, and reflective and automatic motivation (Michie et al., 2011). This model provides a useful framework for identifying multi-level barriers to adherence in OED management: enhancing patient knowledge and skills (capability), ensuring access to regular follow-up and cessation support (opportunity), and fostering both rational understanding and emotional commitment to change (motivation).

These frameworks can be synergised with the LOC theory to maximise impact. Interventions that reinforce internal health control, tackle external barriers, and clarify the personal relevance and value of follow-up care align with evidence showing that multi-component, theory-driven interventions outperform information-only strategies in promoting health behaviours (Brega et al., 2021). Embedding HBM and COM-B components into ODIN-Q-informed educational materials can increase their relevance, personalisation, and ultimately, effectiveness.

Patient education in health care

Research has indicated that patient education, regardless of format and style, must be rigorously derived from patients' specific needs and desired health outcomes (Zangi et al., 2015). It is essential to emphasise that verbal discussions are superior to any information tools and cannot be replaced. Supplementary educational materials can be particularly helpful when consultations are brief, when patients may not obtain all the information they desire, or as an additional source or reference for certain information that patients must remember about their medical condition (Audit, 1993).

Co-design (also referred to as co-creation or participatory design) is a collaborative process in which patients, carers, and healthcare professionals jointly develop educational resources, ensuring that materials address lived experiences, cultural contexts, and specific informational needs. Systematic reviews demonstrate that co-design approaches in healthcare can improve the clarity, relevance, and trustworthiness of educational interventions, which in turn enhances patient engagement and adherence (Greenhalgh et al., 2016, Slattery et al., 2020). In oncology and chronic disease contexts, involving patients in the design of decision aids and educational leaflets has been associated with higher perceived usefulness and greater uptake compared to clinician-designed materials (Bombard et al., 2018). For OED/OPMD, co-design could ensure that risk communication is framed in ways that are both accurate and sensitive, reducing unnecessary anxiety while motivating adherence to surveillance and lifestyle recommendations.

Effective patient education must be equitable, addressing barriers faced by older adults, people with limited literacy, non-native speakers, and those in resource-limited settings. Health literacy research indicates that using plain language, visual aids, and interactive tools significantly improves understanding among low-literacy populations (Berkman et al., 2011, McCormack et al., 2013). For older patients, materials should consider sensory changes, cognitive load, and pacing, incorporating larger fonts, high-contrast layouts, and simple navigation in digital formats (Organization, 2008). For non-native speakers, professional translation combined with cultural adaptation is critical, with evidence showing that culturally tailored education improves comprehension and behavioural uptake in cancer screening programmes (Kreuter et al., 2003). Delivering resources in multiple modes (written, audiovisual, and in-person counselling) and ensuring offline availability can address the digital divide. Embedding these accessibility principles aligns with WHO recommendations on universal health coverage and reduces disparities in the uptake of preventive and surveillance care.

Various tools can be employed as educational methods. Studies have demonstrated the reduced efficacy of written or printable information whilst showing the potential usefulness of audiovisual and digital tools (Trinh et al., 2014a, Armstrong et al., 2011b). A randomised clinical trial of 197 patients examined information gain and patient satisfaction after the introduction of 3 educational materials (face-to-face interviews, brochures, and videos) and found that patients educated with videos achieved the highest scores in satisfaction and gained information (Snyder-Ramos et al., 2005). In their systematic review, (Enver et al., 2020) concluded that in terms of quality and content, educational videos outperformed other sources. They highlighted that only universities or healthcare organisations should create and distribute videos that address health issues. Another systematic review demonstrated that videos containing simply verbally or visually presented health information are ineffective for modifying patient behaviour in comparison with videos (Abed et al., 2014). This finding highlights a key distinction: while videos are excellent tools for information transfer and patient satisfaction, achieving the more complex educational goal of sustained behaviour change requires content that integrates tailored, motivational, and often interactive design principles.

Thus, over the past years, video clip use has grown in popularity popularity as a means of providing patients with fundamental information regarding their condition, treatment procedures, and disease management (Herrmann and Kreuzer, 1989, Healton and Messeri, 1993, Chatterjee et al., 2021). This popularity is driven by the perceived value of visual learning and the ease of access, despite the noted lack of evidence on behaviour change efficacy and the absence of established guidelines or reliable evaluation tools for production quality (Chatterjee et al., 2021). Nevertheless, video production has increased considerably, which is attributed to several reasons such as its simplicity, perceived value of visual learning, easy access, appealing display, and real-people integration (e.g. healthcare providers, patients, and patients' families) (Eaden et al., 2002).

Targeted videos can be used to facilitate educational objectives, enhance shared decision-making, and possibly improve clinical benefits (Chatterjee et al., 2021). Studies have shown that videos have a positive impact on patients and may improve their overall knowledge, preparation for treatment, and satisfaction; reduce their anxiety; enhance their QoL ; and lower their healthcare expenses (Jamshidi et al., 2013, Stenberg et al., 2018, Chatterjee et al., 2021, Tom and Phang, 2022). Whether a patient is preparing to undergo surgery or requires counselling on rehabilitation or information about any other healthcare aspect, using videos as an instructional component of patient education has been demonstrated to be viable and, in many cases, useful in improving patient experience (Chatterjee et al., 2021).

In contrast, some randomised clinical trials have reported no significant difference between groups of patients who read leaflets and watched videos (Meade et al., 1994, Eaden et al., 2002). Research has demonstrated that videotaped education increased short-term knowledge more effectively than other strategies, although knowledge returned to baseline after some time regardless of the educational tool used (Stalonas et al., 1979, Kim et al., 1997). According to previous studies, patient education must be repeated to sustain its beneficial effect, and video education is neither superior nor inferior to other techniques for achieving long-term information retention.

In addition, multiple disadvantages have been reported to be associated with the implications of using videos. (Dahodwala et al., 2018) highlighted that although video-based technologies are widely used in hospitals, these interventions are more useful for improving short-term health goals than for changing patient behaviour or lifestyle. Another study demonstrated that open access to YouTube could facilitate the spread of inaccurate and less trustworthy videos (Ferhatoglu et al., 2019). The same study also indicated that only half of the films were created by health professionals. Although professional accreditation does not guarantee pedagogical effectiveness or high-quality presentation, which some reviewers may lack, the fact that only half of the videos originate from health professionals remains a critical concern. This is because non-professionally sourced content may not only be poorly presented, but also potentially contain scientifically inaccurate, misleading, or harmful information regarding diagnosis, prognosis, and treatment. This unreliable data may misguide and confuse patients.

The internet could be a beneficial medium for disseminating correct information to the public if videos were generated by health professionals and subjected to a rigorous review. On the National Health Service (NHS) Choices website alone, 423 movies on various subjects ranging from "how to wash your hands" to "coping with death and loss" are publicly available (NHS, 2018). Nevertheless, whether allocating resources to create films is more cost-effective than generating simple instructional booklets or narrated slides remains to be clarified (Eaden et al., 2002).

As a result of these conflicting findings, no solid evidence has been found to support the use of video clips in practice or identify the most effective educational format (e.g. written, narrated slides, or videos of real people) (Chatterjee et al., 2021). Moreover, given the widespread use of videos nowadays, along with the limited number of studies in the UK, further research is needed to evaluate the usefulness and feasibility of educational tools for providing patient information (Chatterjee et al., 2021). Several factors such as development protocol, content quality, clip duration, delivery style, frequency of views, patient characteristics, and number of educational aids administered were not clearly addressed in previous studies; hence, these must be taken into account in future research (Chatterjee et al., 2021).

Role of education in the management of OED

While patient education is widely recognised as a cornerstone in managing OED, the evidence base supporting the most effective formats remains tenuous. To date, only a handful of peer-reviewed studies—principally small-scale evaluations of online or leaflet-based materials—have assessed the impact of different educational formats (e.g., written versus audiovisual) in the context of OED or related OPMD (Alsoghier et al., 2018). Notably, one evaluation of web-based resources found that merely 6% of sites met all four key JAMA quality benchmarks, and readability was, on average, well above recommended levels, underscoring severe limitations in available patient messaging (Alsoghier et al., 2018). This dearth of robust comparative trials or format-specific evaluations highlights a crucial gap in existing literature. No randomized controlled trials or even adequately powered comparative cohort studies—that directly compare formats such as printed pamphlets, videos, or interactive tools—have been published for OED or OPMD.

Systematically assessing a patient's IN and addressing them through tailored education tools is a recognised strategy in patient-centred care (Epstein and Street, 2011). In OED management, this approach aims to increase disease-specific knowledge, correct misperceptions of risk, and strengthen self-efficacy for preventive behaviours. Evidence from oncology and chronic disease management demonstrates that targeted education can reduce anxiety linked to diagnostic uncertainty and prognosis (Husson et al., 2011), while improving adherence to surveillance and early intervention protocols (Farias et al., 2020). Behavioural science frameworks, such as the COM-B model and HBM, support the premise that increasing knowledge and clarifying risk perception can drive motivation for sustained engagement with health-protective behaviours (Rosenstock et al., 1988, Michie et al., 2011).

Clearly once the information needs of patients with OED have been established (using ODIN-Q) there is then a need to provide timely, comprehensive and easily understandable information to such individuals. The development and delivery of universally accessible educational materials for patients have been recommended (Alsoghier et al., 2022). Providing educational materials on OED via a patient information leaflet or patient information video clip may increase patients' understanding, mitigate their psychological distress, encourage them to seek regular OC screening, and provide understanding of the importance of OC screening for the early discovery of suspicious lesions (de Nooijer et al., 2001, Boundouki et al., 2004, Allen and Farah, 2015, Alsoghier et al., 2022).

KNOWLEDGE GAP AND OBJECTIVES OF THE RESEARCH

The value of patient education in the management of chronic and cancer-related diseases, such as oral epithelial dysplasia (OED), has been emphasised in a significant body of literature. The available patient information in their different formats (e.g., audiovisual or written) of critical oral diseases such as cancer and pre-cancerous conditions have not received enough attention and analysis. Whilst the most effective means of delivering educational material to patients regarding OED has not been explored to date in the literature. Information needs (IN) of patients with OED have been recently addressed, in which a specific IN instrument, called oral epithelial dysplasia informational needs questionnaire (ODIN-Q) was developed, and has demonstrated good preliminary validity and reliability. However, further psychometric testing was recommended.

Objectives of the research

- To conduct a critical literature review on OED, information needs, and patient education in individuals with OED and related disorders, identifying key gaps and guiding future research directions. *(Chapter I)*

- To evaluate the quality and content of online audiovisual materials related to OED using standardised assessment tools, to determine their reliability and usefulness for patient education. *(Chapter II)*

- To explore the perspectives of patients and clinicians on the information needs and education surrounding OED through qualitative interviews, identifying key themes and priorities for communication and support. *(Chapter III)*

• To assess disease-specific knowledge and educational needs of individuals diagnosed with OED using the ODIN-Q, and to explore related demographic and clinical variables. *(Chapter IV)*

• To assess the structural integrity and responsiveness of the ODIN-Q, using confirmatory factor analysis and pre/post intervention scores following the delivery of a patient information leaflet. *(Chapter V)*

• A summary of conclusions, limitations and future work. *(Chapter VI)*

A summary of the project activities and phases

Pre-study activities

- Review and the existing body of literature about OED and patient education.
- Evaluate online audio-visual information on OED and potentially malignant conditions of the mouth.

Study phase 1

- Explore patient experience and clinical challenges of individuals with OED via qualitative methods.
- Address informational needs of individuals with OED via quantitative methods.

Study phase 2

- Assess the structural validity of ODIN-Q.
- Introduce a patient educational material to individuals with OED to study its impact, and assess the responsiveness of ODIN-Q.

Chapter II. Evaluation of oral epithelial dysplasia web-based audio-visual patient information: Quality, understandability, and actionability

2.1. Introduction

Oral epithelial dysplasia (OED) carries a risk of progression to oral cancer, necessitating life-long follow-up and enhanced patient knowledge for favourable long-term outcomes (Tilakaratne et al., 2019). While patient conversations remain the primary method of information delivery in clinic, online materials have increasingly provided alternative sources of health information (Wasserman et al., 2014; Radonjic et al., 2020).

Acquiring knowledge has never been simpler than in this modern era. Global communications and the spread of various types of information, including health-related information, have substantially evolved because of the internet (Ayantunde et al., 2007). Since its introduction to the public in 1991, the internet has gradually become an integral component of peoples' knowledge lives (Anderson and Klemm, 2008). However, this growing reliance on digital resources introduces a critical issue of health information inequity, often termed the Digital Divide (Hong and Cho, 2017). This discrimination is acutely felt by older populations who frequently face barriers related to limited access, lower digital literacy, and reduced confidence in navigating online platforms, which makes them less able to benefit from the growing mass of digital health-related information (Estacio et al., 2019). Moreover, there is concern that this digital reliance may serve to exacerbate existing health inequalities (Western et al., 2025). Over the past three decades, not only has internet activity surged but also the availability and mass of health-related information have also expanded. In 2000, more than 70,000 websites supplied health-related content (Grandinetti, 2000). Five years later, the word ‘health’ had been searched approximately 473,000,000 times (Ybarra and Suman, 2006).

People are driven to search for health information on the internet to find reassuring answers, seek different views on medical treatments, and further absorb clinically delivered information (Powell et al., 2011). While patient information websites of professional organisations continue to be the most trustworthy sources, the audiovisual (AV) contents offered by video streaming websites such as YouTube may be preferred over the information available on official or scientific websites owing to the popularity of YouTube and the strong cognitive and emotional effects of the videos on the site (Berk, 2009). However, patients seeking for reliable online information about OED and relevant OPMD are unlikely to find it on various online platforms (Wiriyakijja et al., 2016, Alsoghier et al., 2018).

It is important to acknowledge that the distribution of online information is not restricted to academic or professional organisations; hence, publication of unreliable health information is highly possible. Therefore, previous web-based studies have highlighted that the quality and credibility of such materials must be questioned (Eysenbach et al., 2002, Daraz et al., 2011, Yeung et al., 2015, McGoldrick et al., 2017, Garfinkle et al., 2019). In addition, health literacy relies mainly on readability, but other factors, including understandability and actionability, are also cardinal. Health information seekers should be able to understand and convey knowledge and recognise the necessary activities after reading or watching a particular content (Shoemaker et al., 2014).

Online health-related information on OED is insufficient and of low quality (Alsoghier et al., 2018). While only written information of OED has been previously assessed, this study aims to evaluate the AV online information of OED. Websites that provide pertinent, correct, and understandable content can be identified with the aid of validated assessment methods (Alsoghier et al., 2018, Abdouh et al., 2020).

2.1.1 Aims and objectives

To assess the content, quality, understandability, and actionability of online AV information for individuals with OED, a key condition within the spectrum of OPMD.

2.2. Methods

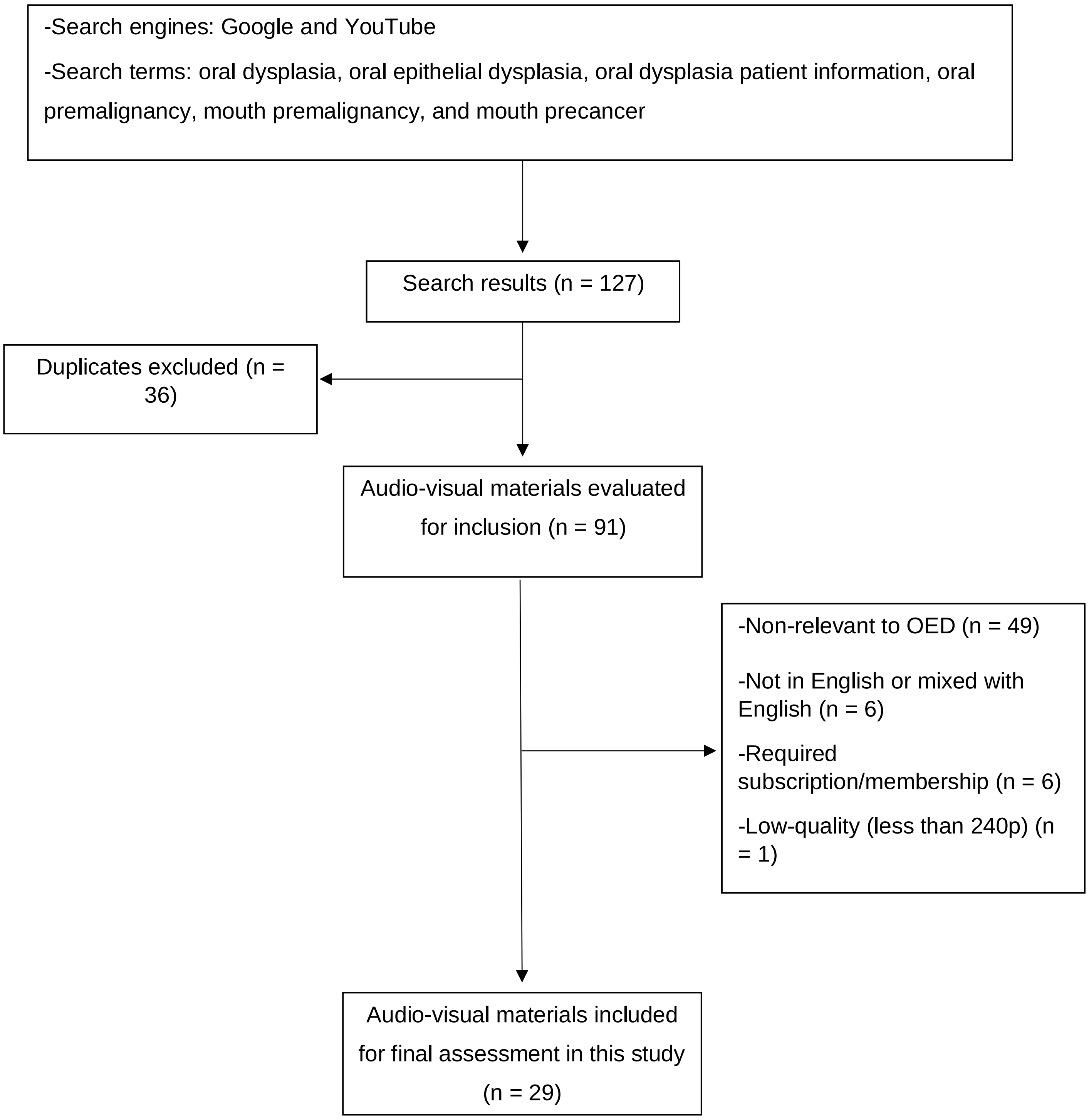
2.2.1. Search strategy

The search terms ‘oral dysplasia’, ‘oral epithelial dysplasia’, ‘oral dysplasia patient information’, ‘oral premalignancy’, ‘mouth premalignancy’, and ‘mouth precancer’ were typed into search engines (Google and YouTube). The video-only option was selected for the Google search. The data gathering period was between December 2022 and January 2023. This finite two-month window was specifically selected to provide a necessary "snapshot" of the videos available and ranked highly on the platforms during that time, which is a standard methodological requirement for analysing dynamic online content.

2.2.2. Excluded and included AV materials

During the search phase, 127 AV materials were identified. After duplicates were removed (n = 36), the overall number decreased to 91. The inclusion criteria were as follows: materials that addressed OED and/or OPMD and/or OC, with clear filming and sound. The following exclusion criteria were then applied: materials that were not relevant to OED (n = 49), non-English or English mixed with another language (n = 6), required membership or subscription to access (n = 6), and low-quality, defined as having a vertical resolution of less than 240p (i.e., less than 240 lines of vertical resolution, resulting in blurry or pixelated video) (n = 1). Finally, 29 videos remained for the final assessment (Figure 2-1).

Figure 2-1 Flow diagram of the eligibility of the chosen 29 audiovisual materials.



2.2.3. Content assessment

The selected videos were categorised according to the following criteria: source, relevance, OED components, content type, origin or country of AV material, length of video, and number of views and likes (Table 2-1).

Table 2-1 Descriptive features of the videos.

Category	Criteria
Source	University or medical centre ‘online scientific lecture’, ‘scientific lecture at a conference’, ‘online webinar’, or ‘short clip facts’ Medical or dental YouTube channel ‘scientific lecture’, ‘narrated slides and graphics’, or ‘slides and graphics without audio’ Profitable online course provider of ‘scientific lectures’, ‘personal experience’ vlogs, or government, commercial, or unclassified courses
Relevance	Videos on OED, OED/oral potentially malignant disorder (OPMD), OED/oral cancer (OC), OED/OMPD/OC, or only OPMD or OC without OED
OED Components	Definition, grading, World Health Organization criteria, diagnosis, treatment, prognosis, impact on QoL, or recommendations
Content type	Medical information, scientific discussion, or human story
Others	Country of video, publication date, duration, number of views, and likes

2.2.4. Quality assessment

To assess the quality, accuracy, and educational value of the AV materials, two reviewers (WA and SRP) performed evaluations independently using the following tools: the DISCERN instrument (Charnock et al., 1999) and Journal of the American Medical Association (JAMA) benchmarks (Silberg et al., 1997). DISCERN is widely regarded as the most important standardised quality index, as it enables healthcare professionals to objectively assess any given health information. This valid and reliable consists of a 16-item questionnaire divided into 3 sections: reliability (questions 1–8), treatment options (questions 9–15), and overall rating (question 16). Each item is given a 5-point rating (1 = no, 2–4 = partially, and 5 = yes) (Table 2-2).

The selection of experts (WA and SRP) was essential for achieving the primary study objective of evaluating the scientific reliability and accuracy of the content. Assessing the nuanced balance of treatment options, benefits, and risks (a core function of the DISCERN tool) requires specialised knowledge of OED/OPMD management.

We acknowledge the methodological limitation that the use of expert reviewers does not fully capture the perspective, comprehension, or preferences of the wider target audience, including nurses, medical students, or "Joe and Josephine Public." Ideally, assessing the videos' educational impact would involve a diverse group to truly gauge intelligibility and actionability.

However, to mitigate this concern and ensure the relevance of the findings to patient education, the analysis relied on objective, validated criteria from the quality assessment tools that serve as proxies for public comprehension and usability.

Specifically, the metrics of understandability and actionability assessed the clarity of language and the practicality of the advice provided, which are universal requirements for effective patient education materials. The expert review, therefore, ensures the content is scientifically safe and credible, while the chosen metrics address its educational utility for the layperson.

Table 2-2 DISCERN (1–5 scoring system) (Charnock et al., 1999).

Domain	DISCERN question	Total score
Reliability	Q1. Explicit aims	/5
	Q2. Attainment of aims	/5
	Q3. Relevance	/5
	Q4. Explicit sources	/5
	Q5. Explicit date	/5
	Q6. Balanced and unbiased	/5
	Q7. Additional sources	/5
Treatment options	Q8. Areas of uncertainty	/5
	Q9. How treatment works	/5
	Q10. Benefits of treatment	/5
	Q11. Risk of treatment	/5
	Q12. Effects of no treatment	/5
	Q13. Effects on quality of life	/5
	Q14. All treatment described	/5
	Q15. Shared decision	/5
Overall rating		/5

The JAMA benchmarks are comprised of 4 criteria (authorship, attribution, disclosure, and currency), and a 4-point scale is used to identify the quality of any selected material. An AV material scored a point if it met the benchmark elements, which encompassed the following: authorship (authors' names, credentials, and affiliations), attribution (copyright, sources, and references), disclosure (ownership acknowledgement, possible conflict of interest, funding and support, advertising, and underwriting), and currency (dates and updates). In the final assessment, the scores of the chosen materials ranged from 0 to 4 (Table 2-3).

Table 2-3 JAMA benchmarks (Silberg et al., 1997).

Domain	Criteria
Authorship	The authors and their contributions, affiliations, and relevant credentials should be provided.
Attribution	The references and sources for all contents should be listed.
Disclosure	Conflicts of interests, funding, sponsorship, advertising, support, and video ownership should be fully disclosed.
Currency	Dates when the content was posted and updated should be indicated.

2.2.5. Understandability and actionability assessment

To assess the understandability and actionability of the information provided in the AV materials, the same reviewers (WA and SRP) used the valid and reliable Patient Education Material Assessment Tool (PEMAT) for AV materials (PEMAT-AV) (Shoemaker et al., 2014). This tool consists of 13 items on understandability that assess the ability of individuals to comprehend and acquire essential information and 4 items on actionability that assess the clarity of recommendations to facilitate user action. The understandability measure is divided into four domains: content (1 item), word choice and style (3 items), organisation (4 items), layout and design (3 items), and use of visual aids (2 items). The answer options for each item are ‘yes’, ‘no’, and ‘not applicable’. When a material meets 80% or more of the item, ‘yes’ is assigned as a response; otherwise, ‘no’ is given (Tables 2-4 and 2-5).

Table 2-4 PEMAT-AV items for understandability assessment (Shoemaker et al., 2014).

Domain	PEMAT question	Response	Result
Content	1. The material makes its purpose completely evident.	Disagree = 0, agree=1	
Word choice and style	2. The material uses common, everyday language.	Disagree = 0, agree = 1	
	3. Medical terms are used only to familiarise audience with the terms. When used, medical terms are defined.	Disagree = 0, agree=1	
	4. The material uses the active voice.	Disagree = 0, agree = 1	
Organisation	5. The material breaks or ‘chunks’ information into short sections.	Disagree = 0, agree=1, very short material = N/A	
	6. The sections in the material have informative headers.	Disagree = 0, agree = 1, very short material = N/A	
	7. The material presents information in a logical sequence.	Disagree = 0, agree = 1	
	8. The material provides a summary.	Disagree = 0, agree = 1, very short material* = N/A	
Layout and design	9. The material uses visual cues (e.g. arrows, boxes, bullets, bold, larger font, and	Disagree = 0, agree = 1, video = N/A	

	highlighting) to draw attention to key points.		
	10. The text on the screen is easy to read.	Disagree = 0, agree = 1, no text or all text is narrated = N/A	
	11. The material allows the user to hear the words clearly (e.g. not too fast and garbled).	Disagree = 0, agree = 1, no narration = N/A	
<u>Use of visual aids</u>	12. The material uses clear and uncluttered illustrations and photographs.	Disagree = 0, agree = 1, no visual aids = N/A	
	13. The material uses simple tables with short and clear row and column headings.	Disagree = 0, agree = 1, no tables = N/A	

***Total Points*:** _____________

***Total Possible Points*:** _____________

Understandability Score (%): _____________ (*total points/total possible points* × 100)

Table 2-5 PEMAT-AV items for actionability assessment (Shoemaker et al., 2014).

Domain	**PEMAT question**	**Response**	**Result**
	14. The material clearly identifies at least one action the user can take.	Disagree = 0, agree = 1	
	15. The material addresses the user directly when describing actions.	Disagree = 0, agree = 1	
	16. The material breaks down any action into manageable, explicit steps.	Disagree = 0, agree = 1	

	17. The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree = 0, agree = 1, no charts, graphs, tables, or diagrams = N/A	

Total Points: _____________

Total Possible Points: _____________

Understandability Score (%): _____________ (*total points*/*total possible points* × 100)

2.2.6. Statistical analysis

To generate descriptive statistics, the data were collected using a proforma tailored to the study and exported to Microsoft Excel. IBM SPSS was used for variable representation (version 22.0).

2.2.7. Ethical consideration

This study does not require ethical approval.

2.3. Results

2.3.1. General characteristics of the AV materials

The sources of the 29 final AV clips were classified in our analysis into 3 categories, namely scientific, educational, and personal experience. Most contents were scientific produced by professionals (n = 25; 86%) affiliated with universities or medical centres, or who were independent. This scientific content was presented as scientific lectures (n = 13), narrated slides and graphics (n = 9), online webinars (n = 2), and one clip was a non-sound slide and graphic presentation. The educational contents included 3 videos (10%), presented as short clips of facts delivered by an expert (n = 2), and one narrated slide and graphic clip. The presenters of the educational contents had various backgrounds and affiliations, including medical centres, profitable online course providers, and independent practice. One individual shared his personal experience with OED through a vlog on YouTube.

Regarding the relevance of the contents to OED, 6 videos addressed OED only, 2 videos addressed both OED and OPMD, one video outlined both OED and OC, and 8 materials highlighted OED, OPMD, and OC. However, 12 videos did not primarily address OED and focused on OPMD or OC. For the clips that covered OED (n = 17), the definition, World Health Organization (WHO) criteria, and grading were mentioned together in 7 videos, while 3 videos highlighted the definition and WHO criteria. The grading only was discussed in 2 videos and the definition only was provided in one video. Diagnostic methods and progression risk were outlined in 2 clips, whereas the various treatment options were mentioned in one clip only. Table 2-6(a) summarises the general characteristics of the 29 selected informative materials.

Most of the materials (n = 25) were presented on YouTube, while only 4 were found on other websites. Approximately half of the contents (n = 14) originated from India; 6, from the United States; and 2, from Malaysia. One video was produced from the following countries: the United Kingdom, Singapore, Iran, South Africa, and Guatemala. The origin of the content was not identified in 2 clips. The recorded dates of the materials ranged from 2012 to 2022, with year 2022 having the most published materials (n = 8), followed by 2020 (n = 6) and 2021 (n = 4).

The durations of the AV presentations ranged from 36 seconds to 110 minutes 12 seconds. Fourteen materials were ≤10 minutes long, 7 ranged from 10 to 30 minutes long, and 8 were >30 minutes long. The number of views ranged from 25 to 71,034, of which 14 videos had been viewed ≤1,000 times, 9 videos had been viewed between 1,001 and 10,000 times, and 3 materials had >10,000 views. The total number of likes ranged from 0 to 1000. However, most clips (n = 22) received ≤100 likes, whereas 3 videos had >100 likes, and 1 presentation only had 1000 likes. Table 2-6(b) summarises the general characteristics of the 29 selected informative materials.

Table 2-6(a) Descriptive features of the videos.

Category	Criteria		Number of videos
Source	Professional (university, medical centres, independent)	Scientific lecture	13
		Online webinar	2
		Narrated slides and graphics	9
		Slides and graphics without audio	1
	Educational (medical centres, profitable organisations, independent)	Short clip facts by an expert	2
		Narrated slides and graphics	1
	Personal experience	Human story vlog	1
	Other	Government, commercial, unclassified	0
Relevance	Video addresses OED only		6
	Video addresses OED and OPMD		2
	Video addresses OED and OC		1
	Video addresses OED, OMPD, and OC		8
	Video does not address OED, only OPMD or OC		12

OED components	Definition only	1
	Grading only	2
	Definition and WHO criteria	3
	Definition, WHO criteria, and grading	7
	Definition, WHO criteria, grading, and diagnosis	1
	Definition, grading, diagnosis, and treatment	1
	Definition, WHO criteria, grading, and prognosis in terms of ‘progression risk’	2
	Impact on QoL and recommendations	0
	None	12

Table 2-6(b) Descriptive features of the videos.

Media platform	YouTube	25
	Non-YouTube	4
Country	United Kingdom	1
	United States	6
	India	14
	Malaysia	2
	Iran	1
	Singapore	1
	South Africa	1
	Guatemala	1
	Unknown	2
Published since (years)	2022	8
	2021	4
	2020	6
	2019	2
	2018	2
	2017	3
	2015	1
	2012	2
	Unknown	1
Duration (minutes)	≤10	14
	Between 10 and 30	7
	>30	8
Number of views	≤1,000	14
	Between 1,000 and 10,000	10
	>10,000	3
	Unknown	2
Number of likes	≤100	22
	>100	3
	>1000	1
	Unknown	3

2.3.2. Quality assessment (DISCERN and JAMA criteria)

DISCERN

Table 2-7 provides a summary of the DISCERN scores of the 29 chosen AV materials. The mean ± SD overall rating was 2.26 ± 0.79, with none of the materials achieving the maximum rating of 5 and with 16 AV materials (55%) obtaining the minimum overall rating. The highest mean scores correlated with the following items: (Q5) explicit date (4.72) (Q6) balanced and unbiased (4.24), and (Q3) relevance (3.68). More than half (60%) of the items obtained mean scores <2, encompassing (Q7) additional sources (1.68), (Q8) areas of uncertainty (1.86), (Q9) how treatment works (1.82), (Q10) benefits of treatment (1.65), (Q11) risks of treatment (1.34), (Q12) effects of no treatment (1.55), (Q13) effects on quality of life (1.34), (Q14) all treatments described (1.48), and (Q15) shared decision (1.62).

Table 2-7 Mean DISCERN scores of the 29 selected AV materials.

Domain	DISCERN question	Mean ± SD
Reliability	Q1. Explicit aims	2.57 ± 1.84
	Q2. Attainment of aims	2.82 ± 2.00
	Q3. Relevance	3.68 ± 1.46
	Q4. Explicit sources	2.06 ± 1.7
	Q5. Explicit date	4.72 ± 1.03
	Q6. Balanced and unbiased	4.24 ± 1.35
	Q7. Additional sources	1.68 ± 1.53
Treatment options	Q8. Areas of uncertainty	1.86 ± 1.18
	Q9. How treatment works	1.82 ± 1.19
	Q10. Benefits of treatment	1.65 ± 1.14
	Q11. Risks of treatment	1.34 ± 1.07
	Q12. Effects of no treatment	1.55 ± 1.15
	Q13. Effects on quality of life	1.34 ± 1.07

	Q14. All treatments described	1.48 ± 1.12
	Q15. Shared decision	1.62 ± 1.42
Overall rating		2.26 ± 0.79

JAMA criteria

Most AV materials (n = 28; 96.55%) met the currency benchmark, of which less than half (n = 12; 41%) met the authorship benchmark. Attribution and disclosure were met by 6 (20.68%) and 3 materials (10.34%), respectively (Table 2-8; Figure 2-2). Regarding the total number of benchmarks reached, no single material fulfilled or lacked all 4 benchmarks, 5 AV materials (17.24%) met 3 benchmarks, 10 materials (34.48%) met 2 benchmarks, and 14 materials (48.27%) met 1 benchmark.

Figure 2-2 Numbers and percentages of the 29 selected AV materials that achieved the JAMA benchmarks.

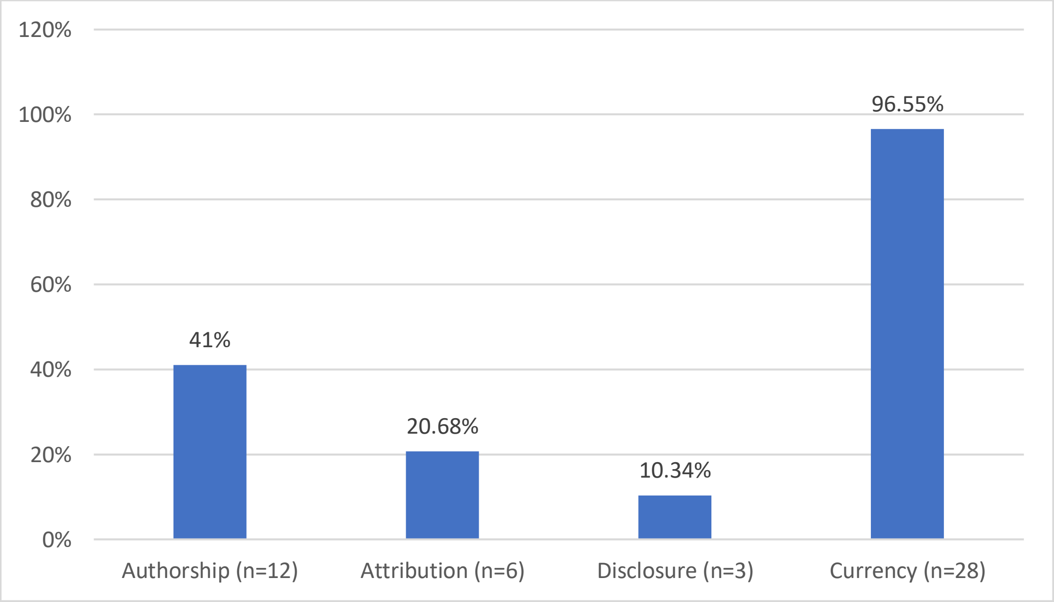


Table 2-8 Numbers and percentages of the 29 selected AV materials that achieved the JAMA benchmarks.

JAMA benchmark	Number of AV materials	Percentage (%)
Authorship	12	41
Attribution	6	20.68
Disclosure	3	10.34
Currency	28	96.55

2.3.3. Understandability and actionability assessment

The mean PEMAT-AV understandability score of the 29 AV materials ranged from 25% to 100%, with an overall mean ± SD of 82% ± 0.25%. The actionability values ranged from 0% to 100%, with a mean ± SD score of 29% ± 0.4%. Items 1–13 assessed understandability, whereas items 14–17 assessed actionability. In regard to understandability, 5 AV materials received scores >90%, including item 4, ‘The material uses the active voice’ (93%); item 9, ‘The material uses visual cues (e.g. arrows, boxes, bullets, bold, larger font, and highlighting) to draw attention to key points’ (91.3%); item 11, ‘The material allows the user to hear the words clearly (e.g. not too fast and not garbled)’ (96%); item 12, ‘The material uses illustrations and photographs that are clear and uncluttered (91.66%)’; and item 13, ‘The material uses simple tables with short and clear row and column headings’ (100%) (Table 2-9).

In terms of actionability, item 14, ‘The material clearly indicates at least one action the user can take’, received the highest rating (37.93%), whereas item 17, ‘The material explains how to use the charts, graphs, tables, or diagrams to take actions’, received the lowest rating (4.76%) but was not applicable among 8 AV materials. Eighteen materials all had a 0 actionability score (Table 2-10).

Table 2-9 Numbers of AV materials that satisfied the PEMAT-AV items for understandability assessment.

Domain	PEMAT item	Number of AV materials that met the item, n (%)
Content	1. The material makes its purpose completely evident.	18 (62)
Word choice and style	2. The material uses common, everyday language.	26 (89.65)
	3. Medical terms are used only to familiarise the audience with the terms. When used, medical terms are defined.	25 (86.2)
	4. The material uses the active voice.	27 (93)
Organisation	5. The material breaks or 'chunks' information into short sections.	19 (86.36) *5 NA
	6. The material's sections have informative headers.	19 (86.36) *5 NA
	7. The material presents information in a logical sequence.	25 (86.20)
	8. The material provides a summary.	57.14% *1 NA
Layout and design	9. The material uses visual cues (e.g. arrows, boxes, bullets, bold, larger font, or highlighting) to draw attention to key points.	91.3% *6 NA
	10. The text on the screen is easy to read.	86.95% *6 NA
	11. The material allows the user to hear the words clearly (e.g. not too fast and not garbled).	96% *4 NA
Use of visual aids	12. The material uses clear and uncluttered illustrations and photographs.	91.66% *5 NA

	13. The material uses simple tables with short and clear row and column headings.	100% *16 NA

*Number of AV materials not applicable for certain understandability items.

Table 2-10 Numbers of AV materials that satisfied the Patient Education Materials Assessment Tool (PEMAT) AV items for actionability assessment.

Domain	PEMAT item	Number of AV materials that met the item (%)
	14. The material clearly identifies at least one action the user can take.	11 (37.93%)
	15. The material addresses the user directly when describing actions.	8 (27.58%)
	16. The material breaks down any action into manageable, explicit steps.	6 (20.68%)
	17. The material explains how to use the charts, graphs, tables, or diagrams to take actions.	1 (4.76%) *8 NA

*Number of AV materials not applicable for certain actionability items.

2.4. Discussion

Numerous research studies have addressed AV contents and oral health, but this is the first study to examine the content and quality of AV materials on OED. Evidence demonstrates that YouTube has been used as a source of information for diverse oral medicine subjects such as oral cancer (Hassona et al., 2016), Sjogren’s syndrome (Delli et al., 2016), oral thrush (Di Stasio et al., 2018a), mouth sores (Di Stasio et al., 2018b), oral leukoplakia (Kovalski et al., 2019), burning mouth syndrome (Fortuna et al., 2019), oral halitosis (Ramadhani et al., 2021), and oral lichen planus (OLP) (Romano et al., 2021). Table 2-11 summarises the research conducted on the quality of AV online information on several oral diseases.

Research has shown that individuals with OPMD routinely use the internet to learn more about their diseases and available treatments, in spite of the possibility of unresolved concerns arising from the knowledge gained (Alcaide-Raya et al., 2010). Although prior research has found the online content on OPMD to be generally acceptable, the analysis was not performed using a valid and reliable assessment tool (Alcaide-Raya et al., 2010).

A relevant previous study that evaluated the quality of written web-based information on OED by (Alsoghier et al., 2018) highlighted that OED-related content was scarce and of poor quality and that further work is necessary to create trustworthy online resources for patients with OED. However, given that the AV materials of OED was never scrutinised, this study aims to provide an analysis of the present online content. After searching on search engines using multiple phrases, we involved materials from multiple sources, including academic institutes, medical centres, scientific lectures, medical or dental YouTube channels, and personal experiences, which ultimately led to the analysis of 29 items created over a 10-year period.

While healthcare centres and providers are increasingly using online patient education, our findings demonstrate a paucity of good-quality AV health information addressing oral diseases such as OED. To our knowledge, no previous study has classified the content and evaluated the quality, understandability, and actionability of AV online information concerning OED.

General characteristics of AV materials on OED

Our total number of examined AV clips (n = 29) was compatible with investigations on other oral disorders such as Sjogren's syndrome (n = 36; (Delli et al., 2016), oral leucoplakia (n = 28; (Kovalski et al., 2019), and OLP (n = 36; (Romano et al., 2021); Table 1-10). Whereas research studies on oral cancer (Hassona et al., 2016), burning mouth syndrome (Fortuna et al., 2019), and oral halitosis (Ramadhani et al., 2021) had larger numbers of examined AV clips (n = 188, n = 114, and n = 105, respectively). This discrepancy in numbers could be explained by the variation in disease seriousness, overall prevalence, and varied inclusion criteria.

In this present analysis, most AV materials (n = 25; 86%) were found on YouTube, which could be explained by the popularity, easy accessibility, and lack of strict peer review process prior to publishing any content on this platform (Ho et al., 2017). Consequently, the information found on YouTube is likely insufficient, inaccurate, and unreliable but still popular among users, as indicated by (Kanlioz and Ekici, 2020). Also, the AV contents offered by video streaming websites such as YouTube could be preferred over written information due to their strong cognitive and emotional effects (Berk, 2009).

Despite the fact that patient information presented on official or scientific websites of professional organisations is most credible and trustworthy, research has revealed that the most commonly viewed videos on YouTube are both personal and television based and that AV materials generated by professionals are less likely to be viewed (Kollia et al., 2017). A systematic review highlighted that these popular clips often contain misinformation regarding various medical conditions (Wang et al., 2019). However, this finding is contrary to that of a previous study that suggested professional videos had far more views than personal productions (Bellon-Harn et al., 2020), which is in line with our data that show that the top 3 clips viewed were connected to professional efforts.

The divergence between earlier studies (Kollia et al., 2017) and more recent data, including our own, likely reflects a significant shift in popular information acquisition driven by changes in online content creation. While personal productions historically received high view counts, recent years have seen the rise of the "professional influencer" model, where healthcare professionals and institutions have successfully adapted their messaging to meet the visual and engagement demands of platforms like YouTube. This change, potentially coupled with algorithmic adjustments to prioritise authoritative sources, suggests that credible content is now better integrated and more readily consumed by the public, provided it adheres to the platform's standards for digital delivery.

Although contents produced by university channels and professional groups were superior in terms of both quality and credibility (Delli et al., 2016), studies have demonstrated that the origin of an AV material does not always necessarily indicate its quality, and that AV clips containing personal or family experiences can deliver high-quality health information (Angulo-Jiménez and DeThorne, 2019). However, this reliance on personal narrative carries inherent risks of bias. These materials may be affected by selection bias (representing non-average experiences) and contain anecdotal evidence or misinterpretation of clinical facts, which can misguide or create unrealistic expectations in viewers. A previous study revealed that patient experience content composed most of the available AV contents on certain conditions such as Bechet's disease (Karakoyun and Yildirim, 2021). Our study included a vlog on the story of a patient who had OED, in which a clip exhibited good quality information about OED; in this instance, the high quality demonstrated that while bias is a risk, personal content can uniquely fill critical information voids, in fact, it was the only AV material that pointed out the different treatment options for OED and addressed essential aspects such as the nature of the disease, diagnostic procedure, and postoperative phase in a simple and understandable approach.

Furthermore, regardless that most included AV materials were generated by professionals, explicit affiliations to formally recognised professional organisations or academic institutions were mentioned in 12 (40%) of the materials, which suggests that the remaining videos may contain potentially misleading information. These trustworthy affiliations are defined by institutional accountability and adherence to established editorial and scientific review processes, which are critical for ensuring content validity and minimising commercial bias. These findings are in line with the finding of (Hassona et al., 2016) that 50% of content on oral cancer and that of (Romano et al., 2021) that 64% of content on OLP were produced by professional groups.

In addition to professional bodies and human stories, other investigations on oral diseases have indicated disparate sources, such as that by (Ramadhani et al., 2021), who found that 65% of online information on AV halitosis was produced by non-professionals. In their study about Sjogren's syndrome, (Delli et al., 2016) highlighted that content was chiefly developed by independent users. (Kovalski et al., 2019) reported that 75% of content on oral leukoplakia was created by independent individuals and commercial groups. Despite that, governments have set up health information portals to provide citizens with accurate and reliable health information, patients frequently disregard these resources in favour of getting information from media outlets such as the internet, social media platforms, and television (Lee et al., 2011). However, in our study, we found no single AV content on OED that has been produced or supported by a government body.

As most of the included AV clips originated from dental professionals (n = 25; 86%), their contents were predominantly scientific, targeting the education of high-end professionals rather than patients or lay persons. Whereas the educational content was considerably lacking, as there were only 3 materials (10%) that were generated for patient education purposes. We believe that this small number is worrying, and academic institutes and professional individuals must also consider patient-centred information production rather than largely focusing on high-end directed content. However, this trend was demonstrated in a study by (Fortuna et al., 2019), who showed that educational content predominantly (46%) represented AV health information about burning mouth syndrome.

Even though that the advanced information from the scientific content may be suitable for professionals or intended for gaining personal recognition, (Cuddy, 2010) outlined that the public could also benefit from this reliable information. In our study, we observed that most contents exhibited scientific information that primarily covered the OED definition and diagnosis, and clinical presentations of OPMD. This information could be useful for promoting overall patient awareness but does not truly shed light on other essential elements such as early detection, decision-making, diagnostic procedures, treatment options, potential complications, and impact on quality of life (QoL). This observation could be attributed to the rarity of OED-related online AV materials and the shortage of educational academic contributions.

The duration of the AV content is a significant factor because as the video length increases, more specific information may be delivered to viewers. However, longer materials may cause boredom, especially if the audience lacks of concentration (Delli et al., 2016). According to (Berk, 2009), the length of a video intended as a patient information tool should be chosen according to its educational purpose; the shorter the clip, the greater the impact on the subject. Moreover, to effectively deliver accurate information to the intended audience, the content and difficulty of the subject may directly affect the length of the video (Khilnani et al., 2020).

In the present study, we observed that short AV contents often receive high numbers of views and likes, among which the top 3 most viewed clips and most liked videos were all short clips that lasted for approximately 5 minutes, whereas the longer contents had lesser numbers of views and likes. This trend strongly aligns with the viewing habits of the young, tech-savvy audience—the demographic most likely to seek and consume online health content (Van Dijck, 2013). In the current "attention economy," viewers demonstrate a shorter attention span, reinforcing the need for educational content to be concise, rapidly engaging, and focused on delivering high-impact information within a few minutes to achieve maximum dissemination and engagement (Guo et al., 2014).

Approximately 60% (n = 18) of AV productions were made between 2020 and 2022, which could be explained by the rapid advancement and use of virtual technology in light of the COVID-19 crisis. Approximately half of these productions (n = 14) originated from India, followed by 6 clips from the United States. From the standpoint of the user, website designers must consider techniques to promote user accessibility to AV contents (Kang and Lee, 2019). In addition, to improve user accessibility, websites should include information on the goals and objectives of the AV resources. If developers utilise the items or guidelines established by trustworthy references when creating AV tools, they can create materials of good quality, which can be easily understood by viewers in the future.

Given the rapid increase in popularity of YouTube over the recent years, it is critical to broaden the spectrum of AV resources and organisations that offer reliable health information on disparate medical conditions, and health experts must increase the quantity and quality of their contributions to this key media platform (Bromley, 2008, Fortuna et al., 2019, Kovalski et al., 2019, Romano et al., 2021). Our search for high-quality AV content regarding oral medicine on YouTube or other media platforms revealed a scarcity of information, highlighting the need for more production of patient-oriented materials (Riordain and McCreary, 2009).

While online platforms, particularly YouTube, offer high accessibility, they are not necessarily the best venue for delivering the complex information required for shared decision-making in OED/OPMD management. This is primarily due to the Digital Divide, as the patient demographic most at risk is often the least digitally literate (Hong and Cho, 2017). Furthermore, the high volume of non-verified content poses a significant risk of misinformation. However, given the documented scarcity of credible and understandable OED resources from official channels, YouTube currently functions as a critical, though imperfect, information source. The platform's role should be viewed as supplementary: it is effective for reinforcing key educational messages and filling the patient's information gap, but it cannot and should not replace the personalised, comprehensive decision-making discussion that must occur between the patient and their healthcare provider.

The quality of online AV OED materials

The assessment of AV content using the DISCERN and JAMA tools revealed that most materials had poor quality. Though using different assessment tools, previous research studies have found that contents addressing various oral disorders had a similar poor quality of patient information, encompassing oral leukoplakia (Kovalski et al., 2019), burning mouth syndrome (Fortuna et al., 2019), oral halitosis (Ramadhani et al., 2021), and OLP (Romano et al., 2021) (Table 2-11).

Regarding the assessment using DISCERN, the mean ± SD overall score (item 16) of the examined AV contents was 2.26 ± 0.79 on a scale of 1–5, which suggests that the quality of the information was poor. This finding is consistent with that of a study by (Romano et al., 2021) that used DISCERN to assess the quality of information concerning OLP, which indicated an overall mean average of 2.33 ± 1.07. Even though the following numbers were obtained from studies conducted on online information from written content, it would be helpful to report the findings given the relevance and similar results, and that include an overall DISCERN score of 2.55 for on oral cancer (Riordain and McCreary, 2009), 2.3 for oral leukoplakia (Wiriyakijja et al., 2016), and 2.24 for OED (Alsoghier et al., 2018).

In the present study, we found that all treatment related DISCERN questions were associated with the lowest scores. This observation was also reported in previous studies by (Riordain and Hodgson, 2014, Wiriyakijja et al., 2016, Alsoghier et al., 2018), where the lack of patient information on the different treatment options, risks of no treatment, and potential adverse effects was evident. Physicians are currently shifting from the unidirectional concept of management to the shared treatment decision-making (Stairmand et al., 2015), which cannot be established without adequate and trustworthy information about all treatment details pertaining to OED.

A previous study also found that a patient's capacity to make decisions about numerous treatment alternatives offered to them by their healthcare provider is hindered by a lack of credible and understandable information (Stairmand et al., 2015). In our study, we found that all treatment related DISCERN questions were associated with the lowest scores. The lack of patient information on oral diseases, particularly on the different treatment options, risks of no treatment, and potential adverse effects, that was observed in a previous study is consistent with the observations in previous studies on patient information on oral health (Riordain and Hodgson, 2014, Wiriyakijja et al., 2016, Alsoghier et al., 2018). Physicians are currently shifting from the unidirectional concept of management to the shared decision-making approach, where patients are aware and more actively engaged in the treatment process

(Braddock III et al., 1999). This patient-clinician connection cannot be established without adequate and trustworthy information about all treatment details pertaining to OED.

We recognise that the low scores on the treatment sections (Q9-Q15) may be partially attributed to some materials not being designed with the intent to cover all treatment options (e.g., short awareness videos). However, the decision to apply the full DISCERN tool was necessary to objectively evaluate the completeness and fitness-for-purpose of the online resources for patients requiring long-term management and shared decision-making for OED/OPMD. The consistently low scores in the treatment domain, particularly Q11 (risks of treatment) and Q13 (effects on quality of life), underscore a critical finding of this study: the overwhelming majority of available audiovisual materials fail to provide the comprehensive, balanced information required for patients to participate fully in informed decisions regarding OED management.

This poor quality is represented by the findings on the JAMA benchmarks. No single AV content met all 4 JAMA benchmarks, raising a question regarding the reliability of the information offered by the 29 materials included in this study. This is comparable with research about the oral involvement of scleroderma in which only 7% of the analysed information fulfilled the 4 benchmarks (Abdouh et al., 2020). Furthermore, the fact that content that does not satisfy at least 3 of the benchmarks could be suspicious (Silberg et al., 1997), and only 5 materials (17.24%) in this analysis achieved this standard emphasises the overall poor sufficiency and reliability of the information displayed on the examined video clips. This finding is also compatible with a study conducted on written OED information that indicated that 80% of online information could be classified as suspicious (Alsoghier et al., 2018).

The understandability and actionability of online AV materials on OED

The PEMAT evaluates patients' comprehension of health information (understandability) and if the information motivates users to do at least one action and breaks a recommended behaviour into phases (actionability) (Shoemaker et al., 2014). Even though both versions (PEMAT-P and PEMAT-AV) have demonstrated good inter-rater reliability, PEMAT has not been used in dentistry studies.

The overall mean understandability score of the selected materials was 82%, while the actionability mean score was significantly low at 29%. Although most of the examined clips (86%) were primarily scientific and only (10%) were educational, the level of understandability was good (82%), which could be attributed to the appealing nature of the AV content, organised and well-structured presentations, clear aims of the material, and inclusion of pictures and graphs. However, this high understandability rating was not necessarily representative of the entire content because certain PEMAT items were not applicable to multiple AV materials, thus the high overall rating (e.g. item 13 was not applicable across 16 materials).

A previous investigation regarding AV content on diabetes had an understandability rating of 50% and an actionability rating of 31% (Kang and Lee, 2019), which are consistent with our findings. Many materials from the examined AV contents in our study (n = 18; 62%) had an actionability rating of 0%. This poor actionability result is worrisome because research suggests that actionability should be taken into account as a cornerstone when creating informational materials (Kang and Lee, 2019). While we acknowledge that the scope for direct, active patient self-management actions in OED/OPMD is limited primarily to tobacco and alcohol cessation, actionability must be broadly defined for this condition. For a potentially malignant disorder, critical patient actions include vigilant oral self-examination, strict compliance with long-term follow-up schedules, and promptly seeking care upon observing clinical changes. The failure of the majority of videos to address these essential monitoring and compliance behaviours is the primary concern highlighted by the low actionability scores. However, 5 materials (17%) received an actionability rating of 100%, as they indicated key messages such as continued self-examination, seeking immediate care when concerning clinical changes occur, importance of long-term follow-up, impact on QoL, and avoiding risk factors and bad habits.

Table 2-11 Summary of research conducted on various oral conditions.

Author (year)	Disease	Number of included materials	Quality assessment tools	Findings
(Hassona et al., 2016)	Oral cancer	188	Usefulness score	-Academic institutes and personal story publication are more useful than individual user materials.
(Delli et al., 2016)	Sjogren's syndrome	70	Global Quality Scale and modified DISCERN	-Half of the videos were classified as useful; less than half, as personal experience; and the rest, as misleading. -Personal content was preferred over educational content.

(Di Stasio et al., 2018b)	Oral thrush in children	29	Unidentified	-About two-thirds of the evaluated contents were slightly useful. -In spite of the source, information about mouth sores in children on YouTube was poor.
(Di Stasio et al., 2018a)	Mouth sores in children	33	Unidentified	-The information on oral thrush from clips was of poor quality.
(Kovalski et al., 2019)	Oral leukoplakia	28	Global Quality Scale, usefulness score, and modified DISCERN	-The analysis revealed that the videos were of poor quality, reliability, and usefulness.
(Fortuna et al., 2019)	Burning mouth syndrome	114	Quality assessment score	-Approximately half of the contents were educational. -However, the quality of the contents was poor.
(Ramadhani et al., 2021)	Halitosis	105	Global Quality Scale, comprehensive score, and DISCERN	-Contents were mostly poor. -Low-quality content was preferred over high-quality content.
(Romano et al., 2021)	Oral lichen planus	36	Global Quality Scale and DISCERN	-The materials mostly presented poor information despite the gradual improvement in content.
Alamoudi et. (2023)	Oral epithelial dysplasia	29	DISCERN, JAMA, and PEMAT-AV	-Content is predominantly scientific, not educational.

Limitations of this study

The present analysis had several limitations, including the following: 1) the dynamic nature of the internet content, 2) only videos provided in English were considered, 3) the analysis chiefly focused on YouTube and did not include contents from other social media platforms, 4) the quality of YouTube content varies widely and is unstandardised, 5) although an extensive search was conducted, the number of included AV materials was only 29, which is considered a small sample.

Future directions and implications for oral health care professionals

Future research should examine videos published on other well-known social media sites and in other languages, in the same analysis. The analysis of video comments is another area of study in the future because it reflects what people need or prefer. However, a critical distinction must be maintained: comments largely reflect patient preferences (e.g., for simplicity, emotional connection, or brevity), which may not accurately represent their true educational needs (e.g., comprehensive, balanced information required for shared decision-making). Nevertheless, analysing these preferences is valuable because comments can reveal unmet information needs and highlight specific areas of confusion or misunderstanding, which are crucial for guiding the development of future educational materials that are both engaging (preferred) and scientifically rigorous (needed).

Our study found sources that have not been produced by professionals; therefore, it is probable that these materials were not reviewed for accuracy, which could ultimately affect the decision of patients on their medical health. Thus, both ethically and legally, media platforms have responsibilities to the audience. Ideally, incorporating a peer-review process prior to posting would be useful to mitigate the dissemination of false knowledge. However, this process is complicated and even not applicable at this phase of development of social media platforms. Accordingly, academic institutes and dental organisations might offset this issue by boosting their social media activity and creating reliable content that could reach a mass number of individuals.

It would seem appropriate for to consider using the DISCERN, JAMA, and PEMAT instruments to evaluate additional educational AV contents in the field of dentistry, which would ultimately shed light on weak or poor areas in regard to health information. This will direct professionals and policy makers where and how to exploit their resources effectively and eventually enhance the overall patient experience and management outcomes. In addition, the findings of this web analysis could be used in the future to guide the development of educational video materials, ensuring that they include essential health information pertinent to OED.

2.5. Conclusions

The results of the present study show that the AV materials on OED were primarily produced on YouTube by dental professionals and therefore could be credible as resources for patient education. The most frequently discussed subjects in the available content were the definition, grading, and WHO histopathological criteria of OED, and the clinical presentations of OPMD. However, owing to the unfiltered nature of YouTube, many clips on OED did not satisfy the minimum criteria for providing comprehensive patient information. Personal experience may be considered as a helpful source of health information. While personal accounts enhance patient engagement and offer practical insights that institutional content often lacks, they carry inherent risks of bias. These risks include selection bias (presenting non-average experiences) and the dissemination of anecdotal evidence or misinterpretation of clinical facts, which can misguide or create unrealistic patient expectations.

The qualities and values of the existing AV contents remain uncertain. Therefore, it is crucial to utilise the available information carefully, keeping in mind where the videos came from and what information is missing. Considering the tremendous reach of social media platforms and the need to disseminate accurate information regarding OED, it is necessary to increase the professional presence on different social media platforms. These materials could also offer reliable links to sources that provide additional information on any given subject.

Chapter III. Experiences, challenges, and informational needs of patients with oral precancer: A qualitative study

3.1. Introduction

Oral epithelial dysplasia (OED) is a term used to describe various changes in the cells and structure of the oral epithelium associated with an increased likelihood of developing oral squamous cell carcinoma (OSCC) (Tilakaratne et al., 2019). OSCC ranks among the 15 most common types of cancer in the United Kingdom (UK), with over 6,000 new cases identified annually (Cancer Research UK, 2017). OED is estimated to affect 2.5 to 5 per 1,000 individuals (Mehanna et al., 2009). Research has shown that OED can elevate the risk of OSCC by 6–36%, depending on the degree of dysplastic changes (Field et al., 2015). Oral potentially malignant disorders can precede the development of OED (Kierce et al., 2021). These disorders include oral lichen planus (OLP), oral submucous fibrosis (OSF), and oral leukoplakia (OL). Regular surveillance and surgical removal are the recommended methods of treatment (Mehanna et al., 2009).

Achieving favourable long-term health outcomes for patients with OED requires accurate diagnosis, optimal treatment options, and a positive and satisfying healthcare experience (Doyle et al., 2013). Patient experience is multifaceted, encompassing various dimensions and perspectives. Definitions of patient experience can vary significantly among healthcare professionals and evolve, particularly in the dynamic healthcare sector (Wolf and Jason, 2014). The Beryl Institute defines patient experience as “the sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care” (Wolf and Jason, 2014).

Core concepts of a positive patient experience include patient-centred care, effective communication, patient education, patient and family partnerships, informational transparency, and personalised and unique care (Wolf et al., 2021). Although satisfaction is essential to the overall patient experience, it is important to note that positive patient experiences are about much more than mere satisfaction. Satisfaction pertains to only certain periods in time, whereas the patient experience encompasses everything a patient encounters, the perspectives they carry with them, and the narratives they share as a consequence (Wolf et al., 2021).

An obstacle that might arise during medical encounters is a disparity in the perception of complaints, signs, or symptoms between the patient and the provider, resulting in inconsistencies in the approach to the disease and the strategy for management (Bensing, 1991). To overcome this obstacle, qualitative research can offer insightful information about patients' subjective experiences and needs, thus facilitating more informed medical decision-making and treatment approaches (Tong et al., 2016). Qualitative research is highly regarded as a good approach for examining important aspects of an individual's issues, such as pain, which may not be adequately explored using other research methods (Osborn and Rodham, 2010).

It is crucial to highlight that patient experience extends beyond mere quantitative measurements and survey results, which typically offer insights into only specific stages or parts of an individual's path (Wolf et al., 2021). Therefore, to deliver detailed insights into everyday problems and human experiences, qualitative research examines phenomena within the contexts of individuals and groups (Moser and Korstjens, 2017), offering a more versatile approach than quantitative research

(Korstjens and Moser, 2017). Previous studies on head and neck cancer (Scott et al., 2006, Deng et al., 2019) and chronic facial pain (Taimeh et al., 2023) have successfully utilised this method to investigate various aspects of patient experiences. Therefore, this study employed a qualitative approach using interviews. A thorough review of existing literature revealed a lack of research explicitly investigating the experiences of individuals with OED.

3.1.1 Aims and objectives

This chapter aimed to provide a comprehensive understanding of the experiences, challenges, and informational needs of patients with OED in a dental hospital in the UK.

3.2. Materials and methods

3.2.1. Ethical considerations and study registration

The study protocol underwent an independent review to confirm its rigour and feasibility. This review was conducted by an impartial external expert, typically a senior clinician or research methodologist appointed by the University College London Hospitals/University College London (UCLH/UCL) Joint Research Office (JRO) or the Institutional Review Board (IRB), ensuring no conflict of interest with the study team. . The study adhered to the Declaration of Helsinki guidelines for medical research involving human subjects. It was registered with the UCLH/UCLJRO under reference/EDGE number 153912 and IRAS project ID 318039. The study received a favourable opinion from the NHS Research Ethics Committees (REC), specifically the London – Surrey Borders Research Ethics Committee (reference 22/PR/1743) (Appendix 1). Additionally, it obtained ethical approval from the Health Research

Authority (HRA) and Health and Care Research Wales (HCRW) (Appendix 1). These multiple approvals are necessary because they fulfill distinct regulatory requirements within the UK health system. The REC granted the formal ethical opinion regarding the rights and safety of participants, while the HRA and HCRW provided the mandatory regulatory permission for the NHS and Welsh health systems to host the study, confirming organisational capacity and legal compliance. Reporting of the qualitative component in this article complies with the guidelines outlined in the Standards for Reporting Qualitative Research checklist.

3.2.2. Study design and participants

This study was a semi-structured, interview-based, qualitative research project conducted at the UCLH Royal National ENT and Eastman Dental Hospitals' Oral Medicine Unit. Purposive sampling was used to select individuals diagnosed with OED through histopathological examination based on the 2017 World Health Organization classification system (El-Naggar et al., 2017). The inclusion criteria for the study were adults aged 18 years or older, proficiency in both written and spoken English and the ability to provide informed consent. Eligible participants were recruited during their routine clinical visits. Qualitative sample size was determined by the principle of data saturation, which was reached at 30 participants, aligning with literature recommendations for semi-structured interview studies of moderately heterogeneous patient groups (Sargeant, 2012). The research team provided each participant with a detailed verbal explanation of the study's objectives and the expected outcomes of their involvement. Participants were then given an information sheet to review and were asked to sign an informed consent form (Appendix 2).

3.2.3. Data collection

Data collection occurred between March and December 2023 and continued until saturation was achieved. The saturation was defined as the point where no new emerging information would allow further development of a category's properties (Strauss, 2017). Each interview lasted between 30 and 40 minutes, with an average duration of 35 minutes. All interviews were documented on paper and recorded in audio format. The interviews were conducted by two moderators (WA and RNR) who identified themselves as researchers and explicitly stated that they were not involved in the clinical service of any individuals. This precaution ensured that participants felt comfortable sharing adverse experiences without hesitation. The moderators, who had clinical backgrounds in oral medicine and were trained in qualitative research, took care to avoid influencing participants' responses with their ideas or opinions. This care was taken by strictly adhering to the semi-structured interview guide, utilising open-ended and non-leading questions, employing neutral probing techniques, and avoiding any evaluative verbal or non-verbal feedback (e.g., nods or affirmative phrases) that could indicate judgment or guide the participant towards a preferred response.

Participants provided data through semi-structured interviews, which enabled the collection of open-ended information while adhering to a set of guiding and predetermined questions (DeJonckheere and Vaughn, 2019). A detailed topic guide was created for the interview discussion (Hancock et al., 2001), serving as a foundation for structured conversations and encouraging engagement between the researcher and participants. Key discussion topics covered a broad range of subjects, including initial appointments with primary healthcare providers, referrals to specialised healthcare facilities, progression to cancer risk, investigation procedures, treatment options, experiences with NHS services, information sources, and the physical and psychosocial impacts of OED. Participants were also free to bring up issues outside the framework that they deemed significant. Throughout the interviews, the guide was revised to obtain data that most effectively addressed the research objectives.

3.2.4. Data analysis

Verbatim transcription was performed for all interviews. The researchers conducted a preliminary data assessment by engaging in reflective notetaking and forming initial impressions while listening to the audiotapes. Common themes within the responses of the participants were identified using thematic analysis. Through line-by-line coding, data were organised into subunits to facilitate pattern recognition. Codes with similar content were grouped to establish common categories. Recognising themes is a dynamic and interpretive task (Kiger and Varpio, 2020). As a result, they were developed through an iterative inductive process, where coded data was merged, examined, and interpreted. Each theme was subsequently accompanied by a detailed narrative description to provide context. Audit trials and data triangulation were applied to increase the reliability of the findings.

To determine data saturation, two researchers (WA and RNR) independently coded each set of three interviews before convening to compare emerging codes and subthemes. As coding progressed, earlier transcripts were revisited to ensure newly identified codes could be integrated. Saturation was deemed reached when no new codes or themes emerged over three consecutive interviews, indicating that further data collection would not deepen understanding of the topic (Strauss, 2017).

3.3. Results

3.3.1. Participants

The study initially included a cohort of 35 participants, consisting of 24 females and 11 males. However, due to personal circumstances (n=2) and time constraints (n=3), only 30 participants consented to partake in the study, resulting in 21 females and nine males. Participants' ages ranged from 44 to 83 years, with a mean age of 64.4. The number of dysplastic sites varied between 1 and 7, averaging 1.8 per participant. The initial diagnosis of dysplasia occurred between 2 and 17 years before the start of the trial, averaging 7.3 years. The clinical features of the participants are presented comprehensively in Table 3-1.

Table 3-1 Clinical characteristics of participants.

Patient ID	Age (years)	Sex	Diagnosis (years)	Dysplasia sites	Location	Degree of dysplasia	Associated OPMD or OSCC
001	73	F	13	2	Buccal mucosa	Mild	OLP
002	44	M	12	1	Palate	Mild	OLP
003	63	F	17	1	Tongue	Mild	OLP
004	72	M	10	3	Buccal mucosa, palate	Moderate, severe	OLP
005	70	F	10	1	Tongue	Mild, moderate, severe	OLP
006	77	F	3	2	Floor of mouth, gingiva	Mild, moderate	OLP
007	68	F	6	2	Gingiva	Mild, moderate	OLP

008	79	F	4	7	Gingiva, palate	Moderate	OSCC
009	54	F	2	1	Tongue	Mild, moderate	OLP
010	66	F	6	1	Tongue	Moderate, severe	OSCC
011	63	M	3	1	Tongue	Moderate	OLP
012	44	F	7	1	Tongue	Mild, moderate, severe	OLP
013	55	M	11	5	Buccal mucosa, palate, gingiva	Mild, moderate	OSF and OSCC
014	65	F	4	3	Buccal mucosa, gingiva, floor of mouth	Mild, moderate	OLP
015	57	F	7	2	Buccal mucosa	Mild, moderate	-
016	50	M	16	2	Tongue, floor of mouth	Mild, moderate, severe	OLP
017	61	F	4	1	Tongue	Mild, moderate, severe	OLP
018	66	M	8	2	Buccal mucosa	Mild, moderate	OLP
019	58	M	3	1	Tongue	Mild	OLP
020	57	F	2	1	Buccal mucosa	Mild	OLP
021	67	M	2	1	Gingiva	Mild	OLP
022	58	F	2	1	Buccal mucosa	Moderate, severe	OLP
023	68	F	7	2	Palate, gingiva	Moderate, severe	OLP and OSCC
024	63	F	8	1	Tongue	Moderate	OLP
025	76	F	9	2	Buccal mucosa, gingiva	Mild, moderate, severe	OLP
026	70	F	6	1	Buccal mucosa	Mild	OLP
027	75	F	6	3	Buccal mucosa, tongue	Moderate, severe	OLP and OSF
028	57	F	3	1	Gingiva	Mild, moderate	OLP
029	68	F	11	1	Tongue	Mild, moderate	OLP

030	70	M	17	1	Buccal mucosa	Mild, moderate	OLP

F: female, M: male, OLP: oral lichen planus, OSF: oral submucous fibrosis, OL: oral leukoplakia, OSCC: oral squamous cell carcinoma

3.3.2. Themes

The interviews generated a variety of perspectives regarding experiences with OED. The participants' responses varied based on disease history and individual characteristics. Four primary themes emerged from the data analysis, which included (i) delays in OED diagnosis, (ii) knowledge about OED, (iii) psychological impact, and (iv) patient education. Table 3-2 presents the themes and subthemes identified from the participants' responses, including some findings and supporting quotations.

Table 3-2 A complete spectrum of subthemes developed from the primary themes.

Theme	Subtheme	Supporting quotations
Delay in OED diagnosis	Patient's inability to identify abnormal signs and symptoms	*"Initially, it began as an ulcer in my cheek, and I assumed I just needed simple treatment in that area"* (001)
	Clinician incompetence	*"My GP referred me to an oral surgeon, suggesting that I should seek their expertise due to a potential issue with the skin in my mouth. I was sent back to my GP with no diagnosis; however, it was the oral medicine specialist who correctly identified and diagnosed the condition"* (012)
	Administrative issues	*"My referral was made incorrectly, necessitating a complete restart of the process. I was so frustrated" (014)*
Knowledge about OED	Nature of the disease	*"I believe that patients should be informed with all knowledge and utmost transparency about their diagnosis and disease"* (013)
	Aetiology and risk factors	*"I didn't know that alcohol can cause this in my mouth; I reduced the amount I drink and tried to*

		stick to the recommended levels" (011)
	Diagnostic tests and treatment options	*"It would be great to learn the particular aim of the biopsy sample and treatment alternatives"* (006)
Psychological impact	Diagnosis of OED	*"Upon receiving my initial diagnosis, I experienced a sense of worry, confusion, and disbelief, as there was a lack of awareness and understanding among others, and I did not encounter anyone who shared comparable experiences" (005)*
	Risk of progression to cancer	*"I'm extremely tired from the number of biopsies I've been having to chase any progression into cancer. It's draining and exhausting" (*025)
	Management adverse effects	*"You know, with mouth dryness, limited mouth opening, and graft I've got after the surgery,* I'm not confident at a table – *and that makes me sad" (023)*
Patient education	Regular education	*"I'd be grateful if the doctor would remind me of my plan each time I see him and not assume that I know everything I need to do because I only see him once a year and, as you can imagine. That's enough time for the information to fall through the cracks"* (026)
	Lack of reliable sources of information	*"Whenever I search for information, I exclusively rely on the NHS, as it provides a sense of security. However, I haven't found reliable sources for mouth precancer or dysplasia" (013)*
	Supplementary educational tools	*"As a non-native English speaker, watching a video would be helpful to better understand the information"* (028)
	Group discussions	*"I'm interested in meeting other individuals who share the same issue in order to get insight from their experiences and compare them to my own. I propose establishing a recurring meeting to exchange experiences"* (014)

OED: oral epithelial dysplasia

3.3.2.1. Delays in OED diagnosis

Many participants expressed frustration about significant delays in their OED diagnosis, often attributed to the failure or inability to recognise abnormal signs and symptoms. Patients frequently perceived their symptoms as minor or temporary, which led them to ignore the issues, delay seeking medical care, and a lack of urgency in addressing their condition.

For example, some participants reported:
“Initially, it began as an ulcer in my cheek, and I assumed I just needed simple treatment in that area” (001).

“I ignored it as I had ulcers as a child. I decided to wait it out and trust that it would resolve itself. I believed it was simply a mouth ulcer that eventually would go away” (009).

“I wouldn't go to a doctor for a tiny discolouration under my tongue because they would think I’m exaggerating” (024).

Many individuals also expressed notable dissatisfaction with the competence of general practitioners (GP) or other healthcare professionals, indicating a preference for the expertise of an OED specialist instead. In addition, this incompetence can lead to numerous clinical visits before receiving suitable medical attention was also reported. Many patients experienced a frustrating cycle of multiple hospital visits and referrals, often enduring considerable delays before being seen by an appropriate clinical team capable of addressing their healthcare needs effectively.
As one participant noted:

“My GP referred me to an oral surgeon, suggesting that I should seek their expertise due to a potential issue with the skin in my mouth. I was sent back to my GP with no

diagnosis; however, it was the OED specialist who correctly identified and diagnosed the condition" (012).

Another participant highlighted the complex nature of dysplasia symptoms:

"One issue with dysplasia is that its symptoms can resemble those caused by other factors, such as lichen planus and certain medications. When I consulted a GP, the initial assumption was often the simplest explanation, as my GP immediately attributed my symptoms to menopause. Only the oral medicine specialist at this hospital recognised the true disease" (007).

Another reported the difficulty in securing a diagnosis:

"I consulted with two general practitioners and one dentist; they all didn't know how to manage or where to refer me for the white patch I've had in my mouth for months. I ultimately ended up seeing a Maxfax surgeon who sampled the lesion and found out that dysplasia was evident. This whole journey took around two years to reach an accurate diagnosis – luckily, the lesion didn't progress into cancer" (021).

Additionally, many individuals faced significant administrative hurdles during the referral process, which led to prolonged and frustrating delays.

"My referral was made incorrectly, necessitating a complete restart of the process. I was so frustrated" (014).

"The referral protocols dealing with mouth dysplasia at this hospital or other hospitals have to be improved" (001).

"I've done my research before seeking a referral, which was very difficult to get through. Without my investigation and persistence, I would not have arrived at this point" (019).

3.3.2.2. Knowledge about OED

Several participants highlighted the critical importance of obtaining comprehensive knowledge about the diagnosis, nature of the disease, risk factors, treatment options, and prognosis of OED. Before their encounters, none of the participants had any awareness of OED. Participants agreed that the moment of diagnosis marked a pivotal turning point, during which detailed information about all aspects of the condition should be communicated to ensure patients are fully informed and prepared to manage their health effectively.

As one participant expressed:

"I believe that patients should be informed with all knowledge and utmost transparency about their diagnosis and disease" (013).

Another indicated the shock at learning about their condition:

"I have never heard of it. I am familiar with breast and prostate cancer. I was surprised to learn that I had mouth precancer" (003).

One proposed the need for specialised patient-specific service:

"Is it possible to have a specialised mouth dysplasia clinic funded by the NHS? Specialists who possess comprehensive knowledge of the disease and its various manifestations and management?" (004).

Many participants were unfamiliar with the aetiology and risk factors associated with OED. Several also lacked knowledge regarding the correlations connecting alcohol and HPV with OED.

One participant admitted:

"I didn't know that alcohol can cause this in my mouth. I reduced the amount I drink and am trying to stick to the recommended levels" (011).

Another reported:

"I know HPV can result in vaginal cancer, but in the mouth – never heard of that" (023).

The participants emphasised the importance of promptly receiving thorough information regarding routine diagnostic tests and available treatment options.

For example, some participants stated:

"It would be great to learn the particular aim of the biopsy sample and treatment alternatives" (006).

"Knowing that I may finally at least receive treatment for my issue was tremendously helpful to me" (015).

"I was advised to have a surgical operation to remove my mouth lesions over regular watching. I appreciated the thorough knowledge I was given" (024).

3.3.2.3. Psychological impact

Several individuals reported that OED has affected their psychological well-being. These impacts arise due to the diagnosis itself, the chronic nature of the condition, the uncertainty of progression to cancer, and the treatments involved. Emotional distress was common at the first diagnosis, with feelings of worry and confusion due to lack of awareness.

One participant described:

"Upon receiving my initial diagnosis, I experienced a sense of worry, confusion, and disbelief, as there was a lack of awareness and understanding among others, and I did not encounter anyone who shared comparable experiences" (005).

Another added:

"Initially, everything was uncertain and ambiguous, as I lacked a clear understanding of what I had for many years. Hence, I was so stressed out and scared until I met Dr. xxx at this hospital" (008).

"Upon discovering the meaning of oral dysplasia, the doctor informed me that it is a condition I must endure, as there is no solution available. He explained that the initial phases of the disease vary across individuals. I had significant distress due to my refusal to acknowledge it as a medical condition" (017).

Some participants expressed apprehension and anxiety about the potential progression to oral cancer and OED recurrence.

*"I'm extremely tired from the number of biopsies I've been having to chase any progression into cancer. It's draining and exhausting" (*025).

"If I had been aware of all the possibilities of having cancer when I received my diagnosis, I would have experienced greater peace of mind, as I have recently acquired a significant amount of knowledge" **(**006).

"The risk, things that warrant cautionary attention. For instance, one of my colleagues was diagnosed with mouth cancer, which made me concerned about the possibility of developing a similar condition. Therefore, it is important to emphasise any relevant symptoms that may arise. If I were to experience any abnormal growth or hardness in that region, what course of action should I take?" (029).

Participants also expressed challenges related to the management of OED, particularly the adverse effects that arose following major surgical procedures. Several individuals recognised the impact of these complications, including dry mouth, limited mouth opening, grafting, and an inability to eat normally, on several aspects of their lives.

“You know, with mouth dryness, limited mouth opening, and graft I’ve got after the surgery, I'm not confident at a table – *and that makes me sad” (023).*

“When I look at myself in the mirror, my smile is not the same anymore, my confidence and intimacy with my husband have gotten affected. I had a couple of plastic surgeries to enhance the surgery's adverse effects, but that didn’t really change a lot” (010).

“The challenges I have in communication, particularly in my profession as a professor, have undeniably caused annoyance and impacted my life” **(**016).

3.3.2.4. Patient education

Participants highlighted the vital significance of receiving ample information and consistent education regarding OED. They conveyed satisfaction with the interactions they had with knowledgeable and skilled clinicians. There was a belief among patients that the provision of information about OED should be ongoing, as knowledge might change over time and relevant disease-specific updates are difficult for non-clinicians to find.

“I’d be grateful if the doctor would remind me of my plan each time I see him and not assume that I know everything I need to do because I only see him once a year and, as you can imagine..that’s enough time for the information to fall through the cracks” (026).

“I’ve been having memory issues recently. I need to be reminded about the important information” (006).

“I can’t remember much about my disease because I had it a long time ago and never recurred. I always need to be reminded and educated” (018).

Several participants appreciated the support they received at diagnosis but thereafter felt abandoned due to a lack of reliable sources of information, which affected their acquisition of deeper knowledge about the condition. Consequently, they sought to gather information from other sources. They turned to the internet to gather information, which resulted in feelings of being swamped and discouraged.

One participant reported:

“Whenever I search for information, I exclusively rely on the NHS, as it provides a sense of security. However, I haven’t found reliable sources for mouth precancer or dysplasia” (013).

Others reported:

“I believe it is beneficial to have a preliminary understanding, but upon initial diagnosis of any condition, one needs some time to fully comprehend and accept the situation, wouldn’t you agree? It may be helpful to direct individuals to helplines or sources of additional information, such as online resources or support groups” (015).

“If you access the internet or Google and encounter the issue of feeling sad due to observing an arbitrary, unskilled collective of individuals who engage in spreading scary narratives” (022).

Alongside individual clinical consultations, the participants emphasised their desire for more extensive information on OED. They cited a diverse array of supplementary educational resources, encompassing written materials such as printed documents and webpages, as well as audio-visual content like YouTube videos. These supplementary tools would be beneficial for obtaining further comprehension of the information provided in the clinic and or to remind the patient of any forgotten information.

Some responses were:

“As a non-native English speaker, watching a video would be helpful to better understand the information” (028).

*“Videos could be easier to digest and understand. And yet, written information and wording is important, especially in advanced cases, as it reflects the seriousness and severity of the condition more than the videos” (*002).

“I can read the booklet anytime, while videos require an electronic device, which I can’t afford” (006).

“I prefer videos because of convenience. I can slow it down, repeat it, see pictures for better imagination” (017).

Some participants suggested attendance at group discussions. Through the exchange of experiences and advice, individuals had medical benefits. Furthermore, engagement with peers facilitated emotional and mental support.

“I’m interested in meeting other individuals who share the same issue to get insight from their experiences and compare them to my own. I propose establishing a recurring meeting to exchange experiences” (14).

“It would be beneficial to have the ability to share experiences, treatment alternatives, and outcomes with individuals who have comparable diagnoses” (022).

3.4. Discussion

Having reviewed the literature, this would seem to be the first qualitative study that investigates patient experiences with OED. The study identified four primary themes identified after data analysis: delays in diagnosis, knowledge about OED, psychological impact, and patient education. The delayed diagnosis could be driven by patients' inability to recognise symptoms, a deficiency in clinician education and awareness regarding OED/OPMD clinical features, and administrative inefficiencies, particularly the absence of clear and rapid local referral pathways to oral medicine or oral and maxillofacial surgery, often leading to lengthy referral processes. Participants also expressed a need for comprehensive knowledge upon diagnosis, including clarity on aetiology, risk factors, diagnostic tests, cancer development risks, and treatments. The psychological impact was significant, with patients reporting uncertainty, confusion, worry, and treatment-related side effects that affected their quality of life (QoL). Additionally, participants highlighted gaps in patient education and support, emphasising the need for reliable resources, supplementary educational tools (e.g., pamphlets and videos), and group discussions to share experiences and coping strategies.

This study indicated that several factors may contribute to delays in diagnosis, including the inability of patients to identify abnormal signs and symptoms, clinician incompetence, and healthcare administrative hurdles. Some patients reported not perceiving their symptoms as serious or indicative of premalignancy. This could be explained by the fact that early symptoms of OED are frequently subtle and painless, leading them to be mistaken for normal mouth issues and easily overlooked. This aligns with a study on advanced-stage oral cancer (Rubright et al., 1996), where 87%

of individuals reported being unable to identify warning signs during self-examinations. However, the current analysis also indicates that experiencing concerning symptoms is not always essential for seeking quick aid, as some patients sought assistance shortly after noticing even mild symptoms, such as a change in colour. Patients who delayed seeking care expressed that they would have sought treatment earlier had they been aware of the seriousness of their symptoms.

The participants in this study also reported that some dentists and GPs demonstrated insufficient competence and training, particularly in assessing mucosal lesions in the mouth such as OED. According to several studies, primary care providers are hesitant to diagnose and manage this category of illnesses (Sardella et al., 2007, Bindakhil et al., 2021). The inability to perceive symptoms as indicative of something warranting serious attention by a clinician has been documented for testicular cancer (Gascoigne et al., 1999), breast cancer (Ramirez et al., 1999), and oral cancers (Scott et al., 2006, Gigliotti et al., 2019). However, distinguishing OED from other conditions as OLP or OL can be challenging for non-specialist clinicians due to overlapping clinical features. Findings indicate that many participants experienced diagnostic delays or uncertainties, a trend also noted in the literature (Sardella et al., 2007). This underscores the importance of improving the training of GPs and primary care teams in recognising subtle mucosal changes that may indicate dysplasia. These results highlight the value of targeted educational efforts and easily accessible resources for both patients and non-specialist clinicians.

The present findings also show that participants were transferred repeatedly between several dentists and GPs, with these clinicians diagnosing the oral lesions incorrectly or not recognising the malignant potential and seriousness of the disease or because of a lack of knowledge about the appropriate centres for their complaints. This finding is consistent with a prior study, where individuals with chronic facial pain reported multiple referrals to both primary and secondary healthcare facilities in their attempts to get medical attention (Taimeh et al., 2023). Well-coordinated referral pathways and stronger interprofessional collaboration could ensure timely management and boost patient confidence. Once participants in this study accessed specialist care, they reported clearer understanding and reduced anxiety. In addition, experts with varied experiences may employ different strategies for managing OED. For example, clinicians with an oral medicine background might suggest regular surveillance and non-invasive treatments, whereas oral surgeons might favour surgical interventions (Mehanna et al., 2009). Therefore, a significant obstacle for patients with OED is a lack of established guidelines for referring patients and determining appropriate treatment techniques. Strengthening the standards of undergraduate and postgraduate training in this field could enhance the efficacy of achieving a timely diagnosis and appropriately managing OED.

The findings of this study demonstrated that participants’ knowledge about OED was insufficient, particularly at the time of their initial diagnosis. This finding is consistent with previous research on oral cancer (de Amorim Póvoa et al., 2025). Additionally, this insufficiency can be attributed to several factors, including clinicians not providing enough information, complexity of information, rarity of OED may limit general awareness, and long intervals between follow-up appointments could lead to forgetfulness. However, once the diagnosis was established, the participants emphasised the importance of thorough and continued communication regarding essential disease-related information. An earlier OED study highlighted that addressing this critical element can enhance shared decision-making, mitigate the negative psychological impacts, improve future health outcomes, and reduce healthcare expenditures (Alsoghier et al., 2022).

This study also showed that throughout the clinical course of the condition, the participants' levels of knowledge exhibited considerable variability. Some individuals demonstrated a high level of understanding about OED, often due to factors such as a long history of the disease, multiple recurrences with varying grades, and a history of progression to cancer. Conversely, other patients in the current analysis displayed limited knowledge and understanding of OED, possibly attributed to factors such as a past diagnosis of a mild disease without progression or recurrence, older age, or medical conditions affecting memory and comprehension. Some participants particularly emphasised the need for detailed information on the risk factors and potential progression to oral cancer, a need that has been corroborated by previous research on OED (Alsoghier et al., 2021). Furthermore, the results of this study underscore the importance of providing patients with comprehensive information about investigative tests and treatment options, aligning with findings from an earlier study on OED (Alsoghier et al., 2023).

The current findings show that several participants experienced significant psychological burdens from OED, adversely affecting their QoL. These burdens were attributed to multiple factors, including delays in diagnosis, uncertainty about the disease, potential progression to cancer, risk of recurrence, challenges in controlling risk factors, and management of adverse effects. A cross-sectional study supports these findings, showing that patients with OED had lower quality-of-life scores (Ashshi et al., 2023). Another investigation revealed that patients with OED often experience heightened anxiety, fear, and emotional distress due to concerns about the potential progression to mouth cancer (Alsoghier et al., 2021). The latter study found that 30% of participants elevated anxiety, 16% suffered from depression, and 26% endured emotional distress. In addition to the adverse effects of investigative sampling and therapeutic surgical procedures involving tissue removal, the participants of this study experienced significant impairments in nutrition and speech. Other studies on OED confirm the negative impact of OED management on the QoL (Alsoghier et al., 2021, Ashshi et al., 2023).

The finding that a large majority of participants (n=27,90%) presented with OED in the setting of clinically diagnosed OLP is highly characteristic of a specialised tertiary referral centre cohort. We recognise that not all OLP patients have OED, nor is OED always found concurrently with OLP; therefore, this mix is not necessarily common in the general patient population.

The site of the OED lesion is likely a significant factor influencing the patient's emotional response and subsequent perception of their diagnosis, distinct from the initial fear of hearing the news. Lesions located on highly mobile or functionally critical sites, such as the tongue or floor of the mouth, can heighten psychological distress due to interference with essential functions (speech, swallowing) (Rogers et al., 2009) and increased fear of malignant transformation (due to known high-risk anatomy) (Amagasa et al., 2011).

Of the 30 participants, those diagnosed with only mild dysplasia (001, 002, 003, 019, 020, 021, 026) underwent incisional or punch biopsy followed by clinical observation, while the remainder underwent repeated surgical excisions over the years due to higher dysplasia grades, progression to cancer, or recurrences. The recurrence of OED, even after an apparently complete surgical removal, is a well-documented challenge (Warnakulasuriya et al., 2011). This is primarily explained by the concept of field Cancerisation, where the entire mucosal field has been genetically damaged, allowing for new dysplastic lesions to develop adjacent to or remote from the original excision site (Van der Waal, 2010).

Although the overarching themes of diagnostic delays, psychological impact, and the need for patient education were common to both groups, individuals who underwent major surgical procedures reported additional concerns regarding post-operative complications (e.g., graft-related difficulties, altered speech, and dryness). Conversely, those on clinical surveillance pathways spoke more frequently of anxiety surrounding potential malignant transformation. These differences underscore the heterogeneity of patient experiences and highlight the importance of personalised approaches to patient support and education.

In the current study, the participants indicated that regular OED education is essential. The provision of continued education is a critical component in the clinical management of both malignancies (Ankem, 2015) and premalignant conditions like OED (Alsoghier et al., 2023). Our findings also demonstrate that the primary and preferred source of information is direct, one-on-one meetings with an OED specialist. Indeed, verbal discussions remain the most effective and irreplaceable method of information exchange (Stewart, 1995). The participants also expressed a desire to access additional information from other reliable resources, such as leaflets or videos. Evidence suggests that supplementary educational tools, including written materials (e.g., booklets) and audio-visual aids (e.g., YouTube video clips), can enhance understanding and provide valuable support (Eckman et al., 2012).

The qualitative data gathered here directly supports the discussion presented in Chapter 2 regarding the Digital Divide and the potential bias against non-digital natives. Participant 006’s comment—"I can read the booklet anytime, while videos require an electronic device, which I can’t afford"—provides empirical evidence for the socioeconomic and technological access barriers that preclude reliance on digital-only platforms like YouTube (Hong & Cho, 2017). Furthermore, Participant 002's observation that "written information... reflects the seriousness and severity of the condition more than the videos" links communication format to the cognitive and emotional processing of the diagnosis. This reinforces the finding that video content often lacks the comprehensive detail and perceived gravity required for patients facing high-risk conditions (consistent with the low DISCERN scores observed for treatment options), underscoring the necessity of providing formal, written materials to fully support informed consent and shared decision-making.

The present analysis shows that, in the case of OED, which predominantly affects older individuals, this age profile is a critical mediating factor influencing information preferences. While Chapter 2 discussed the Digital Divide in general, the specific age vulnerability of this OED cohort was under-emphasised. The older demographic tends to face higher barriers related to digital literacy, technology affordability, and access, leading some participants to favour written materials over videos due to factors like affordability and accessibility. This is empirically demonstrated by the participant who stated, "I can read the booklet anytime, while videos require an electronic device, which I can’t afford" (006). Some participants also highlighted the importance of written information, particularly in advanced cases, as it conveys the gravity of the condition effectively. However, for non-English speakers, videos were preferred as they offer visual aids to overcome language barriers. Additionally, support groups were noted to have a positive impact, providing both medical and emotional support through shared experiences and advice. This aligns with research indicating the beneficial role of support groups in aiding patients with cancer (Hoey et al., 2008).

Implications of this study

Having reviewed the literature, this would seem to be the first qualitative study aimed at investigating the patient experience with OED. This study provides valuable insights into patient-reported outcomes, enabling a better understanding of patient experiences (Rothman et al., 2009). Such findings can be helpful for the development and selection of instruments that effectively capture the lived experiences of individuals with OED. In addition, these findings also can be utilised to further inform a previously developed measurement tool for OED, the oral epithelial dysplasia informational needs questionnaire, created by Alsoghair et al., 2022. This approach ensures the content validity, sensitivity, and responsiveness of measures and enhances their applicability in evaluating patient-centred care for OED (Wiering et al., 2017).

Study limitations

The study was conducted in specific dental department settings. Hence, the findings may lack generalisability to other populations or healthcare systems. In qualitative research, the researcher plays a pivotal role and can significantly shape the study's outcomes (Dodgson, 2019). This underscores the concept of reflexivity, wherein researchers are aware of their impact on participants while acknowledging how the research process influences them personally (Gilgun, 2008). Researchers must also guard against the Hawthorne effect, where participants may alter their behaviour due to awareness of being observed, potentially skewing results (Brinkman et al., 2007). Additionally, retrospective investigations may introduce errors in participant recollections, emphasising the need for caution. Given the exploratory nature of small-sample studies, conducting larger-scale research is vital to affirm findings and enhance the robustness of conclusions.

3.5. Conclusions

This was the first study to employ qualitative methods to explore patients' experiences, challenges, and needs before and after an OED diagnosis. The most prominent issues identified were difficulties establishing a timely diagnosis, insufficient oral health knowledge, psychological burden, and being well informed and educated.

These findings emphasise the need to address the overall deficiencies healthcare systems, patient awareness, and skills and knowledge of healthcare professionals in order to lessen the delays in diagnosis and avoid unfavourable consequences. Comprehensive regular clinical examinations and effective patient education are keys to ensuring favourable long-term health outcome.

Chapter IV. Why patient education matters for individuals with oral epithelial dysplasia: A quantitative study

4.1. Introduction

Oral epithelial dysplasia (OED) is a histological diagnosis that carries an increased risk of the individual developing oral squamous cell carcinoma (OSCC) (Iocca et al., 2020). Individuals with moderate-to-severe dysplasia are at a significantly elevated risk of transformation, with the likelihood of progression to OSCC increasing ten- to twenty-fold compared to those with only cellular atypia or mild dysplasia (Ranganathan and Kavitha, 2019). Oral potentially malignant disorders (OPMD) and several risk factors, including alcohol intake, tobacco use, and human papillomavirus (HPV) infection, have been linked to the development of OED (Iocca et al., 2020, Kierce et al., 2021). While the UK has implemented HPV vaccination programmes for both girls (since 2008) and boys (since 2019, with catch-up for Men who have Sex with Men [MSM] at high risk), definitive evidence of a drop-off in oral cavity OED or OSCC incidence in these cohorts is not yet available (Falcaro et al., 2021). The most frequently affected sites are the tongue, floor of the mouth, and gingiva (Ranganathan and Kavitha, 2019). The current management strategies for OED include vigilant monitoring and surgical excision (Mehanna et al., 2009).

Given the chronic nature of OED, regular and comprehensive patient education (PE) is crucial for achieving favourable long-term outcomes (Alsoghier et al., 2023) The word ‘doctor’ originates from the Latin term ‘docere’, meaning ‘to teach’, underscoring the inherent responsibility of physicians to educate patients, their families, and communities (Allsop et al., 2023). Providing patients with detailed and timely information needs (IN) enhances their understanding of the disease, improves adherence to management plans, and reduces the risk of complications (Coulter and Ellins, 2007). Furthermore, it elevates patient satisfaction, fosters trust, and enables them to make informed decisions about their health. Effective PE lowers healthcare costs by reducing the frequency of visits, referrals, and resource utilisation (Coulter and Ellins, 2007). However, only 302 articles have explicitly addressed the role of PE in oral and dental disorders and an even smaller number of randomised controlled trials (Mann and Sellers, 2003, Albano et al., 2019). Moreover, research on the effect of PE on individuals with oral malignancies and OPMD is limited (Ahuja et al., 2022).

The assessment of IN is fundamental for successful PE (Jönsson et al., 2009). IN pertain to the ways in which patients seek and receive knowledge about their disease, diagnosis, treatment, and follow-up care at the medical centres providing treatment (Sanson-Fisher et al., 2000). Previous studies have explored the IN of patients with cancer (Mesters et al., 2001), OSCC (Chen et al., 2009), and oral precancerous lesions (Lin et al., 2015). Despite the widely recognised importance of IN and PE, there is a significant gap regarding the informational and educational needs of patients with chronic dental and oral cavity conditions (Mann and Sellers, 2003, Albano et al., 2019), including OED (Alsoghier et al., 2023). The Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) is a recently developed instrument that assesses the informational needs of patients with OED [16], which was validated in 86 patients [16]. The instrument demonstrated excellent internal consistency in the previous study, with a Cronbach's alpha of 0.93 for the overall scale. Test-retest reliability was moderate (κ=0.49–0.53). Moreover, construct validity was supported by a significant, albeit limited, correlation with the Krantz Health Opinion Survey.

The Cronbach's alpha alpha of 0.93 indicates excellent internal consistency, meaning all questions in the scale reliably measure the same underlying construct (OED informational needs). The test-retest reliability was moderate (κ=0.49–0.53), demonstrating the stability of patient responses over time, which is acceptable for subjective measures where psychological factors may cause slight fluctuations. Finally, construct validity was supported by a significant, albeit limited, correlation with the Krantz Health Opinion Survey; this shows the ODIN-Q is related to established patient health attitudes (significance) but is measuring a unique, specific construct related to OED needs (limited correlation), confirming it is a distinct and valid measure.

4.1.1. What is patient education?

PE refers to the systematic provision of information to patients related to their medical condition, including details about clinical characteristics, treatment options, anticipated results, potential adverse effects, and guidelines for prevention (Close, 1988). In addition, PE, as defined by the American Academy of Family Physicians, involves a systematic approach to influencing patient behaviour and facilitating the acquisition of essential knowledge, attitudes, and skills for enhancing or maintaining one's health (Schrieber and Colley, 2004).

It is critical that this process respects the principle of patient autonomy (Beauchamp and Childress, 1994). The ultimate goal of PE is to ensure the patient is competent to make an informed decision, meaning they understand the nature of the condition (OED), the risks and benefits of available options (e.g., surgery vs. surveillance), and the potential consequences of their choice. However, competence accepts an individual's right to make a decision that the clinician may deem 'unwise' (e.g., refusing recommended surgery for high-grade dysplasia) as long as that decision is based on a full understanding of the risks and benefits (Gillon, 1994). Therefore, effective PE focuses on imparting knowledge and clarity, not dictating the final choice, upholding the patient's legal and ethical right to self-determination.

There is a growing expectation that patients will assume greater responsibility for managing their own medical conditions, which entails the acquisition of knowledge and skills for medical, behavioural, and emotional self-management (Lorig and Holman, 2003). This expectation is driven both by the necessity of managing chronic conditions like OED (Lorig and Holman, 2003) and by the legal and ethical shift toward patient autonomy (Beauchamp and Childress, 1994). The need for comprehensive PE is reinforced by a concurrent litigious trend, particularly among younger and consumer-influenced populations. The demand for greater accountability (Teixeira et al., 2023) compels healthcare providers to ensure patients are fully informed and competent (as defined by informed consent principles), thereby legally documenting that any unfavourable outcome resulting from non-adherence or refusal of treatment is a consequence of the patient's autonomous, informed decision, not clinical negligence.

According to the World Health Organization (WHO) (Guilbert, 2000), therapeutic PE is a form of education that helps patients to acquire the necessary knowledge and skills to modify their behaviours in order to enhance their health outcomes. The implication of this statement is that there is a need to enhance the health literacy competencies of individuals using PE.

Prior to the 1960s, healthcare personnel held an authoritative role, assuming full responsibility for the diagnosis, treatment, and recovery of patients (Hoving et al., 2010). The patient was perceived as being in a passive role, with limited expectations of active engagement in diagnostic and therapeutic decision-making, as well as a lack of anticipated inquiries. Towards the end of the 1960s, however, an increasing cohort of healthcare professionals, policymakers, and early patient collectives started articulating novel perspectives about patients' entitlement to receive comprehensive disclosures pertaining to their medical status. Subsequently, a gradual increase in the prioritisation of PE developed, with a specific focus on providing more individualised information (Hoving et al., 2010).

By the 1980s, PE was a standard in the training of most medical personnel. In the mid-1990s, legislation came into effect in the majority of Western countries establishing the right of patients to access comprehensive information to guide informed decision-making about diagnostic, therapeutic, and research interventions (Hoving et al., 2010). The implementation of this legislation led to the creation of a plethora of standardised informational resources pertaining to prevalent illnesses and medical procedures. However, these practices often lacked a systematic approach and instead relied on the subjective judgement of healthcare practitioners regarding their perceived significance (Hoving et al., 2010).

Today, there is a significant emphasis on providing care that is both respectful of and responsive to the unique preferences, requirements, and values of individual patients. This approach places a patient’s values at the forefront of all professional choices, thereby promoting patient-centredness (America, 2001). Consequently, there has been a transition in PE from the mere transmission of information to a more collaborative process of knowledge co-creation (Aujoulat et al., 2008). The available research indicates that patient-centred care has positive impacts on both disease outcomes and quality of life (QoL). Moreover, it plays a crucial role in reducing inequities in health care provision and health outcomes related to race, ethnicity, and socioeconomic status (Epstein et al., 2010).

4.1.2. Patient education and dentistry

A common misunderstanding in dentistry is that health education is the same as PE (Albano et al., 2019). Although both types of education involve preventive strategies, they represent different levels of prevention. Health education focuses on primary prevention, targeting the general public or at-risk individuals before disease onset (e.g., promoting cessation to prevent OPMD). In contrast, PE, or therapeutic PE, pertains to secondary and tertiary prevention, as highlighted by the WHO (Organization, 1998). As the name suggests, or therapeutic PE, is directed specifically at patients—individuals who are already affected by oral diseases—and aims to slow disease progression and prevent complications (Organization, 1998), such as periodontitis (Jönsson et al., 2009), chronic facial pain (Aggarwal et al., 2010) and temporomandibular disorders (Story et al., 2016).

Patient education differs from health education in several important ways. First, it typically involves adult patients. Second, it addresses specific learning needs, particularly for patients with low health literacy (Tam et al., 2015) who require a deeper understanding of their condition to improve treatment adherence. It also involves chronic systemic conditions, such as diabetes, for which PE should also address oral health (Kanjirath et al., 2011). Finally, PE does not rely on massive information efforts across several media platforms, though a range of teaching methods can be employed, including booklets (Al-Silwadi et al., 2015), video clips (Al-Silwadi et al., 2015), mobile applications (Li et al., 2016), and 3D animations (Cleeren et al., 2014).

Patient education can be structured into programs comprised of multiple educational sessions in conjunction with clinical visits, focusing on objectives that the patient aims to accomplish (Michelotti et al., 2012). To enhance adherence, PE may implement targeted maintenance strategies, including motivational interviews (Jönsson et al., 2009). It is also important to highlight that the timing of knowledge assessment and subsequent PE are key factors, particularly when patients have just received a diagnosis and may be overwhelmed, making it difficult for them to fully comprehend the information provided at this critical stage. Consequently, the timing of information delivery is crucial, particularly for patients with severe disease involvement, such as those with more advanced OED.

4.1.3. Why does patient education matter for individuals with OED?

Previous research has identified approximately 6,700 articles in the literature related to dental health education, primarily attributable to the significant focus placed by dentists on preventing caries and periodontal diseases in both young and adult populations. However, a noticeable shortage of research on the role of PE in oral and dental disorders is evident (Mann and Sellers, 2003, Albano et al., 2019), with only 302 articles specifically addressing this topic and an even smaller number of randomised controlled trials (Albano et al., 2019). Furthermore, research on the impact of PE in individuals with oral malignancies and OPMD is limited (Ahuja et al., 2022).

Moreover, no studies have specifically explored PE practices among individuals with OED. Hence, this study evaluated the information specific to OED, including self-care practices, educational resources, and sociodemographic and clinical characteristics that influence PE among individuals with OED in the United Kingdom (UK).

For patients with OED, regular and thorough PE is essential for achieving favourable long-term outcomes. Patients must have a thorough understanding of the chronic nature of the condition, potential progression to OSCC, clinical characteristics, risk factors, treatment options, potential complications of therapeutic and investigative procedures, and the physical and psychological burdens associated with OED (Alsoghier et al., 2023). Although healthcare practitioners play a vital role in supporting patients' oral health, they cannot guarantee favourable outcomes. Optimal health outcomes are more likely to occur when patients receive personalised support for their self-care efforts. Therefore, PE is indispensable for managing chronic conditions like OED (Peres et al., 2019). Patients with OED are responsible for practising self-care habits that can potentially delay the onset of oral diseases or mitigate their progression once chronic. These habits include conducting home examinations, recognising signs and symptoms, maintaining proper oral hygiene, avoiding risk factors, and seeking medical care when necessary.

Patients with OED may mistakenly believe that all degrees of dysplasia require surgical removal, when, in fact, mild dysplasia is often managed with careful monitoring. Similarly, patients may assume that any oral signs or symptoms are alarming and indicative of a serious condition. However, these manifestations may only indicate active OLP or oral candidiasis. Such misconceptions can significantly hinder the effective prevention and management of oral diseases in this population. Studies of conditions more strongly linked to HPV than OED have also highlighted a lack of sufficient information available to patients regarding HPV's role in mouth malignancies (Lin et al., 2015, Inglehart et al., 2016), which is in line with the findings of this study. Clinicians may also perceive that the evidence about HPV’s role in the development of OED or its high-risk subtypes is limited (Syrjänen, 2018).

Patients with OPMD and those awaiting a diagnosis of oral cancer are significantly more likely to experience poor psychological health (Tadakamadla et al., 2018), which may explain why many participants in this cohort viewed psychological support and the provision of medical information as insufficient. This observation is congruent with research conducted by Lin et al. (2015) in patients with OPMD, which revealed that individuals with higher levels of anxiety reported greater information insufficiency. Similarly, a comprehensive analysis of German research examining cancer-related informational demands, found that those with higher informational needs tended to experience higher levels of anxiety and despair (Pieper et al., 2015). The finding that higher anxiety correlates with a perception of information insufficiency is not surprising; this congruence confirms a fundamental challenge in medical communication. High psychological distress significantly impairs cognitive function, reducing a patient's capacity to absorb, comprehend, and retain complex medical details during consultations (Zabora et al., 2001). This impairment creates a perceived "information void" or "insufficiency," which in turn escalates the patient's anxiety, perpetuating a vicious cycle.

4.1.4. Indications for patient education

Patient education is often necessary in specific situations, including at discharge from the hospital or during the management of long-term illnesses (Koelling et al., 2005, Organization, 1998). Healthcare education is typically delivered by medical practitioners with specialised training, such as doctors, nurses, and educators (Lorig, 2001).

1. Before and after medical procedures

Patients who have undergone certain medical procedures are provided with discharge PE, which includes detailed instructions about medication administration, the handling of specialised equipment, identification of common side effects, and appropriate treatment measures (Koelling et al., 2005).

2. Management of chronic diseases

The leading causes of mortality worldwide (i.e., ischaemic heart disease, diabetes, stroke, lung disease, and cancer), are closely linked to unhealthy lifestyles (Heron, 2021). Therefore, healthcare professionals will often recommend lifestyle modifications to individuals with these chronic illnesses in order to help them more effectively manage their conditions, addressing concerning signs and symptoms, potential adverse events, drug-related side effects, and sustaining a superior QoL (Mazzuca, 1982, Cooper et al., 2001).

3. Navigation and preventive care

Patient education is an important tool when healthcare providers are encouraging patients to adopt preventive services (Coppola et al., 2016). The utilisation of preventive services, including screenings and vaccine administration, plays a crucial role in safeguarding patients from the onset of chronic or acute illnesses. Moreover, these services can ensure the timely detection of potential illnesses.

4.1.5. Benefits of patient education

1. Patient empowerment and enhanced decision-making

Individuals who encounter unfamiliar circumstances, particularly in relation to a health issue, are likely to experience helplessness and confusion. This emotional and cognitive distress stems from a sudden loss of control and the inability to predict or manage future outcomes, which is a common psychological reaction to a serious, uncertain diagnosis (Li et al., 2024). PE plays a crucial role in enhancing patients' comprehension of their medical condition, the various treatment options at their disposal, and the associated implications, including potential adverse effects (Yeh et al., 2018). When clinicians provide comprehensive information about a disease and available choices, patients experience increased confidence during the decision-making process. Rather than unquestioningly submitting to their physician's instructions without comprehending the underlying processes or anticipating forthcoming developments, individuals feel a sense of agency about their circumstances, to whatever extent is possible (Segal, 1998).

The observation that 50 years ago, patients were expected to submit passively to medical authority contrasts sharply with the current ethical mandate for autonomy (Beauchamp and Childress, 1994). However, it is important to consider whether current generations, such as Gen Z, may revert to a similar state of passivity. The reliance on vast, often poor-quality online information can lead to cognitive overload and information paralysis (Eppler and Mengis, 2004). In the face of a complex diagnosis like OED, this exhaustion may cause patients to delegate trust and submit to the clinician's instructions, resulting in a de facto loss of agency driven by information overload rather than information scarcity. This underscores why effective PE must not only provide information but also teach critical health literacy skills to ensure the increased agency is meaningful and not just superficial.

2. Better health outcomes

In addition to acquiring greater knowledge, individuals who receive PE have more faith in their healthcare providers and treatment courses, exhibiting more cooperation and positive attitudes (Paterick et al., 2017). Consequently, these individuals are more inclined to adhere to physician directives and prescribed drug regimens, ultimately achieving or sustaining a more favourable state of health over an extended period (Martin and Wexler, 2023).

3. Enhancing the quality of life of individuals diagnosed with chronic diseases

Health education plays a key role in the well-being of individuals affected by chronic medical problems, including diabetes, hypertension, and other life-long diseases (Gallefoss et al., 1999, Ellis et al., 2004, Pandit et al., 2009). The management of chronic illnesses must extend beyond the confines of medical institutions due to the all-encompassing nature of these illnesses, often necessitating substantial alterations to lifestyles. The provision of PE has been shown to enhance self-management capabilities and to facilitate the maintenance of both the physical and mental well-being of patients (Cooper et al., 2001). Mental health disorders, including depression and anxiety, are crucial determinants in the process of recovery and the general QoL of these patients. Individuals with chronic illnesses are particularly vulnerable to experiencing these mental health issues.

4. Enhancing healthcare experiences and satisfaction

Healthcare education has been found to contribute to increased levels of patient satisfaction (Schauffler et al., 1996). It is not surprising that patients who are well-informed tend to experience increased reassurance and optimism regarding their future, as well as to possess a greater ability to participate in crucial decision-making processes. Rather than experiencing feelings of confusion and helplessness during their healthcare journey, individuals assume a more active role and engage in every aspect of the process (Yeh et al., 2018).

5. Reducing expenditures in the healthcare system

Patient noncompliance with treatment regimens can result in suboptimal healing or the exacerbation of a condition, necessitating hospital readmission (Rice et al., 2018). This outcome leads to an escalation of expenditures and imposes an additional strain on the healthcare system through a reduction in its overall capability. Moreover, inadequate treatment of certain health disorders can give rise to secondary diseases, thereby further exacerbating the overall situation (Martin and Wexler, 2023).

6. Reduced rates of hospital readmissions

When patients are able to more effectively manage their self-care, there is a decrease in the likelihood of experiencing difficulties that require unscheduled hospital readmissions or additional visits to healthcare providers (Strömberg, 2005).

4.1.6. Tools and resources for patient education

1. One-on-one meetings

The most efficient method of delivering PE is known to be one-on-one or small-group instruction (Schrieber and Colley, 2004). This reliance on individualised encounters aligns perfectly with the principles of a patient-centred approach. This approach not only leads to the development of fundamental interpersonal bonds, but it also enables patients to ask pertinent questions and allows healthcare practitioners to engage in repeated instruction until comprehension is achieved. During these individualised encounters, the process of explanation becomes significantly more manageable, hence mitigating the risk of patients being misinformed or uninformed. In instances where in-person meetings are difficult or unfeasible, virtual meetings can be conducted using modern technologies or a mutually accessible communication platform (van der Kruk et al., 2022).

2. Group sessions

Implementation of group-based educational programmes can also enhance patient understanding and compliance with medical therapy (Nielsen et al., 2010).

3. Learning materials

The use of conventional educational resources plays a crucial role in health education because it enables patients to review vital information in the comfort of their own homes, where they can engage in cognitive processing and document any inquiries (Schrieber and Colley, 2004, Wilson et al., 2010, Abed et al., 2014, Kelly et al., 2022). These types of educational resources include:

- Written: brochures, booklets, and leaflets

- Visual: posters, graphs, PowerPoint presentations, and concise bullet-pointed information
- Audio: radio, podcasts
- Audiovisual: video clips

4. Patient portals

Patient portals facilitate a patient's ability to conveniently access health information via the Internet, including medical records and examination outcomes, thereby minimising the need to directly communicate with healthcare providers or visit a medical establishment (Kruse et al., 2015).

4.1.7. Patient education guidelines for healthcare professionals

The Health Care Education Association has produced the Patient Education Practise Guidelines for Health Care Professionals in order to provide PE-related guidelines to healthcare professionals (Bastable, 2017). The guidelines are derived from the four components of the PE process; namely, assessment, planning, implementation, and evaluation (APIE) (Bastable, 2017, Cutilli, 2020).

A: Assessment

By conducting interviews with the patient and their immediate family members, several potential questions or themes can be explored, including:

- Socioeconomic and cultural information
- Fears or concerns
- Knowledge of current health issues and relevant medical information (e.g., treatment strategies)

- What is the individual's favourite modality of learning (e.g., reading, listening, engaging in practical activities)?
- Potential obstacles to their learning (e.g., constraints on available time or physical disabilities)

P: Planning

Healthcare providers can collaborate with patients to establish shared educational objectives that account for all facets of the assessment. The goals are explicitly articulated, action-focused, capable of being quantified, and realistically attainable.

Create a teaching plan:

- The primary emphasis should be placed on addressing the needs and priorities of patients, as well as understanding their behaviours. Additionally, it is crucial to identify and overcome any obstacles that may hinder the learning process.
- Employing evidence-based teaching tactics, such as utilising easily comprehensible language, employing multimodal and multisensory approaches, ensuring frequent engagement with the material, and personalising the learning experience, can be highly effective in educational settings.
- Identifying various educational tools that can be utilised to effectively attain specific learning goals. These resources may include decision aids, interactive games, movies, written information, phone applications, and kiosks.

I: Implementation

Implement the plan:

- Prioritise the patient's well-being by upholding their self-esteem. This can be achieved by attentively observing and interpreting the patient's verbal and nonverbal cues, thereby demonstrating active listening skills.
- Utilise individualised patient-appropriate language, concentrate on conveying a clear message, and conduct a thorough examination of essential aspects
- Use instructional resources with patients in an efficient manner (i.e., explain how to use them, emphasise important information, and follow up on patient inquiries)

Adapt instructional methods in accordance with patient feedback and educational requirements:

- Promote and address inquiries from patients
- Elucidate communication; use alternative vocabulary or analogies

E: Evaluation

There are multiple methodologies for assessing whether patients are obtaining advantages from specific educational materials:

- Asking follow-up questions
- Administering a survey evaluating educational materials
- Assessing any changes in patient outcomes

4.1.8. Aims and objectives

This chapter aimed to (1) assess the current levels of IN in adults with OED, (2) explore the clinical factors associated with IN levels, and (3) identify the preferred methods of PE within this population before the development and administration of educational tools.

4.2. Materials and methods

4.2.1. Study design and participant recruitment

A prospective observational design with quantitative analysis based on questionnaires as part of the PE in OED (EDUCAT-ED) project was employed. The EDUCAT-ED project aims to identify the IN of individuals with OED and create tailored educational tools based on their needs and preferences. This study was conducted between March 2023 and December 2024 at the Oral Medicine Unit of the Royal National ENT and Eastman Dental Hospitals at the UCLH. Although a larger sample size is necessary to ensure representativeness and a meaningful subgroup analysis, a previous study that assessed IN among patients with oral cavity cancer indicated that a sample size of 92 was required to achieve a power of 0.80 (Chen et al., 2009).

The present study included a convenience sample of 102 adult volunteers (aged >18 years), diagnosed with OED based on the 2017 WHO diagnostic criteria. Eligible participants included UK residents, proficient in spoken and written English, who could provide informed consent and were without concurrent malignancies or undergoing radiotherapy/chemotherapy to the head, neck, or other regions. All participants confirmed their OED diagnosis with a biopsy procedure conducted at the study site or at external facilities. Consequently, all data were collected during the follow-up phase of care—no patients were assessed before biopsy or after discharge. After the study was explained, eligible individuals who agreed to participate were provided with a patient information sheet and asked to sign the consent form (Appendix 2). The participants provided with a printed ODIN-Q (Appendix 3) to complete after their clinical visit or at home and send it back via post.

4.2.2. Measurements

The ODIN-Q consists of three sections (Table 4-1). Section 1 collects sociodemographic details and information on smoking and alcohol intake. Section 2 comprises 33 items that evaluate the adequacy of information provided on various aspects of OED using a 4-point scale (1 = none, 2 = not enough, 3 = enough, 4 = too much), resulting in a total score ranging from 33 to 132. Section 3 examines patients' preferred methods for receiving IN.

Table 4-1 Oral epithelial dysplasia informational needs questionnaire (ODIN-Q) sections.

Section	Components
Section 1	• Seven questions about sociodemographic information, including age, race, ethnic background, level of education, employment status, and smoking and alcohol intake.
Section 2	• Thirty-three questions to assess the knowledge level about the disease, including its diagnostic procedures, therapies, physical and psychosocial impact, and the availability of medical information related to oral epithelial dysplasia. • Scoring: Questions were assessed using a 4-point scale (too much = 4, enough = 3, not enough = 2, none = 1) and making a total score between 132 and 33, interpreted as the following:

	107–132: Too much information received *(case: highly met IN)* 81–106: Enough information received *(case: met IN)* 56–80: Not enough information received *(case: unmet IN)* 33–55: No information received *(case: highly unmet IN)*
Section 3	• One question with multiple options investigating the preferred approach to obtaining information about oral epithelial dysplasia. The options included individual meetings, printed materials, audiovisual resources, and group information sessions.

IN: information needs

4.2.3. Ethical considerations and study registration

The study procedures were carefully developed with strict adherence to the ethical principles of the Declaration of Helsinki for medical research involving human participants. Following registration with the University College London Hospitals/University College London (UCLH/UCL) Joint Research Office (JRO), this study was assigned a JRO reference number/EDGE number 153912; IRAS project ID 318039). This study received a favourable opinion on 16 January 2023, from the National Health Service (NHS) Research Ethics Committees (REC) (specifically, the London – Surrey Borders Research Ethics Committee, reference 22/PR/1743) and ethical approval was obtained on 26 January 2023 from the Health Research Authority (HRA) and Health and Care Research Wales (HCRW) (Appendix 1).

4.2.4. Analysis of data and representation

Microsoft Excel 2022 (version 2410) represented sociodemographic characteristics, clinical variables, and ODIN-Q scores. Analyses were performed using SPSS version 27 (IBM manufacturer). A dataset of 102 patients was assessed using descriptive statistics to summarise demographic and clinical variables, and further assessments were done using logistic regression and Spearman correlation analyses to explore the relationships between these factors and IN. The dependent variable was whether the patient’s IN was met, and the independent variables included demographic and clinical characteristics (Table 4-2). The threshold for statistical significance was set at $p < 0.05$.

The statistical methods were carefully selected based on the nature of the data and the study's objectives:

- **Logistic regression analysis** was necessary because the dependent variable (whether the patient's IN was met) was dichotomous (a binary outcome: met or not met). This analysis allowed to determine the odds that continuous or categorical independent variables (such as age or OED grade) predict the likelihood of this binary outcome.
- **Spearman correlation analysis** was selected to explore the strength and direction of the monotonic relationship (correlation) between variables, such as ODIN-Q scores and anxiety levels. This non-parametric method was appropriate because it does not assume a normal distribution in the data, making it robust for variables that are ordinal or non-normally distributed, such as clinical severity scores.

Table 4-2 The demographic and clinical characteristics of the study participants (n=102).

Variable	Category	Number (%)
Sex	Females	63 (61%)
	Males	39 (38%)
Age, years	20 – 29	1 (0.98%)
	30 – 39	2 (1.69%)
	40 – 49	6 (5.8%)
	50 – 59	18 (17.64%)
	60 – 69	35 (34.31%)
	70 – 79	25 (24.5%)
	80 – 89	14 (13.72%)
	90 – 99	1 (0.98%)
Ethnicity	White (British)	50 (49%)
	White (other)	20 (19.6%)
	Asian or Asian British	31 (30.39%)
	Black	1 (0.98%)
Education	College or higher educational degree	59 (57.84%)
	High school diploma or less	41 (40.19%)
	Not reported	2 (1.96%)
Employment	Retired	59 (57.84%)
	Employed (full-time)	16 (15.68%)
	Employed (part-time)	7 (6.86%)
	Self-employed	15 (14.7%)
	Unemployed	3 (2.9%)
	Not reported	2 (1.96%)
Smoking status	Current	14 (13.72%)
	Past (cigarettes)	44 (43.13%)
	Past (smokeless tobacco)	3 (2.94%)
	Never	41 (40.19%)
Alcohol consumption	Current	40 (39.21%)
	Past	21 (20.58%)
	Never	41 (40.19%)
Dysplasia Type	Mild	74 (43.27%)
	Moderate	55 (32.16%)
	Severe	35 (20.46%)
Site	Tongue	51 (42.85%)
	Buccal mucosa	29 (24.36%)
	Gingiva	21 (17.64%)
	Floor of the mouth	8 (6.72%)
	Hard palate	5 (4.2%)
	Lips	3 (2.52%)
	Soft palate	2 (0.84%)
Associated oral disease	Oral lichen planus	86 (63.7%)
	Oral leukoplakia	18 (13.33%)
	HPV-associated	4 (2.96%)

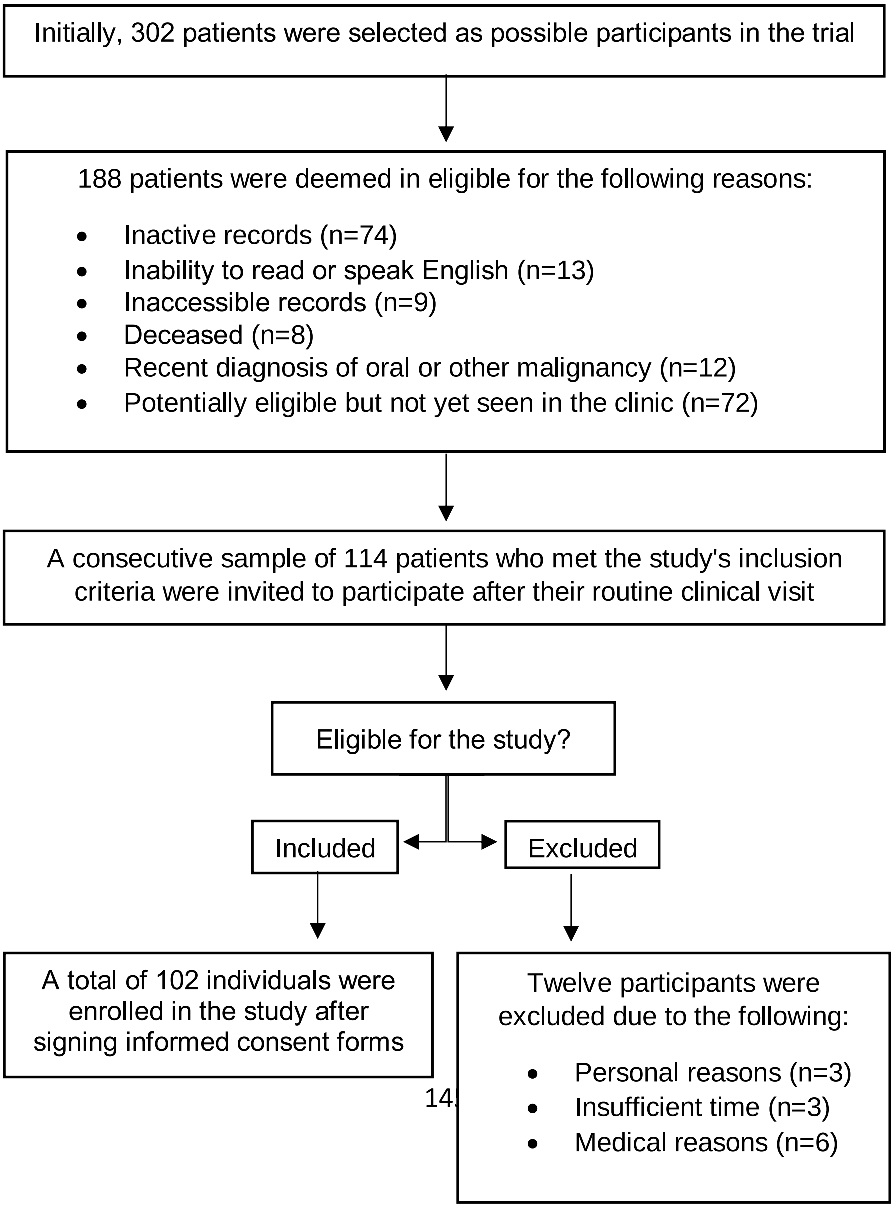
Oral submucous fibrosis	3 (2.22%)
Oral candidiasis	5 (3.7%)
History of OSCC	19 (14.07%)

HPV: Human papilloma virus; OSCC: oral squamous cell carcinoma

4.3. Results

After a comprehensive investigation of the hospital database, 302 patients were identified as potentially eligible for participation. The step-by-step process from identification to final recruitment is shown in Figure 4-1. The study enrolled 102 participants, and all provided consent by signing a consent form after their scheduled clinical visit.

Figure 4-1 Procedures undertaken to identify and recruit potentially eligible patients.



4.3.1. Participants' demographic and clinical characteristics

Table 4-2 summarises the demographic and clinical characteristics of the study participants (Appendix 4). The sample was predominantly female (63, 61%), with most participants falling within older age groups; notably, 34.31% were aged 60–69 years and 24.5% were aged 70–79 years. Regarding ethnicity, 49% were White (British), 19.6% White (other), 30.39% Asian or Asian British, and 0.98% Black. Majority (57.84%) of the study participants had a college or higher education degree. Over half of the participants (57.84%) were retired.

Lifestyle factors revealed that 13.72% were current smokers, 43.13% reported past cigarette use, 2.94% used smokeless tobacco in the past, and 40.19% never smoked; similarly, 39.21% reported alcohol consumption as a current habit, 20.58% as past, and 40.19% had never taken alcohol. Analysis of the clinical data and histopathological reports of all the participants revealed 171 biopsies indicating OED. The number of biopsies per participant ranged from one to nine, with an average of 1.69 biopsies per individual. Dysplasia was most often mild (43.27%), with moderate and severe cases accounting for 32.16% and 20.46%, respectively. The total number of clinical sites was 119, as some participants presented with lesions at multiple sites. The most frequent lesion site was the tongue (42.85%), followed by the buccal mucosa (24.36%) and gingiva (17.64%), with other sites less commonly involved. Additionally, 63.7% of patients had oral lichen planus, 13.33% had oral leukoplakia, 2.96% had HPV-associated lesions, 2.22% had oral submucous fibrosis, 3.7% had oral candidiasis, and 14.07% had a history of OSCC.

4.3.2. Levels of disease-specific IN

According to the predetermined values for the overall ODIN-Q scores indicated in Table 4-1, approximately two-thirds (n=66, 64%) of the participants stated they were satisfied with the amount of IN received. The remaining 36 respondents (35%) stated that their IN was not fulfilled, with 32 of these participants receiving insufficient IN and four respondents receiving no IN on most items. The overall participants' responses to the ODIN-Q are summarised in Table 4-3a.

Table 4-3 (a) Participants' responses to the ODIN-Q (n=102).

ODIN-Q item	**Amount of information received**				
	Too much	**Enough**	**Not enough**	**None**	**N/A**
1. What oral epithelial dysplasia (OED) is?	0 (0%)	86 (84.31%)	8 (7.84%)	8 (7.84%)	0 (0%)
2. How common is it?	4 (3.92%)	56 (54.9%)	23 (22.54%)	19 (18.62%)	0 (0%)
3. What are the risk factors for developing it?	0 (0%)	84 (82.35%)	13 (12.74%)	5 (4.9%)	0 (0%)
4. How it looks in the mouth or lips?	4 (3.92%)	72 (70.58%)	18 (17.64%)	8 (7.84%)	0 (0%)
5. Weather it is contagious or not?	4 (3.92%)	78 (76.47%)	6 (5.88%)	14 (13.72%)	0 (0%)
6. About the role of human papilloma virus.	2 (1.96%)	34 (33.33%)	28 (27.45%)	38 (37.25%)	0 (0%)
7. About the disease grades and risk of developing mouth cancer.	6 (5.88%)	70 (68.62%)	21 (20.58%)	5 (4.9%)	0 (0%)
8. What will happen if I continue to smoke or drink alcohol?	7 (6.86%)	59 (57.84%)	14 (13.72%)	8 (7.84%)	14 (13.72%)
9. What is a safe level of alcohol to drink?	0 (0%)	56 (54.9%)	14 (13.72%)	18 (17.64%)	14 (13.72%)

10. What is likely to happen to OED in the future?	4 (3.92%)	68 (66.66%)	20 (19.6%)	10 (9.8%)	0 (0%)
11. About the screening and early detection.	2 (1.96%)	96 (94.11%)	2 (1.96%)	2 (1.96%)	0 (0%)
12. What are the benefits, risks, how each test works, and the meaning of test results?	0 (0%)	80 (78.43%)	17 (16.66%)	5 (4.9%)	0 (0%)
13. What will happen if it is not treated?	4 (3.92%)	84 (82.35%)	8 (7.84%)	6 (5.88%)	0 (0%)
14. About treatment options, benefits, risks, and how each treatment works?	2 (1.96%)	76 (74.5%)	12 (11.76%)	12 (11.76%)	0 (0%)
15. How the disease/treatment may affect the quality of life?	0 (0%)	58 (56.86%)	32 (31.37%)	12 (11.76%)	0 (0%)
16. About self-management at home.	0 (0%)	72 (70.58%)	23 (22.54%)	7 (6.86%)	0 (0%)
17. About complementary and alternative medicine (e.g. herbal medicine).	0 (0%)	18 (17.64%)	14 (13.72%)	70 (68.62%)	0 (0%)
18. What are the chances of a cure.	0 (0%)	64 (62.74%)	26 (25.49%)	12 (11.76%)	0 (0%)
19. How frequent and severe are the symptoms (e.g. ulceration, swelling, or bleeding)?	2 (1.96%)	76 (74.5%)	13 (12.74%)	11 (10.78%)	0 (0%)
20. About chances of spreading to adjacent or distant body part?	2 (1.96%)	42 (41.17%)	26 (25.49%)	32 (31.37%)	0 (0%)
21. About the effects of the disease/treatment on daily physical activities (e.g. eating, speaking, or maintenance of oral hygiene).	0 (0%)	72 (70.58%)	20 (19.6%)	10 (9.8%)	0 (0%)
22. About the diet and nutrition.	0 (0%)	54 (52.94%)	32 (31.37%)	16 (15.68%)	0 (0%)
23. About the fear of progression to cancer.	0 (0%)	78 (76.47%)	15 (14.7%)	9 (8.82%)	0 (0%)

24. How to cope with the possible effects of the disease/treatment?	0 (0%)	64 (62.74%)	26 (25.49%)	12 (11.76%)	0 (0%)
25. How the disease/treatment may affect social life (e.g. close relationships, family, and friends)?	0 (0%)	40 (39.21%)	34 (33.33%)	28 (27.45%)	0 (0%)
26. About the experience of your doctor and other healthcare staff.	0 (0%)	94 (92.15%)	8 (7.84%)	0 (0%)	0 (0%)
27. About seeking another professional opinion.	0 (0%)	42 (41.17%)	23 (22.54%)	37 (36.27%)	0 (0%)
28. How to obtain physical support and advice (e.g. who to contact if warning signs appear)?	3 (2.94%)	73 (71.56%)	18 (17.64%)	8 (7.84%)	0 (0%)
29. How to obtain psychological support or advice?	0 (0%)	30 (29.41%)	32 (31.37%)	40 (39.21%)	0 (0%)
30. About community and/patient support groups.	2 (1.96%)	16 (15.68%)	16 (15.68%)	68 (66.66%)	0 (0%)
31. About health promotion (e.g. promoting one's health literacy).	0 (0%)	36 (35.29%)	19 (18.62%)	47 (46.07%)	0 (0%)
32. About the lifestyle adjustment (e.g. tobacco and alcohol cessation and safe sex).	2 (1.96%)	52 (50.98%)	14 (13.72%)	20 (19.6%)	14 (13.72%)
33. About the research and recruitment for clinical trials.	0 (0%)	52 (50.98%)	22 (21.56%)	28 (27.45%)	0 (0%)

N/A: not applicable

In addition, the overall analysis of the items of ODIN-Q revealed a low information sufficiency by a mean and median of 2.43 (±0.38) and 2.6 out of 4, respectively. Considering the mean, we adopted the following classification: items with mean scores higher than 2.5 are considered 'often met', scores between 2.4 and 2.5 are considered 'somewhat met', and scores below 2.4 are considered 'unmet' (Table 4-3b and Figure 4-2).

Table 4-3 (b) The mean scores and level of information needs for the ODIN-Q items.

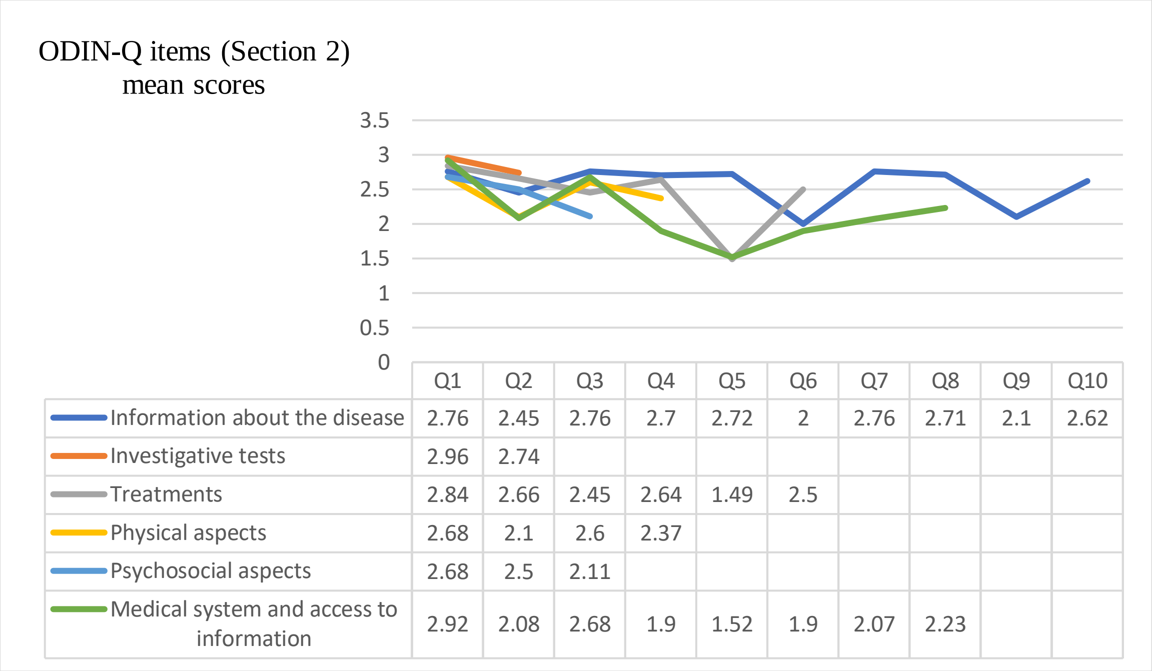
ODIN-Q item	**Mean score**	**Information needs***		
		Often met	**Somewhat met**	**Unmet**
Information about the disease				
1. What oral epithelial dysplasia (OED) is?	2.76	✓		
2. How common is it?	2.45		✓	
3. What are the risk factors for developing it?	2.76	✓		
4. How it looks in the mouth or lips?	2.7	✓		
5. Weather it is contagious or not?	2.72	✓		
6. About the role of human papillomavirus.	2			✓
7. About the disease grades and risk of developing mouth cancer.	2.76	✓		
8. What will happen if I continue to smoke or drink alcohol?	2.71	✓		
9. What is a safe level of alcohol to drink?	2.1			✓
10. What is likely to happen to OED in the future?	2.62	✓		

Information about investigative tests				
11. About the screening and early detection.	2.96	✓		
12. What are the benefits, risks, how each test works, and the meaning of test results?	2.74	✓		
Information about treatment				
13. What will happen if it is not treated?	2.84	✓		
14. About treatment options, benefits, risks, and how each treatment works?	2.66	✓		
15. How the disease/treatment may affect the quality of life?	2.45		✓	
16. About self-management at home.	2.64	✓		
17. About complementary and alternative medicine (e.g. herbal medicine).	1.49			✓
18. What are the chances of a cure.	2.5		✓	
Physical aspects				
19. How frequent and severe are the symptoms (e.g. ulceration, swelling, or bleeding)?	2.68	✓		
20. About chances of spreading to adjacent or distant body part?	2.1			✓
21. About the effects of the disease/treatment on daily physical activities (e.g. eating, speaking, or maintenance of oral hygiene).	2.6	✓		
22. About the diet and nutrition.	2.37			✓
Psychosocial aspects				
23. About the fear of progression to cancer.	2.68	✓		
24. How to cope with the possible effects of the disease/treatment?	2.5		✓	

25. How the disease/treatment may affect social life (e.g. close relationships, family, and friends)?	2.11			✓
Medical system and access to information				
26. About the experience of your doctor and other healthcare staff.	2.92	✓		
27. About seeking another professional opinion.	2.08			✓
28. How to obtain physical support and advice (e.g. who to contact if warning signs appear)?	2.68	✓		
29. How to obtain psychological support or advice?	1.9			✓
30. About community and/patient support groups.	1.52			✓
31. About health promotion (e.g. promoting one's health literacy).	1.9			✓
32. About the lifestyle adjustment (e.g. tobacco and alcohol cessation and safe sex).	2.07			✓
33. About the research and recruitment for clinical trials.	2.23			✓
Overall mean score	2.43			

**Information needs: often met: mean scores higher than 2.5, somewhat met: mean scores between 2.4 and 2.5, unmet: mean scores below 2.4.*

Figure 4-2 Line graph of ODIN-Q Section 2 mean scores for each item (n=33).



	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Information about the disease	2.76	2.45	2.76	2.7	2.72	2	2.76	2.71	2.1	2.62
Investigative tests	2.96	2.74								
Treatments	2.84	2.66	2.45	2.64	1.49	2.5				
Physical aspects	2.68	2.1	2.6	2.37						
Psychosocial aspects	2.68	2.5	2.11							
Medical system and access to information	2.92	2.08	2.68	1.9	1.52	1.9	2.07	2.23		

In consideration of the average scores for each item of the ODIN-Q as presented in Table 4-3b and Figure 4-2, the items were categorised as follows:

- Seventeen items (51.51%) were often met.
- Four items (12.12%) were somewhat met.
- Twelve items (36.36%) were unmet

Items that were often met

A significant proportion of participants received enough information on the following items:

- Definition of OED (Q1)
- Risk factors for developing OED (Q3)
- How OED manifests in the oral cavity (Q4)
- The contagiousness of OED (Q5)

- Disease grading and the risk of developing mouth cancer (Q7)
- Consequences of continuing to smoke or drink alcohol (Q8)
- Prognosis of OED (Q10)
- Tools for screening and early identification (Q11)
- Advantages, disadvantages, functionality, and interpretation of results of various tests (Q12 and Q14)
- Consequences of untreated OED (Q13)
- Self-management strategies at home (Q16)
- Frequency and severity of symptoms, such as ulceration, swelling, or bleeding (Q19)
- Adverse effects of OED on quality of life (Q21)
- Fear about becoming cancerous (Q23)
- Medical providers' experience and knowledge (Q26)
- Obtaining physical help and guidance, including who to call if warning symptoms should appear (Q28).

Items that were somewhat met

- Knowledge about the prevalence of OED (Q2)
- Awareness of how OED or its management might affect life quality (Q15)
- Chances of a cure (Q18)
- Strategies to manage the potential consequences of the condition or treatment (Q24)

Items that were unmet

- Information about the role of HPV (Q6)
- Understanding safe levels of alcohol consumption (Q9)

- Complementary and alternative medicine strategies, such as herbal remedies (Q17)
- Information about the risk of the disease spreading to adjacent or distant body parts (Q20)
- Nutritional and dietary advice (Q22)
- Information on the potential impact of the condition or its treatment on their social life (Q25)
- Guidance on how to seek a second professional opinion (Q27)
- How to obtain psychological support or advice (Q29)
- Information about community and/or patient support groups (Q30)
- Information about health promotion, such as improving health literacy (Q31)
- Habit adjustments, including tobacco and alcohol cessation, and safe sex practices (Q32)
- Details about studies and clinical trial recruiting (Q33)

4.3.3. Clinical variables influencing the IN

Logistic regression analysis revealed no statistically significant predictors. Backward elimination was used to assess their contribution to predicting the outcome. The complete model initially included all clinical variables. However, there was a trend for gender to be associated with IN, with women showing higher odds of having sufficient IN (odds ratio=4.459, 95% confidence interval: 0.800–24.852, P=0.088; Table 4-4). Spearman’s correlation analysis revealed a weak relationship between the severity of dysplasia and IN. For mild-to-moderate dysplasia, there was a weak negative correlation (r=-0.333, p<0.05), indicating that as dysplasia severity increases from mild to moderate, IN may decrease slightly. In contrast, for moderate-to-severe dysplasia, a weak positive correlation was found (r=0.327, p<0.05), indicating that as dysplasia severity increases from moderate to severe, IN tends to increase slightly. Both correlations were statistically significant (p<0.05).

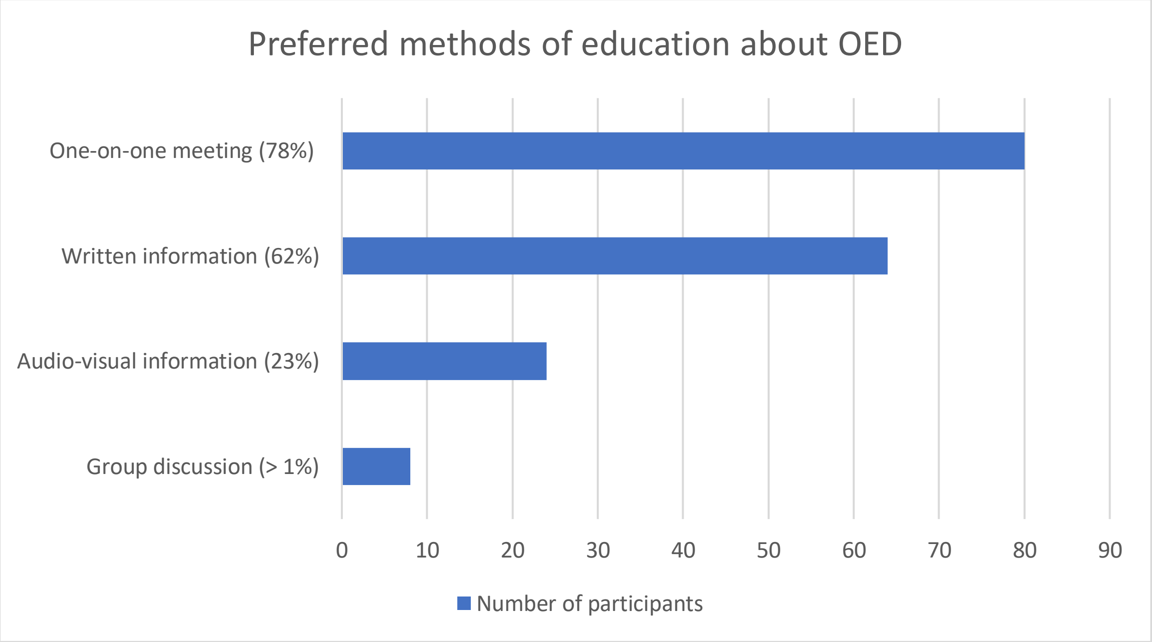
Table 4-4 Full logistic regression model results.

Variable	**Odds ratio (95% CI)**	**p-value**
Age	1.009 (0.952 – 1.070)	0.760
Smoking Status	0.420 (0.075 – 2.357)	0.325
Alcoholic Status	2.727 (0.553 – 13.453)	0.218
Gender of the participant	4.459 (0.800 – 24.852)	0.088
Mild dysplasia	0.715 (0.126 – 4.065)	0.705
Moderate dysplasia	2.225 (0.479 – 10.344)	0.308
Severe dysplasia	0.756 (0.141 – 4.059)	0.744
Ethnicity	0.608 (0.354 – 1.045)	0.702
Education level	0.814 (0.544 – 1.218)	0.318
Employment status	1.029 (0.541 – 1.958)	0.930
Constant	3.292 (N/A)	0.672

4.3.4. Preferred educational methods for information delivery

Participants were allowed to select one or more preferred methods of receiving OED-specific education, including one-on-one meetings (n=80, 78%), written information (printed and online materials) (n=64, 62%), audiovisual resources (videos and podcasts) (n=24, 23%), and group discussions (n=8, <1%) (Figure 4-3). Amongst those who preferred one-on-one meetings, most preferred receiving information directly from the OED specialists (n=80, 100%). A preference for consultations with general dental practitioners and auxiliary healthcare professionals (e.g., dental assistants) followed this preference (n=17, 21.25%).

Figure 4-3 Participants' preferences for various methods of information delivery about OED.



4.4. Discussion

In this study, two-thirds of the participants reported meeting their IN, and one-third had unmet IN. In addition, the overall analysis of the items of ODIN-Q revealed a low information sufficiency by a mean and median of 2.43 and 2.6 out of 4, respectively. This low mean score appears to contradict the finding that approximately two-thirds of the participants reported being satisfied with the amount of information received. This discrepancy is common in patient-reported outcomes; the high satisfaction rate likely reflects the patient's general positive relationship with their healthcare team the "halo effect" (Cleary and Edgman-Levitan, 1997), while the low mean score from the multi-item ODIN-Q more accurately reveals specific, unmet technical and psychological informational needs. The 2.43 mean, which we classified as "somewhat met," confirms a crucial gap in detailed knowledge transfer despite high overall contentment.

The current analysis indicates that topics concerning the nature of the disease, investigations, and treatments were well addressed. A possible explanation for this finding is that patients have an established diagnosis in the past and have undergone investigation and therapy; hence, they have adequate IN levels. Other studies have reported that patients with oral precancerous conditions (Lin et al., 2015), OSCC (Chen et al., 2009), and other cancer types (Mesters et al., 2001) had high unmet IN related to disease and treatment, especially at the time of diagnosis and at the beginning of therapy. One possible reason for the discrepancy between these findings and ours may be the timing of the assessment. Our study primarily involved patients in the follow-up phase after receiving an established diagnosis and undergoing investigations and treatment. Thus, their IN may have been addressed during past clinical consultations. In contrast, studies that assessed IN during the initial diagnostic or early treatment phases likely captured higher levels of unmet needs [13, 14]. Differences in study design, patient populations, and the instruments used to measure IN may also contribute to the observed variations. However, these studies had a longitudinal design and reported that the need for disease-specific IN declined over time after treatment (Chen et al., 2009, Mesters et al., 2001).

The findings of this study showed that various topics on IN were somewhat or insufficiently met, including risk factors and lifestyle adjustment (the role of HPV, safe levels of alcohol, smoking cessation, safe sex, diet, and nutrition), clinical characteristics (prevalence, spread to other parts, chances of cure, and alternative medicine), impacts (psychosocial and physical), seeking support (second opinion, psychological, community), and research and clinical trials. Studies on conditions more strongly linked to HPV than to OED have also highlighted a lack of sufficient IN available to patients regarding the role of HPV in mouth malignancies [15, 17]. The present finding indicates a high proportion of participants who exhibited insufficient IN regarding safe levels of alcohol consumption, which can be explained by the fact that 40% of the patients did not drink alcohol. Thus, they may not be aware of the safe or recommended levels for those affected by OED. In addition, the participants in this study reported unmet IN regarding lifestyle adjustments (smoking, alcohol cessation, and safe sex). Previous cancer research has confirmed that patients express the need for individualised and practical information on how lifestyle modifications, including reducing alcohol consumption, quitting smoking, having safe sex, and making dietary changes, could improve their outcomes (Anand et al., 2008). Participants in a previous study frequently sought information to support behavioural changes, such as guidance on diet and nutrition (Rask et al., 2017). However, this requirement was not met in the current study.

This study showed that participants' IN on the prevalence of OED were somewhat met. The rarity of this disease may explain these findings. In a large-scale study that surveyed over 1,000 patients with cancer in the UK, it was found that many participants reported unmet IN, specifically requiring more context regarding how common or rare their cancer type was (Jenkins et al., 2001). Our findings also indicated that IN regarding the chances of OED cure were somewhat met. This may be because the prognosis and clinical behaviour of OED differ based on the severity and associated oral disease (Mehanna et al., 2009). For example, mild dysplasia can regress without intervention or progress to a greater degree. Therefore, clinicians should demonstrate more educational efforts to their patients regarding all clinical possibilities and the chances of an OED cure in the future. This finding is consistent with a systematic review summarising 23 years of research on IN in patients with cancer (Rutten et al., 2005), which underscores the fact that patients frequently feel that they do not receive sufficient IN about the broader context of their disease, such as prevalence and prognosis, contributing to confusion and anxiety. Our findings also showed that participants had insufficient IN on whether OED could spread to adjacent or distant body parts. This finding agrees with that of previous cancer studies, where many participants reported the need for more in-depth information about the likelihood and nature of cancer spread [20, 21].

The findings of this study revealed unmet IN regarding the psychosocial aspects of OED. Evidence supports that unmet IN can result in psychological distress, such as depression and anxiety, disrupting cognitive processes and reducing adherence to health guidelines amongst patients with cancer (Mesters et al., 2001) and oral precancerous lesions (Lin et al., 2015). This association between unmet IN and psychological distress may play a significant role in the findings of previous research that identified high levels of psychological disorders in individuals with OPMD (Tadakamadla et al., 2017) and OED (Alsoghier et al., 2021) and those at an elevated risk of developing OSCC (Graner et al., 2016). However, these results should not be interpreted to mean that met IN decrease distress associated with cancerous or potentially cancerous conditions. Since the current study did not measure patients' actual knowledge, it is possible that highly distressed patients are informed but continue to express a desire for more information.

The present analysis showed that the level of IN on complementary and alternative medicines was insufficient. However, in a large European sample of over 900 cancer patients, approximately 35.9% used some form of complementary medicine. Yet, many felt that they lacked reliable information from their oncology team and expressed confusion about how to safely combine it with standard treatments and where to find reputable sources of guidance (Molassiotis et al., 2005).

In the present study, a positive relationship between gender and met IN was observed, with females having higher odds of sufficient IN than males. However, it is important to note that this association was not statistically significant. This trend aligns with previous research suggesting that women are generally more proactive in seeking health information, often using multiple sources such as healthcare providers, online resources, and family or friends (Brodie et al., 2000). The current analysis also revealed a weak relationship between the degree of dysplasia and IN. Specifically, weak negative and weak positive correlations were observed for mild-to-moderate and moderate-to-severe dysplasia, respectively. These results are different from those of previous cancer research, showing that patients in the early stages of the disease experience higher IN than those with advanced disease (Mesters et al., 2001). Similar studies have identified significant correlations with other factors, including younger age (Neumann et al., 2011), varying educational levels (Chen et al., 2009, Hsieh et al., 2018), ethnic background, and unemployment status (Hsieh et al., 2018). Other studies have noted an association between sufficient IN and current (Lin et al., 2015) and previous (Chen et al., 2009) alcohol consumption. Correlations between clinical symptoms, no history of cancer (Lin et al., 2015), oral conditions, and diagnostic time (Chen et al., 2009) have also been noted.

In this study, 78% of the participants preferred one-on-one meetings as their primary mode of receiving IN, especially from OED specialists, with 62% preferring printed materials and 23% preferring AV resources. A systematic review of patients with cancer reinforces this observation, revealing that healthcare professionals are consistently identified as the primary source of information, followed by printed informational materials (Rutten et al., 2005). This strong preference for traditional methods (one-on-one and written materials) and the significantly low demand for audiovisual resources (23%) is a clear reflection of the cohort's demographic profile. As the cohort was predominantly senior females, these preferences are likely mediated by age and digital literacy, as older patients generally favour familiar print media for ease of review and place higher trust in direct specialist consultation. Our study also indicates that patients with OED seek online health information to satisfy their IN; however, the quality of the available online written (Alsoghier et al., 2018) and AV (Alamoudi et al., 2023) information about OED remains poor despite five years of analysis.

Based on the available literature, this study appears to be the first to use a validated OED-specific instrument to assess IN in individuals with OED. Similar studies on oral cancer (Chen et al., 2009) and precancerous oral diseases (Lin et al., 2015) employed generic tools. For instance, Chen et al. used the Cancer Needs Questionnaire Short Form (CNQ-SF) and Karnofsky's Performance Status Index [14], whereas Lin et al.

used the CNQ-SF, State Anxiety Inventory, and Attitudinal Oral Cancer Scale [15]. These studies focused on patients' IN during the diagnostic and treatment phases, whereas the current study addresses various other aspects (e.g., post-treatment impacts, medical system challenges, and sources of IN). Furthermore, research of this kind, which is integrated with findings from previous studies that have predominantly focused on the active phase of care, could guide evidence-based interventions to meet the IN of individuals with OED or OSCC. This study provided baseline data for the EDUCAT-ED project, which can be used in longitudinal research to compare changes in IN after administering educational interventions such as patient information leaflets or videos. These data can also be used as a baseline to further evaluate the psychometric properties of the ODIN-Q, including its structural validity and responsiveness. By analysing structural validity (confirmatory factor analysis), it can be verified that the questionnaire items are adequately interrelated to represent the construct, offering more robust evidence of its alignment with patient IN. Similarly, a longitudinal analysis of IN using the ODIN-Q could enable tracking of changes over time and assess the impact of educational interventions before and after their application (responsiveness).

This study has some limitations. First, a convenience sample was employed, which lacked random selection and limited the generalisability of the findings. Consequently, while the statistical tests provide valuable exploratory insights, the conclusions drawn from these analyses should be interpreted considering the evidence from available clinical studies. Second, the findings may not fully reflect the experiences of populations in different contexts because the sample was derived from a single dental hospital in the UK. Third, the recruitment of participants was conducted at a single point in time. Therefore, it is recommended that longitudinal assessments of patients' needs and information sources be conducted. Researchers are encouraged to assess IN from the time of diagnosis and monitor these needs throughout the disease course to capture changes in IN and educational preferences. This longitudinal approach is critical because IN are not static; they change and evolve over a patient's journey. This evolution necessitates an adaptive approach to PE, ensuring information is delivered precisely when the patient is psychologically and cognitively prepared to receive and utilise it. Fourth, self-reported measures—including the ODIN-Q with its Likert-scale items—may introduce response bias. The fact that only closed-ended questions were used could be a drawback of this study, with options such as 'too much/enough/insufficient' used for assessing the IN. This format may have allowed participants to guess the correct answers, potentially influencing the accuracy of the results. Future studies might benefit from incorporating a mix of open- and close-ended questions to capture a more nuanced understanding of participants' needs and reduce the likelihood of guessing.

4.5. Conclusions

Patient education is a structured, dynamic learning practice intended to influence patient behaviours and to foster changes in their knowledge, attitudes, and skills, all of which are essential for maintaining and improving health outcomes. To the best of our knowledge, PE must include an assessment of a patient's prior knowledge and learning needs, which this analysis presents for OED for the first time.

Although most patients possessed sufficient IN, specific essential topics require more educational attention from clinicians, including identifying the risk factors and lifestyle modifications (e.g., tobacco and alcohol consumption, the role of HPV, dietary changes), clinical characteristics (e.g., the possibility of spread, the chance of a cure, and prevalence, alternative medicine), awareness of potential impacts (e.g., psychosocial and physical), and seeking medical and psychological support (e.g., secondary professional opinions and community support).

Participants ranked one-to-one meetings with healthcare professionals as their primary source of IN about OED. This finding, however, is heavily influenced by the cohort's demographic profile, which was predominantly composed of senior females. This group typically prioritises face-to-face interaction for its interpersonal rapport, authoritative assurance, and ease of review compared to digital formats. This preference is reflective of generally lower digital literacy and higher trust in direct communication among older adults. Therefore, while this result is crucial for tailoring educational strategies to the population with OED, it is likely not representative of younger, digitally native cohorts who would demonstrate a higher preference for audiovisual resources.

Although some clinical factors (e.g. gender and degree of dysplasia) appeared to be associated with IN, these relationships require further investigation in more extensive and diverse samples while considering psychosocial and environmental factors. Integrating qualitative methods can provide deeper insights into individual experiences.

These baseline data, informed by informational needs identified through the ODIN-Q, will guide the development of more tailored educational content. Additionally, these data can be used to further evaluate the psychometric properties of the ODIN-Q, particularly its structural validity and responsiveness.

Chapter V. Structural validity and responsiveness of the oral epithelial dysplasia informational needs questionnaire

5.1. Introduction

Oral epithelial dysplasia (OED) is a histological diagnosis of disturbances in cell maturation and proliferation. Although the exact mechanism of malignant transformation in OED is not well understood, it is accepted that a histological diagnosis of OED may lead to the development of oral squamous cell carcinoma (Speight, 2007). Depending on the grading of the histological changes in OED, treatment may include a period of surveillance or ‘watchful waiting’ to monitor for regression or progression before considering whether surgical excision is necessary (Field et al., 2015). These periods of surveillance, investigation, and therapy following the diagnosis of dysplasia have been linked to significant mental, physical, and psychological burdens due to concerns about the development of cancer or its recurrence (Alsoghier et al., 2021). By providing health information, individuals can make better decisions regarding care and mitigate their worries (Gruman et al., 2010, Smith and Keselman, 2015). Well-informed patients face less uncertainty, which increases their satisfaction, strengthens their coping mechanisms, and contributes to improved therapeutic results (Ormandy, 2011, Neumann et al., 2011).

However, a common gap exists between the information patients need and what their physicians offer, raising the chances of ineffective shared decisions and outcomes in the patient-physician relationship (Weymann et al., 2016, Alsoghier et al., 2023). Therefore, evaluating the information needs of patients with OED is crucial and can be achieved deploying the Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) (Alsoghier et al., 2022). This 33-item tool, developed in the

United Kingdom (UK), includes domains such as clinicodemographic information, disease knowledge, investigative procedures, treatments, physical and psychological aspects, healthcare systems, and access to information. Lazarus' (1984) stress, appraisal, and coping theory provides a conceptual basis for developing the ODIN-Q based on the idea that seeking information and taking proactive steps can be effective coping strategies for people dealing with challenging and stressful medical conditions (Galloway et al., 1997; Rutten et al., 2005; White & Gallagher, 2010). The same can also be applied to the diagnosis of oral precancer.

Psychometric assessment of the ODIN-Q in a previous study demonstrated good content and face validity, and excellent internal consistency with a Cronbach's alpha of 0.93, and moderate test-retest reliability (κ = 0.49–0.53) (Alsoghier et al., 2022). The convergent validity of the ODIN-Q was established by comparing it with a similar measure, which is consistent with the accepted guidelines for evaluating construct validity (Mokkink et al., 2019). However, further psychometric testing of the sufficiency of the ODIN-Q, namely structural validity and responsiveness was previously recommended (Alsoghier et al., 2022). For instance, confirmatory factor analysis (CFA) offers a more advanced assessment of structural validity than other assessments of construct validity, such as hypothesis testing and cross-cultural validity assessments (de Vet, 2011). CFA provides ways to verify the fit of the proposed theoretical model for data collection, define measurement model associations, and link items to their domains (Pituch & Stevens, 2015). Additionally, the responsiveness of the ODIN-Q—its ability to detect changes in patient information needs (IN) over time or following educational interventions—has not been thoroughly investigated.

5.1.1 Aims and objectives

Using unvalidated measurement tools often leads to misleading and inaccurate results, potentially causing suboptimal planning and ineffective cessation programs (Hewlett et al., 2007). Hence, this chapter aimed to (1) conduct a CFA, and (2) assess the responsiveness of the ODIN-Q among individuals with OED in the UK.

5.2. Materials and methods

5.2.1. Study design and participants

This cross-sectional study enrolled adult patients with OED. Based on the inclusion criteria, participants were required to be at least 18 years old, able to read and write in English, and willing to participate in the study. A summary of the study and its validation results were provided to those who agreed to participate. All participants signed an informed consent form before completing the ODIN-Q, which included three sections: (1) socio-demographic information, (2) level of information received, and (3) preferred education methods (Table 5-1). The completion time for the questionnaire for laypersons was approximately 10–15 min based on its readability score (4th-grade level). For responsiveness assessment, some participants were provided with a patient information leaflet (PIL) (Appendix 5) and were asked to complete the ODIN-Q again.

Table 5-1 Content and response choices of the ODIN-Q.

ODIN-Q section	No of items	Components	Response choices
Socio-demographics	7	Age, race, ethnicity, level of education, employment status, and smoking and alcohol intake	Open-ended, closed-ended, multiple-choice
Level of information received	33	6 categories, involving questions on knowledge about the disease, investigative procedures, treatments, physical and psychosocial aspects, and medical access and information availability	0 = not applicable 1 = not at all 2 = not enough 3 = enough 4 = too much
Preferred methods of information delivery	1	Individual meetings, printed materials, audiovisual resources, and group information sessions.	Multiple-choice

ODIN-Q, Oral Epithelial Dysplasia Informational Needs Questionnaire

5.2.2. Recruitment site and sample size

The Royal National ENT and Eastman Dental Hospitals' Oral Medicine Unit at the University College London Hospitals (UCLH) recruited eligible participants between March 2023 and March 2025. Convenient sampling was used to recruit 165 patients to complete the ODIN-Q. The Consensus-based Standard for the Selection of Health Measurement Instruments (COSMIN) guidelines, which state that five patients per individual item in the questionnaire are necessary for effective CFA, served as the basis for calculating the sample size (Terwee et al., 2018a, Mokkink et al., 2019). According to the COSMIN guidelines, a minimum of 50 participants is required to analyse responsiveness.

5.2.3. Ethical considerations and study registration

The study procedures were carefully developed with strict adherence to the ethical principles of the Declaration of Helsinki for medical research involving human participants. The protocol was thoroughly reviewed by an independent expert, who confirmed the scientific rigor and feasibility of the study. This study was recorded by the Joint Research Office (JRO) of UCLH and UCL with reference number 153912 (EDGE number) and Integrated Research Application System (IRAS) project ID: 318039. This study received a favourable opinion on 16 January 2023, from the National Health Service (NHS) Research Ethics Committees (REC) (specifically, the London–Surrey Borders Research Ethics Committee, reference 22/PR/1743), and ethical approval was obtained on 26 January 2023, from the Health Research Authority (HRA) and Health and Care Research Wales (HCRW).

5.2.4. Analysis of data and representation

Data of 165 patients was analysed. Descriptive statistics were used to summarise demographic and clinical variables.

5.2.4.1. Confirmatory factor analysis

Confirmatory factor analysis was performed to confirm the factorial structure of ODIN-Q identified in a previous study (Alsoghier et al., 2022). Data were initially entered into Excel version 2410 and transferred to R version 4.1.1. The lavaan R package for Structural Equation Modelling, version 0.5–22 (Rosseel, 2012), was used to analyse the six constructs of the ODIN-Q level of the information received section. Model fit can be confirmed using at least three individual indices (Hair, 2009). No consensus has been reached on omitting items based on a specific loading level, with decisions empirically determined based on the studied construct (Knekta et al., 2019, Ondé and Alvarado, 2020). However, the validity of the construct is supported by a standardised factor loading higher than 0.5 and a p-value below 0.05, which reflects a strong association between items and their respective factors (McQueen et al., 2008).

5.2.4.2. Responsiveness

Responsiveness was assessed by comparing the ODIN-Q scores before and after the PIL administration, using the scoring system detailed in Chapter 4. The magnitude of change was quantified using Cohen's d, a standardized effect size measure that reflects the degree of change relative to the variability at baseline. Interpretation of effect sizes followed conventional thresholds: negligible (<0.2), small (0.2–0.49), medium (0.5–0.79), and large (≥0.8). In this context, higher post-intervention mean scores indicate a reduction in patients perceived information needs, suggesting a positive impact of the educational leaflet.

5.3. Results

5.3.1. Socio-demographic characteristics of participants

Table 5-2 shows the socio-demographic and clinical characteristics of the study participants (n = 165). The participants included 91 females (55%) and 74 males (45%) aged 25–90 years, with a mean and median age of 66 years. Based on histopathology reports, 267 dysplasia diagnoses were recorded. Dysplasia was most often mild 136 (50.93%]), followed by moderate (n = 96; 35.95%) and severe dysplasia (n = 35, 13.1%). The total number of clinical sites was 194 because some participants presented with lesions at multiple sites.

Table 5-2 Socio-demographic and clinical characteristics of participants (n=165).

Variable	**Category**	**Number (%)**
Sex	Female	91 (55%)
	Male	74 (45%)
Age (years)	20 - 29	1 (0.6%)
	30 - 39	4 (2.42%)
	40 - 49	9 (5.45%)
	50 - 59	35 (21.21%)
	60 - 69	68 (41.21%)
	70 - 79	43 (26.06%)
	80 - 89	4 (2.42%)
	90 – 99	1 (0.6%)
Ethnicity	White (British)	88 (53.33%)
	White (other)	31 (18.78%)
	Asian or Asian British	43 (26.06%)
	Black or Black British	3 (1.81%)
Education	College or higher educational degree	98 (59.39%)
	High school diploma or less	63 (38.18%)
	Not reported	4 (2.42%)
Employment	Retired	95 (57.57%)
	Employed (full-time)	27 (16.36%)
	Employed (part-time)	9 (5.45%)
	Self-employed	23 (13.93%)
	Unemployed	5 (3.03%)
	Not reported	6 (3.63%)
Smoking status	Current	22 (13.33%)
	Past	85 (51.51%)
	Never	58 (35.15%)
Alcohol consumption	Current	84 (50.9%)
	Past	26 (15.75%)
	Never	55 (33.33%)
OED histopathological examination	Mild dysplasia	136 (50.93%)
	Moderate dysplasia	96 (35.95%)
	Severe dysplasia	35 (13.1%)
OED sites	Tongue	88 (45.36%)
	Buccal mucosa	46 (23.71%)
	Gingiva	30 (15.46%)
	Hard palate	12 (6.18%)
	Floor of the mouth	10 (5.15%)
	Soft palate	5 (2.57%)
	Lips	3 (1.54%)
Associated oral disease	Oral lichen planus	115 (70.12%)
	Oral leukoplakia	28 (17.07%)
	Oral candidiasis	9 (5.48%)
	HPV-associated lesion	7 (4.26%)

Oral submucous fibrosis	5 (3.04%)

OED, oral epithelial dysplasia

5.3.2. Confirmatory factor analysis

Descriptive statistics, fit indices, chi-square tests of fit, factor loadings, and interfactor correlations were computed to analyse the structural validity of the measurement tool.

5.3.2.1. Descriptive statistics for factors

Table 5-3 summarises the central tendencies and variabilities of the scores across the six ODIN-Q factors. Investigative tests (F2) had the highest mean score (2.70), reflecting a stronger informational need in this domain than in others. In contrast, the medical system and access to information (F6) had the lowest mean (2.11), indicating comparatively less perceived importance or relevance. Psychosocial aspects (F5) exhibited the highest variability (SD = 0.64), suggesting that respondents provided diverse responses. In contrast, the questions under general information (F1) showed the least variability (SD = 0.49), indicating more consistent responses. The scores span a broad range, with minimum values as low as 0.75 and maximum values reaching 3.33, indicating adequate dispersion across factors. These results demonstrate that the ODIN-Q is sensitive to variability in informational needs across its domains.

Table 5-3 Central tendency and variability of the six factors of the ODIN-Q.

Factor	Mean	SD	Min	Max
General information (F1)	2.45	0.49	1.10	3.30
Investigative tests (F2)	2.70	0.51	1.00	3.00
Treatments (F3)	2.42	0.50	1.00	3.17
Physical aspects (F4)	2.37	0.59	1.00	3.00
Psychosocial aspects (F5)	2.38	0.64	1.00	3.33
Medical system & access to information (F6)	2.11	0.52	0.75	3.25

SD, standard deviation; ODIN-Q, Oral Epithelial Dysplasia Informational Needs Questionnaire

5.3.2.2. Confirmatory factor analysis fit indices

The significant chi-square value ($\chi^2 = 947.041$, df = 480, $p < 0.001$) indicated a lack of perfect alignment between the observed and model-implied covariance matrices. Since the Chi-square test is often sensitive to sample size, further indices were assessed (Table 5-4).

Table 5-4 Fit indices for the ODIN-Q.

Fit measure	Value	Threshold	Interpretation
Degrees of freedom (df)	480	N/A	Sufficient degrees of freedom
Chi-square (χ^2)	947.041	$p > 0.05$ (non-significant)	Significant ($p < 0.001$), poor fit
Comparative Fit Index (CFI)	0.744	≥ 0.90	Sub-optimal fit
Tucker-Lewis Index (TLI)	0.719	≥ 0.90	Sub-optimal fit
Root Mean Square Error of Approximation (RMSEA)	0.085	< 0.08	Moderate fit
Standardised Root Mean Square Residual (SRMR)	0.095	≤ 0.08	Sub-optimal fit
Goodness-of-fit index (GFI)	0.592	≥ 0.90	Sub-optimal fit

ODIN-Q, Oral Epithelial Dysplasia Informational Needs Questionnaire

5.3.2.3. Complete standardised factor loadings

Table 5-5 presents the factor loadings of ODIN-Q. Notably, the factors related to general information (F1) and psychosocial aspects (F5) were relatively consistent, whereas variability was noted for the medical system and access to information (F6). Items related to '*coping with disease effects'* [Q24] and *'chance of cure'* [Q18] strongly contributed to their respective factors, indicating well-defined constructs. Items with weaker associations with their constructs included those related to lack of *doctor experience'* [Q26] and Q32 '*lifestyle adjustments*'[Q32].

Table 5-5 Factor loadings of the items of the ODIN-Q.

Factor	***Item***	***Standardised loading****
General information (F1)	Q1 What is OED	0.705
	Q2 How common is it	0.625
	Q3 Risk factors	0.684
	Q4 Appearance in mouth or lips	0.571
	Q5 Is it contagious	0.574
	Q6 Role of HPV	0.421
	Q7 Disease grades and cancer risk	0.700
	Q8 Effects of smoking or drinking	0.365
	Q9 Safe level of alcohol	0.431
	Q10 Future of OED	0.537
Investigative tests (F2)	Q11 Screening and detection	0.516
	Q12 Benefits risks of tests	0.771
Treatments (F3)	Q13 If untreated	0.524
	Q14 Treatment options	0.739
	Q15 Effects on quality of life	0.757
	Q16 Self-management	0.562
	Q17 Alternative medicine	0.400
	Q18 Chance of cure	0.790
Physical aspects (F4)	Q19 Symptom severity	0.651
	Q20 Spread to other parts	0.549
	Q21 Effects on daily activities	0.778
	Q22 Diet and nutrition	0.618
Psychosocial aspects (F5)	Q23 Fear of cancer progression	0.652
	Q24 Coping with disease effects	0.847
	Q25 Effects on social life	0.634
Medical system & access to information (F6)	Q26 Doctor experience	0.280
	Q27 Seeking second opinion	0.559
	Q28 Physical support access	0.435
	Q29 Psychological support access	0.813
	Q30 Patient support groups	0.709
	Q31 Health promotion	0.776
	Q32 Lifestyle adjustments	0.290
	Q33 Research and clinical trials	0.452

OED, oral epithelial dysplasia; HPV, human papillomavirus; ODIN-Q, Oral Epithelial Dysplasia Informational Needs Questionnaire

5.3.2.4. Inter-factor correlations

Table 5-6 shows that most inter-factor correlations are low (<0.20), supporting the distinctiveness of the ODIN-Q factors. Psychosocial aspects (F5) and physical aspects (F4) are moderately correlated (0.170), reflecting conceptual overlap.

Table 5-6 Inter-factor correlations of items of the ODIN-Q.

ODIN-Q Domains	F1	F2	F3	F4	F5	F6
General information (F1)	0.135	0.070	0.085	0.097	0.118	0.023
Investigative tests (F2)	0.070	0.073	0.067	0.077	0.080	0.017
Treatments (F3)	0.085	0.067	0.111	0.123	0.131	0.027
Physical aspects (F4)	0.097	0.077	0.123	0.201	0.170	0.039
Psychosocial aspects (F5)	0.118	0.080	0.131	0.170	0.208	0.043
Medical system & access to information (F6)	0.023	0.017	0.027	0.039	0.043	0.019

5.3.3. Responsiveness

Fifty participants from the original cohort were provided with the PIL and asked to complete the ODIN-Q to assess the potential change in response over time. Table 5-7 and Figure 5-1 present the baseline and post-intervention mean scores for each item in the ODIN-Q, along with the calculated effect sizes (Cohen's *d*) and interpretation of responsiveness.

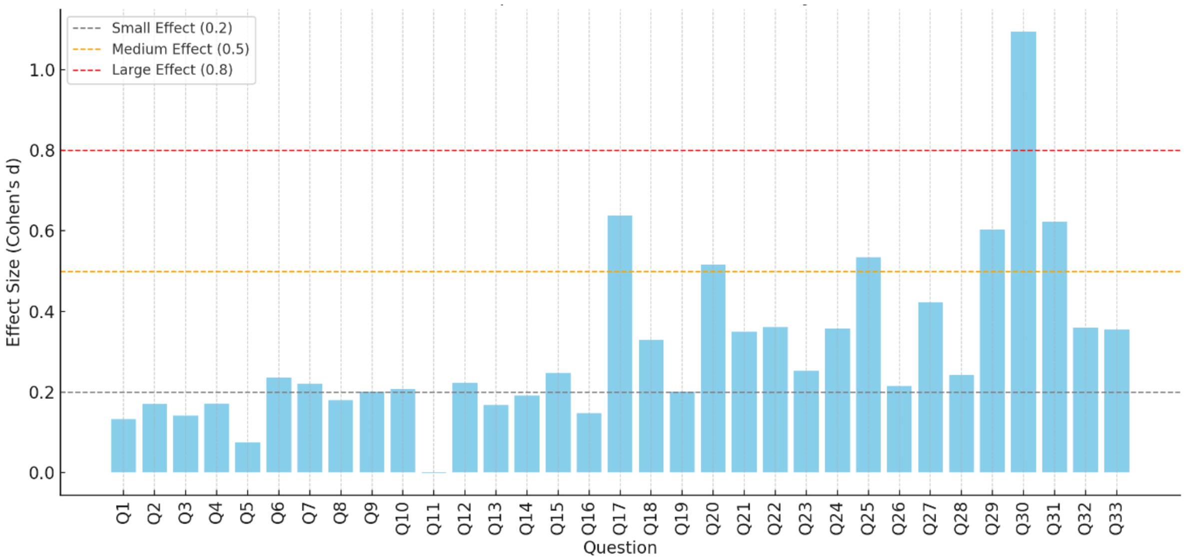
Table 5-7 Responsiveness of the ODIN-Q following an educational intervention.

Question	Baseline Mean	Baseline SD	Latest Follow-up Mean	Latest Effect Size (Cohen's d)	Latest Interpretation
Q1	2.769	0.5813	2.846	0.133	Negligible
Q2	2.451	0.8559	2.596	0.17	Negligible
Q3	2.769	0.5465	2.846	0.141	Negligible
Q4	2.712	0.6668	2.827	0.172	Negligible
Q5	2.731	0.7699	2.788	0.075	Negligible
Q6	2.0	0.8944	2.212	0.236	Small
Q7	2.769	0.6141	2.904	0.22	Small
Q8	2.72	0.8091	2.865	0.18	Negligible
Q9	2.292	1.1316	2.519	0.201	Small
Q10	2.627	0.7758	2.788	0.208	Small
Q11	2.962	0.3408	2.962	-0.001	Negligible
Q12	2.75	0.5192	2.865	0.222	Small
Q13	2.846	0.5734	2.942	0.168	Negligible
Q14	2.673	0.7063	2.808	0.191	Negligible
Q15	2.462	0.6991	2.635	0.247	Small
Q16	2.667	0.6904	2.769	0.148	Negligible
Q17	1.529	0.8284	2.058	0.638	Medium
Q18	2.519	0.6999	2.75	0.33	Small
Q19	2.692	0.6727	2.827	0.201	Small

Q20	2.154	0.8941	2.615	0.516	Medium
Q21	2.615	0.6614	2.846	0.35	Small
Q22	2.385	0.745	2.654	0.361	Small
Q23	2.692	0.6116	2.846	0.252	Small
Q24	2.519	0.6999	2.769	0.357	Small
Q25	2.118	0.8597	2.577	0.534	Medium
Q26	2.923	0.2691	2.981	0.215	Small
Q27	2.08	0.9497	2.481	0.422	Small
Q28	2.686	0.7417	2.865	0.242	Small
Q29	1.902	0.8638	2.423	0.603	Medium
Q30	1.529	0.8518	2.462	1.095	Large
Q31	1.902	0.9294	2.481	0.623	Medium
Q32	2.3	1.0907	2.692	0.36	Small
Q33	2.235	0.9083	2.558	0.355	Small

ODIN-Q, Oral Epithelial Dysplasia Informational Needs Questionnaire; SD, standard deviation

Figure 5-1 ODIN-Q responsiveness: Effect sizes by item.



5.4. Discussion

5.4.1. Confirmatory factor analysis

The CFA of the ODIN-Q conducted in this study provides valuable insights into its structural validity while confirming its clinical feasibility in capturing multiple dimensions of patient informational needs, including OED-related general knowledge, investigative tests, treatments, physical aspects, psychosocial aspects, and access to healthcare. Unlike unidimensional tools, the ODIN-Q covers a broad spectrum of aspects, where factors are expected to be distinct rather than highly correlated (Knekta et al., 2019). Therefore, despite the suboptimal values of the fit indices, the six-factor model remains conceptually sound, in line with its previously demonstrated strong reliability and content validity (Alsoghier et al., 2022). It also considers the limitations of statistical validation models when assessing multi-item instruments where diverse constructs are assessed simultaneously (Byrne, 2013). Additionally, it is not uncommon for health information needs instruments to encounter similar challenges in achieving optimal CFA fit, owing to the broad range of constructs they encompass (Coulter et al., 2008).

The variability observed in these factors further underscores the sensitivity of the ODIN-Q in capturing diverse informational needs. Psychosocial aspects exhibited the highest variability, demonstrating diverse personal coping mechanisms, social support, and psychological resilience, emphasising the importance of tailoring interventions to address individual needs (Ungar and Theron, 2020). In contrast, general information about OED had the least variability, indicating more consistent responses, possibly because of the universal nature of the information in this domain (Epstein & Street, 2011). The broad score range for the ODIN-Q also showed sensitivity in capturing variability to measure patients' informational requirements, aligning with recommendations for designing patient-centred instruments that cater to diverse populations (Coulter et al., 2008).

The observation that patients prioritise information on OED investigative tests and diagnostic processes is indeed not surprising; this finding confirms a predictable and foundational psychological coping mechanism in response to a threatening health diagnosis. This high mean score is driven by the urgent need to address the profound loss of control and the intense illness uncertainty that the diagnosis of a precancerous condition creates. Patients prioritise understanding the diagnostic roadmap and its implications because knowing "what is going to happen to me" allows them to transform the unknown into the known, thereby attempting to re-establish psychological agency over their circumstances (Epstein and Street, 2011). This essential foundation of certainty is a prerequisite for the patient to mentally absorb subsequent information, such as complex surveillance protocols or prognosis. The finding is congruent with research showing that patients seek actionable information to cope with uncertainty and aid decision-making (Li et al., 2024). Additionally, many patients with OED and other oral precancerous changes will undergo multiple excisions as part of their care plans and may feel that their available knowledge is insufficient (Awadallah et al., 2018). In contrast, the low scores given to the medical system and access to information by many participants confirmed the often-varying subjective perceived need for health information (Dawkins et al., 2021). Another explanation is that patients may have already received an OED diagnosis and management in a tertiary care unit, as previously addressed by primary and secondary care clinicians (Mehanna et al., 2009).

However, previous studies investigating this domain and its subcomponents have reported conflicting findings, indicating that many patients perceive access to healthcare information as an unmet or necessary need. Alsoghier et al. (2023) found that patients and clinicians identified healthcare navigation, clarity of diagnostic communication, and access to specialist support as critical unmet needs. Furthermore, a psychometric evaluation of the ODIN-Q (Alsoghier et al., 2022) demonstrated that patients frequently reported gaps in access to information about clinical trials, patient support groups, and secondary opinions, reinforcing the importance of this domain despite its low scores in this study. These findings highlight the potential variability in patient preferences, suggesting that, although some may feel that their informational needs have been met through previous healthcare interactions, others experience ongoing gaps in understanding and accessing medical resources, warranting further exploration.

In psychometric evaluations, instruments often exhibit suboptimal fit index validations. Researchers frequently justify these findings by emphasising the instrument's theoretical foundation, practical utility, and complexity of the measured constructs. This approach of justifying a suboptimal statistical fit by citing a clinical or theoretical imperative is a sound, pragmatic practice in applied health research (Kline, 2023). The justification is considered sound because the complexity and subjective nature of health-related constructs (like quality of life or informational needs) rarely conform perfectly to stringent statistical models. Content validity—ensuring the instrument covers all clinically relevant domains—must override statistical idealism to maintain the tool's utility for patient care and treatment planning (Terwee et al., 2018b). For instance, researchers have encountered challenges in achieving ideal fit indices in developing health-related (QoL) measures such as emPHasis-10 for patients with pulmonary hypertension. Despite these challenges, the instrument was deemed valuable because of its comprehensive coverage of the construct and applicability in diverse settings (Yorke et al., 2014). Similarly, researchers validating the Chronic Heart Failure Health-Related Quality of Life Questionnaire reported certain suboptimal fit indices. However, they justified the retention of specific items based on their clinical significance and the overall content validity of the instrument, ensuring its relevance to the target population (Zhao et al., 2024). These examples underscore the importance of balancing statistical rigour with theoretical and practical considerations.

Notably, the reported RMSEA (0.085) exceeded the adopted threshold of 0.08 and remains appropriate for multi-dimensional scales (Browne and Cudeck, 1992). This value is consistent with other multidomain patient-reported measures, where slight deviations from the ideal model fit are often attributed to the diversity of patient needs rather than measurement flaws (Kline, 2023). Additionally, the SRMR (0.095), whereas above the threshold of 0.08, does not necessarily indicate a significant measurement problem but rather the need for minor revisions in item wording and factor structure.

The inter-factor correlations provided further support for maintaining the six-factor structure of the ODIN-Q. Most correlations remained below 0.20, indicating that the factors were conceptually distinct, which was expected given the diverse nature of patient informational needs (Della et al., 2013). Although the medical system and access factors had weaker inter-factor correlations, this does not necessarily imply poor construct validity. Instead, it reflects the unique nature of access-related concerns that may not always be strongly correlated with knowledge- or symptom-related factors (Ng, 2013). Other studies on patient information needs have also found that system-related constructs often behave differently in statistical models owing to external influences such as healthcare accessibility, literacy levels, and individual patient experiences (Zikmund-Fisher et al., 2010). Therefore, the lower correlations observed in the ODIN-Q medical system and access domain did not reduce its clinical relevance. Instead, they underscore the complexity of assessing patients' experiences with healthcare systems. Retaining these items, even with moderate statistical performance, ensures that the ODIN-Q captures a comprehensive picture of patients' informational needs, particularly for individuals facing barriers to healthcare access and navigation (Scott et al., 2002).

This study provides evidence of the conceptual overlap between some factors. Notably, information concerning psychosocial and physical aspects were moderately correlated (0.170), suggesting that physical health concerns influence psychosocial well-being, as observed in other studies on health-related QoL (Epstein & Street, 2011). This relationship aligns with the understanding that physical and psychological domains are often interconnected in health contexts, particularly in individuals managing chronic or potentially malignant conditions (Chapman et al., 2004). Similarly, psychosocial aspects demonstrate slightly stronger correlations with other factors, reflecting the central role of psychosocial considerations in patients' experiences and information needs (Pourhaji et al., 2023).

The ODIN-Q is a rigorously developed instrument that has undergone extensive reliability and validity testing**,** making it a valuable tool for assessing the diverse information needs of patients with OED. The broad response range and variability in the factor scores demonstrate its sensitivity in measuring the perceived importance of different informational needs. Future research should focus on further validation in diverse populations to ensure that the ODIN-Q is applicable across different clinical settings and patient cohorts in the UK**.** Additionally, a longitudinal approach to assessing the informational needs of patients with OED is essential for understanding how patient concerns evolve throughout the care pathway from diagnosis to long-term management. Studies using patient-reported outcome measures and patient-reported experience measures have demonstrated the importance of capturing evolving patient concerns, with findings showing that information needs related to diagnosis and prognosis often give way to treatment and survivorship concerns (Di Maio et al., 2022). This is particularly relevant for OED, where patients frequently undergo multiple excisions and long-term surveillance, making tailored, stage-specific information critical for patient engagement and adherence to follow-up care (Mehanna et al., 2009).

5.4.2. Responsiveness

Assessing the responsiveness of patient-reported outcome measures (PROM) is crucial, as it determines the instrument’s sensitivity to changes resulting from clinical interventions or the natural progression of a condition (Patrick et al., 2011). A systematic review highlighted the need for more psychometric studies on measures of patient IN, emphasising the importance of evaluating responsiveness to ensure that these tools can effectively capture dynamic changes in patient perspectives (Balitsky et al., 2024). In other medical fields, the responsiveness of IN assessments has been explored. For instance, the Family Reported Outcome Measure, a tool designed to assess the impact of a patient’s disease on their family members, has undergone studies to evaluate its responsiveness and minimal important change (Shah et al., 2024). The responsiveness of the EQ-5D, a standardized measure of health-related QoL, has been assessed in various health conditions, including cardiovascular disease and mental health populations (Devlin and Brooks, 2017). These studies highlight the need for establishing the responsiveness of PROM, to ensure their validity in assessing evolving patient needs.

The present study evaluated the responsiveness of the ODIN-Q following an educational intervention using a patient information leaflet. The findings indicate that the ODIN-Q demonstrates low-to-moderate and consistent responsiveness, with most items showing negligible to small effect sizes and a few reaching the moderate range. These results suggest that the ODIN-Q is sensitive to detecting changes in patient-reported information needs over time, particularly in response to targeted educational material. From a clinical perspective, even modest reductions in IN may carry important implications (Kinnersley et al., 2008). Patients who feel more informed are more likely to engage in shared decision-making, adhere to treatment plans, and report higher satisfaction with care (Stiggelbout et al., 2015). The ODIN-Q, by highlighting domain-specific gaps in understanding, may help clinicians tailor discussions and materials to each patient’s needs. In this sense, the observed changes — albeit modest — are meaningful and point to the tool’s potential for use in routine patient-centred communication.

The overall small effect size pattern is common in tools measuring health-related perceptions, particularly in short interventions. Similar studies in health literacy and information needs in medicine and dentistry have reported comparable responsiveness. For example, tools like the Health Literacy Questionnaire and Oral Health Impact Profile have shown small-to-moderate effect sizes after patient education programs or brief interventions (Osborne et al., 2013; Slade, 1997). Moreover, studies evaluating patient IN in oncology and cardiology also report modest responsiveness, emphasising the importance of repeated or multifaceted interventions to yield larger behavioural or perceptual shifts (Rutten et al., 2005; Kinnersley et al., 2008).

Several studies in dentistry and oral health have also demonstrated that educational interventions—particularly those targeting IN, health behaviours, or literacy—produce modest improvements in outcomes. These studies often involve diverse target populations (e.g., schoolchildren, caregivers, older adults, or vulnerable groups such as refugees) and a range of delivery methods, from traditional lectures to multimedia tools. For example, school-based oral health programs have improved plaque control and hygiene knowledge, while digital tools have enhanced oral health literacy among general populations. Interventions tailored to caregivers of children or patients with specific conditions, such as OPMD, have also reported small-to-moderate effect sizes. These findings align with the current study, where a simple educational leaflet yielded measurable, though modest, reductions in patients' IN. Table 5-8 summarizes selected oral health education interventions and highlights both their methodological diversity and the generally consistent pattern of modest responsiveness, underscoring the incremental but meaningful role such tools play in improving oral health outcomes.

Table 5-8 Oral health education intervention studies (n=8)

Author (Year)	Oral Disease Focus	Educational Method	Target Population	Evaluation / Follow-up	Outcomes Measured	Key Findings
(Nakre and Harikiran, 2013)	General oral health	School-based lectures and demonstrations	Schoolchildren	6 months	KAP, Plaque Index	Improved knowledge, attitude, practice; reduced plaque
(Alsada, 2004)	Dental caries	Interactive caregiver sessions	Preschoolers & mothers	12 months	Caries incidence, hygiene	Improved hygiene, fewer caries
(Tai et al., 2001)	Gingival health	Regular educational sessions	Adolescents	6 years	Gingival scores, attitudes	Sustained improvement in health and attitudes
(Subedi et al., 2021)	Oral hygiene	School-based oral health education	12–15-year-old schoolchildren	6 months	KAP, plaque control, gingival health	Significant improvements in oral hygiene and gingival health
(Angarita-Díaz et al., 2024)	Dental caries	Neuroeducational strategy for caregivers	Mothers and caregivers	Not specified	Knowledge, attitudes, practices	Enhanced caregiver knowledge and attitudes
(Kitsaras et al., 2023)	Oral health literacy	Digital oral health intervention (Know Your OQ™)	General population	Variable	Knowledge, attitudes, practices	Improved oral health behaviors and awareness
(Zimmerman et al., 1993)	Oral health in refugees	Simplified preventive dentistry program	Chilean refugees	6 months	Attitudes, knowledge, gingival health	Improved preventive knowledge and reduced gingival bleeding
Current Study (2025)	Oral dysplasia	Patient information leaflet	Individuals with PMODs	2–12 months	ODIN-Q scores	Small-moderate effect sizes; reduced IN

This study has some limitations. First, the sample was recruited from a single dental hospital; therefore, the results may not be generalisable to broader populations. Variations in health literacy, cultural background, and access to healthcare services can influence how patients perceive and report their IN, potentially affecting the tool's applicability across diverse settings. Second, this cross-sectional study only provides a snapshot of IN at a single time point. It does not capture how patients' needs evolve throughout the care pathway, limiting the ODIN-Q's assessment of longitudinal utility. Third, the analysis relied on group-level summary statistics, which, while practical, constrain the precision of responsiveness estimates compared to individual-level change scores. Fourth, the intervention—a single patient information leaflet—may not have been sufficient to elicit substantial changes across all domains of information needs. Fifth, participant responses may have been influenced by social desirability bias, particularly in items related to knowledge or behaviour, potentially underestimating true gaps. Finally, although the study confirmed the factor structure of the ODIN-Q, other aspects of validity, such as predictive validity, criterion-related validity, and test-retest reliability, were not addressed, leaving some psychometric properties unexplored.

5.5. Conclusions

This study provided a comprehensive psychometric evaluation of the ODIN-Q, confirming its clinical utility and validity for assessing the diverse IN of patients with OED. The ODIN-Q effectively distinguishes between key informational domains—including general knowledge, investigative tests, treatments, physical aspects, psychosocial aspects, medical systems, and access to information—making it a valuable tool for delivering patient-centred care. Although the statistical fit indices suggest minor areas for improvement, such as refining or subdividing items within the medical system and access to information domain, the six-factor model remains conceptually sound and reflective of the multidimensional nature of patient needs.

In addition, the ODIN-Q demonstrates adequate responsiveness to changes in patient IN following a brief educational intervention. Its structured, multi-domain format supports its application in both clinical and research contexts to guide and personalise patient education in oral healthcare.

Future research should explore the ODIN-Q’s responsiveness across more diverse populations and clinical settings. Comparative studies evaluating different types of educational interventions (e.g., video-based, face-to-face counselling, or written materials) may provide insights into how different formats influence patient understanding. Embedding the ODIN-Q within broader decision-support systems could also enhance its clinical utility. Moreover, longitudinal studies tracking ODIN-Q scores over time—particularly during key transitions in care, such as post-biopsy discussions, treatment initiation, or post-operative follow-up—would offer a richer picture of how patients’ information needs evolve. Studies involving culturally tailored materials or multimedia tools may also help optimize the delivery of information for diverse patient groups.

Chapter VI. Summary of conclusions, limitations, and future work

Overall aim

The central aim of this thesis was to address the critical gap in patient education for individuals diagnosed with oral epithelial dysplasia (OED). Through a sequence of complementary studies, this work evaluated the quality of available online audiovisual resources, explored the experiences and informational needs of patients, and tested the oral epithelial dysplasia informational needs questionnaire (ODIN-Q), including its structural validity and responsiveness. The overarching objective was to generate an evidence base and a practical toolkit for delivering patient-centred education that will potentially improve patient understanding, engagement, and outcomes across the OED care pathway.

Summary of chapter conclusions

Chapter I – knowledge gap and objectives

This chapter established the importance of patient education in the management of OED and identified a lack of systematic evaluation of educational materials. It introduced the ODIN-Q as a necessary and promising instrument for assessing informational needs, with early evidence of validity and reliability but a clear requirement for further psychometric testing.

Chapter II – online audiovisual information

An analysis of online audiovisual content revealed that while some credible OED-related materials are available, primarily via YouTube, overall quality was inconsistent and often incomplete. Given the popularity of social media platforms and their cognitive impact, the study emphasised the need for greater professional presence on social media and the production of accessible, peer-reviewed content tailored to the needs of patients.

Chapter III – patient experiences and needs (qualitative study)

Qualitative interviews highlighted the challenges faced by patients with OED, including delays in diagnosis, insufficient knowledge, and significant psychological burdens. Patients consistently valued clear and comprehensive information, underscoring the essential role of education and communication in fostering trust and improving outcomes. These findings reinforced the need for patient-centred approaches and informed the refinement of the ODIN-Q.

Chapter IV – informational needs and preferences (quantitative study)

This quantitative study demonstrated, for the first time, baseline levels of informational needs among patients found to have OED. While some knowledge was adequate, important gaps were identified around risk factors, psychosocial implications, and available support systems. One-to-one consultations with healthcare professionals were found to be the preferred and most trusted information source. The study established clear targets for the education of patients and a platform for longitudinal evaluation.

Chapter V – structural validity and responsiveness of the ODIN-Q

A confirmatory factor analysis validated the multidimensional structure of the ODIN-Q, confirming its reliability across domains including disease knowledge, treatments, psychosocial aspects, and healthcare systems. Although the confirmatory factor analysis fit indices demonstrated only moderate fit (as is often the case with complex, subjective health constructs), the instrument's utility is strongly supported by its comprehensive content validity. Responsiveness testing further demonstrated its crucial ability to detect meaningful changes in patient knowledge following intervention. These combined results affirm the ODIN-Q as a robust, clinically useful tool for assessing and addressing informational needs of OED in affected patients, prioritising its demonstrated sensitivity to change and theoretical completeness over strict statistical perfection.

Limitations of the work

Although this work is original and extensive, several limitations are acknowledged. Recruitment was single-centre within the United Kingdom, potentially limiting generalisability across health systems and cultures. The cross-sectional design of most quantitative work precluded understanding how needs evolve over time. Self-report measures (Likert scales and closed-ended items) may have introduced bias and restricted nuance. The qualitative work, though novel and insightful, was exploratory and based on a relatively small sample. Similarly, the online content analysis was constrained by the dynamic and unregulated nature of digital platforms, with English-language YouTube materials serving as the primary focus. Finally, while psychometric testing of the ODIN-Q confirmed its structural validity and responsiveness, additional properties such as predictive validity and broader cross-cultural validation remain to be addressed.

Future directions

The findings of this thesis provide a foundation for practical applications and future research in OED patient education. The immediate next step is the rollout of an information protocol within England. This should:

- develop concise, ODIN-Q-informed materials (leaflet + short video) that cover risk factors and behaviour change, prognosis and surveillance, psychosocial impacts, and routes to clinical and community support.
- integrate materials into clinic consultations (teach-back methods), patient portals/QR codes, and trusted professional social-media accounts.
- assess patient uptake, gather feedback on the clarity and usefulness of the materials, and evaluate their impact on decision-making and psychosocial outcomes.

Beyond content delivery, future work should integrate behavioural science frameworks to maximise the effectiveness of educational tools. A key insight is the role of locus of control (LOC): patients with a strong internal LOC, who perceive greater self-control over their health, are more likely to adopt preventive behaviours and adhere to surveillance. Educational interventions informed by the LOC theory can reinforce patients' sense of autonomy while addressing external barriers to care.

Similarly, embedding the principles of the Health Belief Model (HBM) into OED education can support behavioural change by targeting patients' perceptions of susceptibility (risk of malignant transformation) and perceived severity (impact of oral cancer), highlighting benefits (early detection, reduced anxiety), reducing barriers (time, cost, stigma), providing cues to action (reminders, checklists), and building self-efficacy (skills for oral self-check, communication with clinicians).

Complementing this, the COM-B model offers a systems perspective, emphasising the need to enhance patient capability (knowledge and skills), opportunity (access to follow-up and cessation support), and motivation (both rational and emotional) to sustain health-protective behaviours.

Taken together, these frameworks suggest that future educational materials should not be purely informational but theory-driven, personalised, and behaviour-oriented. By synergising ODIN-Q–identified patient needs with LOC, HBM, and COM-B principles, educational strategies can be tailored to reinforce self-control, reduce anxiety, and promote adherence. Evidence indicates that such multi-component, theory-based interventions outperform information-only approaches, offering a promising path toward improving OED management outcomes.

Further research should expand the scope of these interventions across different communities and cultural settings. For example, conducting similar studies such as validation of ODIN-Q in Saudi Arabia and other Middle Eastern populations will provide insights into how cultural beliefs, family involvement, economic, and healthcare system differences shape patient concerns and needs. Comparative work in regions with high prevalence of tobacco and betel quid use, such as India, will be essential in tailoring educational strategies for at-risk populations. These studies will not only refine patient information tools but also demonstrate the importance of context-specific approaches to OED education and management.

Finally, future efforts should include longitudinal studies to capture how informational needs evolve throughout the care pathway—from diagnosis through treatment and follow-up—and how different educational modalities (e.g., written leaflets, video-based content, face-to-face counselling) impact patient understanding. Embedding the ODIN-Q into clinical practice as a decision-support tool will help clinicians personalise education, improve shared decision-making, and ultimately contribute to better patient outcomes in OED.

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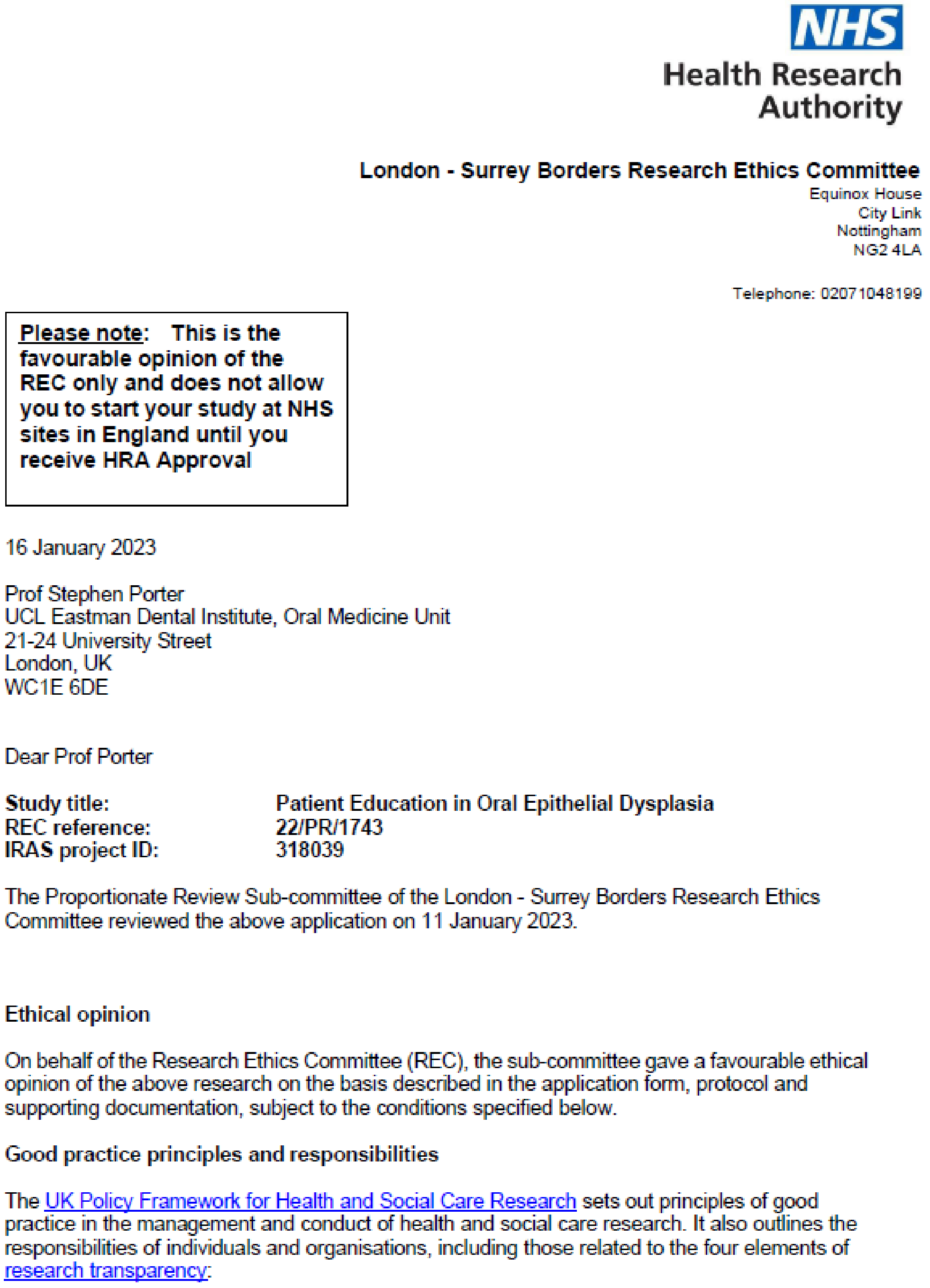
APPENDICES

Appendix 1. Ethics approvals for EDUCAT-ED study



NHS
Health Research
Authority

London - Surrey Borders Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

Telephone: 02071048199

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 January 2023

Prof Stephen Porter
UCL Eastman Dental Institute, Oral Medicine Unit
21-24 University Street
London, UK
WC1E 6DE

Dear Prof Porter

Study title: **Patient Education in Oral Epithelial Dysplasia**
REC reference: **22/PR/1743**
IRAS project ID: **318039**

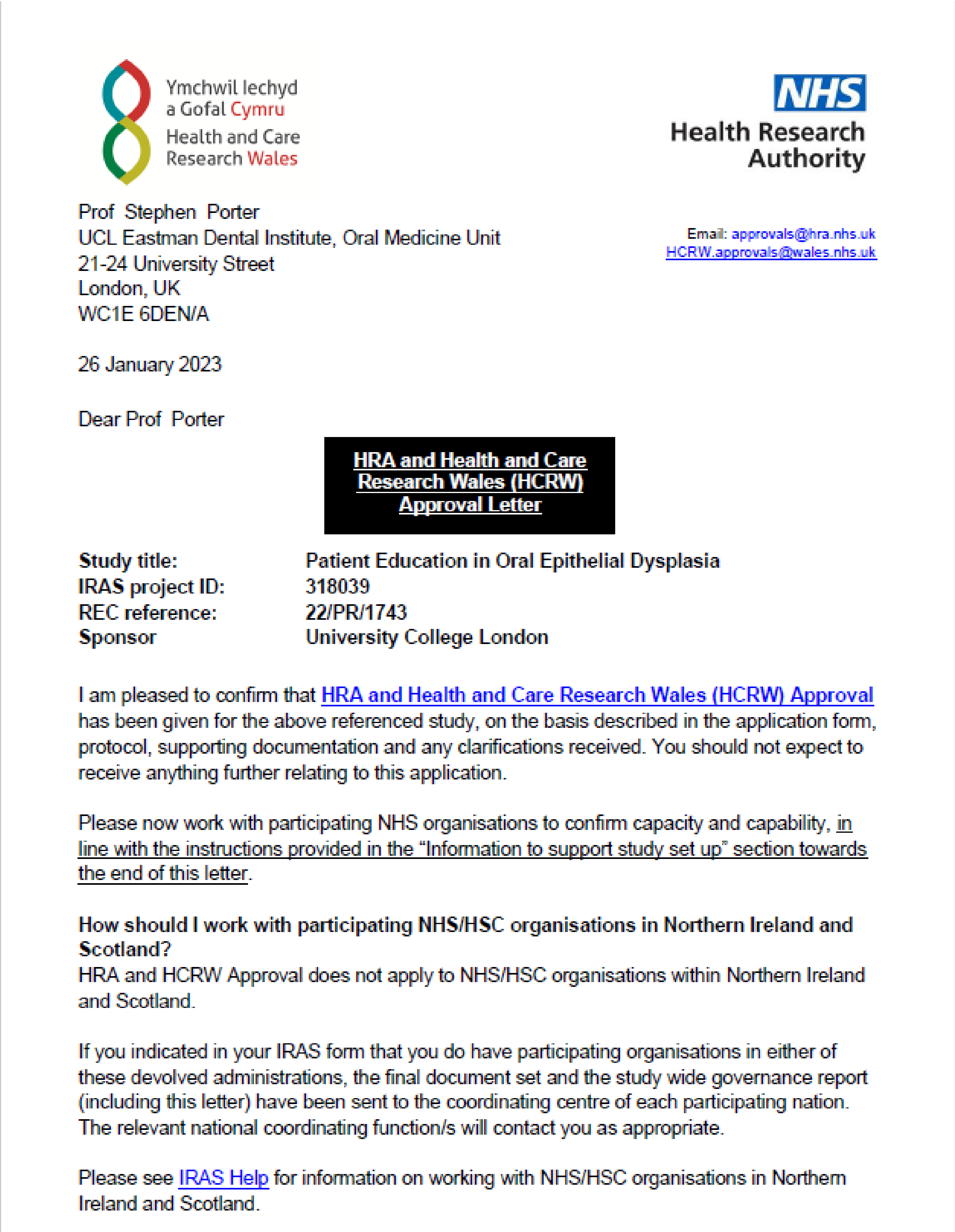
The Proportionate Review Sub-committee of the London - Surrey Borders Research Ethics Committee reviewed the above application on 11 January 2023.

Ethical opinion

On behalf of the Research Ethics Committee (REC), the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Prof Stephen Porter
UCL Eastman Dental Institute, Oral Medicine Unit
21-24 University Street
London, UK
WC1E 6DEN/A

26 January 2023

Dear Prof Porter

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: Patient Education in Oral Epithelial Dysplasia
IRAS project ID: 318039
REC reference: 22/PR/1743
Sponsor University College London

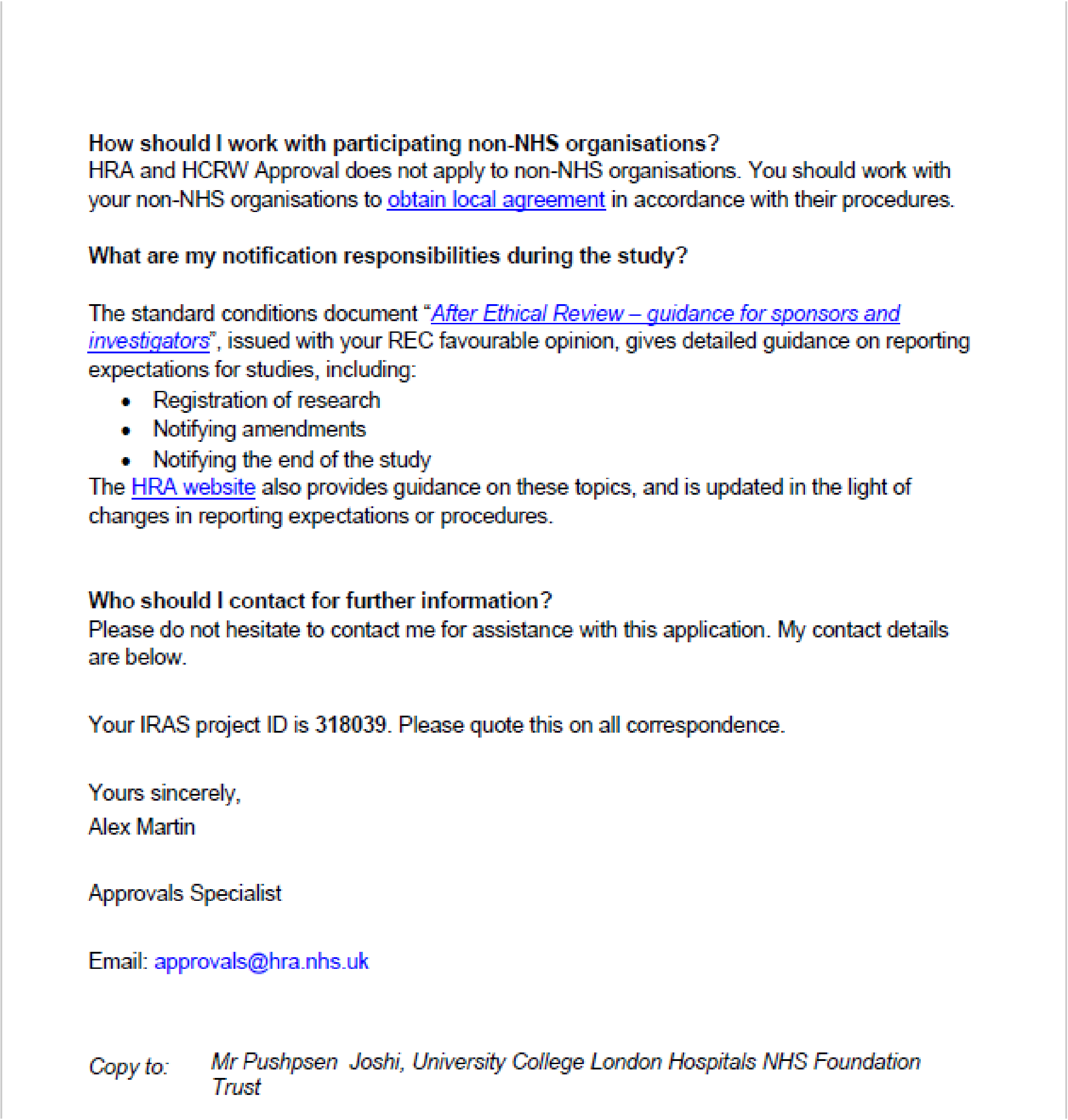
I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.



How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

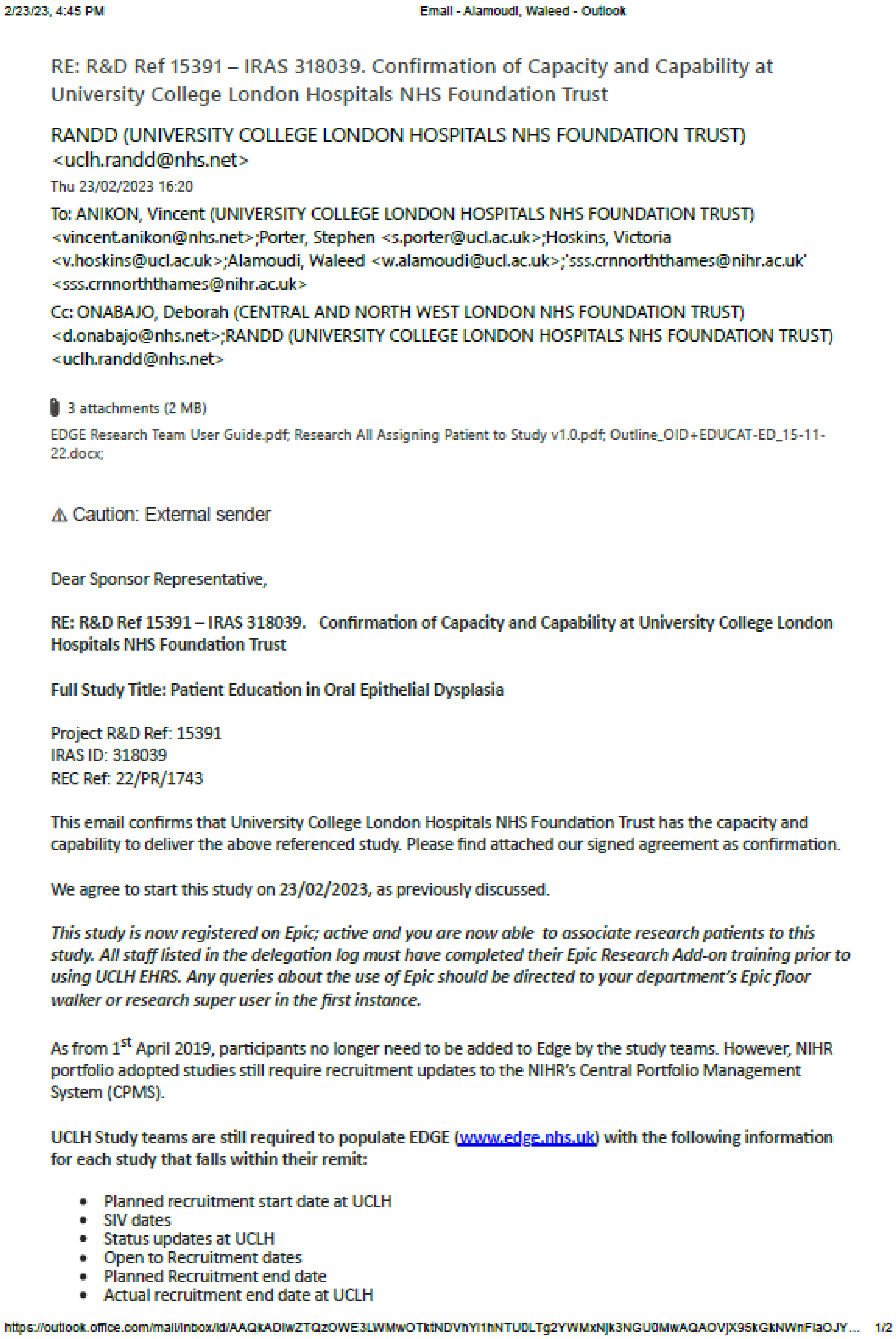
Your IRAS project ID is 318039. Please quote this on all correspondence.

Yours sincerely,
Alex Martin

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Mr Pushpsen Joshi, University College London Hospitals NHS Foundation Trust*



2/23/23, 4:45 PM Email - Alamoudi, Waleed - Outlook

RE: R&D Ref 15391 – IRAS 318039. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust

RANDD (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <uclh.randd@nhs.net>
Thu 23/02/2023 16:20
To: ANIKON, Vincent (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <vincent.anikon@nhs.net>;Porter, Stephen <s.porter@ucl.ac.uk>;Hoskins, Victoria <v.hoskins@ucl.ac.uk>;Alamoudi, Waleed <w.alamoudi@ucl.ac.uk>;'sss.crnnorththames@nihr.ac.uk' <sss.crnnorththames@nihr.ac.uk>
Cc: ONABAJO, Deborah (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST) <d.onabajo@nhs.net>;RANDD (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <uclh.randd@nhs.net>

3 attachments (2 MB)
EDGE Research Team User Guide.pdf; Research All Assigning Patient to Study v1.0.pdf; Outline_OID+EDUCAT-ED_15-11-22.docx;

⚠ Caution: External sender

Dear Sponsor Representative,

RE: R&D Ref 15391 – IRAS 318039. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust

Full Study Title: Patient Education in Oral Epithelial Dysplasia

Project R&D Ref: 15391
IRAS ID: 318039
REC Ref: 22/PR/1743

This email confirms that University College London Hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our signed agreement as confirmation.

We agree to start this study on 23/02/2023, as previously discussed.

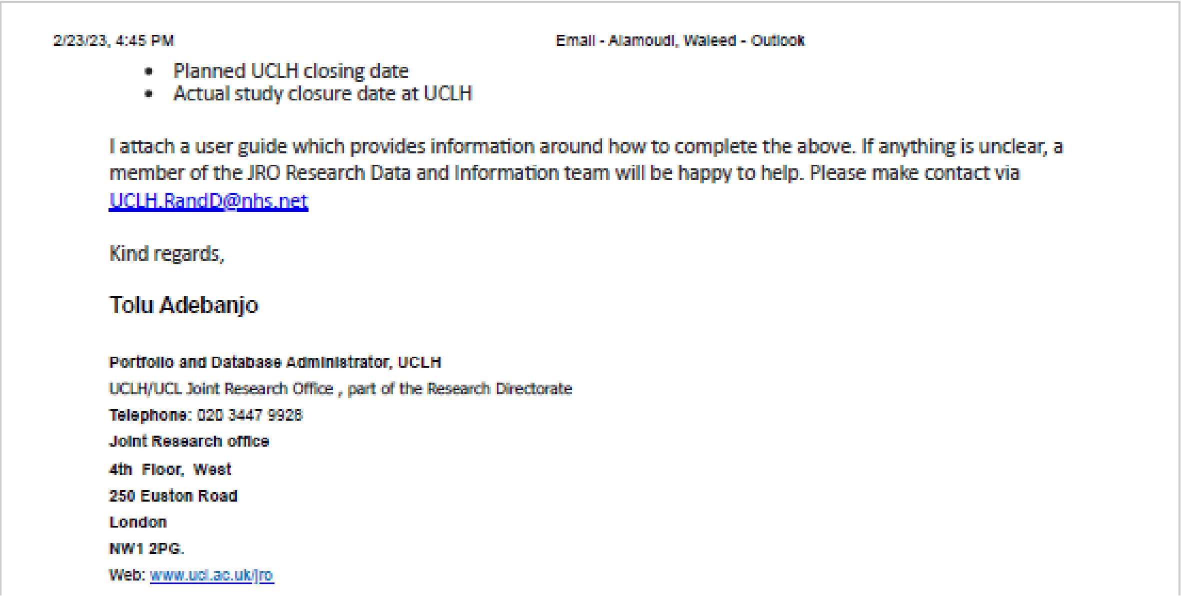
This study is now registered on Epic; active and you are now able to associate research patients to this study. All staff listed in the delegation log must have completed their Epic Research Add-on training prior to using UCLH EHRS. Any queries about the use of Epic should be directed to your department's Epic floor walker or research super user in the first instance.

As from 1st April 2019, participants no longer need to be added to Edge by the study teams. However, NIHR portfolio adopted studies still require recruitment updates to the NIHR's Central Portfolio Management System (CPMS).

UCLH Study teams are still required to populate EDGE (www.edge.nhs.uk) with the following information for each study that falls within their remit:

- Planned recruitment start date at UCLH
- SIV dates
- Status updates at UCLH
- Open to Recruitment dates
- Planned Recruitment end date
- Actual recruitment end date at UCLH

https://outlook.office.com/mail/inbox/id/AAQkADIwZTQzOWE3LWMwOTktNDVhYi1hNTU0LTg2YWMxNjk3NGU0MwAQAOVjX95kGkNWnFlaOJY... 1/2



2/23/23, 4:45 PM Email - Alamoudi, Waleed - Outlook

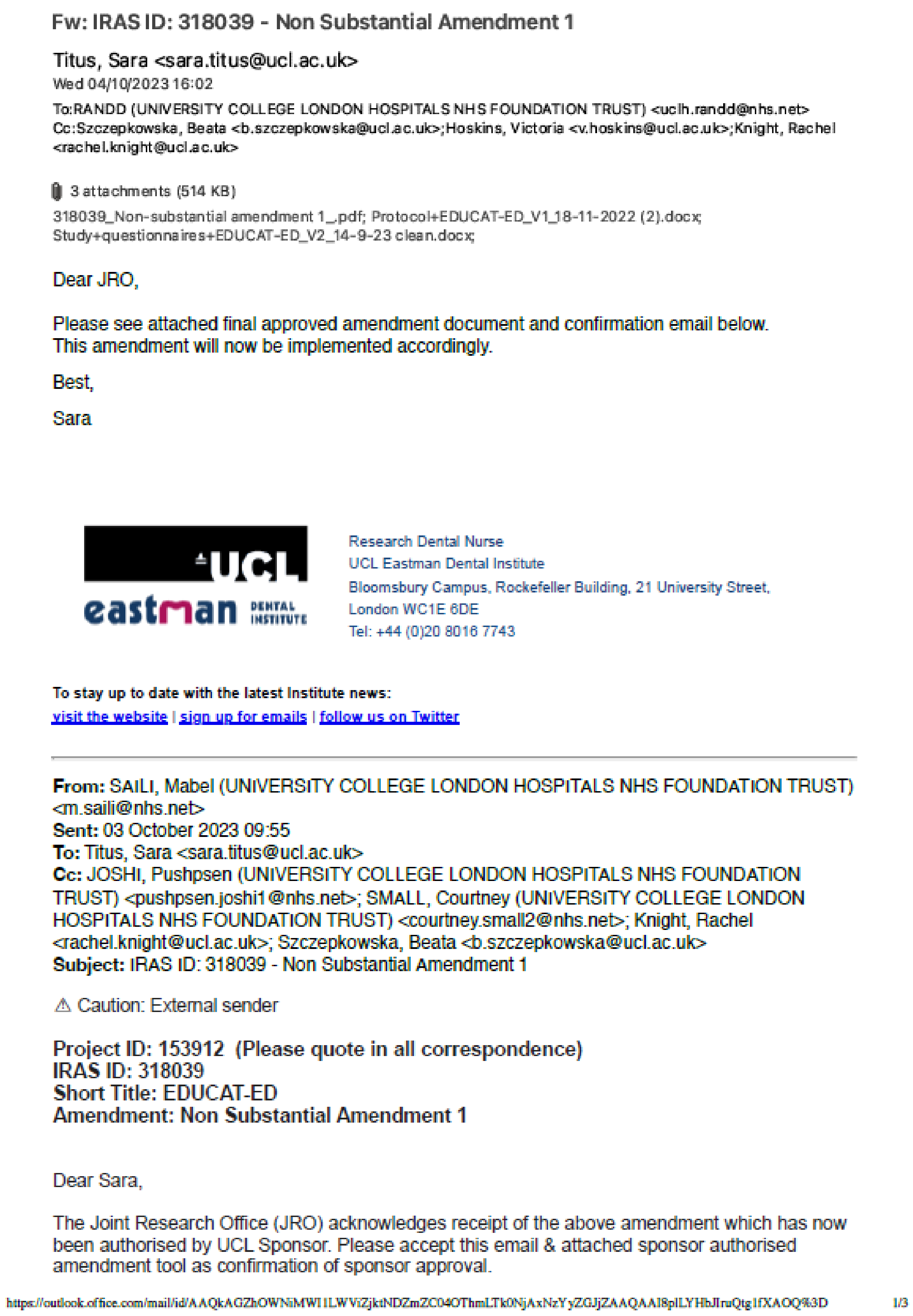
- Planned UCLH closing date
- Actual study closure date at UCLH

I attach a user guide which provides information around how to complete the above. If anything is unclear, a member of the JRO Research Data and Information team will be happy to help. Please make contact via UCLH.RandD@nhs.net

Kind regards,

Tolu Adebanjo

Portfolio and Database Administrator, UCLH
UCLH/UCL Joint Research Office , part of the Research Directorate
Telephone: 020 3447 9928
Joint Research office
4th Floor, West
250 Euston Road
London
NW1 2PG.
Web: www.ucl.ac.uk/jro



Fw: IRAS ID: 318039 - Non Substantial Amendment 1

Titus, Sara <sara.titus@ucl.ac.uk>
Wed 04/10/2023 16:02
To:RANDD (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <uclh.randd@nhs.net>
Cc:Szczepkowska, Beata <b.szczepkowska@ucl.ac.uk>;Hoskins, Victoria <v.hoskins@ucl.ac.uk>;Knight, Rachel <rachel.knight@ucl.ac.uk>

3 attachments (514 KB)
318039_Non-substantial amendment 1_.pdf; Protocol+EDUCAT-ED_V1_18-11-2022 (2).docx; Study+questionnaires+EDUCAT-ED_V2_14-9-23 clean.docx;

Dear JRO,

Please see attached final approved amendment document and confirmation email below.
This amendment will now be implemented accordingly.

Best,

Sara

Research Dental Nurse
UCL Eastman Dental Institute
Bloomsbury Campus, Rockefeller Building, 21 University Street,
London WC1E 6DE
Tel: +44 (0)20 8016 7743

To stay up to date with the latest Institute news:
visit the website | sign up for emails | follow us on Twitter

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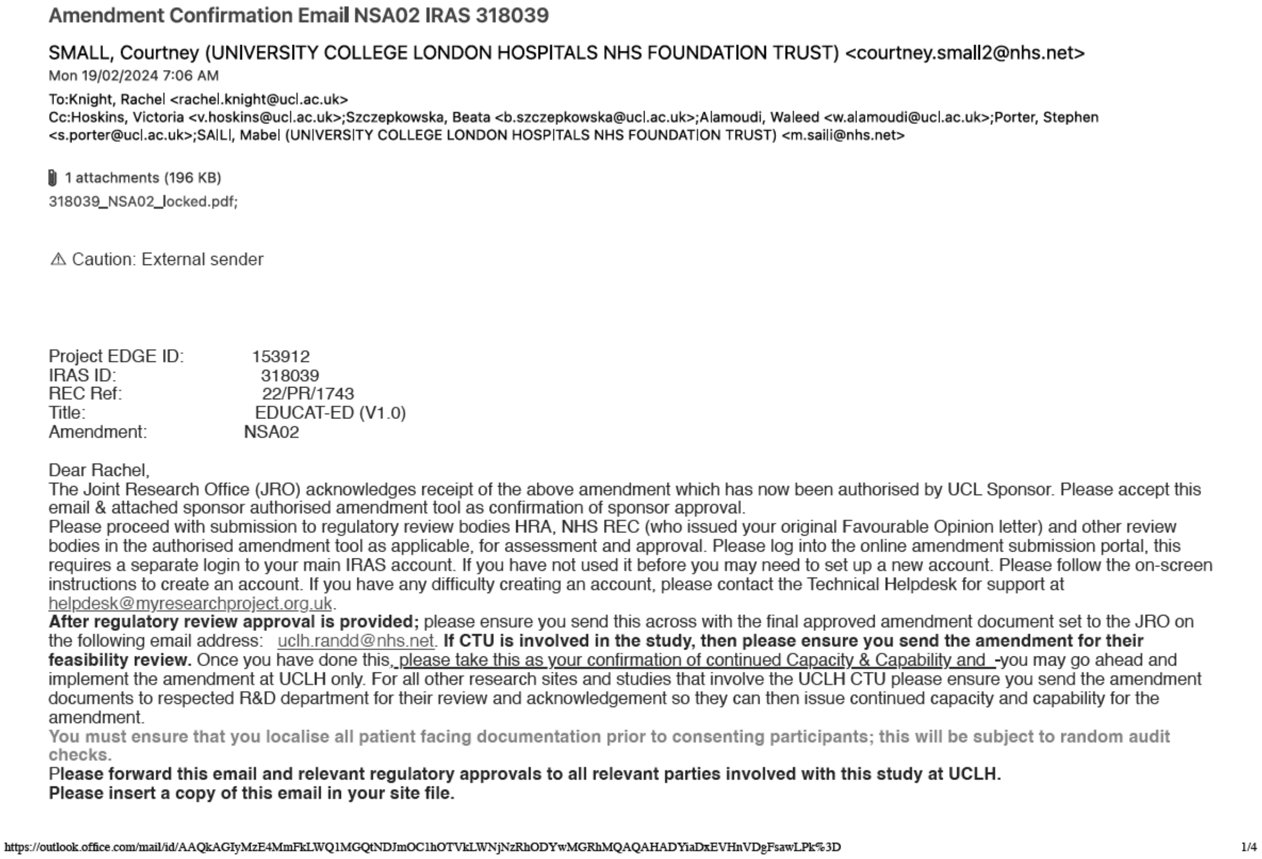
From: SAILI, Mabel (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <m.saili@nhs.net>
Sent: 03 October 2023 09:55
To: Titus, Sara <sara.titus@ucl.ac.uk>
Cc: JOSHI, Pushpsen (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <pushpsen.joshi1@nhs.net>; SMALL, Courtney (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <courtney.small2@nhs.net>; Knight, Rachel <rachel.knight@ucl.ac.uk>; Szczepkowska, Beata <b.szczepkowska@ucl.ac.uk>
Subject: IRAS ID: 318039 - Non Substantial Amendment 1

⚠ Caution: External sender

Project ID: 153912 (Please quote in all correspondence)
IRAS ID: 318039
Short Title: EDUCAT-ED
Amendment: Non Substantial Amendment 1

Dear Sara,

The Joint Research Office (JRO) acknowledges receipt of the above amendment which has now been authorised by UCL Sponsor. Please accept this email & attached sponsor authorised amendment tool as confirmation of sponsor approval.



Amendment Confirmation Email NSA02 IRAS 318039

SMALL, Courtney (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <courtney.small2@nhs.net>
Mon 19/02/2024 7:06 AM
To:Knight, Rachel <rachel.knight@ucl.ac.uk>
Cc:Hoskins, Victoria <v.hoskins@ucl.ac.uk>;Szczepkowska, Beata <b.szczepkowska@ucl.ac.uk>;Alamoudi, Waleed <w.alamoudi@ucl.ac.uk>;Porter, Stephen <s.porter@ucl.ac.uk>;SAILI, Mabel (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <m.saili@nhs.net>

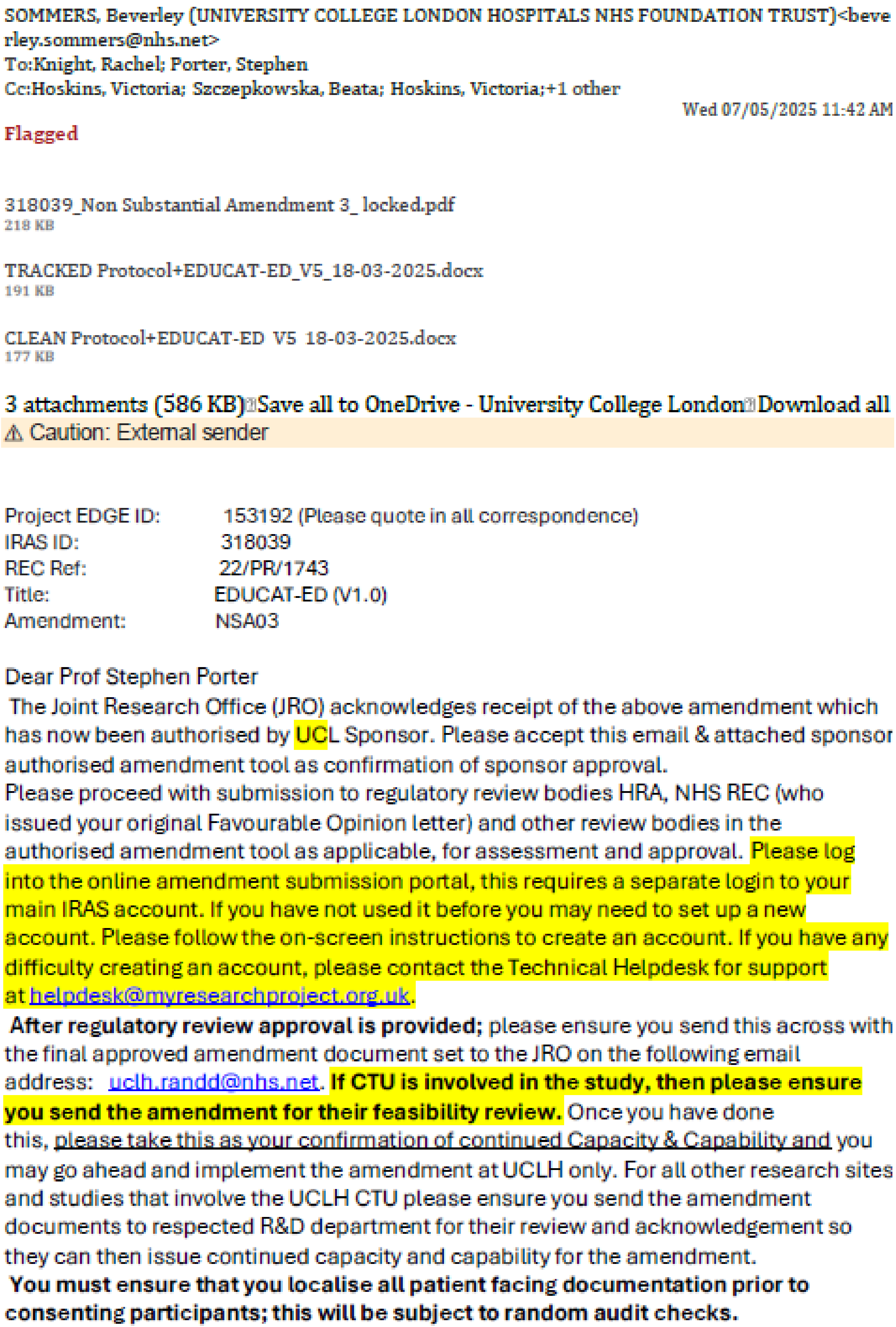
1 attachments (196 KB)
318039_NSA02_locked.pdf;

⚠ Caution: External sender

Project EDGE ID:	153912
IRAS ID:	318039
REC Ref:	22/PR/1743
Title:	EDUCAT-ED (V1.0)
Amendment:	NSA02

Dear Rachel,
The Joint Research Office (JRO) acknowledges receipt of the above amendment which has now been authorised by UCL Sponsor. Please accept this email & attached sponsor authorised amendment tool as confirmation of sponsor approval.
Please proceed with submission to regulatory review bodies HRA, NHS REC (who issued your original Favourable Opinion letter) and other review bodies in the authorised amendment tool as applicable, for assessment and approval. Please log into the online amendment submission portal, this requires a separate login to your main IRAS account. If you have not used it before you may need to set up a new account. Please follow the on-screen instructions to create an account. If you have any difficulty creating an account, please contact the Technical Helpdesk for support at helpdesk@myresearchproject.org.uk.
After regulatory review approval is provided; please ensure you send this across with the final approved amendment document set to the JRO on the following email address: uclh.randd@nhs.net. **If CTU is involved in the study, then please ensure you send the amendment for their feasibility review.** Once you have done this, please take this as your confirmation of continued Capacity & Capability and -you may go ahead and implement the amendment at UCLH only. For all other research sites and studies that involve the UCLH CTU please ensure you send the amendment documents to respected R&D department for their review and acknowledgement so they can then issue continued capacity and capability for the amendment.
You must ensure that you localise all patient facing documentation prior to consenting participants; this will be subject to random audit checks.
Please forward this email and relevant regulatory approvals to all relevant parties involved with this study at UCLH.
Please insert a copy of this email in your site file.

https://outlook.office.com/mail/id/AAQkAGIyMzE4MmFkLWQ1MGQtNDJmOC1hOTVkLWNjNzRhODYwMGRhMQAQAHADYiaDxEVHnVDgFsawLPk%3D 1/4



SOMMERS, Beverley (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST)<beverley.sommers@nhs.net>
To:Knight, Rachel; Porter, Stephen
Cc:Hoskins, Victoria; Szczepkowska, Beata; Hoskins, Victoria;+1 other
Wed 07/05/2025 11:42 AM
Flagged

318039_Non Substantial Amendment 3_ locked.pdf
218 KB

TRACKED Protocol+EDUCAT-ED_V5_18-03-2025.docx
191 KB

CLEAN Protocol+EDUCAT-ED V5 18-03-2025.docx
177 KB

3 attachments (586 KB)▯Save all to OneDrive - University College London▯Download all
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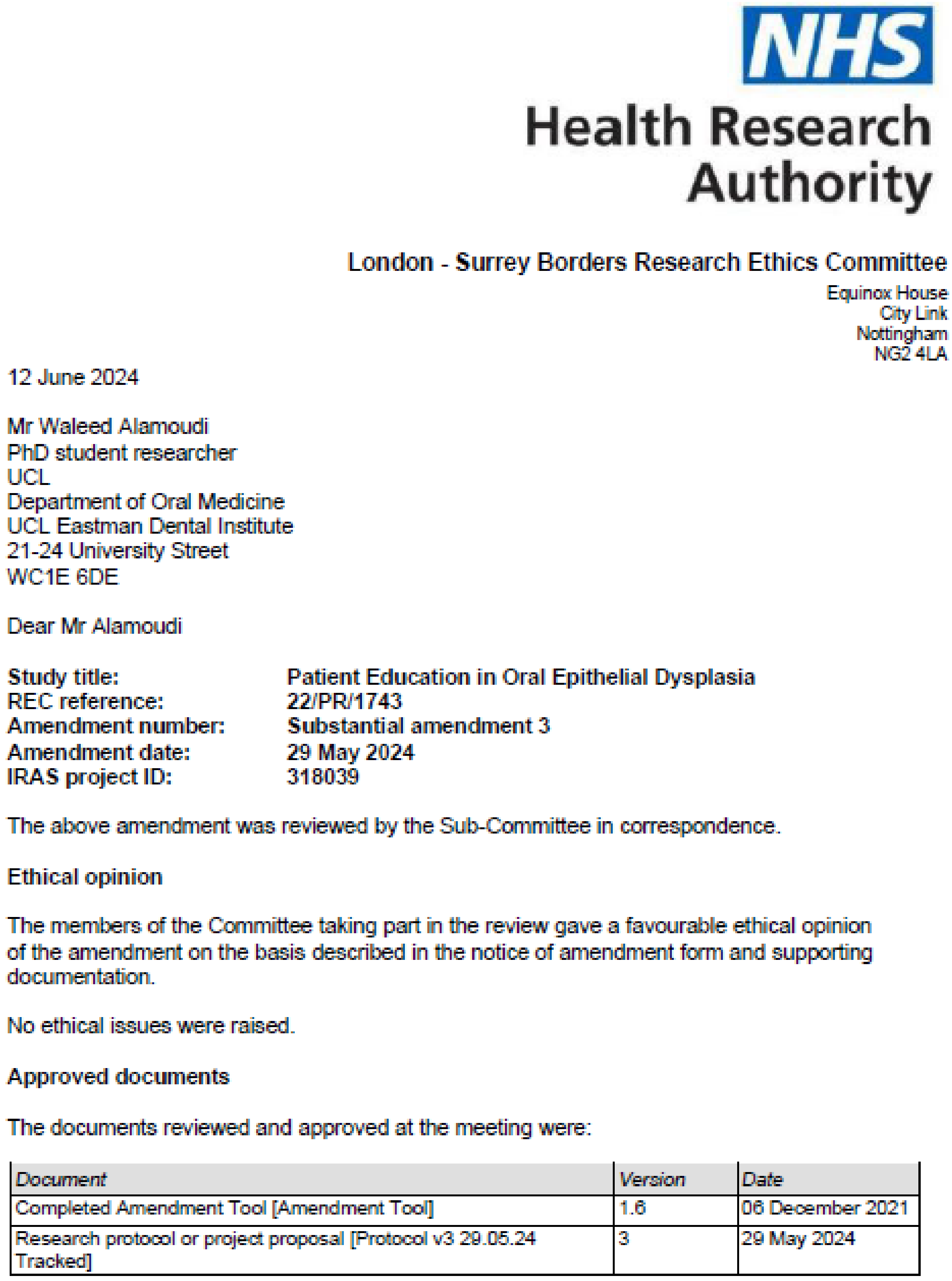
Project EDGE ID: 153192 (Please quote in all correspondence)
IRAS ID: 318039
REC Ref: 22/PR/1743
Title: EDUCAT-ED (V1.0)
Amendment: NSA03

Dear Prof Stephen Porter
The Joint Research Office (JRO) acknowledges receipt of the above amendment which has now been authorised by UCL Sponsor. Please accept this email & attached sponsor authorised amendment tool as confirmation of sponsor approval.
Please proceed with submission to regulatory review bodies HRA, NHS REC (who issued your original Favourable Opinion letter) and other review bodies in the authorised amendment tool as applicable, for assessment and approval. Please log into the online amendment submission portal, this requires a separate login to your main IRAS account. If you have not used it before you may need to set up a new account. Please follow the on-screen instructions to create an account. If you have any difficulty creating an account, please contact the Technical Helpdesk for support at helpdesk@myresearchproject.org.uk.
After regulatory review approval is provided; please ensure you send this across with the final approved amendment document set to the JRO on the following email address: uclh.randd@nhs.net. **If CTU is involved in the study, then please ensure you send the amendment for their feasibility review.** Once you have done this, please take this as your confirmation of continued Capacity & Capability and you may go ahead and implement the amendment at UCLH only. For all other research sites and studies that involve the UCLH CTU please ensure you send the amendment documents to respected R&D department for their review and acknowledgement so they can then issue continued capacity and capability for the amendment.
You must ensure that you localise all patient facing documentation prior to consenting participants; this will be subject to random audit checks.



NHS
Health Research
Authority

London - Surrey Borders Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

12 June 2024

Mr Waleed Alamoudi
PhD student researcher
UCL
Department of Oral Medicine
UCL Eastman Dental Institute
21-24 University Street
WC1E 6DE

Dear Mr Alamoudi

Study title:	**Patient Education in Oral Epithelial Dysplasia**
REC reference:	**22/PR/1743**
Amendment number:	**Substantial amendment 3**
Amendment date:	**29 May 2024**
IRAS project ID:	**318039**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

No ethical issues were raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment Tool]	1.6	06 December 2021
Research protocol or project proposal [Protocol v3 29.05.24 Tracked]	3	29 May 2024

NHS
Health Research Authority

London - Surrey Borders Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

04 November 2024

Mr Waleed Alamoudi
PhD student researcher
UCL
Department of Oral Medicine
UCL Eastman Dental Institute
21-24 University Street
WC1E 6DE

Dear Mr Alamoudi

Study title: **Patient Education in Oral Epithelial Dysplasia**
REC reference: **22/PR/1743**
Amendment number: **Substantial Amendment 04**
Amendment date: **09 September 2024**
IRAS project ID: **318039**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

No ethical issues were raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [318039_Substantial Amendment 04_locked]	1.6	09 September 2024
Other [UCL Sponsorship Approval]	N/A	17 October 2024
Other [No Cost Extension Letter from CI]	N/A	16 October 2024
Other [Permission from Student - ODIN-Q Data]	N/A	18 September 2024

Appendix 2. Participant Information Sheets, Informed Consent Forms and GPletters for both study phases

UCL
NHS
University College London Hospitals
NHS Foundation Trust

Royal National ENT and Eastman Dental Hospital

47-49 Huntley Street

London

WC1E 6DG

Participant Information Sheet for phase 1

Title of the Project: Patient **Educat**ion in Oral **E**pithelial **D**ysplasia (**EDUCAT-ED** Study, phase 1)

Investigators: Professor Stephen Porter, Dr Richeal Ni Riordain, Professor Stefano Fedele, Waleed Alamoudi (PhD student)

Please read this sheet carefully. Please ask if you do not understand or would like more information.

1. Invitation to participate

We would like to invite you to take part in our research study. This is a student research project which will be contributing to a PhD. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

2. What is the purpose of the study?

Research has showed that patients receiving appropriate and timely information about their disease report less uncertainty and distress, show better compliance and adherence to therapy, are more likely to fully take part in decisions about their health care, and show increased ability to cope with their disease. It is however difficult for doctors to understand what patients want to know about their disease, as patients' priorities often do not correspond with topics considered important by healthcare professionals. In the management of chronic and perhaps cancer-linked disease, a specific standardised questionnaire may overcome this problem. Doctors can use this questionnaire to understand the informational needs priorities of individual patients and provide them with tailored and personalised information.

Using a questionnaire we specifically developed for this condition, we wish to investigate whether your informational needs concerning oral epithelial dysplasia

(OED), which you may have experienced since being diagnosed, were met. In the same questionnaire, we will ask you to select the important information aspects that you wish to know. Your responses to this questionnaire will be used to test the suitability of this questionnaire to be used in clinical care for individuals affected by OED.

3. Why have I been invited?

You have been identified as a potential participant by doctors in your clinic because you have been diagnosed with OED.

4. Do I have to take part?

No, it is up to you to decide whether or not to join the study. If you are interested, we will go through this information sheet with you and answer any questions you may have regarding the study. You can take as much time as you need to decide if you would like to participate in the study, and you are free to take this information sheet with you and consider the matter further at home. Even if you agree to take part in the study you are free to withdraw at any time, without giving a reason. This would not affect the standard care you receive in this hospital. Participation in this study will in no way affect your legal rights.

5. How do I take part in the study?

If you decide to take part in this study, you will be asked to sign a consent form, which you will have a copy of.

6. What will happen to me if I take part?

A total of 165 individuals with OED will participate in this part of the study. You will be asked to complete the Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q). The estimated time needed to complete the questionnaire may last between 10-15 minutes. If you wish to complete the ODIN-Q at another time, a stamped addressed envelope will be provided for you to return the questionnaire to the hospital on a later day.

7. What will I have to do?

Potential participants will be identified in routine Oral Medicine clinics. If you have been selected as a potential patient for the study we will verbally introduce the study to you and if you are amenable we will provide you with the associated Patient Information Sheet (PIS). You will then be given adequate time to decide whether to participate further in the study. The inclusion criteria are as follows:

A diagnosis of OED as per current standard diagnostic criteria. No concurrent malignancy/radiotherapy/chemotherapy in the head and neck or elsewhere. You will be invited to complete a recently developed questionnaire about the information needs of patients with OED. This questionnaire will be completed initially at your review appointment in Royal National ENT & Eastman Dental Hospitals or we will provide you with the questionnaire and a stamped addressed envelope to allow you to return it completed to the UCL Eastman Dental Institute.

8. Will my normal care be affected?

Your treatment will not be altered in any way by your participation in this study. Also, we would like to inform your general practitioner if you decide to participate.

9. What are the possible risks of taking part?

We do not foresee any risks in participating in this research.

10. Are there any benefits?

We hope that by learning what information patients with OED require we can provide tailored information that may reduce worries or concerns patients have about their health. It may also allow patients to participate more in decisions about their healthcare, as they will be better informed about the risks and benefits of treatments.

11. What happens when the research study stops?

After we have performed our analysis we can provide you with the results and explain what it means. You will need to continue the regular visits to the Oral Medicine Department at the Royal National ENT & Eastman Dental Hospitals. The results of this study might also be published in scientific conferences and medical journals.

12. What will happen to my data?

We will need to use information from you and from your medical records for this research project. This information will include your NHS number, name, contact details, history of radiation, history of head and neck cancer. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

13. What happens if I decide to withdraw from the study?

You can stop being part of the study at any time, without giving a reason. This will not affect your medical care in any way. We would still like to use the information you have already provided for the purposes of the study. If you do not want this to happen, please tell us and we will stop.

14. What happens if I give informed consent and lose capacity to consent during study?

You will be withdrawn from the study. Identifiable data with consent would be retained and used in the study. No further data would be collected.

15. What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information concerning this is given in the next part of this information sheet. If you have any concerns or complaints you should contact your study doctor in the first instance.

University College London (UCL) holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach of the hospital's duty of care or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

If you are concerned about any aspect of this study, please speak to the researchers who will do their best to answer your questions. Please contact Professor Stephen Porter (s.porter@ucl.ac.uk). If you remain unhappy, you can make a formal complaint through the National Health Service (NHS) complaints procedure. Details can be obtained through the University College London Hospitals (UCLH) Patient Advice and Liaison Service (PALS) on 0207 3447 3041, email: PALS@uclh.nhs.uk, address: PALS, Ground Floor Atrium, University College Hospital, and 235 Euston Road, London, NW1 2BU.

16. How will my information be kept confidential?

You will be given a unique personal identification code on both copies of the questionnaire. We will store the questionnaire and the code sheet in a locked filing cabinet in a secure magnetic card-accessed building. A second copy will be kept on a password-protected computer as a backup. Only researchers associated with the study will have access to completed questionnaires and your code. You will not be able to be identified through any of the data and information released from this study.

All patient information will be treated in the strictest confidence, by the UK Data Protection Act 2018. UCL is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for 3 years after the study has finished.

The information will include:

Initials.

NHS number.

Contact details.

Medical details in relation to the research project.

This information will be obtained from you and the medical records. You can find out more about how we use your information:

at www.hra.nhs.uk/information-about-patients/

by sending an email to data-protection@ucl.ac.uk

- by asking one of the research team: Professor Stephen Porter: s.porter6@nhs.net

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

17. Who will have access to my information?

- University College London Hospitals (UCLH) will collect information from you and your medical records for this research study by our instructions.

  UCLH will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded for your care, and oversee the quality of the study. Certain individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. UCLH will pass these details to UCL along with the information collected from you. *UCL will only receive information without any identifying information. The people who analyse the information will not* *be able to identify you and will not be able to find out your name, NHS number or contact details.*

- *UCLH will keep identifiable information about you* from this study for 3 years after the study has finished.

18. What if new information becomes available?

Sometimes during a research project, new information becomes available. If this happens, we shall tell you about it and discuss whether you want to continue in the study. If you decide to continue you will be asked to sign an updated consent form.

19. Will my GP be informed?

With your consent we would like to inform your GP of your participation in this study by sending a letter. If you would rather we do not inform your GP, you can indicate so by leaving that option blank in the consent form.

20. What will happen to the study results?

The results will be used to perform medical research, and the results might be disseminated in scientific conferences and as publication in medical/scientific journals. We hope that this will help in the management of OED. No details that specifically identify you will be included. We can provide you with details of any publication and a lay summary of the results of the study, at your request**.** These can be sent to you with one of your clinical appointment letters. Please use the contact details at the back of this document to reach us.

21. Who is organizing and funding the research

This study has been designed and organized by senior staff members of the Eastman Dental Institute. The research costs for the study will be supported by a PhD Scholarship and NHS treatment costs [standard and excess] will be supported by UCLH and Service Support Costs via the NIHR Clinical Research Network North Thames.

22. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable ethical opinion by NHS Research Ethics Committee.

23. Further information and contact details

You are encouraged to ask any questions you wish, before, during or after your participation in this study.

Name : Professor Stephen Porter (Chief Investigator)
Telp : +44(0)2080117741
e-mail : s.porter6@nhs.net
Address : 21-24 University Street
Eastman Dental Institute, London, WC1E 6DE

Name : Dr. Richeal Ni Riordain (Principal Investigator)
Telp : +44 (0) 2034567890
e-mail : Richeal.NiRiordain@uclh.nhs.uk
Address : 21-24 University Street
Eastman Dental Institute, London, WC1E 6DE

Name : Waleed Alamoudi (student researcher)
Telp : +44 (0) 7576960677
e-mail : waleed.alamoudi@nhs.net
Address : 21-24 University Street
Eastman Dental Institute, London, WC1E 6DE

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

University College London Hospitals
NHS Foundation Trust
Royal National ENT and Eastman Dental Hospital

47-49 Huntley Street

London

WC1E 6DG

INFORMED CONSENT FORM 1

Title project: Patient Education in Oral Epithelial Dysplasia (EDUCAT-ED Study, phase 1)

Investigators: Professor Stephen Porter, Dr Richeal Ni Riordain, Professor Stefano Fedele, Waleed Alamoudi (PhD Student)

Please initial here

1.	I confirm that I have read and understood the information sheet dated 16/01/2023 version 2.0 for the above study. I have had the opportunity to consider information, ask questions, and had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am are free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3.	I agree that sections of my medical notes may be looked at by researchers, responsible individuals from regulatory authorities where it is relevant to my taking part in research, the sponsor University College London (UCL), and NHS Trust. I give permission for these individuals to have access to my records.	
4.	I agree to be contacted by letter/phone/email in case researchers need to clarify some information about my health, or using my data and sample already collected for research even though I withdraw from the study. I understand I do not have to agree with this and can withdraw at any time without my medical care being affected.	
5.	I agree to my GP being informed of my involvement in this study	
6.	I agree to take part in the above study	

Name of participant ____________________ Date __________

____________________ __________

Name of person taking consent (If different from researcher)	Date
Researcher	Date

When completed:

1 paper copy to be given to the participant, 1 copy (original) to be filed in investigator site file (and scanned to electronic patient records.

University College London Hospitals
NHS Foundation Trust
Royal National ENT and Eastman Dental Hospital
47-49 Huntley Street
London
WC1E 6DG

GP letter for phase 1

Professor Stephen Porter
Institute Director, Professor of Oral Medicine
UCL Eastman Dental Institute
21-24 University Street
London, WC1E 6DE
Email: s.porter@ucl.ac.uk

Date:

Dear Dr

Patient name:
Patient DOB:

Patient Address:

The above patient has kindly agreed to participate in a student PhD study UCL investigating the informational needs and education of patients with oral epithelial dysplasia (EDUCAT-ED Study).

The patient will be asked to provide his/her information needs concerning oral epithelial dysplasia, which he/she may have experienced since being diagnosed and about his/her preferences of information about this condition using a recently developed instrument, oral epithelial informational needs questionnaire (ODIN-Q). This new instrument will then undergo psychometric testing to ensure it is valid and reliable for use in a clinical setting.

Yours sincerely,

Professor Stephen Porter

Chief Investigator

NHS
University College London Hospitals
NHS Foundation Trust
Royal National ENT and Eastman Dental Hospital
47-49 Huntley Street
London
WC1E 6DG

Participant Information Sheet for phase 2

Title of the Project: Patient **Educat**ion in Oral **E**pithelial **D**ysplasia (**EDUCAT-ED** Study, phase 2)

Investigators: Professor Stephen Porter, Dr Richeal Ni Riordain, Professor Stefano Fedele, Waleed Alamoudi (PhD student)

Please read this sheet carefully. Please ask if you do not understand or would like more information

1. Invitation to participate

We would like to invite you to take part in our research study. This is a student research project which will be contributing to a PhD. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

2. What is the purpose of the study?

Research has showed that patients living with a chronic and potentially malignant disease such as oral epithelial dysplasia (OED) need to be aware oftheir disease and be provided with the information necessary to maintain their good health. Those who receive appropriate and timely information about theirdisease report less uncertainty and distress, show better compliance andadherence to therapy, are more likely to fully take part in decisions about their own health care, and show increased ability to cope with their disease.

Reliable personalized health information can then be provided for patients withOED by their doctors in the form of written or visual health information (leaflets and videos). It is however difficult for doctors to understand what patients want to know about their disease, as patients' priorities often do not correspond with topics considered important by healthcare professionals. We therefore have investigated the informational needs of a group of 165 patients with OED attending Royal National ENT & Eastman Dental Hospitals in the first phase of the current study (EDUCAT-ED study, phase 1). Those patients were asked about their unmet information needs since being diagnosed and which aspect of information they believe is important to them.

We then developed a patient information leaflet (PIL) and patient information video clip (PIVC) on OED which have been reviewed by specialists, nurses and junior doctors. This phase of the study aims to evaluate the change in patient information after the application of these educational tools via the re-administration of Oral Epithelial Informational Needs Questionnaire (ODIN-Q) in a cohort of 100 patients who participated in phase 1. The information presented in these educational tools needs to be easy to understand. We also aim to explore the most effective methods and patients' preferred ways of delivering easy and comprehensive educational information about OED.

3. Why have I been invited?

You have been identified as a potential participant by doctors in your clinic because you have been diagnosed with OED.

4. Do I have to take part?

No, it is up to you to decide whether or not to join the study. If you are interested, we will go through this information sheet with you and answer any questions you may have regarding the study. You can take as much time as you need to decide if you would like to participate in the study, and you are free to take this information sheet with you and consider the matter further at home. Even if you agree to take part in the study you are free to withdraw at any time, without giving a reason. This would not affect the standard care you receive in this hospital. Participation in this study will in no way affect your legal rights.

5. How do I take part in the study?

If you decide to take part in this study, you will be asked to sign a consent form, which you will have a copy of.

6. What will happen to me if I take part?

A total of 100 individuals with OED will participate in this part of the study. You will be asked to read or listen to the educational information presented in a leaflet or video about OED and complete the ODIN-Q afterwards. The estimated time needed to finish the educational material and complete the ODIN-Q may last between 15-20 minutes.

7. What will I have to do?

Potential participants will be identified in routine Oral Medicine clinics. If you have been selected as a potential patient for the study, we will verbally introduce the study to you and if you are amenable, we will provide you with the associated Patient Information Sheet (PIS). You will then be given adequate time to decide whether to participate further in the study. The inclusion criteria are as follows: A diagnosis of OED as per current standard diagnostic criteria. Have prior participation in phase 1 of the present study (EDUCAT-ED, phase 1).

8. Will my normal care be affected?

Your treatment will not be altered in any way by your participation in this study. Also, we would like to inform your general practitioner if you decide to participate.

9. What are the possible risks of taking part?

We do not foresee any risks in participating in this research.

10. Are there any benefits?

We hope that by learning what information patients with OED require we can provide tailored educational information that may reduce worries or concerns patients have about their health.

11. What happens when the research study stops?

After we have performed our analysis, we can provide you with the results and explain what it means. You will need to continue the regular visits to the Oral Medicine Department at the Royal National ENT & Eastman Dental Hospitals. The results of this study might also be published in scientific conferences and medical journals.

12. What will happen to my data?

We will need to use information from you and from your medical records for this research project. This information will include your NHS number, name, contact details, history of radiation, history of head and neck cancer. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

13. What happens if I decide to withdraw from the study?

You can withdraw from the study at any time. This will not affect your medical care in any way. We would still like to use the information you have already provided for the purposes of the study. If you do not wish us to do so, please indicate that in the consent form by leaving that option blank.

14. What happens if I give informed consent and lose capacity to consent during study?

You will be withdrawn from the study. Identifiable data with consent would be retained and used in the study. No further data would be collected.

15. What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information concerning this is given in the next part of this information sheet. If you have any concerns or complaints you should contact your study doctor in the first instance.

University College London (UCL) holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach of the hospital’s duty of care or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

If you are concerned about any aspect of this study, please speak to the researchers who will do their best to answer your questions. Please contact Professor Stephen Porter (s.porter@ucl.ac.uk). If you remain unhappy, you can make a formal complaint through the National Health Service (NHS) complaints procedure. Details can be obtained through the University College London Hospitals (UCLH) Patient Advice and Liaison Service (PALS) on 0207 3447 3041, email: PALS@uclh.nhs.uk, address: PALS, Ground Floor Atrium, University College Hospital, and 235 Euston Road, London, NW1 2BU.

16. How will my information be kept confidential?

You will be given a unique personal identification code on both copies of the questionnaire. We will store the questionnaire and the code sheet in a locked filing cabinet in a secure magnetic card-accessed building. A second copy will be kept on a password-protected computer as a backup. Only researchers associated with the study will have access to completed questionnaires and your code. You will not be able to be identified through any of the data and information released from this study.

All patient information will be treated in the strictest confidence, by the UK Data Protection Act 2018. UCL is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for 3 years after the study has finished.

The information will include:

Initials.

NHS number.

Contact details.

Medical details in relation to the research project.

This information will be obtained from you and the medical records. You can find out more about how we use your information:

at www.hra.nhs.uk/information-about-patients/

by sending an email to data-protection@ucl.ac.uk

by asking one of the research team: Professor Stephen Porter: s.porter6@nhs.net

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

17. Who will have access to my information?

University College London Hospitals (UCLH) will collect information from you and your medical records for this research study by our instructions. *UCLH will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded for your care, and oversee the quality of the study. Certain individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study.* UCLH will pass these details to UCL along with the information collected from you. *UCL will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details. UCLH will keep identifiable information about you* from this study for 3 years after the study has finished.

18. What if new information becomes available?

Sometimes during a research project, new information becomes available. If this happens, we shall tell you about it and discuss whether you want to continue in the study. If you decide to continue you will be asked to sign an updated consent form.

19. Will my GP be informed?

With your consent we would like to inform your GP of your participation in this study by sending a letter. If you would rather we do not inform your GP, you can indicate so by leaving that option blank in the consent form.

20. What will happen to the study results?

The results will be used to perform medical research, and the results might be disseminated in scientific conferences and as publication in medical/scientific journals. We hope that this will help in the management of OED. No details that specifically identify you will be included. We can provide you with details of any publication and a lay summary of the results of the study, at your request**.** These can be sent to you with one of your clinical appointment letters. Please use the contact details at the back of this document to reach us.

21. Who is organizing and funding the research

This study has been designed and organized by senior staff members of the Eastman Dental Institute. The research costs for the study will be supported by a PhD Scholarship and NHS treatment costs [standard and excess] will be supported by UCLH and Service Support Costs via the NIHR Clinical Research Network North Thames.

22. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable ethical opinion by NHS Research Ethics Committee.

23. Further information and contact details

You are encouraged to ask any questions you wish, before, during or after your participation in this study.

Name : Professor Stephen Porter (Chief Investigator)

Telp : +44(0)2080117741

e-mail : s.porter6@nhs.net

Address : 21-24 University Street

Eastman Dental Institute, London, WC1E 6DE

Name : Dr. Richeal Ni Riordain (Principal Investigator)

Telp : +44 (0) 2034567890

e-mail : Richeal.NiRiordain@uclh.nhs.uk

Address : 21-24 University Street

Eastman Dental Institute, London, WC1E 6DE

Name : Waleed Alamoudi (student researcher)

Telp : +44 (0) 7576960677

e-mail : waleed.alamoudi@nhs.net

Address : 21-24 University Street

Eastman Dental Institute, London, WC1E 6DE

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

University College London Hospitals
NHS Foundation Trust
Royal National ENT and Eastman Dental Hospital

47-49 Huntley Street

London

WC1E 6DG

INFORMED CONSENT FORM 2

Title project: Patient Education in Oral Epithelial Dysplasia (EDUCAT-ED Study, phase 2)

Investigators: Professor Stephen Porter, Dr Richeal Ni Riordain, Professor Stefano Fedele, Waleed Alamoudi (PhD Student)

Please initial here

1.	I confirm that I have read and understood the informationsheet dated 16/01/2023 version 2.0 for the above study. I have had the opportunity to consider information, askquestions, and had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am are free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3.	I agree that sections of my medical notes may be looked at by researchers, responsible individuals from regulatory authorities where it is relevant to my taking part in research, the sponsor University College London (UCL), and NHS Trust. I give permission for these individuals to have access to my records.	
4.	I agree to be contacted by letter/phone/email in case researchers need to clarify some information about my health, or using my data and sample already collected forresearch even though I withdraw from the study. I understand I do not have to agree with this and can withdraw at any time without my medical care being affected.	
5.	I agree to my GP being informed of my involvement in this study	
6.	I agree to take part in the above study	

Name of participant	Date
Name of person taking consent (If different from researcher)	Date
Researcher	Date

When completed:

1 paper copy to be given to the participant, 1 copy (original) to be filed in investigator site file (and scanned to electronic patient records.

University College London Hospitals
NHS Foundation Trust

Royal National ENT and Eastman Dental Hospital
47-49 Huntley Street
London
WC1E 6DG

GP letter for phase 2

Professor Stephen Porter
Institute Director, Professor of Oral Medicine
UCL Eastman Dental Institute
21-24 University Street
London, WC1E 6DE
Email: s.porter@ucl.ac.uk

Date:

Dear Dr

Patient name:

Patient DOB:

Patient Address:

The above patient has kindly agreed to participate in a student PhD study UCL investigating the informational needs and education of patients with oral epithelial dysplasia (EDUCAT-ED Study).

A patient information leaflet (PIL) and patient information video clip (PIVC) on oral epithelial dysplasia were generated using patients' feedback to an oral epithelial dysplasia information needs questionnaire, (ODIN-Q). This new leaflet and video clip will be presented during the regular clinical care for individuals with oral epithelial dysplasia who attend UCLH Eastman Dental Hospital. The patient will be asked to read the PIL or watch the PIVC and then complete ODIN-Q to examine the change in their knowledge about OED, and to determine the most effective means of delivering easy, comprehensive, and understandable educational information.

Yours sincerely,

Professor Stephen Porter

Chief Investigator

Appendix 3. Oral Epithelial Informational Needs Questionnaire (ODIN-Q)

To ensure making informed decisions, and to help us plan better services for people affected by oral epithelial dysplasia (OED), **we are interested to know whether your information needs, which you may have experienced since being diagnosed, have been met and your preferences of information about OED.**

At section 1, please **fill/tick** that best describes your **background information**.

1. Background information

Please answer the following questions in the spaces provided, circle or tick the most appropriate options.

1. Age: _________

2. Gender (please tick as necessary): ☐ Male ☐ Female

3. Ethnicity:

A. White

☐ White – British

☐ White – Irish

☐ White - Any other White background

B – Mixed

☐ Mixed - White and Black Caribbean

☐ Mixed - White and Black African

☐ Mixed - White and Asian

☐ Mixed - Any other mixed background

C – Asian or Asian British

☐ Asian or Asian British – Indian

☐ Asian or Asian British – Pakistani

☐ Asian or Asian British – Bangladeshi

☐ Asian or Asian British - Any other Asian background

D – Black or Black British

☐ Black or Black British – Caribbean

☐ Black or Black British – African

☐ Black or Black British - Any other

Black background

E – Chinese or another ethnic group

☐ Chinese

☐ Any other ethnic group

4. Educational level:

☐ Less than high school ☐ Bachelor's degree ☐ High school diploma

☐ Postgraduate degree ☐ Some college ☐ Other (please describe): ______

5. Employment status:

☐ Student ☐ Employed full-time ☐ Employed part-time

☐ Self-employed ☐ Retired ☐ Other (please specify): ______

6. Smoking:

☐ Never smoke ☐ Past smoker ☐ Current smoker

If choose current smoker, please tick one or more of the following:

☐ Chewed tobacco (Type?): _________ ☐ Cigarettes (number/day): _________

☐ Other (Please specify): ________

7. Alcohol:

☐ Never drink ☐ Past drinking ☐ Current drinking

If you have indicated that you are currently drinking, can you specify how many units of alcohol do you have on a typical day when you are drinking?
☐ 1-2 units a day ☐ 3-4 units ☐ 5-6 units ☐ 7-8 units ☐ 9 or

more units

* Please refer to the NHS website for further information about alcohol units
https://www.nhs.uk/Livewell/alcohol/Pages/alcohol-units.aspx

2. Information needs in oral epithelial dysplasia (OED)

For **every item** on the following pages, please rate '**the amount of information you received since being diagnosed'** and '**is this item important to you?** on a scale from 1 to 4. If you are unsure about how to answer a question, give **the best answer** you can.

Information about the disease	Amount of information received since being diagnosed:				Is this item important to you?			
1. How common the disease is?	☐Too much	☑Enough	☐Not enough	☐None	☑Very	☐Yes	☐Not very	☐Not at all

For example:

If you answered as we have, it means you have received **'enough'** information about how common the disease is, and it is **'very'** important for you to know.

Tick only one box for each section

Information about the disease	Amount of information received since being diagnosed:				Is this item important to you?			
1. What oral epithelial dysplasia (OED) is?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
2. How common is it?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
3. What are the risk factors for	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

developing it?								
4. How it looks in the mouth or lips?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
5. Whether it is contagious or not?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
6. About the role of human papilloma virus.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
7. About the disease grades and risk of developing mouth cancer.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
8. What will happen if I continue to smoke or drink alcohol?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
9. What is a safe level of alcohol to drink?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
10. What is likely to happen to OED in the future?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

Information about investigative tests of OED	Amount of information received since being diagnosed:				Is this item important to you?			
11. About the screening and early detection.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

12. What are the benefits, risks, how each test works, and the meaning of test results?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

Information about treatments for OED	Amount of information received since being diagnosed:				Is this item important to you?			
13. What will happen if it is not treated?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
14. About treatment options, benefits, risks, and how each treatment works?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
15. How the disease/treatment may affect the quality of life?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
16. About self-management at home.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
17. About complementary and alternative medicine	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

(e.g. herbal medicine).								
18. What are the chances of a cure?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

Physical aspects of OED	Amount of information received since being diagnosed:				Is this item important to you?			
19. How frequent and severe are the symptoms (e.g. ulceration, swelling, or bleeding)?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
20. About chances of spreading to adjacent or distant body part?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
21. About the effects of the disease/treatment on daily physical activities (e.g. eating, speaking, or maintenance of oral hygiene).	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
22. About the diet and nutrition.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

Psychosocial aspects of OED	Amount of information received since being diagnosed:				Is this item important to you?			
23. About the fear of progression to cancer.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

24. How to cope with the possible effects of the disease/treatment?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
25. How the disease/treatment may affect social life (e.g. close relationships, family, and friends)?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

Medical system and access to information about OED	Amount of information received since being diagnosed:				Is this item important to you?			
26. About the experience of your doctor and other health care staff.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
27. About seeking another professional opinion.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
28. How to obtain physical support and advice (e.g. who to contact if the warning signs appear)?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
29. How to obtain psychological support and advice?	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
30. About community/ patient support groups.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
31. About health								

promotion (e.g. promoting one’s health literacy).	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
32. About the lifestyle adjustment (e.g. tobacco and alcohol cessation, and safe sex).	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all
33. About the research and recruitment for clinical trials.	☐Too much	☐Enough	☐Not enough	☐None	☐Very	☐Yes	☐Not very	☐Not at all

- Please **circle** your **one or more choice** to receive information from with regard to OED:
  1. One-on-one meeting
  2. Group information session
  3. Written information (e.g. pamphlets, books, world wide web)
  4. Audio-visual information (TV, YouTube, audio recording, radio)

- If you have selected **‘One-on-one meeting’**, please **rank** the health care professionals that you want to receive the information from (from 1 to 4):
  - a. General dental practitioner
  - b. General practitioner
  - c. OED specialists (e.g. specialists in oral medicine, oral surgery, or ENT)
  - d. Auxiliary medical staff (e.g. medical or dental nurses)

- Please indicate other topics not included in the list.

For further information please contact:
Name **:** Professor Stephen Porter
e-mail **:** s.porter@ucl.ac.uk
Address **:** 21-24 University Street
Eastman Dental Institute, London, WC1E 6DE

Appendix 4. The demographic and clinical characteristics for participants for the assessment of disease specific information needs (n=102).

Participant n.	Gender/age	Ethnic background	Education level	Employment position	Smoking status	Alcohol status	Diagnosis (years)	OED lesions n.	(degree)	Oral condition/ disease
101	F/76	White - British	Bachelor's degree	Retired	Current	Past	13	2	BM (mild)	OLP
102	M/71	White - British	Less than high school	Retired	Never	Current	12	1	HP (mild)	OLP
103	F/82	White - Other	Less than high school	Retired	Past	Past	17	1	FOM (mild)	OLP
104	M/71	White - British	Less than high school	Retired	Past	Never	10	3	BM, HP (moderate, severe)	OLP, OSCC
105	F/70	White - Other	Bachelor's degree	Retired	Never	Never	10	1	T (mild, moderate, severe)	OLP
106	F/76	White - British	Postgraduate degree	Self-employed	Past	Never	3	2	FOM, G (mild, moderate)	OLP
107	F/67	White - British	Bachelor's degree	Retired	Current	Current	6	2	G (mild, moderate)	OLP
108	F/75	White - British	Less than high school	Retired	Never	Never	4	7	G (moderate, severe)	OLP
109	F/53	White - Other	Bachelor's degree	Self-employed	Past	Past	2	1	T (mild, moderate)	OLP
110	F/66	White - British	Postgraduate degree	Self-employed	Never	Current	6	1	T (moderate, severe)	OLP
111	M/63	White - Other	Bachelor's degree	Self-employed	Past	Past	3	1	T (moderate)	OLP
112	F/43	White - British	Postgraduate degree	Self-employed	Past	Current	7	1	T (mild, moderate, severe)	OLP

113	M/54	Asian or Asian British - Other	Postgraduate degree	Self-employed	Never	Current	11	5	BM, G (mild, moderate)	OSF, OSCC
114	F/65	Asian or Asian British - Indian	High school diploma	Employed full-time	Never	Never	4	3	BM, G, FOM (mild, moderate)	OLP
115	F/58	Asian or Asian British - Indian	High school diploma	Employed full-time	Current	Past	7	2	BM (mild, moderate)	OSF
116	M/47	White - Other	Postgraduate degree	Employed full-time	Never	Current	16	2	T, FOM (mild, moderate, severe)	OLP, OSCC
117	F/60	White - British	Bachelor's degree	Retired	Past	Current	4	1	T (mild, moderate, severe)	OLP
118	M/66	White - British	Postgraduate degree	Retired	Never	Never	8	2	BM (mild, moderate)	OLP
119	M/57	White - Other	High school diploma	Retired	Past	Current	3	1	T (mild)	OLP
120	F/74	White - British	Some college	Retired	Past	Current	2	1	BM (mild)	OLP
121	M/66	Asian or Asian British - Indian	Postgraduate degree	Retired	Past	Never	2	1	G (mild)	OLP
122	F/57	Asian or Asian British - Indian	Bachelor's degree	Employed full-time	Never	Never	2	1	BM (moderate, severe)	OLP
123	F/67	Asian or Asian British - Indian	Less than high school	Retired	Never	Never	7	2	HP, G (moderate, severe)	OLP, OSCC
124	F/62	White - British	High school diploma	Retired	Past	Current	8	1	T (moderate)	OLP

125	F/76	White - British	High school diploma	Retired	Never	Never	9	2	BM, G (mild, moderate, severe)	OLP
126	F/70	White - Other	Postgraduate degree	Retired	Never	Current	6	1	BM (mild)	OLP, OSCC
127	F/74	Asian or Asian British - Indian	High school diploma	Retired	Never	Current	6	3	T, BM (moderate, severe)	OLP, OSF
128	F/56	Mixed - White and Asian	Bachelor's degree	Employed part-time	Past	Current	3	1	G (mild, moderate)	OLP
129	F/68	Asian or Asian British - Pakistani	Less than high school	Retired	Never	Never	11	1	T (mild, moderate)	OLP
130	M/70	White - Other	Some college	Retired	Current	Never	17	1	BM (mild, moderate)	OLP
131	F/62	White - British	Some college	Retired	Past	Current	7	1	T (mild)	OLP
132	M/43	Asian or Asian British - Pakistani	Bachelor's degree	Retired	Past	Never	12	3	HP (mild)	OLP
133	M/73	Asian or Asian British - Other	Some college	Retired	Past	Past	12	1	L (severe)	OLP, OSCC
134	M/66	Asian or Asian British - Other	Some college	Retired	Never	Never	2	1	L (mild, moderate, severe)	OLP
135	M/74	White - British	Some college	Retired	Current	Current	4	2	FOM (mild, moderate, severe)	OLP, OL
136	F/61	White - British	Bachelor's degree	Self-employed	Current	Current	3	1	BM (mild, moderate, severe)	OLP

137	M/64	White - British	High school diploma	Employed full-time	Current	Past	3	1	BM (mild)	OLP
138	F/54	White - Other	Postgraduate degree	Employed full-time	Never	Past	19	9	T (moderate, severe)	OLP
139	M/63	White - British	High school diploma	Retired	Current	Current	3	1	BM (mild)	OLP
140	F/81	White - British	High school diploma	Retired	Past	Current	11	1	T (moderate)	OLP, OSCC
141	F/64	White - Other	Bachelor’s degree	Employed full-time	Never	Current	10	1	G (mild)	OLP
142	F/57	Asian or Asian British - Bangladeshi	High school diploma	Employed part-time	Never	Never	3	1	T (mild, moderate)	OLP
143	F/67	White - Other	Some college	Retired	Never	Never	3	3	T, BM, G (mild, moderate, severe)	OLP, OSCC
144	F/78	White - British	Some college	Retired	Never	Current	13	1	T (mild)	OLP
145	F/46	Asian or Asian British - Other	Less than high school	Retired	Never	Never	3	1	HP (mild)	OLP
146	M/78	White - British	High school diploma	Retired	Never	Current	4	1	T (mild)	OLP
147	M/68	White - Other	Postgraduate degree	Retired	Current	Past	3	3	G (moderate, severe)	OLP, OSCC
148	F/62	Asian or Asian British - Indian	Some college	Self-employed	Never	Current	1	1	T (severe)	OLP
149	M/75	White - British	Less than high school	Retired	Past	Never	7	1	L (severe)	OLP, OSCC
150	F/25	White - British	Bachelor’s degree	Employed part-time	Never	Current	3	1	T (mild)	OLP

151	F/73	Asian or Asian British - Other	Less than high school	Retired	Never	Never	2	1	T (mild)	OLP, OC
152	F/86	Asian or Asian British - Other	Less than high school	Retired	Never	Never	4	1	BM (mild)	OLP
153	M/81	White - British	High school diploma	Retired	Past	Past	3	1	T (mild, moderate)	OLP, OL, OC
154	F/43	White - British	Some college	Employed full-time	Never	Never	2	2	T (mild)	OLP
155	F/63	White - British	Postgraduate degree	Employed part-time	Never	Past	6	2	T (mild, moderate)	OLP, OSCC
156	M/82	Asian or Asian British - Other	Less than high school	Retired	Past	Past	4	2	T (moderate)	OL, OSCC
157	M/66	White - British	Bachelor’s degree	Self-employed	Never	Current	12	1	T (moderate)	OLP, OSCC
158	F/62	Asian or Asian British - Indian	Less than high school	Unemployed	Never	Never	12	4	T, FOM (mild, moderate, severe)	OLP, OL
159	M/69	White - Other	Some college	Retired	Past	Current	1	2	BM (moderate, severe)	OL, HPV+
160	F/81	Asian or Asian British - Other	Less than high school	Retired	Never	Never	7	5	BM, G (mild, moderate, severe)	OLP, OL, HPV+
161	F/68	White - British	Bachelor’s degree	Retired	Past	Current	12	2	T (mild, severe)	OLP
162	F/61	White - British	X	X	Current	Current	11	1	SP (mild)	OL
163	M/75	White - British	Postgraduate degree	Retired	Past	Current	11	1	G (mild, moderate)	OL
164	M/30	White - British	High school diploma	Self-employed	Current	Current	1	1	T (mild)	OL

165	F/81	White - British	High school diploma	Retired	Never	Past	3	1	T (mild)	OLP
166	F/63	Asian or Asian British - Other	High school diploma	Retired	Never	Never	3	5	T, G (mild, moderate, severe)	OLP, OSCC
167	M/51	Asian or Asian British - Bangladeshi	High school diploma	Employed part-time	Past	Never	3	1	G (mild)	OL
168	F/85	White - British	High school diploma	Retired	Never	Past	13	1	G (mild)	OLP
169	M/73	White - British	Postgraduate degree	Retired	Past	Current	8	3	T (mild, moderate)	OLP, OC
170	F/76	White - Other	High school diploma	Never	Past	Past	7	4	G, BM (mild, moderate)	OLP, OSCC
171	F/61	Black or Black British Caribbean	Bachelor's degree	Employed full-time	Past	Current	6	1	T (mild, moderate)	OLP
172	F/74	White - British	High school diploma	Retired	Never	Past	4	1	T (severe)	OLP
173	M/87	White - Other	High school diploma	Retired	Past	Past	3	1	T (moderate)	OLP
174	F/76	White - British	X	X	Past	Current	1	1	T (moderate)	OL
175	M/44	Asian or Asian British - Other	Some college	Employed full-time	Never	Never	1	1	G (mild)	OLP
176	F/90	White - Other	Less than high school	Retired	Never	Never	17	2	BM (moderate, severe)	OLP
177	F/77	Asian or Asian British - Other	Less than high school	Retired	Never	Never	21	3	T, BM (moderate, severe)	OLP

178	M/58	White - British	Postgraduate degree	Employed full-time	Past	Current	11	2	T (mild)	OL
179	M/54	Asian or Asian British - Other	Postgraduate degree	Self-employed	Past	Current	3	1	T (moderate to severe), laryngeal cancer	OL, HPV+
180	F/66	White - British	Postgraduate degree	Self-employed	Never	Past	1	2	T (mild, severe)	OLP, OSCC
181	F/73	White - British	Some college	Retired	Never	Past	3	1	BM (mild)	OL, OC
182	M/81	Asian or Asian British - Indian	High school diploma	Retired	Past	Never	1	1	BM (mild)	OLP
183	F/82	White - British	Some college	Retired	Never	Never	9	1	BM (mild)	OLP
184	F/84	Asian or Asian British - Other	Less than high school	Retired	Never	Never	1	1	T (mild)	OLP, OC
185	M/68	White - Other	Some college	Retired	Never	Never	1	1	BM (mild)	OL
186	F/50	White - British	Postgraduate degree	Employed full-time	Never	Never	2	1	G (mild, moderate)	OLP
187	M/81	Asian or Asian British - Indian	High school diploma	Retired	Never	Never	9	2	T (mild, moderate, severe)	OLP, OC
188	M/61	Asian or Asian British - Other	High school diploma	Unemployed	Never	Current	6	1	T (mild)	OLP
189	M/57	White - British	Postgraduate degree	Self-employed	Never	Never	3	1	BM (mild)	OLP
190	F/50	White - British	Postgraduate degree	Employed full-time	Current	Current	6	1	G (mild)	OLP
191	F/63	White - British	Some college	Self-employed	Current	Current	14	1	SP (mild)	OL

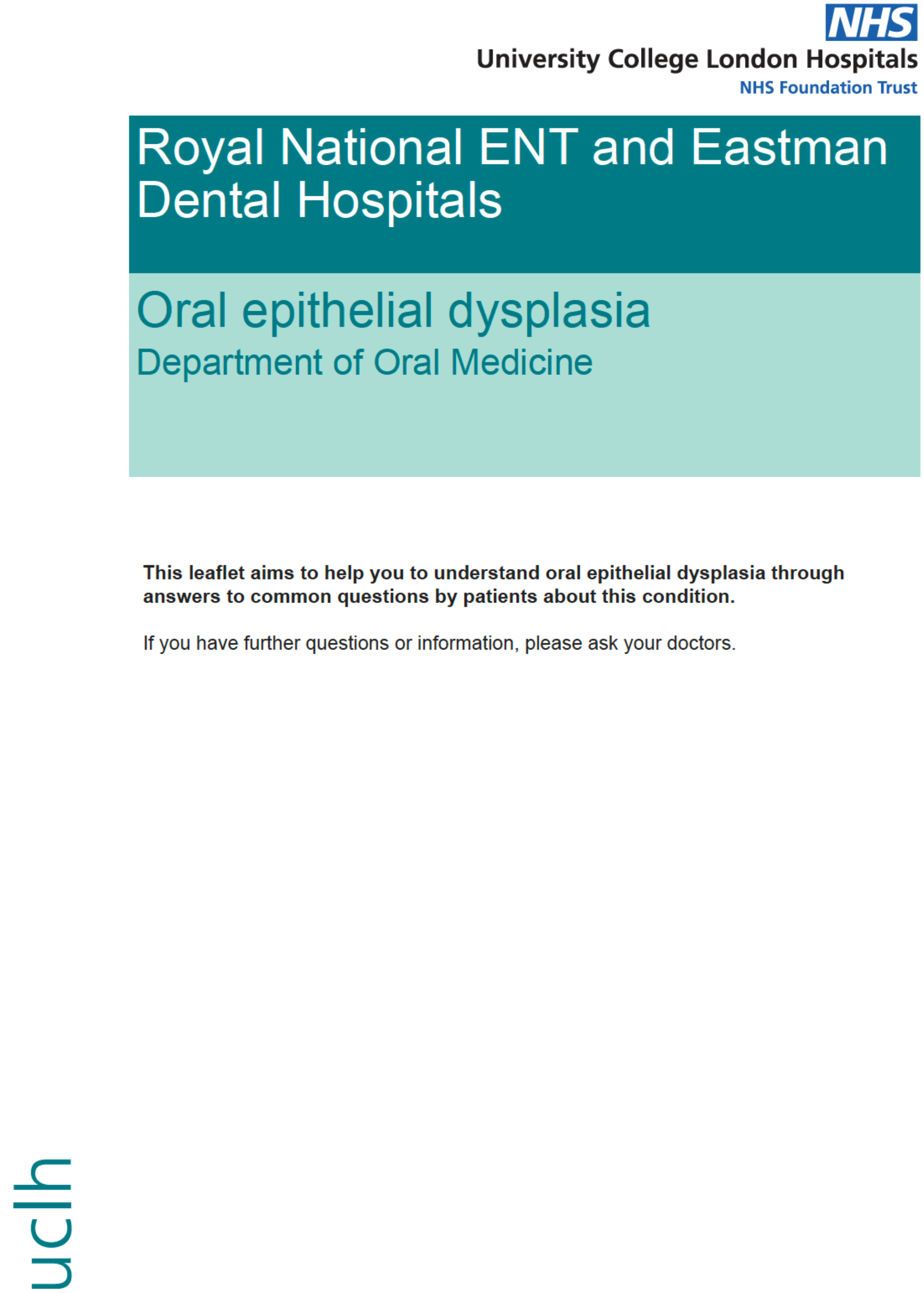
192	F/53	White - Other	Bachelor's degree	Self-employed	Never	Never	14	3	T (mild, moderate)	OLP
193	F/69	White - British	Some college	Retired	Past	Current	6	1	BM (mild)	OLP
194	F/64	Asian or Asian British - Other	High school diploma	Retired	Never	Never	12	2	BM (mild, moderate)	OLP
195	F/62	White - British	Postgraduate degree	Self-employed	Current	Current	2	2	FOM (severe)	OL, OSCC
196	M/80	White - British	Less than high school	Retired	Never	Never	15	1	T (moderate)	OL
197	M/53	White - British	Bachelor's degree	Employed full-time	Current	Current	8	1	FOM (mild)	OLP
198	F/74	Asian or Asian British - Indian	High school diploma	Retired	Never	Never	5	1	T (mild)	OLP
199	M/37	White - Other	Bachelor's degree	Employed full-time	Past	Past	7	1	T (moderate, severe)	OLP
1100	F/62	White - British	Bachelor's degree	Employed part-time	Never	Never	1	1	T (mild)	OLP
1101	M/54	White - British	Some college	Employed full-time	Past	Past	9	1	T (moderate, severe)	OLP, OSCC
1102	F/53	White - Other	Some college	Unemployed	Past	Never	1	1	T (severe)	OLP, OSCC, HPV+

***Gender**: **M**, male; **F**, female*

***Oral conditions/disease: OLP,** oral lichen planus; **OL**, oral leukoplakia; **OC**, oral candidiasis; **OSCC,** oral squamous cell carcinoma; **HPV**, human papilloma virus*

***Sites of dysplasia: T,** tongue**; BM,** buccal mucosa; **FOM**, floor of the mouth; **G**: gingiva; **HP**, hard palate; **SP**, soft palate; **L**, lip*

Appendix 5. Patient information leaflet on oral epithelial dysplasia



NHS
University College London Hospitals
NHS Foundation Trust

Royal National ENT and Eastman Dental Hospitals

Oral epithelial dysplasia

Department of Oral Medicine

This leaflet aims to help you to understand oral epithelial dysplasia through answers to common questions by patients about this condition.

If you have further questions or information, please ask your doctors.

uclh

What is oral epithelial dysplasia?

- This is when there are **abnormal cells** in the lining of your mouth.
- **It is not a mouth cancer.**
- It has the **possibility** of turning into **cancer**.
- It usually affects the tongue, floor of mouth, and/or gums. It can also affect the inside of the cheeks.
- It may affect 2 to 5 people per 100,000 of a population.
- It can affect **people of any age or gender.**
- Dysplasia **does not spread** to other parts of the mouth or body.
- It is **typically not infectious or inherited.**

Fig 1 Healthy mouth lining

What does oral epithelial dysplasia look like?

- **A red, white or mixed-colour patch** in the mouth lining that persists for more than a few weeks.
- It is **unlikely** to be **an ulcer** or **lump**.

What causes oral epithelial dysplasia?

- This risk is increased by habits such as **tobacco smoking or chewing and alcohol drinking.**
- Some mouth conditions such as **oral lichen planus** can increase the chance of dysplasia.
- **Human papilloma virus** may lead to the development of dysplasia or mouth cancer. This virus can be acquired by sexual encounters.

How do we diagnose Oral Epithelial Dysplasia?

- We need to **remove a small piece** of the lining of your mouth. This is called a biopsy.
- The **pathologist** will examine this and tell us if there is dysplasia and how bad it is (what the degree of dysplasia is).
- The **degree of dysplasia** is usually graded as **mild, moderate or severe**.
- Please ask for our Oral Mucosal Biopsy information leaflet for more information.

What are the risks for developing mouth cancer?

- It remains difficult to estimate the **personal risk** for a dysplasia to change to cancer.
- This risk is **low** in **mild dysplasia** and **high** in the **severe** dysplasia.

How do we treat oral epithelial dysplasia?

- Your specialist will suggest the treatment based on your **personal risk** and **dysplasia grade.**
- The treatment aims to prevent cancer developing in the mouth.
- We want **all dysplasia to be removed** whenever possible.
- We may not remove the areas with mild dysplasia but examine you periodically.
- Most moderate dysplasia and all severe dysplasia needs removal.
- Treatment usually requires **surgical removal** of the abnormal area.
- You will need **periodic follow-ups** with your dentist or us after treatment. This is to look for any further changes in the lining of your mouth.

How to manage the possible effects of the disease or treatment?

- You can speak to your dentist, doctor or dysplasia specialist for support and advice.
- You can speak to the GP if your diagnosis is affecting how you feel. You may search for the available mental health service around you: https://beta.nhs.uk/find-a-psychological-therapies-service/

What can you do?

- **Avoid smoking or chewing tobacco** - both are linked to dysplasia.
- **Limit alcohol intake** to as little as possible.
- **Visit** your dentist and/or specialist **regularly**. This is to identify any changes of your mouth lining.
- Ask for **help** from your dentist or doctor if you notice **unusual changes** in your mouth or lips. Examples include **a patch ulcer or a lump that lasts longer than 2 weeks**. This can be with or without pain.
- **Talk to your GP to talk for smoking / alcohol advice.** You can also look for web-based NHS services such as Smoke Free and Alcohol Support.
- **Avoid unsafe sex.** It may increase the chance of getting human papilloma virus.
- **Eat plenty of fruits and vegetables.** This may reduce the risk of dysplasia and mouth cancer.

How can you help other patients?

- Ask your doctors about research and clinical trials for dysplasia.
- You can find more information on the NHS Clinical Trials page: https://www.nhs.uk/conditions/clinical-trials/

Where can I get more information?

You can find further information about dysplasia or its related conditions on the web:

- British and Irish Society of Oral Medicine https://www.bisom.org.uk
- British Association of Dermatologists https://www.bad.org.uk

UCLH cannot accept responsibility for information provided by external organisations.

Contact

Department of Oral Medicine reception 020 3456 1061

If you need a large print, audio, braille, easy read, age-friendly or translated copy of the document, please contact us on:

Telephone: 020 3456 5076.

We will try our best to meet your needs.

PALS - If you have any concerns

PALS is a patient-friendly, easy to access service designed to provide a personal contact point to assist patients, relatives and carers. If you have a problem that you have not been able to sort out we can help you to resolve it.

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PALS are open:	Monday to Friday: 10:00 till 16:00
Telephone:	020 3447 3042
Email:	uclh.pals@nhs.net

How to find us

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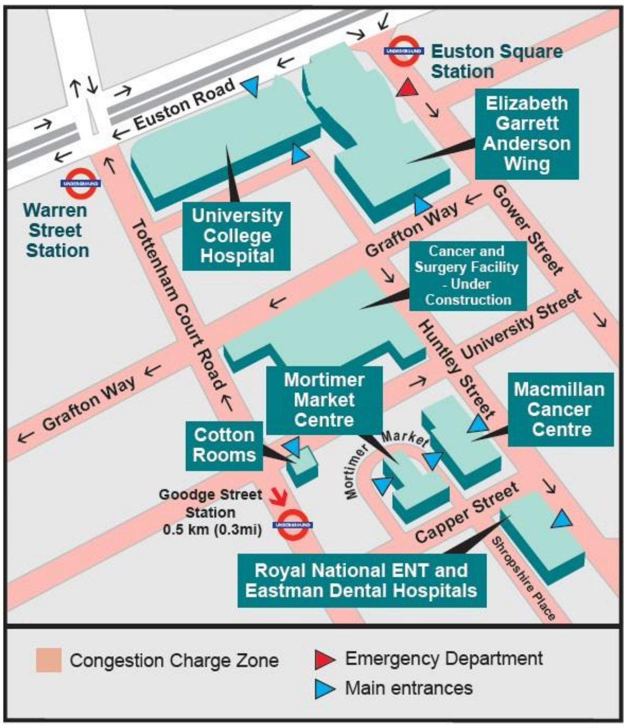
Huntley Street is close to Euston, Warren Street and Goodge Street Underground Stations and there are bus stops nearby. Apart from limited disabled parking there is no car parking at the hospital. You are advised to travel by public transport.



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Appendix 6. Publications from the present thesis

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ORAL DISEASES WILEY

ORIGINAL ARTICLE

Audiovisual information of oral epithelial dysplasia: Quality, understandability and actionability

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Abstract

Objectives: Online information on oral epithelial dysplasia (OED) is insufficient and of low quality. While only written information has been previously assessed, this study aims to evaluate the content and quality of audiovisual (AV) online information about OED.

Methods: One hundred and twenty-seven materials were initially considered using six key words across two search engines (YouTube and Google). Ultimately, 29 materials remained for the final assessment. These materials were then analysed for content, quality (DISCERN instrument, JAMA benchmarks), understandability and actionability.

Results: Most contents were scientific ($n = 25$), while three videos were educational, and one video was a personal experience with OED. On a scale of 1–5, the overall DISCERN score was ($\text{mean} \pm \text{SD} = 2.26 \pm 0.79$), suggesting poor quality of information. Regarding JAMA benchmarks, there was no single material that fulfilled or lacked all four benchmarks. The overall mean understandability score was 82% and the actionability mean score was significantly low at 29%.

Conclusion: Although the vast majority of AV materials on OED were primarily produced for scientific purposes, these materials could be helpful as resources for patient education. Keeping in mind, however, that the desired quality and essential patient information about OED available online remains largely poor and missing.

KEYWORDS
audiovisual health information, health education, mouth precancer education, oral epithelial dysplasia information, patient education, patient information

1 | INTRODUCTION

Oral epithelial dysplasia (OED) is a condition characterised by epithelial changes that have been associated with an elevated risk of progression to oral cancer (OC) (Tilakaratne et al., 2019). Some OED lesions or relevant conditions such as oral potentially malignant disorders (OPMDs) require life-long follow-up; thus, enhancing patient information and knowledge of these chronic and potentially carcinogenic conditions is key to achieving favourable long-term outcomes (Iocca et al., 2020). The primary and most effective method in delivering the patient information needed is through conversations with patients during their clinic visits. However, online materials have also provided sources of patient-related health information (Radonjic et al., 2020; Wasserman et al., 2014).

Acquiring knowledge has never been simpler than in this modern era. Global communications and the spread of various types of information, including health-related information, have substantially evolved because of the Internet (Ayantunde et al., 2007). Since its

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introduction to the public in 1991, the Internet has gradually become an integral component of peoples' knowledge lives (Anderson & Klemm, 2008). Over the past three decades, not only has Internet activity surged but also the availability and mass of health-related information have also expanded. In 2000, more than 70,000 websites supplied health-related content (Grandinetti, 2000). Five years later, the word 'health' had been searched approximately 473,000,000 times (Ybarra & Suman, 2006).

People are driven to search for health information on the Internet to find reassuring answers, seek different views on medical treatments and further absorb clinically delivered information (Powell et al., 2011). While patient information websites of professional organisations continue to be the most trustworthy sources, the audiovisual (AV) contents offered by video streaming websites such as YouTube may be preferred over the information available on official or scientific websites owing to the popularity of YouTube and the strong cognitive and emotional effects of the videos on the site (Berk, 2009). However, patients seeking for reliable online information about OED and relevant OPMDs are unlikely to find it on various online platforms (Alsoghier et al., 2018; Wiriyakijja et al., 2016).

It is important to acknowledge that the distribution of online information is not restricted to academic or professional organisations; hence, publication of unreliable health information is highly possible. Therefore, previous web-based studies have highlighted that the quality and credibility of such materials must be questioned (Daraz et al., 2011; Eysenbach et al., 2002; Garfinkle et al., 2019; McGoldrick et al., 2017; Yeung et al., 2015). In addition, health literacy relies mainly on readability, but other factors, including understandability and actionability, are also cardinal. Health information seekers should be able to understand and convey knowledge and recognise the necessary activities after reading or watching a particular content (Shoemaker et al., 2014).

Online health-related information on OED is insufficient and of low quality (Alsoghier et al., 2018). While only written information of OED has been previously assessed, this study aims to evaluate the AV online information of OED. Websites that provide pertinent, correct and understandable content can be identified with the aid of validated assessment methods (Abdouh et al., 2020; Alsoghier et al., 2018).

2 | AIMS

To assess the content, quality, understandability and actionability of online AV information for individuals with OED.

3 | METHODS

3.1 | Search strategy

The search terms 'oral dysplasia', 'oral epithelial dysplasia', 'oral dysplasia patient information', 'oral premalignancy', 'mouth premalignancy' and 'mouth precancer' were typed into search engines (Google and YouTube). The video-only option was selected for the Google search. The data gathering period was between December 2022 and January 2023.

3.2 | Excluded and included AV materials

During the search phase, 127 AV materials were identified. After duplicates were removed ($n = 36$), the overall number decreased to 91. The inclusion criteria were as follows: materials that addressed OED and/or OPMDs and/or OC, with clear filming and sound. The following exclusion criteria were then applied: Materials that were not relevant to OED ($n = 49$), non-English or English mixed with another language ($n = 6$), required membership or subscription to access ($n = 6$) and low quality or less than 240p ($n = 1$). Finally, 29 videos remained for the final assessment (Figure 1).

3.3 | Content assessment

The selected videos were categorised according to the following criteria: Source, relevance, OED components, content type, origin or country of AV material, length of video and number of views and likes.

3.4 | Quality assessment

To assess the quality, accuracy and educational value of the AV materials, two reviewers (WA and SRP) performed evaluations independently using the following tools: the DISCERN instrument (Charnock et al., 1999) and *Journal of the American Medical Association* (JAMA) benchmarks (Silberg et al., 1997). DISCERN is widely regarded as the most important standardised quality index, as it enables healthcare professionals to objectively assess any given health information. This valid and reliable consists of a 16-item questionnaire divided into three sections: reliability (questions 1–8), treatment options (questions 9–15) and overall rating (question 16). Each item is given a 5-point rating (1 = no, 2–4 = partially and 5 = yes).

The JAMA benchmarks are comprised of four criteria (authorship, attribution, disclosure and currency), and a 4-point scale is used to identify the quality of any selected material. An AV material scored a point if it met the benchmark elements, which encompassed the following: authorship (authors' names, credentials and affiliations), attribution (copyright, sources and references), disclosure (ownership acknowledgement, possible conflict of interest, funding and support, advertising and underwriting) and currency (dates and updates). In the final assessment, the scores of the chosen materials ranged from 0 to 4.

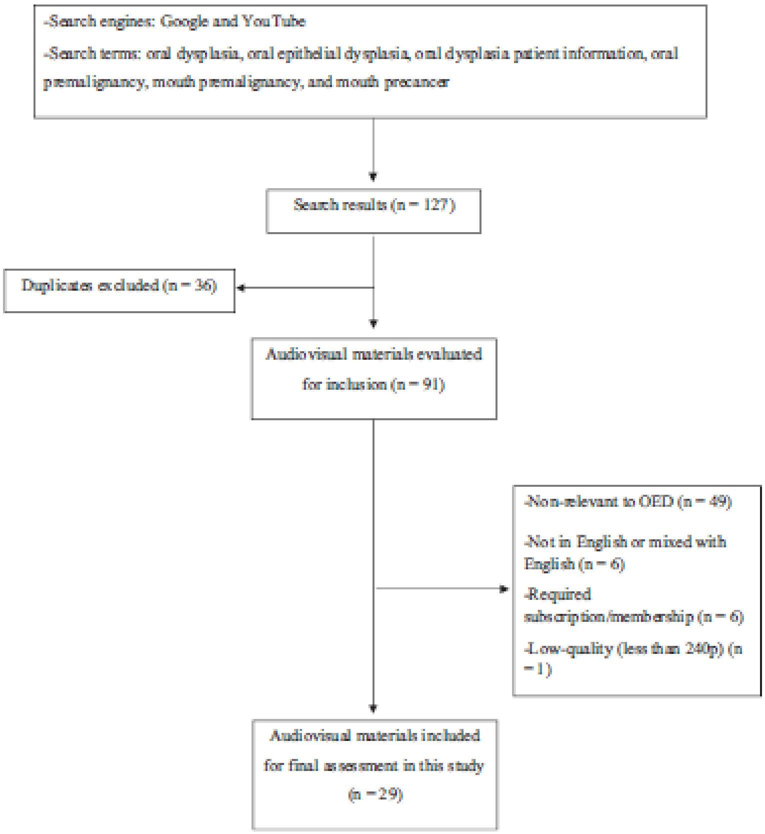

FIGURE 1 Flow diagram of the eligibility of the chosen 29 audiovisual materials.

3.5 | Understandability and actionability assessment

To assess the understandability and actionability of the information provided in the AV materials, the same reviewers (WA and SRP) used the valid and reliable Patient Education Material Assessment Tool (PEMAT) for AV materials (PEMAT-AV) (Shoemaker et al., 2014). This tool consists of 13 items on understandability that assess the ability of individuals to comprehend and acquire essential information and four items on actionability that assess the clarity of recommendations to facilitate user action. The understandability measure is divided into four domains: content (one item), word choice and style (three items), organisation (four items), layout and design (three items) and use of visual aids (two items). The answer options for each item are 'yes', 'no' and 'not applicable'. When a material meets 80% or more of the item, 'yes' is assigned as a response; otherwise, 'no' is given.

3.6 | Statistical analysis

To generate descriptive statistics, the data were collected using a proforma tailored to the study and exported to Microsoft Excel. IBM SPSS was used for variable representation (version 22.0).

3.7 | Ethical consideration

This study does not require ethical approval.

4 | RESULTS

4.1 | General characteristics of the AV materials

The sources of the 29 final AV clips were classified in our analysis into three categories, namely scientific, educational and personal experience. Most contents were scientific produced by professionals ($n=25$; 86%) affiliated with universities or medical centres, or who were independent. This scientific content was presented as scientific lectures ($n=13$), narrated slides and graphics ($n=9$), online webinars ($n=2$) and one clip was a non-sound slide and graphic presentation. The educational contents included three videos (10%), presented as short clips of facts delivered by an expert ($n=2$) and one narrated slide and graphic clip. The presenters of the educational contents had various backgrounds and affiliations, including medical centres, profitable online course providers and independent practice. One individual shared his personal experience with OED through a vlog on YouTube.

Regarding the relevance of the contents to OED, six videos addressed OED only, two videos addressed both OED and OPMDs, one video outlined both OED and OC and eight materials highlighted OED, OPMDs and OC. However, 12 videos did not primarily address OED and focused on OPMDs or OC. For the clips that covered OED ($n=17$), the definition, WHO criteria and grading were mentioned together in seven videos, while three videos highlighted the definition and WHO criteria. The grading only was discussed in two videos and the definition only was provided in one video. Diagnostic methods and progression risk were outlined in two clips, whereas the various treatment options were mentioned in one clip only.

Most of the materials ($n=25$) were presented on YouTube, while only four were found on other websites. Approximately, half of the contents ($n=14$) originated from India; six from the United States and two from Malaysia. One video was produced from the following countries: the United Kingdom, Singapore, Iran, South Africa and Guatemala. The origin of the content was not identified in two clips. The recorded dates of the materials ranged from 2012 to 2022, with year 2022 having the most published materials ($n=8$), followed by 2020 ($n=6$) and 2021 ($n=4$).

The durations of the AV presentations ranged from 36 s to 110 min 12 s. Fourteen materials were ≤ 10 min long, seven ranged from 10 to 30 min long and eight were > 30 min long. The number of views ranged from 25 to 71,034, of which 14 videos had been viewed ≤1000 times, nine videos had been viewed between 1001 and 10,000 times and three materials had >10,000 views. The total number of likes ranged from 0 to 1000. However, most clips ($n=22$) received ≤100 likes, whereas three videos had >100 likes, and one presentation only had 1000 likes. Table 1 summarises the general characteristics of the 29 selected informative materials.

4.2 | Quality assessment

4.2.1 | DISCERN

Table 2 provides a summary of the DISCERN scores of the 29 chosen AV materials. The mean ± SD overall rating was 2.26 ± 0.79, with none of the materials achieving the maximum rating of 5 and with 16 AV materials (55%) obtaining the minimum overall rating. The highest mean scores correlated with the following items: (Q5) explicit date (4.72), (Q6) balanced and unbiased (4.24) and (Q3) relevance (3.68). More than half (60%) of the items obtained mean scores <2, encompassing (Q7) additional sources (1.68), (Q8) areas of uncertainty (1.86), (Q9) how treatment works (1.82), (Q10) benefits of treatment (1.65), (Q11) risks of treatment (1.34), (Q12) effects of no treatment (1.55), (Q13) effects on quality of life (1.34), (Q14) all treatments described (1.48) and (Q15) shared decision (1.62).

4.2.2 | JAMA criteria

Most AV materials ($n=28$; 96.55%) compiled the currency standard, of which less than half ($n=12$; 41%) met the authorship benchmark. Attribution and disclosure were met by six (20.68%) and three materials (10.34%) respectively. Regarding the total number of benchmarks reached, no single material fulfilled or lacked all four benchmarks, five AV materials (17.24%) met three benchmarks, 10 materials (34.48%) met two benchmarks and 14 materials (48.27%) met one benchmark (Table 3).

4.3 | Understandability and actionability assessment

The mean PEMAT-AV understandability score of the 29 AV materials ranged from 25% to 100%, with an overall mean ± SD of 82% ± 0.25%. The actionability values ranged from 0% to 100%, with a mean ± SD score of 29% ± 0.4%. Items 1–13 assessed understandability, whereas items 14–17 assessed actionability. In regard to understandability, five AV materials received scores >90%, including item 4, 'The material uses the active voice' (93%); item 9, 'The material uses visual cues (e.g. arrows, boxes, bullets, bold, larger font, and highlighting) to draw attention to key points' (91.3%); item 11, 'The material allows the user to hear the words clearly (e.g. not too fast and not garbled)' (96%); item 12, 'The material uses illustrations and photographs that are clear and uncluttered (91.66%)'; and item 13, 'The material uses simple tables with short and clear row and column headings' (100%) (Table 4).

In terms of actionability, item 14, 'The material clearly indicates at least one action the user can take', received the highest rating (37.93%), whereas item 17, 'The material explains how to use the charts, graphs, tables, or diagrams to take actions', received the lowest rating (4.76%) but was not applicable among eight AV materials. Eighteen materials all had a 0 actionability score (Table 5).

5 | DISCUSSION

Numerous research studies have addressed AV contents and oral health, but this is the first study to examine the content and quality of AV materials on OED. Evidence demonstrates that YouTube has been used as a source of information for diverse oral medicine subjects such as oral cancer (Hassona et al., 2016), Sjogren's syndrome (Delli et al., 2016), oral thrush (Di Stasio, Romano, Paparella, Gentile, Minervini, et al., 2018), mouth sores (Di Stasio, Romano, Paparella, Gentile, Serpico, et al., 2018), oral leukoplakia (Kovalski et al., 2019), burning mouth syndrome (Fortuna et al., 2019), oral halitosis (Ramadhani et al., 2021) and oral lichen planus (OLP) (Romano et al., 2021). Table 6 summarises the research conducted on the quality of AV online information on several oral diseases.

A relevant previous study that evaluated the quality of written web-based information on OED by Alsoghier et al. (2018) highlighted that OED-related content was scarce and of poor quality and that further work in necessary to create trustworthy online resources for patients with OED. However, given that the AV materials of OED was never scrutinised, this study aims to provide an analysis of the

TABLE 1 Descriptive features of the selected audiovisual materials.

Category	Criteria		Number of videos
Source	Professional (university, medical centres and independent)	Scientific lecture	13
		Online webinar	2
		Narrated slides and graphics	9
		Slides and graphics without audio	1
	Educational (medical centres, profitable organisations and independent)	Short clip facts by an expert	2
		Narrated slides and graphics	1
	Personal experience	Human story vlog	1
	Other	Government, commercial and unclassified	0
Relevance	Video addresses OED only		6
	Video addresses OED and OPMDs		2
	Video addresses OED and OC		1
	Video addresses OED, OMPDs and OC		8
	Video does not primarily address OED		12
OED components	Definition only		1
	Grading only		2
	Definition and WHO criteria		3
	Definition, WHO criteria and grading		7
	Definition, WHO criteria, grading and diagnosis		1
	Definition, grading, diagnosis and treatment		1
	Definition, WHO criteria, grading and prognosis in terms of 'progression risk'		2
	Impact on QoL and recommendations		0
	None		12
Media platform	YouTube		25
	Non-YouTube		4
Country	United Kingdom		1
	United States		6
	India		14
	Malaysia		2
	Iran		1
	Singapore		1
	South Africa		1
	Guatemala		1
	Unknown		2
Published since (years)	2022		8
	2021		4
	2020		6
	2019		2
	2018		2
	2017		3
	2015		1
	2012		2
	Unknown		1

(Continues)

TABLE 1 (Continued)

Category	Criteria	Number of videos
Duration (min)	≤10	14
	Between 10 and 30	7
	>30	8
Number of views	≤1000	14
	Between 1000 and 10,000	10
	>10,000	3
	Unknown	2
Number of likes	≤100	22
	>100	3
	>1000	1
	Unknown	3

Abbreviations: OC, oral cancer; OED, oral epithelial dysplasia; OPMDs, oral potentially malignant disorders; QoL, quality of life; WHO, World Health Organization.

TABLE 2 Mean DISCERN scores of the selected audiovisual materials.

Domain	DISCERN question	Mean ± SD
Reliability	Q1. Explicit aims	2.57 ± 1.84
	Q2. Attainment of aims	2.82 ± 2.00
	Q3. Relevance	3.68 ± 1.46
	Q4. Explicit sources	2.06 ± 1.7
	Q5. Explicit date	4.72 ± 1.03
	Q6. Balanced and unbiased	4.24 ± 1.35
	Q7. Additional sources	1.68 ± 1.53
Treatment options	Q8. Areas of uncertainty	1.86 ± 1.18
	Q9. How treatment works	1.82 ± 1.19
	Q10. Benefits of treatment	1.65 ± 1.14
	Q11. Risks of treatment	1.34 ± 1.07
	Q12. Effects of no treatment	1.55 ± 1.15
	Q13. Effects on quality of life	1.34 ± 1.07
	Q14. All treatments described	1.48 ± 1.12
	Q15. Shared decision	1.62 ± 1.42
Overall rating		2.26 ± 0.79

TABLE 3 Numbers and percentages of the selected audiovisual (AV) materials that achieved the JAMA benchmarks.

JAMA benchmark	Number of AV materials	Percentage (%)
Authorship	12	41
Attribution	6	20.68
Disclosure	3	10.34
Currency	28	96.55

present online content. After searching on search engines using multiple phrases, we involved materials from multiple sources, including academic institutes, medical centres, scientific lectures, medical or dental YouTube channels and personal experiences, which ultimately led to the analysis of 29 items created over a 10-year period.

While healthcare centres and providers are increasingly using online patient education, our findings demonstrate a paucity of good-quality AV health information addressing oral diseases such as OED. To the best of our knowledge, no previous study has classified the content and evaluated the quality, understandability and actionability of AV online information concerning OED.

5.1 | General characteristics of AV materials on OED

In this present analysis, most AV materials (*n* = 25; 86%) were found on YouTube, which could be explained by the popularity, easy accessibility and lack of strict peer review process prior to publishing any content on this platform (Ho et al., 2017). Cosequently, the patient information found on YouTube is likely insufficient, inaccurate and unreliable but still popular among users, as indicated by Kanlioz and Ekici (2020).

Although contents produced by university channels and professional groups were superior in terms of both quality and credibility (Delli et al., 2016), studies have demonstrated that the origin of an AV material does not always necessarily indicate its quality and that AV clips containing personal or family experiences can deliver high-quality health information (Angulo-Jiménez & Dethorne, 2019). A previous study revealed that patient experience content composed most of the available AV contents on certain conditions such as Bechet's disease (Karakoyun & Yildirim, 2021). Our study included a vlog on the story of a patient who had OED, in which a clip exhibited good quality information about OED; in fact, it was the only AV material that pointed out the different treatment options for OED and addressed essential aspects such as the nature of the disease,

TABLE 4 Numbers of audiovisual (AV) materials that satisfied the Patient Education Materials Assessment Tool (PEMAT) items for understandability assessment.

Domain	PEMAT item	Number of AV materials that met the item, *n* (%)
Content	1. The material makes its purpose completely evident.	18 (62)
Word choice and style	2. The material uses common, everyday language.	26 (89.65)
	3. Medical terms are used only to familiarise the audience with the terms. When used, medical terms are defined.	25 (86.2)
	4. The material uses the active voice.	27 (93)
Organisation	5. The material breaks or 'chunks' information into short sections.	19 (86.36) [a]5 NA
	6. The material's sections have informative headers.	19 (86.36) [a]5 NA
	7. The material presents information in a logical sequence.	25 (86.20)
	8. The material provides a summary.	57.14% [a]1 NA
Layout and design	9. The material uses visual cues (e.g. arrows, boxes, bullets, bold, larger font or highlighting) to draw attention to key points.	91.3% [a]6 NA
	10. The text on the screen is easy to read.	86.95% [a]6 NA
	11. The material allows the user to hear the words clearly (e.g. not too fast and not garbled).	96% [a]4 NA
Use of visual aids	12. The material uses clear and uncluttered illustrations and photographs.	91.66% [a]5 NA
	13. The material uses simple tables with short and clear row and column headings.	100% [a]16 NA

[a]Number of AV materials not applicable for certain understandability items.

TABLE 5 Numbers of audiovisual (AV) materials that satisfied the Patient Education Materials Assessment Tool (PEMAT) items for actionability assessment.

Domain	PEMAT item	Number of AV materials that met the item (%)
Actionability	14. The material clearly identifies at least one action the user can take.	11 (37.93%)
	15. The material addresses the user directly when describing actions.	8 (27.58%)
	16. The material breaks down any action into manageable, explicit steps.	6 (20.68%)
	17. The material explains how to use the charts, graphs, tables or diagrams to take actions.	1 (4.76%) [a]8 NA

[a]Number of AV materials not applicable for certain actionability items.

diagnostic procedure and postoperative phase in a simple and understandable approach.

As most of the included AV clips originated from dental professionals ($n=25$; 86%), their contents were predominantly scientific, targeting the education of high-end professionals rather than patients or lay persons. Whereas the educational content was considerably lacking, as there were only three materials (10%) that were generated for patient education purposes. We believe that this small number is worrying, and academic institutes and professional individuals must also consider patient-centred information production rather than largely focusing on high-end directed content. However, this trend was demonstrated in a study by Fortuna et al. (2019), who showed that educational content predominantly (46%) represented AV health information about burning mouth syndrome.

Although the advanced information from the scientific content may be suitable for professionals or intended for gaining personal recognition, Cuddy (2010) outlined that the public could also benefit from this reliable information. In our study, we observed that most contents exhibited scientific information that primarily covered the OED definition and diagnosis and clinical presentations of OPMDs. This information could be useful for promoting overall patient awareness but does not truly shed light on other essential elements such as early detection, decision-making, diagnostic procedures, treatment options, potential complications and impact on quality of life.

5.2 | The quality of online AV OED materials

The assessment of AV content using the DISCERN and JAMA tools revealed that most materials had poor quality. Though using different

TABLE 6 Summary of research conducted of audiovisual patient information materials on various oral diseases.

Author (year)	Disease	Number of included materials	Quality assessment tools	Major findings
Hassona et al. (2016)	Oral cancer	188	Usefulness score	• Academic institutes and personal story publication are more useful than individual user materials.
Delli et al. (2016)	Sjogren's syndrome	70	Global Quality Scale and modified DISCERN	• Half of the videos were classified as useful; less than half, as personal experience; and the rest, as misleading. • Personal content was preferred over educational content.
Di Stasio, Romano, Paparella, Gentile, Minervini, et al. (2018)	Oral thrush in children	29	Unidentified	• About two thirds of the evaluated contents were slightly useful. • In spite of the source, information about mouth sores in children on YouTube was poor.
Di Stasio, Romano, Paparella, Gentile, Serpico, et al. (2018)	Mouth sores in children	33	Unidentified	• The information on oral thrush from clips was of poor quality.
Kovalski et al. (2019)	Oral leukoplakia	28	Global Quality Scale, usefulness score and modified DISCERN	• The analysis revealed that the videos were of poor quality, reliability and usefulness.
Fortuna et al. (2019)	Burning mouth syndrome	114	Quality assessment score	• Approximately half of the contents were educational. • However, the quality of the contents was poor.
Ramadhani et al. (2021)	Halitosis	105	Global Quality Scale, comprehensive score and DISCERN	• Contents were mostly poor. • Low-quality content was preferred over high-quality content.
Romano et al. (2021)	Oral lichen planus	36	Global Quality Scale and DISCERN	• The materials mostly presented poor information despite the gradual improvement in content.
Alamoudi et al. (this study)	Oral epithelial dysplasia	29	DISCERN, JAMA and PEMAT-AV	• Content is predominantly scientific, not educational.

assessment tools, previous research studies have found that contents addressing various oral disorders had a similar poor quality of patient information, encompassing oral leukoplakia (Kovalski et al., 2019), burning mouth syndrome (Fortuna et al., 2019), oral halitosis (Ramadhani et al., 2021) and OLP (Romano et al., 2021) (Table 6).

Regarding the assessment using DISCERN, the mean ± SD overall score (item 16) of the examined AV contents was 2.26 ± 0.79 on a scale of 1–5, which suggests that the quality of the information was poor. This finding is consistent with that of a study by Romano et al. (2021) that used DISCERN to assess the quality of information concerning OLP, which indicated an overall mean average of 2.33 ± 1.07. Even though the following numbers were obtained from studies conducted on online information from written content, it would be helpful to report the findings given the relevance and similar results, and that include an overall DISCERN score of 2.55 for on oral cancer (Riordain & Mccreary, 2009), 2.3 for oral leukoplakia (Wiriyakijja et al., 2016) and 2.24 for oral epithelial dysplasia (Alsoghier et al., 2018).

In our study, we found that all treatment related DISCERN questions were associated with the lowest scores. This observation was also reported in previous studies by Alsoghier et al. (2018), Riordain and Hodgson (2014) and Wiriyakijja et al. (2016), where the lack of patient information on the different treatment options, risks of no treatment and potential adverse effects was evident. Physicians are currently shifting from the unidirectional concept of management to the shared treatment decision-making (Stairmand et al., 2015), which cannot be established without adequate and trustworthy information about all treatment details pertaining to OED.

This poor quality is represented by the findings on the JAMA benchmarks. No single AV content met all four JAMA benchmarks, raising a question regarding the reliability of the information offered by the 29 materials included in this study. This is comparable with research about the oral involvement of scleroderma in which only 7% of the analysed information fulfilled the four benchmarks (Abdouh et al., 2020). Furthermore, the fact that content that does not satisfy at least three of the benchmarks could be suspicious (Silberg et al., 1997), and only five materials (17.24%) in our analysis achieved this standard emphasises the overall poor sufficiency and reliability of the information displayed on the examined video clips. This finding is also compatible with a study conducted on written OED information that indicated that 80% of online information could be classified as suspicious (Alsoghier et al., 2018).

5.3 | The understandability and actionability of online AV materials on OED

The PEMAT evaluates patients' comprehension of health information (understandability) and if the information motivates users to do at least one action and breaks a recommended behaviour into phases (actionability) (Shoemaker et al., 2014). Even though both versions (PEMAT-P and PEMAT-AV) have demonstrated good inter-rater reliability, PEMAT has not been used in dentistry studies.

The overall mean understandability score of the selected materials was 82%, while the actionability mean score was significantly low at 29%. Although most of the examined clips (86%) were primarily scientific and only (10%) were educational, the level of understandability was good (82%), which could be attributed to the appealing nature of the AV content, organised and well-structured presentations, clear aims of the material and inclusion of pictures and graphs. However, this high understandability rating was not necessarily representative of the entire content because certain PEMAT items were not applicable to multiple AV materials, thus the high overall rating (e.g. item 13 was not applicable across 16 materials).

Many materials from the examined AV contents in our study (*n* = 18; 62%) had an actionability rating of 0%. This poor actionability result is worrisome because research suggests that actionability should be taken into account as a cornerstone when creating informational materials (Kang & Lee, 2019). However, five materials (17%) received an actionability rating of 100%, as they indicated key messages such as continued self-examination, seeking immediate care when concerning clinical changes occur, importance of long-term follow-up, impact on quality of life and avoiding risk factors and bad habits.

This analysis had several limitations, including the dynamic nature of the internet content, only videos provided in English were considered, the analysis chiefly focused on YouTube and did not include contents from other social media platforms and although an extensive search was conducted, the number of included AV materials was only 29, which is considered a small sample.

6 | CONCLUSIONS

This study shows that although the online AV materials on OED were primarily produced by dental professionals for scientific purposes, these materials could be helpful as resources for patient education. However, many clips did not satisfy the minimum criteria for providing high quality and comprehensive patient information.

Considering the tremendous reach of social media platforms and the need to disseminate accurate information regarding OED, it is necessary to create credible patient information resources and increase the professional presence on the different social media platforms. We also suggest that future research should consider using the DISCERN, JAMA and PEMAT instruments to evaluate additional educational AV contents in the field of oral diseases.

AUTHOR CONTRIBUTIONS

Waleed Alamoudi: Conceptualization; writing – original draft; investigation; methodology; data curation; formal analysis. **Richeal Ni Riordain:** Conceptualization; investigation; writing – review and editing; methodology; project administration; supervision; resources. **Stefano Fedele:** Conceptualization; investigation; methodology; writing – review and editing; project administration; supervision; resources. **Stephen Porter:** Conceptualization; investigation; writing – original draft; writing – review and editing; methodology; project administration; supervision; resources.

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CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest related to this study.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Oral Diseases

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ORIGINAL ARTICLE OPEN ACCESS

Experiences, Challenges and Informational Needs of Patients With Oral Epithelial Dysplasia

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ABSTRACT

Objectives: This study aims to explore the patients' experiences with oral epithelial dysplasia (OED) to identify associated clinical challenges and informational needs.

Methods: Semi-structured interviews, guided by a topic outline, addressed disease-specific information, investigative procedures, treatments, impacts on quality of life, healthcare systems and information sources. The interviews were audio recorded, transcribed verbatim and analysed using thematic analysis.

Results: A total of 30 individuals participated in the study. Four primary themes were identified: delays in diagnosis, knowledge about OED, the psychological impact of the disease and patient education.

Conclusion: To our knowledge, this is the first qualitative study to explore the lived experiences of patients with OED. It highlights significant challenges, including accessing appropriate medical services, delays in diagnosis, physical and psychological burdens and the need for better education. Positive experiences were noted when patients received care from knowledgeable clinicians who provided consistent education and effective communication. The findings of this study may guide the future development of measurement tools on the outcome measures of individuals with OED.

1 | Introduction

Oral epithelial dysplasia (OED) is a term used to describe various changes in the cells and structure of the oral epithelium associated with an increased likelihood of developing oral squamous cell carcinoma (OSCC) (Tilakaratne et al. 2019). OSCC ranks among the 15 most common types of cancer in the United Kingdom (UK), with over 6000 new cases identified annually (Cancer Research UK 2017). OED is estimated to affect 2.5–5 per 1000 individuals (Mehanna et al. 2009). Research has shown that OED can elevate the risk of OSCC by 6%–36%, depending on the degree of dysplastic changes (Field et al. 2015). Oral potentially malignant disorders can precede the development of OED (Kierce et al. 2021). These disorders include oral lichen planus (OLP), oral submucous fibrosis (OSF) and oral leukoplakia (OL). Regular surveillance and surgical removal are the recommended methods of treatment (Mehanna et al. 2009).

Achieving favourable long-term health outcomes for patients with OED requires accurate diagnosis, optimal treatment options and a positive and satisfying healthcare experience (Doyle et al. 2013). Patient experience is multifaceted, encompassing various dimensions and perspectives. Definitions of patient experience can vary significantly among healthcare professionals and evolve, particularly in the dynamic healthcare sector (Wolf and Jason 2014). The Beryl Institute defines

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patient experience as 'the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care' (Wolf and Jason 2014). Core concepts of a positive patient experience include patient-centred care, effective communication, patient education, patient and family partnerships, informational transparency and personalised and unique care (Wolf et al. 2021). Although satisfaction is essential to the overall patient experience, it is important to note that positive patient experiences are about much more than mere satisfaction. Satisfaction pertains to only certain periods in time, whereas the patient experience encompasses everything a patient encounters, the perspectives they carry with them and the narratives they share as a consequence (Wolf et al. 2021).

An obstacle that might arise during medical encounters is a disparity in the perception of complaints, signs or symptoms between the patient and the provider, resulting in inconsistencies in the approach to the disease and the strategy for management (Bensing 1991). To overcome this obstacle, qualitative research can offer insightful information about patients' subjective experiences and needs, thus facilitating more informed medical decision-making and treatment approaches (Tong et al. 2016). Qualitative research is highly regarded as a good approach for examining important aspects of an individual's issues, such as pain, which may not be adequately explored using other research methods (Osborn and Rodham 2010).

It is crucial to highlight that patient experience extends beyond mere quantitative measurements and survey results, which typically offer insights into only specific stages or parts of an individual's path (Wolf et al. 2021). Therefore, to deliver detailed insights into everyday problems and human experiences, qualitative research examines phenomena within the contexts of individuals and groups (Moser and Korstjens 2017), offering a more versatile approach than quantitative research (Korstjens and Moser 2017). Previous studies on head and neck cancer (Scott et al. 2006; Deng et al. 2019) and chronic facial pain (Taimeh et al. 2023) have successfully utilised this method to investigate various aspects of patient experiences. Therefore, this study employed a qualitative approach using interviews. A thorough review of existing literature revealed a lack of research explicitly investigating the experiences of individuals with OED. Hence, this study aimed to provide a comprehensive understanding of the experiences, challenges and informational needs of patients with OED in a dental hospital in the UK.

2 | Materials and Methods

2.1 | Ethical Considerations and Study Registration

An impartial expert reviewed the study protocol and confirmed its rigour and feasibility. The study adhered to the Declaration of Helsinki guidelines for medical research involving human subjects. It was registered with the University College London Hospitals/University College London (UCLH/UCL) Joint Research Office under reference/EDGE number 153912 and IRAS project ID 318039. The study received a favourable opinion from the National Health Service (NHS) Research Ethics Committees, specifically the London–Surrey Borders Research Ethics Committee (reference 22/PR/1743). Additionally, it obtained ethical approval from the Health Research Authority and Health and Care Research Wales. Reporting of the qualitative component in this article complies with the guidelines outlined in the Standards for Reporting Qualitative Research (SRQR) checklist.

2.2 | Study Design and Participants

This study was a semi-structured, interview-based, qualitative research project conducted at the UCLH Royal National ENT and Eastman Dental Hospitals' Oral Medicine Unit. Purposive sampling was used to select individuals diagnosed with OED through histopathological examination based on the 2017 World Health Organization classification system (El-Naggar et al. 2017). The inclusion criteria for the study were adults aged 18 years or older, proficiency in both written and spoken English and the ability to provide informed consent. Eligible participants were recruited during their routine clinical visits. Qualitative sample size was determined by the principle of data saturation, which was reached at 30 participants, aligning with literature recommendations for semi-structured interview studies of moderately heterogeneous patient groups (Sargeant 2012). The research team provided each participant with a detailed verbal explanation of the study's objectives and the expected outcomes of their involvement. Participants were then given an information sheet to review and were asked to sign an informed consent form.

2.3 | Data Collection

Data collection occurred between March and December 2023 and continued until saturation was achieved. The saturation was defined as the point where no new emerging information would allow further development of a category's properties (Strauss 2017). Each interview lasted between 30 and 40 min, with an average duration of 35 min. All interviews were documented on paper and recorded in audio format. The interviews were conducted by two moderators (WA and RNR) who identified themselves as researchers and explicitly stated that they were not involved in the clinical service of any individuals. This precaution ensured that participants felt comfortable sharing adverse experiences without hesitation. The moderators, who had clinical backgrounds in oral medicine and were trained in qualitative research, took care to avoid influencing participants' responses with their ideas or opinions.

Participants provided data through semi-structured interviews, which enabled the collection of open-ended information while adhering to a set of guiding and predetermined questions (DeJonckheere and Vaughn 2019). A detailed topic guide was created for the interview discussion (Hancock et al. 2001), serving as a foundation for structured conversations and encouraging engagement between the researcher and participants. Key discussion topics covered a broad range of subjects, including initial appointments with primary healthcare providers, referrals to specialised healthcare facilities, progression to cancer risk, investigation procedures, treatment options, experiences with NHS services, information sources, and the physical and psychosocial impacts of OED. Participants were also free to bring up issues outside the framework that they deemed significant. Throughout the interviews, the guide was revised to obtain data that most effectively addressed the research objectives.

2.4 | Data Analysis

Verbatim transcription was performed for all interviews. The researchers conducted a preliminary data assessment by engaging in reflective notetaking and forming initial impressions while listening to the audiotapes. Common themes within the responses of the participants were identified using thematic analysis. Through line-by-line coding, data were organised into subunits to facilitate pattern recognition. Codes with similar content were grouped to establish common categories. Recognising themes is a dynamic and interpretive task (Kiger and Varpio 2020). As a result, they were developed through an iterative inductive process, where coded data was merged, examined and interpreted. Each theme was subsequently accompanied by a detailed narrative description to provide context. Audit trails and data triangulation were applied to increase the reliability of the findings.

To determine data saturation, two researchers (WA and RNR) independently coded each set of three interviews before convening to compare emerging codes and subthemes. As coding progressed, earlier transcripts were revisited to ensure newly identified codes could be integrated. Saturation was deemed reached when no new codes or themes emerged over three consecutive interviews, indicating that further data collection would not deepen understanding of the topic (Strauss 2017).

3 | Results

3.1 | Participants

The study initially included a cohort of 35 participants, consisting of 24 females and 11 males. However, due to personal circumstances ($n=2$) and time constraints ($n=3$), only 30 participants consented to partake in the study, resulting in 21 females and nine males. Participants' ages ranged from 44 to 83 years, with a mean age of 64.4. The number of dysplastic sites varied between 1 and 7, averaging 1.8 per participant. The initial diagnosis of dysplasia occurred between 2 and 17 years before the start of the trial, averaging 7.3 years. The clinical features of the participants are presented comprehensively in Table 1.

3.2 | Themes

The interviews generated a variety of perspectives regarding experiences with OED. The participants' responses varied based on disease history and individual characteristics. Four primary themes emerged from the data analysis, which included (i) delays in OED diagnosis, (ii) knowledge about OED, (iii) psychological impact and (iv) patient education. Table 2 presents the themes and subthemes identified from the participants' responses, including some findings and supporting quotations.

3.2.1 | Delays in OED Diagnosis

Many participants expressed frustration about significant delays in their OED diagnosis, often attributed to the failure or inability to recognise abnormal signs and symptoms. Patients frequently perceived their symptoms as minor or temporary, which led them to ignore the issues, delay seeking medical care and a lack of urgency in addressing their condition.

For example, some participants reported:

> Initially, it began as an ulcer in my cheek, and I assumed I just needed simple treatment in that area.
>
> (001)

> I ignored it as I had ulcers as a child. I decided to wait it out and trust that it would resolve itself. I believed it was simply a mouth ulcer that eventually would go away.
>
> (009)

> I wouldn't go to a doctor for a tiny discolouration under my tongue because they would think I'm exaggerating.
>
> (024)

Many individuals also expressed notable dissatisfaction with the competence of general practitioners (GPs) or other healthcare professionals, indicating a preference for the expertise of an OED specialist instead. In addition, this incompetence can lead to numerous clinical visits before receiving suitable medical attention was also reported. Many patients experienced a frustrating cycle of multiple hospital visits and referrals, often enduring considerable delays before being seen by an appropriate clinical team capable of addressing their healthcare needs effectively.

As one participant noted:

> My GP referred me to an oral surgeon, suggesting that I should seek their expertise due to a potential issue with the skin in my mouth. I was sent back to my GP with no diagnosis; however, it was the OED specialist who correctly identified and diagnosed the condition.
>
> (012)

Another participant highlighted the complex nature of dysplasia symptoms:

> One issue with dysplasia is that its symptoms can resemble those caused by other factors, such as lichen planus and certain medications. When I consulted a GP, the initial assumption was often the simplest explanation, as my GP immediately attributed my symptoms to menopause. Only the oral medicine specialist at this hospital recognised the true disease.
>
> (007)

TABLE 1 | Clinical characteristics of participants.

Patient ID	Age (years)	Sex	Diagnosis (years)	Dysplasia sites	Location	Degree of dysplasia/ associated disease
001	73	F	13	2	Buccal mucosa	Mild/OLP
002	44	M	12	1	Palate	Mild/OLP
003	63	F	17	1	Tongue	Mild/OLP
004	72	M	10	3	Buccal mucosa, palate	Moderate, severe/OLP
005	70	F	10	1	Tongue	Mild, moderate, severe/OLP
006	77	F	3	2	Floor of mouth, gingiva	Mild, moderate/OLP
007	68	F	6	2	Gingiva	Mild, moderate/OLP
008	79	F	4	7	Gingiva, palate	Moderate/OSCC
009	54	F	2	1	Tongue	Mild, moderate/OLP
010	66	F	6	1	Tongue	Moderate, severe/OSCC
011	63	M	3	1	Tongue	Moderate/OLP
012	44	F	7	1	Tongue	Mild, moderate, severe/OLP
013	55	M	11	5	Buccal mucosa, palate, gingiva	Mild, moderate/OSF, OSCC
014	65	F	4	3	Buccal mucosa, gingiva, floor of mouth	Mild, moderate/OLP
015	57	F	7	2	Buccal mucosa	Mild, moderate
016	50	M	16	2	Tongue, floor of mouth	Mild, moderate, severe/OLP
017	61	F	4	1	Tongue	Mild, moderate, severe/OLP
018	66	M	8	2	Buccal mucosa	Mild, moderate/OLP
019	58	M	3	1	Tongue	Mild/OLP
020	57	F	2	1	Buccal mucosa	Mild/OLP
021	67	M	2	1	Gingiva	Mild/OLP
022	58	F	2	1	Buccal mucosa	Moderate, severe/OLP
023	68	F	7	2	Palate, gingiva	Moderate, severe/ OLP, OSCC
024	63	F	8	1	Tongue	Moderate/OLP
025	76	F	9	2	Buccal mucosa, gingiva	Mild, moderate, severe/OLP
026	70	F	6	1	Buccal mucosa	Mild/OLP
027	75	F	6	3	Buccal mucosa, tongue	Moderate, severe/OLP, OSF
028	57	F	3	1	Gingiva	Mild, moderate/OLP
029	68	F	11	1	Tongue	Mild, moderate/OLP
030	70	M	17	1	Buccal mucosa	Mild, moderate/OLP

Abbreviations: F, female; M, male; OL, oral leukoplakia; OLP, oral lichen planus; OSCC, oral squamous cell carcinoma; OSF, oral submucous fibrosis.

TABLE 2 | A complete spectrum of subthemes developed from the primary themes.

Theme	Subtheme	Supporting quotations
Delay in OED diagnosis	Patient's inability to identify abnormal signs and symptoms	'Initially, it began as an ulcer in my cheek, and I assumed I just needed simple treatment in that area' (001)
	Clinician incompetence	'My GP referred me to an oral surgeon, suggesting that I should seek their expertise due to a potential issue with the skin in my mouth. I was sent back to my GP with no diagnosis; however, it was the oral medicine specialist who correctly identified and diagnosed the condition' (012)
	Administrative issues	'My referral was made incorrectly, necessitating a complete restart of the process. I was so frustrated' (014)
Knowledge about OED	Nature of the disease	'I believe that patients should be informed with all knowledge and utmost transparency about their diagnosis and disease' (013)
	Aetiology and risk factors	'I didn't know that alcohol can cause this in my mouth; I reduced the amount I drink and tried to stick to the recommended levels' (011)
	Diagnostic tests and treatment options	'It would be great to learn the particular aim of the biopsy sample and treatment alternatives' (006)
Psychological impact	Diagnosis of OED	'Upon receiving my initial diagnosis, I experienced a sense of worry, confusion, and disbelief, as there was a lack of awareness and understanding among others, and I did not encounter anyone who shared comparable experiences' (005)
	Risk of progression to cancer	'I'm extremely tired from the number of biopsies I've been having to chase any progression into cancer. It's draining and exhausting' (025)
	Management adverse effects	'You know, with mouth dryness, limited mouth opening, and graft I've got after the surgery, I'm not confident at a table—and that makes me sad' (023)
Patient education	Regular education	'I'd be grateful if the doctor would remind me of my plan each time I see him and not assume that I know everything I need to do because I only see him once a year and, as you can imagine. That's enough time for the information to fall through the cracks' (026)
	Lack of reliable sources of information	'Whenever I search for information, I exclusively rely on the NHS, as it provides a sense of security. However, I haven't found reliable sources for mouth precancer or dysplasia' (013)
	Supplementary educational tools	'As a non-native English speaker, watching a video would be helpful to better understand the information' (028)
	Group discussions	'I'm interested in meeting other individuals who share the same issue in order to get insight from their experiences and compare them to my own. I propose establishing a recurring meeting to exchange experiences' (014)

Abbreviation: OED, oral epithelial dysplasia.

Another reported the difficulty in securing a diagnosis:

> I consulted with two general practitioners and one dentist; they all didn't know how to manage or where to refer me for the white patch I've had in my mouth for months. I ultimately ended up seeing a Maxfax surgeon who sampled the lesion and found out that dysplasia was evident. This whole journey took around two years to reach an accurate diagnosis—luckily, the lesion didn't progress into cancer.

(021)

Additionally, many individuals faced significant administrative hurdles during the referral process, which led to prolonged and frustrating delays.

> My referral was made incorrectly, necessitating a complete restart of the process. I was so frustrated.

(014)

> The referral protocols dealing with mouth dysplasia at this hospital or other hospitals have to be improved.

(001)

> I've done my research before seeking a referral, which was very difficult to get through. Without my investigation and persistence, I would not have arrived at this point.

(019)

3.2.2 | Knowledge About OED

Several participants highlighted the critical importance of obtaining comprehensive knowledge about the diagnosis, nature of the disease, risk factors, treatment options and prognosis of OED. Before their encounters, none of the participants had any awareness of OED. Participants agreed that the moment of diagnosis marked a pivotal turning point, during which detailed information about all aspects of the condition should be communicated to ensure patients are fully informed and prepared to manage their health effectively.

As one participant expressed:

> I believe that patients should be informed with all knowledge and utmost transparency about their diagnosis and disease.

(013)

Another indicated the shock at learning about their condition:

> I have never heard of it. I am familiar with breast and prostate cancer. I was surprised to learn that I had mouth precancer.

(003)

One proposed the need for specialised patient-specific service:

> Is it possible to have a specialised mouth dysplasia clinic funded by the NHS? Specialists who possess comprehensive knowledge of the disease and its various manifestations and management?

(004)

Many participants were unfamiliar with the aetiology and risk factors associated with OED. Several also lacked knowledge regarding the correlations connecting alcohol and HPV with OED.

One participant admitted:

> I didn't know that alcohol can cause this in my mouth. I reduced the amount I drink and am trying to stick to the recommended levels.

(011)

Another reported:

> I know HPV can result in vaginal cancer, but in the mouth—never heard of that.

(023)

The participants emphasised the importance of promptly receiving thorough information regarding routine diagnostic tests and available treatment options.

For example, some participants stated:

> It would be great to learn the particular aim of the biopsy sample and treatment alternatives.

(006)

> Knowing that I may finally at least receive treatment for my issue was tremendously helpful to me.

(015)

> I was advised to have a surgical operation to remove my mouth lesions over regular watching. I appreciated the thorough knowledge I was given.

(024)

3.2.3 | Psychological Impact

Several individuals reported that OED has affected their psychological well-being. These impacts arise due to the diagnosis itself, the chronic nature of the condition, the uncertainty of progression to cancer and the treatments involved. Emotional distress was common at the first diagnosis, with feelings of worry and confusion due to lack of awareness.

One participant described:

> Upon receiving my initial diagnosis, I experienced a sense of worry, confusion, and disbelief, as there was a lack of awareness and understanding among others, and I did not encounter anyone who shared comparable experiences.
>
> (005)

Another added:

> Initially, everything was uncertain and ambiguous, as I lacked a clear understanding of what I had for many years. Hence, I was so stressed out and scared until I met Dr. xxx at this hospital.
>
> (008)

> Upon discovering the meaning of oral dysplasia, the doctor informed me that it is a condition I must endure, as there is no solution available. He explained that the initial phases of the disease vary across individuals. I had significant distress due to my refusal to acknowledge it as a medical condition.
>
> (017)

Some participants expressed apprehension and anxiety about the potential progression to oral cancer and OED recurrence.

> I'm extremely tired from the number of biopsies I've been having to chase any progression into cancer. It's draining and exhausting.
>
> (025)

> If I had been aware of all the possibilities of having cancer when I received my diagnosis, I would have experienced greater peace of mind, as I have recently acquired a significant amount of knowledge.
>
> (006)

> The risk, things that warrant cautionary attention. For instance, one of my colleagues was diagnosed with mouth cancer, which made me concerned about the possibility of developing a similar condition. Therefore, it is important to emphasise any relevant symptoms that may arise. If I were to experience any abnormal growth or hardness in that region, what course of action should I take?
>
> (029)

Participants also expressed challenges related to the management of OED, particularly the adverse effects that arose following major surgical procedures. Several individuals recognised the impact of these complications, including dry mouth, limited mouth opening, grafting and an inability to eat normally, on several aspects of their lives.

> You know, with mouth dryness, limited mouth opening, and graft I've got after the surgery, I'm not confident at a table—and that makes me sad.
>
> (023)

> When I look at myself in the mirror, my smile is not the same anymore, my confidence and intimacy with my husband have gotten affected. I had a couple of plastic surgeries to enhance the surgery's adverse effects, but that didn't really change a lot.
>
> (010)

> The challenges I have in communication, particularly in my profession as a professor, have undeniably caused annoyance and impacted my life.
>
> (016)

3.2.4 | Patient Education

Participants highlighted the vital significance of receiving ample information and consistent education regarding OED. They conveyed satisfaction with the interactions they had with knowledgeable and skilled clinicians. There was a belief among patients that the provision of information about OED should be ongoing, as knowledge might change over time and relevant disease-specific updates are difficult for non-clinicians to find.

> I'd be grateful if the doctor would remind me of my plan each time I see him and not assume that I know everything I need to do because I only see him once a year and, as you can imagine...that's enough time for the information to fall through the cracks.
>
> (026)

> I've been having memory issues recently. I need to be reminded about the important information.
>
> (006)

> I can't remember much about my disease because I had it a long time ago and never recurred. I always need to be reminded and educated.
>
> (018)

Several participants appreciated the support they received at diagnosis but thereafter felt abandoned due to a lack of reliable sources of information, which affected their acquisition of deeper knowledge about the condition. Consequently, they sought to gather information from other sources. They turned to the internet to gather information, which resulted in feelings of being swamped and discouraged.

One participant reported:

> Whenever I search for information, I exclusively rely on the NHS, as it provides a sense of security. However, I haven't found reliable sources for mouth precancer or dysplasia.
>
> (013)

Others reported:

> I believe it is beneficial to have a preliminary understanding, but upon initial diagnosis of any condition, one needs some time to fully comprehend and accept the situation, wouldn't you agree? It may be helpful to direct individuals to helplines or sources of additional information, such as online resources or support groups.
>
> (015)

> If you access the internet or Google and encounter the issue of feeling sad due to observing an arbitrary, unskilled collective of individuals who engage in spreading scary narratives.
>
> (022)

Alongside individual clinical consultations, the participants emphasised their desire for more extensive information on OED. They cited a diverse array of supplementary educational resources, encompassing written materials such as printed documents and webpages, as well as audio-visual content like YouTube videos. These supplementary tools would be beneficial for obtaining further comprehension of the information provided in the clinic and or to remind the patient of any forgotten information.

Some responses were:

> As a non-native English speaker, watching a video would be helpful to better understand the information.
>
> (028)

> Videos could be easier to digest and understand. And yet, written information and wording is important, especially in advanced cases, as it reflects the seriousness and severity of the condition more than the videos.
>
> (002)

> I can read the booklet anytime, while videos require an electronic device, which I can't afford.
>
> (006)

> I prefer videos because of convenience. I can slow it down, repeat it, see pictures for better imagination.
>
> (017)

Some participants suggested attendance at group discussions. Through the exchange of experiences and advice, individuals had medical benefits. Furthermore, engagement with peers facilitated emotional and mental support.

> I'm interested in meeting other individuals who share the same issue to get insight from their experiences and compare them to my own. I propose establishing a recurring meeting to exchange experiences.
>
> (14)

> It would be beneficial to have the ability to share experiences, treatment alternatives, and outcomes with individuals who have comparable diagnoses.
>
> (022)

4 | Discussion

This is the first qualitative study, to our knowledge, that investigates patient's experience with OED. The study identified four primary themes identified after data analysis: delays in diagnosis, knowledge about OED, psychological impact and patient education. The delayed diagnosis could be driven by patients' inability to recognise symptoms, clinician incompetence and administrative inefficiencies, often leading to lengthy referral processes. Participants also expressed a need for comprehensive knowledge upon diagnosis, including clarity on aetiology, risk factors, diagnostic tests, cancer development risks and treatments. The psychological impact was significant, with patients reporting uncertainty, confusion, worry and treatment-related side effects that affected their quality of life. Additionally, participants highlighted gaps in patient education and support, emphasising the need for reliable resources, supplementary educational tools (e.g., pamphlets and videos) and group discussions to share experiences and coping strategies.

This study indicated that several factors may contribute to delays in diagnosis, including the inability of patients to identify abnormal signs and symptoms, clinician incompetence and healthcare administrative hurdles. Some patients reported not perceiving their symptoms as serious or indicative of premalignancy. This could be explained by the fact that early symptoms of OED are frequently subtle and painless, leading them to be mistaken for normal mouth issues and easily overlooked. This aligns with a study on advanced-stage oral cancer (Rubright et al. 1996), where 87% of individuals reported being unable to identify warning signs during self-examinations. However, the current analysis also indicates that experiencing concerning symptoms is not always essential for seeking quick aid, as some patients sought assistance shortly after noticing even mild symptoms, such as a change in colour. Patients who delayed seeking care expressed that they would have sought treatment earlier had they been aware of the seriousness of their symptoms.

The participants in this study also reported that some dentists and GPs demonstrated insufficient competence and training, particularly in assessing mucosal lesions in the mouth such as OED. According to several studies, primary care providers are hesitant to diagnose and manage this category of illnesses (Sardella et al. 2007; Bindakhil et al. 2021). The inability to perceive symptoms as indicative of something warranting serious attention by a clinician has been documented for testicular cancer (Gascoigne et al. 1999), breast cancer (Ramirez et al. 1999) and oral cancers (Scott et al. 2006; Gigliotti et al. 2019). However, distinguishing OED from other conditions such as OLP or OL can be challenging for non-specialist clinicians due to overlapping clinical features. Findings indicate that many participants experienced diagnostic delays or uncertainties, a trend also noted in the literature (Sardella et al. 2007). This underscores the importance of improving the training of GPs and primary care teams in recognising subtle mucosal changes that may indicate dysplasia. These results highlight the value of targeted educational efforts and easily accessible resources for both patients and non-specialist clinicians.

Our findings also show that participants were transferred repeatedly between several dentists and GPs, with these clinicians diagnosing the oral lesions incorrectly or not recognising the malignant potential and seriousness of the disease or because of a lack of knowledge about the appropriate centres for their complaints. This finding is consistent with a prior study, where individuals with chronic facial pain reported multiple referrals to both primary and secondary healthcare facilities in their attempts to get medical attention (Taimeh et al. 2023). Well-coordinated referral pathways and stronger interprofessional collaboration could ensure timely management and boost patient confidence. Once participants in this study accessed specialist care, they reported clearer understanding and reduced anxiety. In addition, experts with varied experiences may employ different strategies for managing OED. For example, clinicians with an oral medicine background might suggest regular surveillance and non-invasive treatments, whereas oral surgeons might favour surgical interventions (Mehanna et al. 2009). Therefore, a significant obstacle for patients with OED is a lack of established guidelines for referring patients and determining appropriate treatment techniques. Strengthening the standards of undergraduate and postgraduate training in this field could enhance the efficacy of achieving a timely diagnosis and appropriately managing OED.

The findings of this study demonstrated that participants' knowledge about OED was insufficient, particularly at the time of their initial diagnosis. This finding is consistent with previous research on oral cancer (de Amorim Póvoa et al. 2025). Additionally, this insufficiency can be attributed to several factors, including clinicians not providing enough information, complexity of information, rarity of OED may limit general awareness and long intervals between follow-up appointments could lead to forgetfulness. However, once the diagnosis was established, the participants emphasised the importance of thorough and continued communication regarding essential disease-related information. An earlier OED study highlighted that addressing this critical element can enhance shared decision-making, mitigate the negative psychological impacts, improve future health outcomes and reduce healthcare expenditures (Alsoghier et al. 2022).

This study also showed that throughout the clinical course of the condition, the participants' levels of knowledge exhibited considerable variability. Some individuals demonstrated a high level of understanding about OED, often due to factors such as a long history of the disease, multiple recurrences with varying grades and a history of progression to cancer. Conversely, other patients in the current analysis displayed limited knowledge and understanding of OED, possibly attributed to factors such as a past diagnosis of a mild disease without progression or recurrence, older age or medical conditions affecting memory and comprehension. Some participants particularly emphasised the need for detailed information on the risk factors and potential progression to oral cancer, a need that has been corroborated by previous research on OED (Alsoghier et al. 2021). Furthermore, the results of this study underscore the importance of providing patients with comprehensive information about investigative tests and treatment options, aligning with findings from an earlier study on OED (Alsoghier et al. 2024).

Our findings show that several participants experienced significant psychological burdens from OED, adversely affecting their quality of life. These burdens were attributed to multiple factors, including delays in diagnosis, uncertainty about the disease, potential progression to cancer, risk of recurrence, challenges in controlling risk factors and management of adverse effects. A cross-sectional study supports these findings, showing that patients with OED had lower quality-of-life scores (Ashshi et al. 2023). Another investigation revealed that patients with OED often experience heightened anxiety, fear and emotional distress due to concerns about the potential progression to mouth cancer (Alsoghier et al. 2021). The latter study found that 30% of participants elevated anxiety, 16% suffered from depression and 26% endured emotional distress. In addition to the adverse effects of investigative sampling and therapeutic surgical procedures involving tissue removal, the participants of this study experienced significant impairments in nutrition and speech. Other studies on OED confirm the negative impact of OED management on the quality of life (Alsoghier et al. 2021; Ashshi et al. 2023).

Of the 30 participants, those diagnosed with only mild dysplasia (001, 002, 003, 019, 020, 021, 026) underwent an incisional or punch biopsy followed by clinical observation, while the remainder underwent repeated surgical excisions over the years due to higher dysplasia grades, progression to cancer or recurrences. Although the overarching themes of diagnostic delays, psychological impact and the need for patient education were common to both groups, individuals who underwent major surgical procedures reported additional concerns regarding post-operative complications (e.g., graft-related difficulties, altered speech and dryness). Conversely, those on clinical surveillance pathways spoke more frequently of anxiety surrounding potential malignant transformation. These differences underscore the heterogeneity of patient experiences and highlight the importance of personalised approaches to patient support and education.

In the current study, the participants indicated that regular OED education is essential. The provision of continued education is a critical component in the clinical management of both malignancies (Ankem 2015) and premalignant conditions like OED (Alsoghier et al. 2024). Our findings also demonstrate that the primary and preferred source of information is direct, one-on-one meetings with an OED specialist. Indeed, verbal discussions remain the most effective and irreplaceable method of information exchange (Stewart 1995). The participants also expressed a desire to access additional information from other reliable resources, such as leaflets or videos. Evidence suggests that supplementary educational tools, including written materials (e.g., booklets) and audio-visual aids (e.g., YouTube video clips), can enhance understanding and provide valuable support (Eckman et al. 2012).

Our analysis shows that, in the case of OED, which predominantly affects older individuals, written materials were favoured over videos by some patients due to factors like affordability and accessibility. Some participants also highlighted the importance of written information, particularly in advanced cases, as it conveys the gravity of the condition effectively. However, for non-English speakers, videos were preferred as they offer visual aids to overcome language barriers. Additionally, support groups were noted to have a positive impact, providing both medical and emotional support through shared experiences and advice. This aligns with research indicating the beneficial role of support groups in aiding patients with cancer (Hoey et al. 2008).

4.1 | Implications of This Study

This is the first qualitative study, to our knowledge, aimed at investigating the patient experience with OED. This study provides valuable insights into patient-reported outcomes, enabling a better understanding of patient experiences (Rothman et al. 2009). Such findings can be helpful for the development and selection of instruments that effectively capture the lived experiences of individuals with OED. In addition, these findings also can be utilised to further inform a previously developed measurement tool for OED, the oral epithelial dysplasia informational needs questionnaire, created by Alsoghier et al. (2022). This approach ensures the content validity, sensitivity and responsiveness of measures and enhances their applicability in evaluating patient-centred care for OED (Wiering et al. 2017).

4.2 | Study Limitations

The study was conducted in specific dental department settings. Hence, the findings may lack generalisability to other populations or healthcare systems. In qualitative research, the researcher plays a pivotal role and can significantly shape the study's outcomes (Dodgson 2019). This underscores the concept of reflexivity, wherein researchers are aware of their impact on participants while acknowledging how the research process influences them personally (Gilgun 2008). Researchers must also guard against the Hawthorne effect, where participants may alter their behaviour due to awareness of being observed, potentially skewing results (Brinkman et al. 2007). Additionally, retrospective investigations may introduce errors in participant recollections, emphasising the need for caution. Given the exploratory nature of small-sample studies, conducting larger-scale research is vital to affirm findings and enhance the robustness of conclusions.

Author Contributions

Waleed Alamoudi: conceptualization, methodology, data curation, investigation, formal analysis, project administration, writing – original draft, writing – review and editing. **Richeal Ni Riordain:** conceptualization, methodology, investigation, supervision, resources, writing – review and editing. **Stefano Fedele:** conceptualization, methodology, supervision, resources, writing – review and editing. **Stephen Porter:** conceptualization, methodology, supervision, project administration, resources, writing – review and editing.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Patient Education and Levels of Disease-Specific Information Needs Among Individuals With Oral Epithelial Dysplasia

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ABSTRACT

Background: Oral epithelial dysplasia (OED) is a histological diagnosis that carries an increased risk of the individual developing oral squamous cell carcinoma. We assessed the information needs (IN) and explored the sources of education used by individuals with OED using a validated OED-specific measurement.

Methods: A total of 102 adults with OED from the oral medicine clinic of a dental hospital in Central London were selected using convenience sampling. A cross-sectional survey was conducted in which participants completed the 33-item Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q), which assessed IN and gathered perspectives on patient education.

Results: Approximately two-thirds of the participants ($n = 66$, 64%) reported meeting the IN, whereas the remaining participants ($n = 36$, 35%) did not. The mean and median total scores from the questionnaire were 2.43 (±0.38) and 2.6, respectively, indicating a low sufficient level of IN. Most participants ($n = 80$, 78%) preferred one-on-one meetings as the primary mode of obtaining information, followed by written materials ($n = 64$, 62%), audiovisual resources ($n = 24$, 23%), and group discussions ($n = 8$, 0.7%).

Conclusions: Some topics were insufficiently met, necessitating additional educational efforts, such as risk factors and lifestyle modifications, physical and psychological impacts, awareness of potential complications, and seeking medical and psychological support. Sex and degree of dysplasia were associated with the levels of IN. These findings may guide future longitudinal research on OED IN assessment, support the creation of tailored educational tools, and facilitate further evaluation of the psychometric properties of the ODIN-Q.

1 | Introduction

Oral epithelial dysplasia (OED) is a histological diagnosis that carries an increased risk of the individual developing oral squamous cell carcinoma (OSCC) [1]. Individuals with moderate-to-severe dysplasia are at a significantly elevated risk of oral cancer development, with the likelihood of progression to OSCC increasing 10- to 20-fold compared with those with only cellular atypia or mild dysplasia [2]. Oral potentially malignant disorders (OPMDs) and several risk factors, including alcohol intake, tobacco use, and human papillomavirus (HPV) infection, have been linked to the development of OED [1, 3]. The most

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frequently affected sites are the tongue, floor of the mouth, and gingiva [2]. The current management strategies for OED include vigilant monitoring and surgical excision [4].

Given the chronic nature of OED, regular and comprehensive patient education (PE) is crucial for achieving favorable long-term outcomes [5]. The word "doctor" originates from the Latin term "docere," meaning "to teach," underscoring the inherent responsibility of physicians to educate patients, their families, and communities [6]. Providing patients with detailed and timely information needs (IN) enhances their understanding of the disease, improves adherence to management plans, and reduces the risk of complications [7]. Furthermore, it elevates patient satisfaction, fosters trust, and enables them to make informed decisions about their health. Effective PE lowers healthcare costs by reducing the frequency of visits, referrals, and resource utilization [7]. However, only 302 articles have explicitly addressed the role of PE in oral and dental disorders and an even smaller number of randomized controlled trials [8, 9]. Moreover, research on the effect of PE on individuals with oral malignancies and OPMDs is limited [10].

The assessment of IN is fundamental for successful PE [11]. IN pertains to the ways in which patients seek and receive knowledge about their disease, diagnosis, treatment, and follow-up care at the medical centers providing treatment [12]. Previous studies have explored the IN of patients with cancer [13], OSCC [14], and oral precancerous lesions [15]. Despite the widely recognized importance of IN and PE, there is a significant gap regarding the informational and educational needs of patients with chronic dental and oral cavity conditions [8, 9], including OED [5]. The Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) is a recently developed instrument that assesses the informational needs of patients with OED [16], which was validated in 86 patients [16]. The instrument demonstrated excellent internal consistency in the previous study, with a Cronbach's alpha of 0.93 for the overall scale. Test–retest reliability was moderate ($\kappa = 0.49$–0.53). Moreover, construct validity was supported by a significant, albeit limited, correlation with the Krantz Health Opinion Survey.

We aimed to (1) assess the current levels of IN in adults with OED, (2) explore the clinical factors associated with IN levels, and (3) identify the preferred methods of PE within this population before the development and administration of educational tools.

2 | Materials and Methods

2.1 | Study Design and Participant Recruitment

A prospective observational design with quantitative analysis based on questionnaires as part of the PE in OED (EDUCAT-ED) project was employed. The EDUCAT-ED project aims to identify the IN of individuals with OED and create tailored educational tools based on their needs and preferences. This study was conducted between March 2023 and December 2024 at the Oral Medicine Unit of the Royal National ENT and Eastman Dental Hospitals at the University College London Hospital (UCLH). Although a larger sample size is necessary to ensure representativeness and a meaningful subgroup analysis, a previous study that assessed IN among patients with oral cavity cancer indicated that a sample size of 92 was required to achieve a power of 0.80 [14].

The present study included a convenience sample of 102 adult volunteers (aged > 18 years), diagnosed with OED based on the 2017 World Health Organization (WHO) diagnostic criteria. Eligible participants included UK residents, proficient in spoken and written English, who could provide informed consent and were without concurrent malignancies or undergoing radiotherapy/chemotherapy to the head, neck, or other regions. All participants confirmed their OED diagnosis with a biopsy procedure conducted at the study site or at external facilities. Consequently, all data were collected during the follow-up phase of care—no patients were assessed before biopsy or after discharge. After the study was explained, eligible individuals who agreed to participate were provided with a patient information sheet and asked to sign the consent form. The participants were provided with a printed ODIN-Q to complete after their clinical visit or at home and send it back via post.

2.2 | Measurements

The ODIN-Q consists of three sections (Table 1). Section 1 collects sociodemographic details and information on smoking and alcohol intake. Section 2 comprises 33 items that evaluate the adequacy of information provided on various aspects of OED using

TABLE 1 | Oral epithelial dysplasia informational needs questionnaire (ODIN-Q) sections.

Section	Components
Section 1	• Seven questions about sociodemographic information, including age, race, ethnic background, level of education, employment status, and smoking and alcohol intake.
Section 2	• Thirty-three questions to assess the knowledge level about the disease, including its diagnostic procedures, therapies, physical and psychosocial impact, and the availability of medical information related to oral epithelial dysplasia. • Scoring: Questions were assessed using a 4-point scale (*too much* = 4, *enough* = 3, *not enough* = 2, *none* = 1) and making a total score between 132 and 33, interpreted as the following: 107–132: Too much information received *(case: highly met IN)* 81–106: Enough information received *(case: met IN)* 56–80: Not enough information received *(case: unmet IN)* 33–55: No information received *(case: highly unmet IN)*
Section 3	• One question with multiple options investigating the preferred approach to obtaining information about oral epithelial dysplasia. The options included individual meetings, printed materials, audiovisual resources, and group information sessions.

Abbreviation: IN: information needs.

a 4-point scale (1 = *none*, 2 = not enough, 3 = *enough*, 4 = *too much*), resulting in a total score ranging from 33 to 132. Section 3 examines patients' preferred methods for receiving IN.

2.3 | Analysis of Data and Representation

Microsoft Excel 2022 (version 2410) represented the sociodemographic characteristics, clinical variables, and ODIN-Q scores. Analyses were performed using SPSS version 27 (IBM manufacturer). A dataset of 102 patients was assessed using descriptive statistics to summarize demographic and clinical variables, and further assessments were done using logistic regression and Spearman's correlation analyses to explore the relationships between these factors and IN. The dependent variable was whether the patient's IN was met, and the independent variables included demographic and clinical characteristics (Table 2). The threshold for statistical significance was set at $p < 0.05$.

3 | Results

After a comprehensive investigation of the hospital database, 302 patients were identified as potentially eligible for participation. The step-by-step process from identification to final recruitment is shown in Figure 1. The study enrolled 102 participants, and all provided consent by signing a consent form after their scheduled clinical visit.

3.1 | Participants' Demographic and Clinical Characteristics

Table 2 summarizes the demographic and clinical characteristics of the study participants. The sample was predominantly female (63, 61%), with most participants falling within older age groups; notably, 34.31% were aged 60–69 years and 24.5% were aged 70–79 years. Regarding ethnicity, 49% were White (British), 19.6% White (other), 30.39% Asian or Asian British, and 0.98% Black. The majority (57.84%) of the study participants had a college or higher education degree. Over half of the participants (57.84%) were retired. Lifestyle factors revealed that 13.72% were current smokers, 43.13% reported past cigarette use, 2.94% used smokeless tobacco in the past, and 40.19% never smoked; similarly, 39.21% reported alcohol consumption as a current habit, 20.58% as past, and 40.19% had never taken alcohol.

Analysis of the clinical data and histopathological reports of all the participants revealed 171 biopsies indicating OED. The number of biopsies per participant ranged from one to nine, with an average of 1.69 biopsies per individual. Dysplasia was most often mild (43.27%), with moderate and severe cases accounting for 32.16% and 20.46%, respectively. The total number of clinical sites was 119, as some participants presented with lesions at multiple sites. The most frequent lesion site was the tongue (42.85%), followed by the buccal mucosa (24.36%) and gingiva (17.64%), with other sites less commonly involved. Additionally, 63.7% of patients had oral lichen planus, 13.33% had oral leukoplakia, 2.96% had HPV-associated lesions, 2.22% had oral submucous fibrosis, 3.7% had oral candidiasis, and 14.07% had a history of OSCC.

3.2 | Levels of Disease-Specific IN

According to the predetermined values for the overall ODIN-Q scores indicated in Table 1, approximately two-thirds ($n = 66$, 64%) of the participants were satisfied with the amount of IN received. The remaining 36 respondents (35%) stated that their IN was not fulfilled, with 32 of these participants receiving insufficient IN and four respondents receiving no IN on most items. The overall participants' responses to the ODIN-Q are summarized in Table 3A.

In addition, the overall analysis of the items of ODIN-Q revealed a low information sufficiency by a mean and median of 2.43 (±0.38) and 2.6 out of 4, respectively. Considering the mean, we adopted the following classification: items with mean scores higher than 2.5 are considered "often met," scores between 2.4 and 2.5 are considered "somewhat met," and scores below 2.4 are considered "unmet" (Table 3B).

3.3 | Clinical Variables Influencing the IN

Logistic regression analysis revealed no statistically significant predictors. Backward elimination was used to assess their contribution to predicting the outcome. The complete model initially included all clinical variables. However, there was a trend for sex to be associated with IN, with women showing higher odds of having sufficient IN (odds ratio = 4.459, 95% confidence interval: 0.800–24.852, $p = 0.088$; Table 4). Spearman's correlation analysis revealed a weak relationship between the severity of dysplasia and IN. For mild-to-moderate dysplasia, there was a weak negative correlation ($r = -0.333$, $p < 0.05$), indicating that as dysplasia severity increases from mild to moderate, IN may decrease slightly. In contrast, for moderate-to-severe dysplasia, a weak positive correlation was found ($r = 0.327$, $p < 0.05$), indicating that as dysplasia severity increases from moderate to severe, IN tends to increase slightly. Both correlations were statistically significant ($p < 0.05$).

3.4 | Preferred Educational Methods for Information Delivery

Participants were allowed to select one or more preferred methods of receiving OED-specific education, including one-on-one meetings ($n = 80$, 78%), written information (printed and online materials) ($n = 64$, 62%), audiovisual resources (videos and podcasts) ($n = 24$, 23%), and group discussions ($n = 8$, <1%). Among those who preferred one-on-one meetings, most preferred receiving information directly from the OED specialists ($n = 80$, 100%). A preference for consultations with general dental practitioners and auxiliary healthcare professionals (e.g., dental assistants) followed this preference ($n = 17$, 21.25%).

4 | Discussion

In this study, two-thirds of the participants reported meeting their IN, and one-third had unmet IN. The current analysis indicates that topics concerning the nature of the disease, investigations, and treatments were well addressed. A possible explanation for this finding is that patients have an established diagnosis in the

TABLE 2 | The demographic and clinical characteristics of the study participants ($n = 102$).

Variable	Category	Number (%)
Sex	Females	63 (61%)
	Males	39 (38%)
Age, years	20–29	1 (0.98%)
	30–39	2 (1.69%)
	40–49	6 (5.8%)
	50–59	18 (17.64%)
	60–69	35 (34.31%)
	70–79	25 (24.5%)
	80–89	14 (13.72%)
	90–99	1 (0.98%)
Ethnicity	White (British)	50 (49%)
	White (other)	20 (19.6%)
	Asian or Asian British	31 (30.39%)
	Black	1 (0.98%)
Education	College or higher educational degree	59 (57.84%)
	High school diploma or less	41 (40.19%)
	Not reported	2 (1.96%)
Employment	Retired	59 (57.84%)
	Employed (full-time)	16 (15.68%)
	Employed (part-time)	7 (6.86%)
	Self-employed	15 (14.7%)
	Unemployed	3 (2.9%)
	Not reported	2 (1.96%)
Smoking status	Current	14 (13.72%)
	Past (cigarettes)	44 (43.13%)
	Past (smokeless tobacco)	3 (2.94%)
	Never	41 (40.19%)
Alcohol consumption	Current	40 (39.21%)
	Past	21 (20.58%)
	Never	41 (40.19%)
Dysplasia	Mild	74 (43.27%)
Type	Moderate	55 (32.16%)
	Severe	35 (20.46%)
Site	Tongue	51 (42.85%)
	Buccal mucosa	29 (24.36%)
	Gingiva	21 (17.64%)
	Floor of the mouth	8 (6.72%)
	Hard palate	5 (4.2%)
	Lips	3 (2.52%)
	Soft palate	2 (0.84%)
Associated oral disease	Oral lichen planus	86 (63.7%)
	Oral leukoplakia	18 (13.33%)
	HPV-associated	4 (2.96%)
	Oral submucous fibrosis	3 (2.22%)
	Oral candidiasis	5 (3.7%)
	History of OSCC	19 (14.07%)

Abbreviations: HPV: human papilloma virus; OSCC: oral squamous cell carcinoma.

past and have undergone investigation and therapy; hence, they have adequate IN levels. Other studies have reported that patients with oral precancerous conditions [15], OSCC [14], and other cancer types [13] had high unmet IN related to disease and treatment, especially at the time of diagnosis and at the beginning of therapy. One possible reason for the discrepancy between these findings and ours may be the timing of the assessment. Our study primarily involved patients in the follow-up phase after receiving an established diagnosis and undergoing investigations and treatment. Thus, their IN may have been addressed during past clinical consultations. In contrast, studies that assessed IN during the initial diagnostic or early treatment phases likely captured higher levels of unmet needs [13, 14]. Differences in study design, patient populations, and the instruments used to measure IN may also contribute to the observed variations. However, these studies had a longitudinal design and reported that the need for disease-specific IN declined over time after treatment [13, 14].

The findings of this study showed that various topics on IN were somewhat or insufficiently met, including risk factors and lifestyle adjustment (the role of HPV, safe levels of alcohol, smoking cessation, safe sex, diet, and nutrition), clinical characteristics (prevalence, spread to other parts, chances of cure, and alternative medicine), impacts (psychosocial and physical), seeking support (second opinion, psychological, community), and research and clinical trials. Studies on conditions more strongly linked to HPV than to OED have also highlighted a lack of sufficient IN available to patients regarding the role of HPV in mouth malignancies [15, 17]. The present finding indicates a high proportion of participants who exhibited insufficient IN regarding safe levels of alcohol consumption, which can be explained by the fact that 40% of the patients did not drink alcohol. Thus, they may not be aware of the safe or recommended levels for those affected by OED. In addition, the participants in this study reported unmet IN regarding lifestyle adjustments (smoking, alcohol cessation,

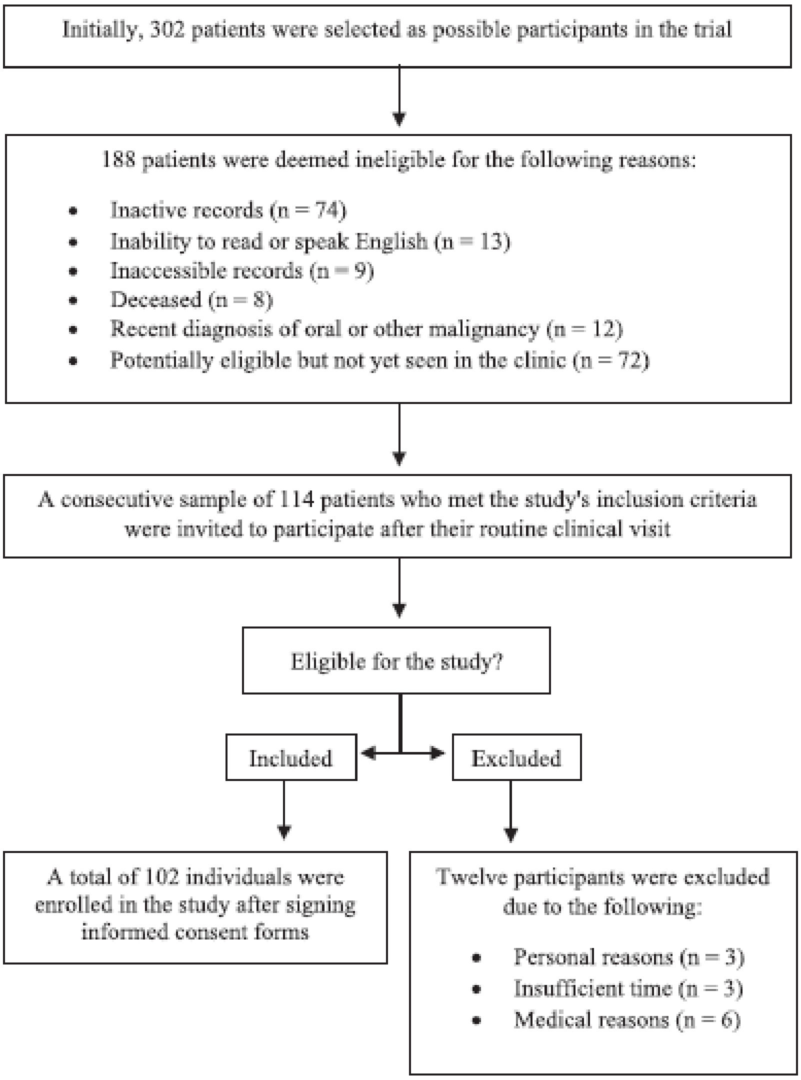

FIGURE 1 | Procedures undertaken to identify and recruit potentially eligible patients.

and safe sex). Previous cancer research has confirmed that patients express the need for individualized and practical information on how lifestyle modifications, including reducing alcohol consumption, quitting smoking, having safe sex, and making dietary changes, could improve their outcomes [18]. Participants in a previous study frequently sought information to support behavioral changes, such as guidance on diet and nutrition [19]. However, this requirement was not met in the current study.

This study showed that participants' IN on the prevalence of OED were somewhat met. The rarity of this disease may explain these findings. In a large-scale study that surveyed over 1000 patients with cancer in the United Kingdom, it was found that many participants reported unmet IN, specifically requiring more context regarding how common or rare their cancer type was [20]. Our findings also indicated that IN regarding the chances of OED cure were somewhat met. This may be because the prognosis and clinical behavior of OED differ based on the severity and associated oral disease [4]. For example, mild dysplasia can regress without intervention or progress to a greater degree. Therefore, clinicians should demonstrate more educational efforts to their patients regarding all clinical possibilities and the chances of an OED cure in the future. This finding is consistent with a systematic review summarizing 23 years of research on IN in patients with cancer [21], which underscores the fact that patients frequently feel that they do not receive sufficient IN about the broader context of their disease, such as prevalence and prognosis, contributing to confusion and anxiety. Our findings also showed that participants had insufficient IN on whether OED could spread to adjacent or distant body parts. This finding agrees with that of previous cancer studies, where many participants reported the need for more in-depth information about the likelihood and nature of cancer spread [20, 21].

The findings of this study revealed unmet IN regarding the psychosocial aspects of OED. Evidence supports that unmet IN can

TABLE 3A | Participants' responses to the ODIN-Q ($n = 102$).

	Amount of information received				
ODIN-Q item	**Too much**	**Enough**	**Not enough**	**None**	**N/A**
1. What oral epithelial dysplasia (OED) is?	0 (0%)	86 (84.31%)	8 (7.84%)	8 (7.84%)	0 (0%)
2. How common is it?	4 (3.92%)	56 (54.9%)	23 (22.54%)	19 (18.62%)	0 (0%)
3. What are the risk factors for developing it?	0 (0%)	84 (82.35%)	13 (12.74%)	5 (4.9%)	0 (0%)
4. How it looks in the mouth or lips?	4 (3.92%)	72 (70.58%)	18 (17.64%)	8 (7.84%)	0 (0%)
5. Weather it is contagious or not?	4 (3.92%)	78 (76.47%)	6 (5.88%)	14 (13.72%)	0 (0%)
6. About the role of human papilloma virus.	2 (1.96%)	34 (33.33%)	28 (27.45%)	38 (37.25%)	0 (0%)
7. About the disease grades and risk of developing mouth cancer.	6 (5.88%)	70 (68.62%)	21 (20.58%)	5 (4.9%)	0 (0%)
8. What will happen if I continue to smoke or drink alcohol?	7 (6.86%)	59 (57.84%)	14 (13.72%)	8 (7.84%)	14 (13.72%)
9. What is a safe level of alcohol to drink?	0 (0%)	56 (54.9%)	14 (13.72%)	18 (17.64%)	14 (13.72%)
10. What is likely to happen to OED in the future?	4 (3.92%)	68 (66.66%)	20 (19.6%)	10 (9.8%)	0 (0%)
11. About the screening and early detection.	2 (1.96%)	96 (94.11%)	2 (1.96%)	2 (1.96%)	0 (0%)
12. What are the benefits, risks, how each test works, and the meaning of test results?	0 (0%)	80 (78.43%)	17 (16.66%)	5 (4.9%)	0 (0%)
13. What will happen if it is not treated?	4 (3.92%)	84 (82.35%)	8 (7.84%)	6 (5.88%)	0 (0%)
14. About treatment options, benefits, risks, and how each treatment works?	2 (1.96%)	76 (74.5%)	12 (11.76%)	12 (11.76%)	0 (0%)
15. How the disease/treatment may affect the quality of life?	0 (0%)	58 (56.86%)	32 (31.37%)	12 (11.76%)	0 (0%)
16. About self-management at home.	0 (0%)	72 (70.58%)	23 (22.54%)	7 (6.86%)	0 (0%)
17. About complementary and alternative medicine (e.g., herbal medicine).	0 (0%)	18 (17.64%)	14 (13.72%)	70 (68.62%)	0 (0%)
18. What are the chances of a cure.	0 (0%)	64 (62.74%)	26 (25.49%)	12 (11.76%)	0 (0%)
19. How frequent and severe are the symptoms (e.g., ulceration, swelling, or bleeding)?	2 (1.96%)	76 (74.5%)	13 (12.74%)	11 (10.78%)	0 (0%)
20. About chances of spreading to adjacent or distant body part?	2 (1.96%)	42 (41.17%)	26 (25.49%)	32 (31.37%)	0 (0%)
21. About the effects of the disease/treatment on daily physical activities (e.g., eating, speaking, or maintenance of oral hygiene).	0 (0%)	72 (70.58%)	20 (19.6%)	10 (9.8%)	0 (0%)
22. About the diet and nutrition.	0 (0%)	54 (52.94%)	32 (31.37%)	16 (15.68%)	0 (0%)
23. About the fear of progression to cancer.	0 (0%)	78 (76.47%)	15 (14.7%)	9 (8.82%)	0 (0%)
24. How to cope with the possible effects of the disease/treatment?	0 (0%)	64 (62.74%)	26 (25.49%)	12 (11.76%)	0 (0%)
25. How the disease/treatment may affect social life (e.g., close relationships, family, and friends)?	0 (0%)	40 (39.21%)	34 (33.33%)	28 (27.45%)	0 (0%)
26. About the experience of your doctor and other healthcare staff.	0 (0%)	94 (92.15%)	8 (7.84%)	0 (0%)	0 (0%)
27. About seeking another professional opinion.	0 (0%)	42 (41.17%)	23 (22.54%)	37 (36.27%)	0 (0%)

(Continues)

TABLE 3A | (Continued)

ODIN-Q item	Amount of information received				
	Too much	Enough	Not enough	None	N/A
28. How to obtain physical support and advice (e.g., who to contact if warning signs appear)?	3 (2.94%)	73 (71.56%)	18 (17.64%)	8 (7.84%)	0 (0%)
29. How to obtain psychological support or advice?	0 (0%)	30 (29.41%)	32 (31.37%)	40 (39.21%)	0 (0%)
30. About community and/patient support groups.	2 (1.96%)	16 (15.68%)	16 (15.68%)	68 (66.66%)	0 (0%)
31. About health promotion (e.g., promoting one's health literacy).	0 (0%)	36 (35.29%)	19 (18.62%)	47 (46.07%)	0 (0%)
32. About the lifestyle adjustment (e.g., tobacco and alcohol cessation and safe sex).	2 (1.96%)	52 (50.98%)	14 (13.72%)	20 (19.6%)	14 (13.72%)
33. About the research and recruitment for clinical trials.	0 (0%)	52 (50.98%)	22 (21.56%)	28 (27.45%)	0 (0%)

Abbreviation: N/A: not applicable.

result in psychological distress, such as depression and anxiety, disrupting cognitive processes and reducing adherence to health guidelines among patients with cancer [13] and oral precancerous lesions [15]. This association between unmet IN and psychological distress may play a significant role in the findings of previous research that identified high levels of psychological disorders in individuals with OPMDs [22] and OED [23] and those at an elevated risk of developing OSCC [24]. However, these results should not be interpreted to mean that met IN decreases distress associated with cancerous or potentially cancerous conditions. Since the current study did not measure patients' actual knowledge, it is possible that highly distressed patients are informed but continue to express a desire for more information.

The present analysis showed that the level of IN on complementary and alternative medicines was insufficient. However, in a large European sample of over 900 cancer patients, approximately 35.9% used some form of complementary medicine. Yet, many felt that they lacked reliable information from their oncology team and expressed confusion about how to safely combine it with standard treatments and where to find reputable sources of guidance [25].

In the present study, we observed a positive relationship between sex and met IN, with females having higher odds of sufficient IN than males. However, it is important to note that this association was not statistically significant. This trend aligns with previous research suggesting that women are generally more proactive in seeking health information, often using multiple sources such as healthcare providers, online resources, and family or friends [26]. The current analysis also revealed a weak relationship between the degree of dysplasia and IN. Specifically, weak negative and weak positive correlations were observed for mild-to-moderate and moderate-to-severe dysplasia, respectively. These results are different from those of previous cancer research, showing that patients in the early stages of the disease experience higher IN than those with advanced disease [13]. Similar studies have identified significant correlations with other factors, including younger age [27], varying educational levels [14, 28], ethnic background, and unemployment status [28]. Other studies have noted an association between sufficient IN and current [15] and previous [14] alcohol consumption. Correlations between clinical symptoms, no history of cancer [15], oral conditions, and diagnostic time [14] have also been noted.

In this study, 78% of the participants preferred one-on-one meetings as their primary mode of receiving IN, especially from OED specialists, with 62% preferring printed materials and 23% preferring audiovisual resources. A systematic review of patients with cancer reinforces this observation, revealing that healthcare professionals are consistently identified as the primary source of information, followed by printed informational materials [21]. Our study also indicates that patients with OED seek online health information to satisfy their IN; however, the quality of the available online written [29] and audiovisual [30] information about OED remains poor despite 5 years of analysis.

To our knowledge, this study is the first to use a validated OED-specific instrument to assess IN in individuals with OED. Similar studies on oral cancer [14] and precancerous oral diseases [15] employed generic tools. For instance, Chen et al. used the Cancer Needs Questionnaire Short Form (CNQ-SF) and Karnofsky's Performance Status Index [14], whereas Lin et al. used the CNQ-SF, State Anxiety Inventory, and Attitudinal Oral Cancer Scale [15]. These studies focused on patients' IN during the diagnostic and treatment phases, whereas the current study addresses various other aspects (e.g., posttreatment impacts, medical system challenges, and sources of IN). Furthermore, research of this kind, which is integrated with findings from previous studies that have predominantly focused on the active phase of care, could guide evidence-based interventions to meet the IN of individuals with OED or OSCC. This study provided baseline data for the EDUCAT-ED project, which can be used in longitudinal research to compare changes in IN after administering educational interventions such as patient information leaflets or videos. These data can also be used as a baseline to further evaluate the psychometric properties of the ODIN-Q, including its structural validity and responsiveness. By analyzing structural validity (confirmatory factor analysis), it can be verified that the questionnaire items are adequately interrelated to represent the construct, offering more robust evidence of its alignment with patient IN. Similarly, a longitudinal analysis of IN using the

TABLE 3B | The mean scores and level of information needs for the ODIN-Q items.

		Information needs[a]		
ODIN-Q item	**Mean score**	**Often met**	**Somewhat met**	**Unmet**
Information about the disease				
1. What oral epithelial dysplasia (OED) is?	2.76	✓		
2. How common is it?	2.45		✓	
3. What are the risk factors for developing it?	2.76	✓		
4. How it looks in the mouth or lips?	2.7	✓		
5. Weather it is contagious or not?	2.72	✓		
6. About the role of human papillomavirus.	2			✓
7. About the disease grades and risk of developing mouth cancer.	2.76	✓		
8. What will happen if I continue to smoke or drink alcohol?	2.71	✓		
9. What is a safe level of alcohol to drink?	2.1			✓
10. What is likely to happen to OED in the future?	2.62	✓		
Information about investigative tests				
11. About the screening and early detection.	2.96	✓		
12. What are the benefits, risks, how each test works, and the meaning of test results?	2.74	✓		
Information about treatment				
13. What will happen if it is not treated?	2.84	✓		
14. About treatment options, benefits, risks, and how each treatment works?	2.66	✓		
15. How the disease/treatment may affect the quality of life?	2.45		✓	
16. About self-management at home.	2.64	✓		
17. About complementary and alternative medicine (e.g., herbal medicine).	1.49			✓
18. What are the chances of a cure.	2.5		✓	
Physical aspects				
19. How frequent and severe are the symptoms (e.g., ulceration, swelling, or bleeding)?	2.68	✓		
20. About chances of spreading to adjacent or distant body part?	2.1			✓
21. About the effects of the disease/treatment on daily physical activities (e.g., eating, speaking, or maintenance of oral hygiene).	2.6	✓		
22. About the diet and nutrition.	2.37			✓
Psychosocial aspects				
23. About the fear of progression to cancer.	2.68	✓		
24. How to cope with the possible effects of the disease/treatment?	2.5		✓	
25. How the disease/treatment may affect social life (e.g., close relationships, family, and friends)?	2.11			✓
Medical system and access to information				
26. About the experience of your doctor and other healthcare staff.	2.92	✓		
27. About seeking another professional opinion.	2.08			✓

(Continues)

TABLE 3B | (Continued)

ODIN-Q item	Mean score	Information needs[a]		
		Often met	Somewhat met	Unmet
28. How to obtain physical support and advice (e.g., who to contact if warning signs appear)?	2.68	✓		
29. How to obtain psychological support or advice?	1.9			✓
30. About community and/patient support groups.	1.52			✓
31. About health promotion (e.g., promoting one's health literacy).	1.9			✓
32. About the lifestyle adjustment (e.g., tobacco and alcohol cessation and safe sex).	2.07			✓
33. About the research and recruitment for clinical trials.	2.23			✓
Overall mean score	2.43			

[a]Information needs: often met: mean scores higher than 2.5, somewhat met: mean scores between 2.4 and 2.5, unmet: mean scores below 2.4.

TABLE 4 | Full logistic regression model results.

Variable	Odds ratio (95% CI)	*p*
Age	1.009 (0.952–1.070)	0.760
Smoking status	0.420 (0.075–2.357)	0.325
Alcoholic status	2.727 (0.553–13.453)	0.218
Gender of the participant	4.459 (0.800–24.852)	0.088
Mild dysplasia	0.715 (0.126–4.065)	0.705
Moderate dysplasia	2.225 (0.479–10.344)	0.308
Severe dysplasia	0.756 (0.141–4.059)	0.744
Ethnicity	0.608 (0.354–1.045)	0.702
Education level	0.814 (0.544–1.218)	0.318
Employment status	1.029 (0.541–1.958)	0.930
Constant	3.292 (N/A)	0.672

ODIN-Q could enable tracking of changes over time and assess the impact of educational interventions before and after their application (responsiveness).

This study has some limitations. First, our study employed a convenience sample, which lacks random selection, limiting the generalisability of the findings. Consequently, while the statistical tests provide valuable exploratory insights, the conclusions drawn from these analyses should be interpreted considering the evidence from available clinical studies. Second, the findings may not fully reflect the experiences of populations in different contexts because the sample was derived from a single dental hospital in the United Kingdom. Third, the recruitment of participants was conducted at a single point in time. Therefore, it is recommended that longitudinal assessments of patients' needs and information sources be conducted. Researchers are encouraged to assess IN from the time of diagnosis and monitor these needs throughout the disease course to capture changes in IN and educational preferences. Fourth, self-reported measures—including the ODIN-Q with its Likert-scale items—may introduce response bias. The fact that only closed-ended questions were used could be a drawback of this study, with options such as "too much/enough/insufficient" used for assessing the IN. This format may have allowed participants to guess the correct answers, potentially influencing the accuracy of the results. Future studies might benefit from incorporating a mix of open- and close-ended questions to capture a more nuanced understanding of participants' needs and reduce the likelihood of guessing.

In conclusion, although most patients possessed sufficient IN, specific essential topics require more educational attention from clinicians, including identifying the risk factors and lifestyle modifications (e.g., tobacco and alcohol consumption, the role of HPV, dietary changes), clinical characteristics (e.g., the possibility of spread, the chance of a cure, and prevalence, alternative medicine), awareness of potential impacts (e.g., psychosocial and physical), and seeking medical and psychological support (e.g., secondary professional opinions and community support). Participants ranked one-to-one meetings with healthcare professionals as their primary source of IN about OED. Although some clinical factors (e.g., sex and degree of dysplasia) appeared to be associated with IN, these relationships require further investigation in more extensive and diverse samples while considering psychosocial and environmental factors. Integrating qualitative methods can provide deeper insights into individual experiences.

Author Contributions

Waleed Alamoudi: writing – original draft, writing – review and editing, conceptualisation, methodology, funding acquisition, project administration, resources, investigation, formal analysis, data curation, and visualization. **Abdullah Alsoghier:** writing – review and editing, conceptualisation. **Richeal Ni Riordain:** writing – review and editing, conceptualisation, methodology, funding acquisition, resources, supervision. **Stefano Fedele:** funding acquisition, project administration, resources, supervision. **Stephen Porter:** writing – review and editing, conceptualisation, methodology, funding acquisition, project administration, resources, investigation, supervision.

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Ethics Statement

Following registration with the University College London Hospitals/ University College London (UCLH/UCL) Joint Research Office (JRO), this study was assigned a JRO reference number/EDGE number 153912; IRAS project ID 318039). This study received a favourable opinion on 16 January 2023, from the National Health Service (NHS) Research Ethics Committees (REC) (specifically, the London—Surrey Borders Research Ethics Committee, reference 22/PR/1743) and ethical approval was obtained on January 26, 2023 from the Health Research Authority (HRA) and Health and Care Research Wales (HCRW).

Consent

Written informed consent was obtained from participants.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Peer Review

The peer review history for this article is available at https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jop.13642.

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Confirmatory Factor Analysis of the Oral Epithelial Dysplasia Informational Needs Questionnaire

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ABSTRACT

Objective: The Oral Epithelial Dysplasia Information Needs Questionnaire (ODIN-Q) was developed to assess the informational needs of patients with oral epithelial dysplasia (OED). This study aimed to evaluate the six-factor ODIN-Q model to determine its psychometric properties and alignment with a theoretical framework.

Methods: Confirmatory factor analysis (CFA) was conducted with 165 participants to assess the model's fit. Consensus-based standards for selecting health measurement instruments were followed, and five participants per item in the assessment tool were required for effective CFA. Various fit indices, factor loadings and inter-factor correlations were analysed.

Results: The CFA results indicated a moderate model fit, which was consistent with other multidimensional patient-reported instruments. The average factor loading for all 33 items was 0.58 (highest = 0.84, lowest = 0.28). Only two items with relatively low loadings (<0.3) were related to doctors' experience and lifestyle adjustments. Additionally, the ODIN-Q distinguished conceptually distinct domains with low inter-factor correlations (<0.20).

Conclusion: The current six-factor ODIN-Q is a psychometrically sound instrument for assessing the informational needs of individuals with OED. Further cross-cultural assessments of the ODIN-Q are required to demonstrate its cultural sensitivity in other English-speaking patient cohorts and globally.

1 | Introduction

Oral epithelial dysplasia (OED) is a histological diagnosis of disturbances in cell maturation and proliferation. Although the exact mechanism of malignant transformation in OED is not well understood, it is accepted that a histological diagnosis of OED may lead to the development of oral squamous cell carcinoma (Speight 2007). Depending on the grading of the histological changes in OED, treatment may include a period of surveillance or 'watchful waiting' to monitor for regression or progression before considering whether surgical excision is necessary (Field et al. 2015). These periods of surveillance, investigation and therapy following the diagnosis of dysplasia have been linked to significant mental, physical and psychological burdens due to concerns about the development of cancer or its recurrence (Alsoghier et al. 2021). By providing health information, individuals can make better decisions regarding care and mitigate their worries (Gruman et al. 2010). Well-informed patients face less uncertainty, which increases their satisfaction, strengthens their coping mechanisms and contributes to improved therapeutic results (Ormandy 2011; Neumann et al. 2011).

However, a common gap exists between the information patients need and what their physicians offer, raising the chances

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of ineffective shared decisions and outcomes in the patient–physician relationship (Weymann et al. 2016; Alsoghier et al. 2024). Therefore, evaluating the information needs of patients with OED is crucial and can be achieved by deploying the Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) (Alsoghier et al. 2022). This 33-item tool, developed in the United Kingdom, includes domains such as clinicodemographic information, disease knowledge, investigative procedures, treatments, physical and psychological aspects, healthcare systems and access to information. Lazarus and Folkman' (1984) stress, appraisal and coping theory provides a conceptual basis for developing the ODIN-Q based on the idea that seeking information and taking proactive steps can be effective coping strategies for people dealing with challenging medical circumstances (Galloway et al. 1997; Rutten et al. 2005; White and Gallagher 2010). This framework is relevant for the diagnosis of oral precancer. The convergent validity of the ODIN-Q was established by comparing it with a similar measure, which is consistent with the accepted guidelines for evaluating construct validity (Mokkink et al. 2019). Further evidence of construct validity was shown through hypothesis testing, revealing that patients with more pre-existing medical conditions reported insufficient information on all items compared to those with fewer or no conditions (Mokkink et al. 2019). This aligns with the notion that individuals facing stressful situations, such as a new oral precancer diagnosis, along with other health concerns, are inclined to seek additional information as a coping method (Lazarus and Folkman 1984).

An initial assessment of the ODIN-Q in a previous study demonstrated good content and face validity and internal consistency reliability (Alsoghier et al. 2022). However, further psychometric testing of the sufficiency of the ODIN-Q regarding assessing information needs related to OED (i.e., structural validity) was previously recommended (De Vet 2011; Alsoghier et al. 2022). For instance, confirmatory factor analysis (CFA) offers a more advanced assessment of structural validity than other assessments of construct validity, such as hypothesis testing and cross-cultural validity assessments (De Vet 2011). CFA shares similarities with structural equation modelling, mainly in its association with model measurements (Brown 2015). CFA provides ways to verify the fit of the proposed theoretical model for data collection, define measurement model associations and link items to their domains (Pituch and Stevens 2015). Accordingly, CFA is believed to be a very successful technique for confirming concepts in the social and behavioural sciences (Brown 2015). Using unvalidated measurement tools often leads to misleading and inaccurate results, potentially causing suboptimal planning and ineffective cessation programmes (Hewlett et al. 2007). Hence, this study aimed to conduct a CFA for the ODIN-Q.

2 | Materials and Methods

2.1 | Study Design and Participants

This cross-sectional study enrolled adult patients with OED. Based on the inclusion criteria, participants were required to be at least 18years old, able to read and write in English, and willing to participate in the study. A summary of the study and its validation results was provided to those who agreed to participate. All participants signed an informed consent form before completing the ODIN-Q, which included three sections: (1) socio-demographic information, (2) level of information received and (3) preferred education methods (Table 1). The completion time for the questionnaire for laypersons was approximately 10–15min based on its readability score (4th-grade level).

2.2 | Recruitment Site and Sample Size

The Royal National ENT and Eastman Dental Hospitals' Oral Medicine Unit at University College London Hospitals (UCLH) recruited eligible participants between March 2023 and December 2024. Convenient sampling was used to recruit 165 patients to complete the ODIN-Q. The Consensus-based Standard for the Selection of Health Measurement Instruments (COSMIN) guidelines, which state that five patients per individual item in the questionnaire are necessary for effective CFA, served as the basis for calculating the sample size (Terwee et al. 2018; Mokkink et al. 2019).

2.3 | Ethical Considerations and Study Registration

The study procedures were carefully developed with strict adherence to the ethical principles of the Declaration of

TABLE 1 | Content and response choices of the ODIN-Q.

ODIN-Q section	No of items	Components	Response choices
Socio-demographics	7	Age, race, ethnicity, level of education, employment status and smoking and alcohol intake	Open-ended, closed-ended, multiple-choice
Level of information received	33	6 categories, involving questions on knowledge about the disease, investigative procedures, treatments, physical and psychosocial aspects and medical access and information availability	0 = not applicable 1 = not at all 2 = not enough 3 = enough 4 = too much
Preferred methods of information delivery	1	Individual meetings, printed materials, audiovisual resources and group information sessions.	Multiple-choice

Abbreviation: ODIN-Q, oral epithelial dysplasia informational needs questionnaire.

Helsinki for medical research involving human participants. The protocol was thoroughly reviewed by an independent expert, who confirmed the scientific rigor and feasibility of the study. This study was recorded by the Joint Research Office of UCLH and UCL with reference number 153912 (EDGE number) and Integrated Research Application System project ID: 318039. On 11 January 2023, the London–Surrey Borders Research Ethics Committee (reference 22/PR/1743) and the NHS Health Research Authority approved the study with favourable comments.

2.4 | Development and Psychometric Analysis of ODIN-Q

The stress, appraisal and coping theory introduced by Lazarus in 1984 served as the theoretical framework for developing ODIN-Q (Lazarus and Folkman 1984). Researchers have viewed this theory as a good foundation for developing tools that meet patients' information needs, where seeking information and engaging in active behaviour are helpful coping mechanisms for a range of stressful medical conditions (Galloway et al. 1997; Rutten et al. 2005; White and Gallagher 2010). The same can also be applied to the diagnosis of oral precancer. Convergent validity was confirmed by comparing the ODIN-Q with another instrument with a similar focus as part of the hypothesis testing process to evaluate construct validity (Mokkink et al. 2019).

2.5 | CFA

CFA was performed to confirm the factorial structure of ODIN-Q identified in a previous study (Alsoghier et al. 2022). Data were initially entered into Excel version 2410 and transferred to R version 4.1.1. The lavaan R package for Structural Equation Modelling, version 0.5–22 (Rosseel 2012), was used to analyse the six constructs of the ODIN-Q level of the information received section. Model fit can be confirmed using at least three individual indices (Hair et al. 2009). No consensus has been reached on omitting items based on a specific loading level, with decisions empirically determined based on the studied construct (Knekta et al. 2019; Ondé and Alvarado 2020). However, the validity of the construct is supported by a standardised factor loading higher than 0.5 and a *p*-value below 0.05, which reflects a strong association between items and their respective factors (McQueen et al. 2008).

3 | Results

3.1 | Socio-Demographic Characteristics of Participants

Table 2 shows the socio-demographic and clinical characteristics of the study participants ($n = 165$). The participants included 91 females (55%) and 74 males (45%) aged 25–90 years, with a mean and median age of 66 years. Based on histopathology reports, 267 dysplasia diagnoses were recorded. Dysplasia was most often mild 136 (50.93%), followed by moderate ($n = 96$; 35.95%) and severe dysplasia ($n = 35$, 13.1%). The total number of

TABLE 2 | Socio-demographic and clinical characteristics of participants ($n = 165$).

Variable	Category	Number (%)
Sex	Female	91 (55%)
	Male	74 (45%)
Age (years)	20–29	1 (0.6%)
	30–39	4 (2.42%)
	40–49	9 (5.45%)
	50–59	35 (21.21%)
	60–69	68 (41.21%)
	70–79	43 (26.06%)
	80–89	4 (2.42%)
	90–99	1 (0.6%)
Ethnicity	White (British)	88 (53.33%)
	White (other)	31 (18.78%)
	Asian or Asian British	43 (26.06%)
	Black or Black British	3 (1.81%)
Education	College or higher educational degree	98 (59.39%)
	High school diploma or less	63 (38.18%)
	Not reported	4 (2.42%)
Employment	Retired	95 (57.57%)
	Employed (full-time)	27 (16.36%)
	Employed (part-time)	9 (5.45%)
	Self-employed	23 (13.93%)
	Unemployed	5 (3.03%)
	Not reported	6 (3.63%)
Smoking status	Current	22 (13.33%)
	Past	85 (51.51%)
	Never	58 (35.15%)
Alcohol consumption	Current	84 (50.9%)
	Past	26 (15.75%)
	Never	55 (33.33%)
OED histopathological examination	Mild dysplasia	136 (50.93%)
	Moderate dysplasia	96 (35.95%)
	Severe dysplasia	35 (13.1%)
OED sites	Tongue	88 (45.36%)
	Buccal mucosa	46 (23.71%)
	Gingiva	30 (15.46%)
	Hard palate	12 (6.18%)
	Floor of the mouth	10 (5.15%)
	Soft palate	5 (2.57%)
	Lips	3 (1.54%)

(Continues)

TABLE 2 | (Continued)

Variable	Category	Number (%)
Associated oral disease	Oral lichen planus	115 (70.12%)
	Oral leukoplakia	28 (17.07%)
	Oral candidiasis	9 (5.48%)
	HPV-associated lesion	7 (4.26%)
	Oral submucous fibrosis	5 (3.04%)

Abbreviation: OED, oral epithelial dysplasia.

clinical sites was 194 because some participants presented with lesions at multiple sites.

3.2 | CFA

CFA was performed to verify the factorial structure of the ODIN-Q identified in a previous study (Alsoghier et al. 2022). The ODIN-Q was divided into six theoretical constructs. Descriptive statistics, fit indices, chi-squared tests of fit, factor loadings and interfactor correlations were computed to analyse the structural validity of the measurement tool.

3.2.1 | Descriptive Statistics for Factors

Table 3 summarises the central tendencies and variabilities of the scores across the six ODIN-Q factors. Investigative tests (F2) had the highest mean score (2.70), reflecting a stronger informational need in this domain than in others. In contrast, the medical system and access to information (F6) had the lowest mean (2.11), indicating comparatively less perceived importance or relevance. Psychosocial aspects (F5) exhibited the highest variability (SD = 0.64), suggesting that respondents provided diverse responses. In contrast, the questions under general information (F1) showed the least variability (SD = 0.49), indicating more consistent responses. The scores span a broad range, with minimum values as low as 0.75 and maximum values reaching 3.33, indicating adequate dispersion across factors. These results demonstrate that the ODIN-Q is sensitive to variability in informational needs across its domains.

3.2.2 | CFA Fit Indices

The significant chi-squared value ($\chi^2 = 947.041$, df = 480, $p < 0.001$) indicated a lack of perfect alignment between the observed and model-implied covariance matrices. Since the chi-squared test is often sensitive to sample size, further indices were assessed (Table 4).

3.2.3 | Complete Standardised Factor Loadings

Table 5 presents the factor loadings of ODIN-Q. Notably, the factors related to general information (F1) and psychosocial aspects (F5) were relatively consistent, whereas variability was noted for the medical system and access to information (F6). Items related to '*coping with disease effects*' [Q24] and 'chance of cure' [Q18] strongly contributed to their respective factors, indicating well-defined constructs. Items with weaker associations with their constructs included those related to lack of '*doctor experience*' [Q26] and Q32 '*lifestyle adjustments*' [Q32].

TABLE 3 | Central tendency and variability of the six factors of the ODIN-Q.

Factor	Mean	SD	Min	Max
General information (F1)	2.45	0.49	1.10	3.30
Investigative tests (F2)	2.70	0.51	1.00	3.00
Treatments (F3)	2.42	0.50	1.00	3.17
Physical aspects (F4)	2.37	0.59	1.00	3.00
Psychosocial aspects (F5)	2.38	0.64	1.00	3.33
Medical system & access to information (F6)	2.11	0.52	0.75	3.25

Abbreviations: ODIN-Q, oral epithelial dysplasia informational needs questionnaire; SD, standard deviation.

3.2.4 | Inter-Factor Correlations

Table 6 shows that most inter-factor correlations are low (<0.20), supporting the distinctiveness of the ODIN-Q factors. Psychosocial aspects (F5) and physical aspects (F4) are moderately correlated (0.170), reflecting conceptual overlap.

4 | Discussion

The CFA of the ODIN-Q conducted in this study provides valuable insights into its structural validity while confirming its clinical feasibility in capturing multiple dimensions of patient informational needs, including OED-related general knowledge, investigative tests, treatments, physical aspects, psychosocial aspects and access to healthcare. Unlike unidimensional tools, the ODIN-Q covers a broad spectrum of aspects, where factors are expected to be distinct rather than highly correlated (Knekta et al. 2019). Therefore, despite the suboptimal values of the fit indices, the six-factor model remains conceptually sound, in line with its previously demonstrated strong reliability and content validity (Alsoghier et al. 2022). It also considers the limitations of statistical validation models when assessing multi-item instruments where diverse constructs are assessed simultaneously (Byrne 2010). Additionally, it is not uncommon for health information needs' instruments to encounter similar challenges in achieving optimal CFA fit, owing to the broad range of constructs they encompass (Coulter et al. 2008).

The variability observed in these factors further underscores the sensitivity of the ODIN-Q in capturing diverse informational needs. Psychosocial aspects exhibited the highest variability, demonstrating diverse personal coping mechanisms, social support and psychological resilience, emphasising the importance of tailoring interventions to address individual needs (Ungar

TABLE 4 | Fit indices for the ODIN-Q.

Fit measure	Value	Threshold	Interpretation
Degrees of freedom (df)	480	N/A	Sufficient degrees of freedom
Chi-square (χ^2)	947.041	$p > 0.05$ (non-significant)	Significant ($p < 0.001$), poor fit
Comparative fit index (CFI)	0.744	≥ 0.90	Sub-optimal fit
Tucker–Lewis index (TLI)	0.719	≥ 0.90	Sub-optimal fit
Root mean square error of approximation (RMSEA)	0.085	< 0.08	Moderate fit
Standardised root mean square residual (SRMR)	0.095	≤ 0.08	Sub-optimal fit
Goodness-of-fit index (GFI)	0.592	≥ 0.90	Sub-optimal fit

Abbreviation: ODIN-Q, oral epithelial dysplasia informational needs questionnaire.

and Theron 2020). In contrast, general information about OED had the least variability, indicating more consistent responses, possibly because of the universal nature of the information in this domain (Epstein and Street 2011). The broad score range for the ODIN-Q also showed sensitivity in capturing variability to measure patients' informational requirements, aligning with recommendations for designing patient-centred instruments that cater to diverse populations (Coulter et al. 2008).

The highest mean score was observed in the OED investigative tests, indicating that patients often prioritise information related to diagnostic processes and their implications to better understand their condition (Epstein and Street 2011). Additionally, many patients with OED and other oral precancerous changes will undergo multiple excisions as part of their care plans and may feel that their available knowledge is insufficient (Awadallah et al. 2018). In contrast, the low scores given to the medical system and access to information by many participants confirmed the often-varying subjective perceived need for health information (Dawkins et al. 2021). Another explanation is that patients may have already received an OED diagnosis and management in a tertiary care unit, as previously addressed by primary and secondary care clinicians (Mehanna et al. 2009).

However, previous studies investigating this domain and its subcomponents have reported conflicting findings, indicating that many patients perceive access to healthcare information as an unmet or necessary need. Alsoghier et al. (2022) found that patients and clinicians identified healthcare navigation, clarity of diagnostic communication and access to specialist support as critical unmet needs. Furthermore, a psychometric evaluation of the ODIN-Q (Alsoghier et al. 2022) demonstrated that patients frequently reported gaps in access to information about clinical trials, patient support groups and secondary opinions, reinforcing the importance of this domain despite its low scores in this study. These findings highlight the potential variability in patient preferences, suggesting that, although some may feel that their informational needs have been met through previous healthcare interactions, others experience ongoing gaps in understanding and accessing medical resources, warranting further exploration.

In psychometric evaluations, instruments often exhibit suboptimal fit index validations. Researchers frequently justify these findings by emphasising the instrument's theoretical foundation, practical utility and complexity of the measured constructs. For instance, researchers have encountered challenges in achieving ideal fit indices in developing health-related quality of life measures such as emPHasis-10 for patients with pulmonary hypertension. Despite these challenges, the instrument was deemed valuable because of its comprehensive coverage of the construct and applicability in diverse settings (Yorke et al. 2014). Similarly, researchers validating the Chronic Heart Failure Health-Related Quality of Life Questionnaire reported certain suboptimal fit indices. However, they justified the retention of specific items based on their clinical significance and the overall content validity of the instrument, ensuring its relevance to the target population (Zhao et al. 2024). These examples underscore the importance of balancing statistical rigour with theoretical and practical considerations.

Notably, the reported RMSEA (0.085) exceeded the adopted threshold of 0.08 and remains appropriate for multidimensional scales (Browne and Cudeck 1992). This value is consistent with other multidomain patient-reported measures, where slight deviations from the ideal model fit are often attributed to the diversity of patient needs rather than measurement flaws (Kline 2023). Additionally, the SRMR (0.095), whereas above the threshold of 0.08, does not necessarily indicate a significant measurement problem but rather the need for minor revisions in item wording and factor structure.

The inter-factor correlations provided further support for maintaining the six-factor structure of the ODIN-Q. Most correlations remained below 0.20, indicating that the factors were conceptually distinct, which was expected given the diverse nature of patient informational needs (Della et al. 2013). Although the medical system and access factors had weaker inter-factor correlations, this does not necessarily imply poor construct validity. Instead, it reflects the unique nature of access-related concerns that may not always be strongly correlated with knowledge- or symptom-related factors (Ng 2013). Other studies on patient information needs have also found that system-related constructs often behave differently in statistical models owing to external influences such as healthcare accessibility, literacy levels and individual patient experiences (Zikmund-Fisher et al. 2010). Therefore, the lower correlations observed in the ODIN-Q medical system and access domain did not reduce its clinical relevance. Instead, they underscore the complexity of assessing patients' experiences with healthcare

TABLE 5 | Factor loadings of the items of the ODIN-Q.

Factor	Item	Standardised loading
General information (F1)	Q1 What is OED	0.705
	Q2 How common is it	0.625
	Q3 Risk factors	0.684
	Q4 Appearance in mouth or lips	0.571
	Q5 Is it contagious	0.574
	Q6 Role of HPV	0.421
	Q7 Disease grades and cancer risk	0.700
	Q8 Effects of smoking or drinking	0.365
	Q9 Safe level of alcohol	0.431
	Q10 Future of OED	0.537
Investigative tests (F2)	Q11 Screening and detection	0.516
	Q12 Benefits risks of tests	0.771
Treatments (F3)	Q13 If untreated	0.524
	Q14 Treatment options	0.739
	Q15 Effects on quality of life	0.757
	Q16 Self-management	0.562
	Q17 Alternative medicine	0.400
	Q18 Chance of cure	0.790
Physical aspects (F4)	Q19 Symptom severity	0.651
	Q20 Spread to other parts	0.549
	Q21 Effects on daily activities	0.778
	Q22 Diet and nutrition	0.618
Psychosocial aspects (F5)	Q23 Fear of cancer progression	0.652
	Q24 Coping with disease effects	0.847
	Q25 Effects on social life	0.634
Medical system & access to information (F6)	Q26 Doctor experience	0.280
	Q27 Seeking second opinion	0.559
	Q28 Physical support access	0.435
	Q29 Psychological support access	0.813
	Q30 Patient support groups	0.709
	Q31 Health promotion	0.776
	Q32 Lifestyle adjustments	0.290
	Q33 Research and clinical trials	0.452

Abbreviations: HPV, human papillomavirus; ODIN-Q, oral epithelial dysplasia informational needs questionnaire; OED, oral epithelial dysplasia.

systems. Retaining these items, even with moderate statistical performance, ensures that the ODIN-Q captures a comprehensive picture of patients' informational needs, particularly for individuals facing barriers to healthcare access and navigation (Scott et al. 2002).

This study provides evidence of the conceptual overlap between some factors. Notably, information concerning psychosocial and physical aspects was moderately correlated (0.170), suggesting that physical health concerns influence psychosocial well-being, as observed in other studies on health-related quality of life (Epstein and Street 2011). This relationship aligns with the understanding that physical and psychological domains are often interconnected in health contexts, particularly in individuals managing chronic or potentially malignant conditions (Chapman et al. 2005). Similarly, psychosocial aspects demonstrate slightly stronger correlations with other factors, reflecting the central role of psychosocial considerations in patients' experiences and information needs (Pourhaji et al. 2023).

The ODIN-Q is a rigorously developed instrument that has undergone extensive reliability and validity testing, making it a valuable tool for assessing the diverse information needs of patients with OED. The broad response range and variability in the factor scores demonstrate its sensitivity in measuring the perceived importance of different informational needs. Future research should focus on further validation in diverse populations to ensure that the ODIN-Q is applicable across different clinical settings and patient cohorts in the United Kingdom. Additionally, a longitudinal approach to assessing the informational needs of patients with OED is essential for understanding how patient concerns evolve throughout the care pathway from diagnosis to long-term management. Studies using patient-reported outcome measures and patient-reported experience measures have demonstrated the importance of capturing evolving patient concerns, with findings showing that information needs related to diagnosis and prognosis often give way to treatment and survivorship concerns (Di Maio et al. 2022). This is particularly relevant for OED, where patients frequently undergo multiple excisions and long-term surveillance, making tailored, stage-specific information critical for patient engagement and adherence to follow-up care (Mehanna et al. 2009).

This study had some limitations. First, the sample was recruited from a single dental hospital; thus, the findings may not be generalisable to a broader population. Differences in health literacy, cultural background and access to healthcare can influence responses and affect a tool's applicability across various contexts. Second, this cross-sectional study only provides a snapshot of informational needs at a single time point. It does not capture the changes in patients' informational needs or experiences over time, thus limiting its ability to assess the tool's longitudinal utility. Third, the participants may have provided socially desirable responses, particularly in domains related to knowledge and behaviour. Such biases could affect the accuracy of the results and mask the true informational gaps. Fourth, although the study focused on confirming the factor structure of the ODIN-Q, additional aspects of validation, such as predictive validity, criterion-related validity and test–retest

TABLE 6 | Inter-factor correlations of items of the ODIN-Q.

ODIN-Q domains	F1	F2	F3	F4	F5	F6
General information (F1)	0.135	0.070	0.085	0.097	0.118	0.023
Investigative tests (F2)	0.070	0.073	0.067	0.077	0.080	0.017
Treatments (F3)	0.085	0.067	0.111	0.123	0.131	0.027
Physical aspects (F4)	0.097	0.077	0.123	0.201	0.170	0.039
Psychosocial aspects (F5)	0.118	0.080	0.131	0.170	0.208	0.043
Medical system & access to information (F6)	0.023	0.017	0.027	0.039	0.043	0.019

reliability, were not addressed, leaving specific psychometric properties unexplored.

5 | Conclusions

This study provided a comprehensive psychometric evaluation of the ODIN-Q, confirming its clinical utility and validity for assessing the diverse informational needs of patients with OED. The ODIN-Q effectively distinguishes distinct informational domains, including general knowledge, investigative tests, treatments, physical aspects, psychosocial aspects, medical systems and access to information, making it a valuable tool for patient-centred care. Although the statistical fit indices suggest minor areas of improvement, such as refining or subdividing some items within the medical system and access to the information domain, the six-factor model remains conceptually sound, reflecting the multidimensional nature of patient needs. Future studies should continue to validate this tool across diverse populations and explore its longitudinal applicability in assessing evolving patient information needs.

Author Contributions

Waleed Alamoudi: conceptualization, investigation, funding acquisition, writing – original draft, methodology, validation, writing – review and editing, software, formal analysis, project administration, data curation. **Abdullah Alsoghier:** conceptualization, writing – review and editing. **Richeal Ni Riordain:** conceptualization, investigation, methodology, validation, writing – review and editing, supervision. **Stefano Fedele:** conceptualization, investigation, writing – review and editing, supervision, resources. **Stephen Porter:** conceptualization, investigation, funding acquisition, methodology, writing – review and editing, project administration, supervision, resources.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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