


# How dental teams can help patients with temporomandibular disorders receive general dental care: An International Delphi process

James R. Allison<sup>1,2</sup>  | Elizabeth Offen<sup>1,2</sup> | Terrie Cowley<sup>3</sup> | Deanne Clare<sup>3</sup> | Suzie Bergman<sup>4</sup> | Jennifer Ginsburg Feldman<sup>5</sup> | Lisa Marie Schmidt<sup>5</sup> | Tricia Kalinowski<sup>5</sup> | Jens C. Türp<sup>6</sup>  | Daniele Manfredini<sup>7</sup>  | Donald R. Nixdorf<sup>8</sup>  | Ann-Marie C. DePalma<sup>9</sup> | Justin Durham<sup>1,2</sup>  | International Network for Orofacial Pain and Related Disorders Methodology (INFORM)

<sup>1</sup>School of Dental Sciences, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

<sup>2</sup>Newcastle upon Tyne Hospitals, Newcastle upon Tyne, UK

<sup>3</sup>The TMJ Association Limited, Wisconsin, Milwaukee, USA

<sup>4</sup>TMD Patient and Dentist, Vancouver, Washington, USA

<sup>5</sup>TMD Patient, USA

<sup>6</sup>University Center of Dental Medicine Basel UZB, Basel, Switzerland

<sup>7</sup>School of Dentistry, Department of Biomedical Technologies, University of Siena, Siena, Italy

<sup>8</sup>Division of TMD and Orofacial Pain, School of Dentistry and Department of Neurology, Medical School, University of Minnesota, Minnesota, Minneapolis, USA

<sup>9</sup>TMD Patient and Dental Hygienist, Boston, Massachusetts, USA

## Correspondence

James R. Allison, School of Dental Sciences, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, NE2 4BW, UK.

Email: [james.allison@newcastle.ac.uk](mailto:james.allison@newcastle.ac.uk)

## Abstract

**Background:** Many patients with temporomandibular disorders (TMD) find it difficult to undergo dental care due to challenges caused by their condition, previous temporomandibular joint surgery or invasive dental procedures, and the impact of comorbid conditions. Managing routine dental care for some patients with TMD can be seen as challenging by some dental practitioners.

**Objective:** The objective of this study was to work with patients experiencing TMD and clinicians to co-produce recommendations aimed at helping general dentists to provide routine dental care for patients with TMD.

**Methods:** A modified Delphi process was used to co-produce recommendations. Six patients experiencing TMD, patient advocates and seven clinicians took part, including international TMD clinicians. Two meetings were held with patient participants, mediated by a trained facilitator. Recommendations suggested by patient participants were distributed to clinicians who were asked to add additional suggestions, but not to modify patients' recommendations unless to aid clarity. Additional themes were identified from the existing literature, and the recommendations were then reviewed by the International Network for Orofacial Pain and Related Disorders Methodology (INFORM) consortium.

**Results:** Recommendations were given to support patients before, during and after dental treatment. Participants identified specific and practical recommendations to help patients with TMD receive routine dental care, but also emphasised the need for professionals to listen sensitively to patients' concerns and work with patients in an empathetic and non-judgmental way.

International Network for Orofacial Pain and Related Disorders Methodology (INFORM): A Network within the International Association for Dental Research (IADR).

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Journal of Oral Rehabilitation* published by John Wiley & Sons Ltd.

**Conclusion:** These recommendations, co-developed with patients experiencing TMD, should help dental professionals to provide supportive general dental care for patients with TMD.

**KEYWORDS**

chronic pain, dental care, facial pain, oro-facial pain, patient and public involvement

## 1 | INTRODUCTION

Temporomandibular Disorders (TMD) are a group of conditions that affect the temporomandibular joints (TMJs), muscles of mastication and associated structures. Symptoms and their severity often vary widely between individuals, as well as over time, and these include: pain in the face, mouth and jaws; TMJ noises, such as clicking, popping or crepitus; limitation of mandibular movement; and jaw locking (open or closed). Most commonly, patients report symptoms that are worsened by mandibular function, such as eating, chewing and speaking.<sup>1</sup> Current diagnostic criteria<sup>2</sup> include several specific diagnoses, and these can largely be divided into those which are muscular in origin, those arising from the temporomandibular joint (TMJ) and associated structures and other conditions.

The pathophysiology of TMD is complex and incompletely understood; however, a range of biological, psychological and social phenomena all interact to initiate, potentiate and prolong the patient's condition.<sup>3</sup> The estimated incidence of a first episode of TMD in adults is around 4% per year,<sup>3</sup> and many patients with TMD experience recurring symptoms.<sup>1</sup> For some patients with TMD, their condition has a significant detrimental effect on their quality of life and ability to go about their usual work, recreational and social activities.<sup>4,5</sup> Additionally, many patients with TMD also suffer from other extensive and impactful comorbidities, such as primary headache disorders, fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome.<sup>6</sup> Importantly, many patients report their frustration in being unable to receive effective care in a timely manner<sup>7,8</sup> and difficulties in getting healthcare professionals to understand their condition.<sup>9</sup>

General consensus for the management of TMD is that treatment should mainly focus on conservative and reversible therapies in the first instance, without the need for unnecessary irreversible dental procedures, and with surgical interventions reserved only for when there are specific indications.<sup>10-12</sup> For many patients with TMD, their existing painful symptoms, the need for prolonged jaw opening, previous TMJ surgery or the impact of comorbid conditions make receiving routine dental care difficult. Very little literature currently exists on the challenges patients with TMD experience when trying to access general dental care, although the specific needs of patients who suffer from TMD can be seen (erroneously) as 'difficult' by dental practitioners when providing general dental care.<sup>13</sup>

The aim of this study was to co-produce a series of recommendations, in collaboration with patients who experience TMD, and clinicians experienced in the management of TMD, which could be

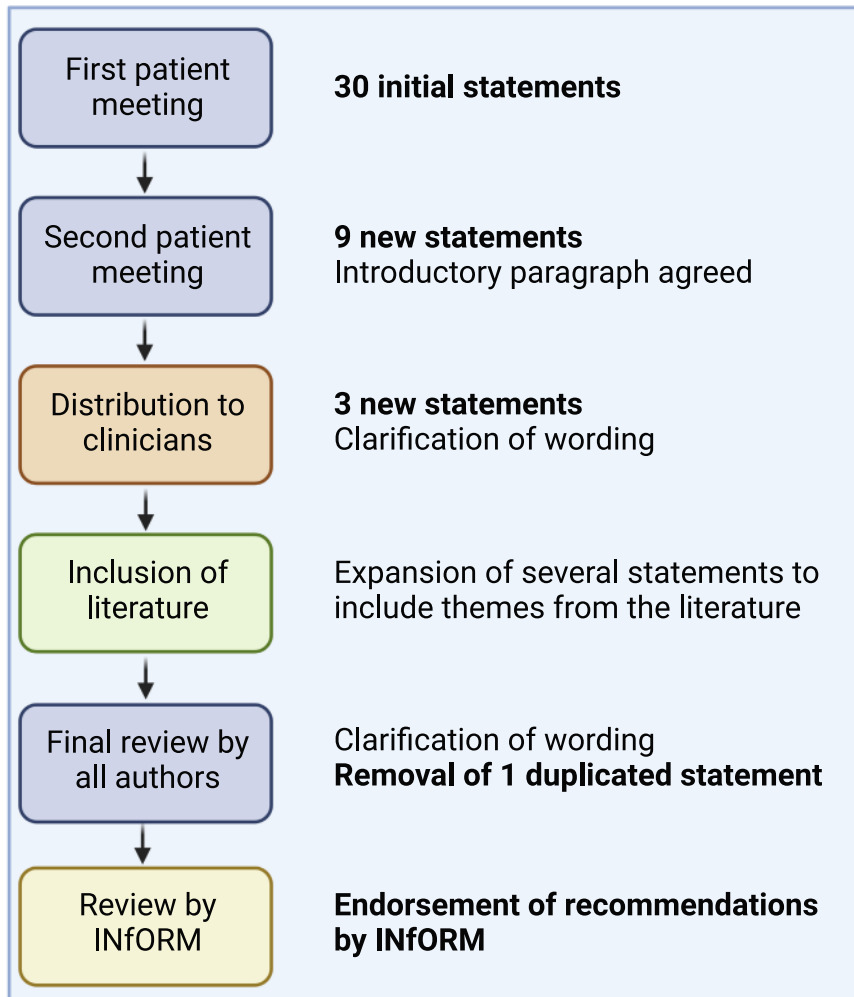
used to inform general dentists in how to provide routine dental care in a way which is acceptable for patients who suffer from TMD. The project was initiated by the North American TMD patient support group, The TMJ Association, in response to requests from patients for measures to help them obtain dental care in a supportive way.

## 2 | METHODS

A modified Delphi process was used to derive recommendations for general dental practitioners and dental teams on how best to provide routine dental care for patients with TMD (Figure 1). Seven female TMD patients and patient advocates based in the United States (TC, DC, SB, JGF, LMS, TK, A-MCD) were included in the process through their involvement with The TMJ Association. One of these TMD patients (SB) was also a practising general dentist and one was also a dental hygienist (A-MCD). Six other clinicians in total (five male, one female), from the United Kingdom (JRA, EO, JD), Switzerland (JCT), Italy (DM) and United States (DN) also took part. This included clinicians with significant expertise in the clinical management of TMD and in TMD research (DM, JCT, DN, JD).

An initial meeting with patient participants (TC, DC, SB, JGF, LMS; also attended by JRA and JD) was held online in November 2021. Discussion was mediated by a trained facilitator (JD) with care taken not to influence the suggestions of patients, by seeking to clarify statements and stimulate comments and further suggestions from other participants. The meeting was structured around the following themes: recommendations for general dental practitioners in treating patients with TMD before routine dental treatment; during treatment; and after treatment. Topics and recommendations were recorded in writing during the meeting and confirmed as accurate with the participants by verbal feedback. They were then collated afterwards into an electronic document under the above themes by JRA and EO.

The recommendations derived at the first round were then distributed to participants ahead of a second meeting (TC, DC, SB, JGF, LMS, TK; also attended by JRA and JD) held online in December 2021 and mediated by JD. At this meeting, participants aimed to reach consensus on the previously derived recommendations, and to add any new recommendations to each of the themes. All participants were asked to confirm agreement with each statement, and where disagreement was present, this was resolved by discussion until consensus was reached. All disagreements were resolved in this way.



**FIGURE 1** Schematic of the process used in this study to co-develop recommendations. INfORM, International Network for Orofacial Pain and Related Disorders Methodology.

Following the second meeting, the derived recommendations were collated by JRA and EO and were distributed electronically to all participants of the online meetings to check accuracy and to offer any additional comments or suggestions. After reconciling participant comments, the recommendations were distributed to clinicians (JRA, EO, JCT, DM, DN, A-MCD, JD), whose suggestions were then incorporated. Again, care was taken to ensure the suggestions of patients were not modified, unless to aid clarity for the intended audience (dental professionals), or to add new recommendations. Consensus was reached after the second round and so no further rounds were completed.

Following the Delphi process, the results of a recently published meta-synthesis of qualitative data on the experiences of people living with TMD<sup>9</sup> and other relevant qualitative papers<sup>13-15</sup> identified by TMD clinicians and patients were used to ensure that any missed themes were identified from the literature and included in the recommendations. The recommendations were then distributed to all participants for their final approval.

Finally, the recommendations were sent to the International Network for Orofacial Pain and Related Disorders Methodology (INfORM) to have their review and subsequently their endorsement of the patient-derived recommendations. Review was undertaken by

members of the INfORM Executive Committee who gave approval after minor comments relating to clarity and inclusion of relevant literature had been addressed.

Reporting in the study conforms to the recommendations of GRIPP2 for reporting of patient and public involvement in research (Appendix S1).<sup>16</sup>

### 3 | RESULTS

An overview of how the recommendations were derived is shown in Figure 1, including the number of new statements generated at each stage. During the first meeting, patient participants discussed some of the difficulties they encountered when undergoing dental care and suggested recommendations for dental teams to help patients with TMD to receive supportive general dental care. Minor comments were given by participants after distribution of the recommendations derived at the first meeting, mainly providing clarity around the recommendations that the participants suggested. Further suggestions were given by participants in the second online meeting, and participants were given the opportunity to correct or modify any previously added recommendations.

Minor comments providing clarity were again returned by participants after distribution of the recommendations derived at the second meeting.

Distribution of the recommendations to clinicians (JCT, DM, DN, JD) produced minor suggestions to terms used in the recommendations to make them more appropriate for dental professionals; the content of patient participants' suggestions were not altered.

Evaluation of the existing literature<sup>8,13,15,17</sup> including a recent meta-synthesis of qualitative evidence<sup>9</sup> identified several themes relating to the experiences of patients with TMD. The three general themes listed below were used to support the recommendations suggested by patient participants in the Delphi process. We ensured that the recommendations adequately reflected these aspects of patients' experiences where appropriate:

1. Patients report that TMD has significant disruptive effects on almost all activities of daily life, which fluctuated over time, and that this should be recognised by healthcare practitioners.
2. Patients' conditions and the resulting disability may not be visible and are frequently minimised.
3. Patients feel that there is a stigma related to TMD and appropriately expect more understanding from health professionals about the challenges their condition presents to them both in everyday life and while undergoing dental care.

Participants in the Delphi process identified that in general, the traditionally paternalistic hierarchy of dentistry, or the perception of this, could be a concern for some patients with TMD, and could make them feel their concerns were not likely to be believed or valued. Participants felt that this could, for some, be compounded by perceptions of sexist sentiment towards patients with TMD, a condition that more commonly affects women. Participants stressed that each patient is an expert in *their own* condition, and that it is vital for practitioners to trust, listen to and work with patients when providing care.

A summary of the derived recommendations is given under each theme below, and the complete recommendations can be found in the Appendix S2.

### 3.1 | Before dental treatment

Participants felt that it was important for members of the dental team to (a) understand how best to approach the general management of patients with TMD, and (b) for all members of the dental team, from receptionists to dentists, to have some understanding of their specific needs. There was an emphasis on the need for professionals to listen to patients' concerns in a non-judgmental, empathetic manner, and to involve them in diagnostic and therapeutic decisions. Participants felt that most patients with TMD should be able to receive routine dental care in a general dental practice, but that it may take more time than usual to deliver treatment due to patients' needs. It was particularly important to participants that dental teams understood that patients' conditions often fluctuated,

and there may occasionally be a need to cancel or reschedule appointments at short notice.

Participants felt that it was important that dental teams understood that some patients with TMD may experience additional psychosocial distress due to their previous healthcare experiences; clinicians should therefore aim to spend time building patients' trust, and they should expect patients with TMD to ask questions about their care given their prior experiences. Equally important was the need to avoid minimisation of a patient's symptoms or the impact of these, and to avoid trivialising or dismissing their concerns.

Some practical recommendations were to schedule a telephone or video consultation before any face-to-face visit to ensure practitioners understand how to help patients with TMD in managing their dental care. Offering longer appointment times was also considered helpful, as well as offering advice on the need for prophylactic or post-operative analgesics for operative procedures to minimise discomfort. Pain from prolonged jaw opening was reported as a problem for participants, and ways of minimising this, either by taking breaks or splitting treatment over multiple appointments, were recommended.

### 3.2 | During dental treatment

During treatment, participants felt it was important that dental practitioners worked in partnership with them and listened to their suggestions regarding what has worked for them in the past, for example, using smaller radiograph holders, taking frequent breaks, supporting the mandible with a mouth prop during treatment, and methods of relaxation, such as listening to music or masticatory muscle massage. Of great importance to participants was the need to stress that no one approach will work for all patients, and that it is vital to understand what works for individuals, and what does not. Participants stressed that members of the dental team should not knowingly, or inadvertently, place blame on the patient for their condition or any difficulties experienced in providing dental care.

Participants recommended that additional support in achieving optimal oral hygiene and maintaining a non-cariogenic diet should be considered, as patients with TMD may find this particularly difficult due to limited dietary options caused by their condition and other comorbidities. As patients with TMD may have visited multiple medical and dental healthcare professionals for their condition, they may have multiple investigations such as radiographs available from other providers; efforts should be made to utilise relevant existing radiographs rather than obtaining new ones where appropriate.

### 3.3 | After dental treatment

After dental treatment, participants felt that it was important for dental practitioners to offer appropriate advice on post-operative analgesia, the likelihood of post-operative pain and discomfort, dietary recommendations (e.g. a soft diet for a limited time if appropriate) and the need for follow-up.

## 4 | DISCUSSION

The recommendations derived in this international Delphi process give dental teams practical advice on how best to provide supportive general dental care for their patients who live with TMD. The recommendations add to the surprisingly sparse literature on the specific challenges faced by people with TMD in receiving dental healthcare services and the attitudes of health professionals in treating them.<sup>13</sup> One of the recurring themes endorsed by patient participants was the need for members of the dental team to listen to patients, value their concerns and opinions and to work with them as experts on their own condition. This is concordant with themes identified in work exploring the experiences of people with TMD both within and outside of healthcare generally.<sup>9</sup> It is our hope that these recommendations can be used to empower both patients with TMD and members of the dental team to work together in providing effective and supportive general dental care which is responsive to patients' needs.

This project was initiated by patients and patient advocates and the recommendations were predominantly derived by patients, with input and facilitation from expert clinicians. Care was taken not to influence patient participants' suggestions, and for this reason, the first two rounds of the Delphi process were undertaken with patient participants only so that the influence of clinicians on patients' suggestions were minimised. It is possible however, that the involvement of clinicians in the process may have influenced the responses of patient participants, for example by making them less likely to speak openly and honestly than if a clinician had not been involved; the risk of this is likely to be low however given the mitigations employed.

The Delphi process has been used elsewhere in dentistry to derive expert consensus;<sup>18-22</sup> however, it has rarely been used to elicit recommendations from patients. Typically, responses are anonymous, nonetheless we felt that allowing open discussion between patient participants was appropriate to stimulate discussion and encourage participants to share their experiences. An obvious limitation was that the views of patient participants were largely from a North American and female perspective, which may introduce bias. Elements of patient experience were also identified from the literature however, and these were well aligned to the concerns and recommendations of the patient participants involved in the Delphi process. The literature which informed the recommendations in this study included European and North American settings as well as both male and female participants, and international input from clinicians and InFORM was incorporated. Although this process may have affected the content of the recommendations, the design of the study aimed to incorporate a diverse range of perspectives into the derived recommendations as described.

Although this project provides useful insight into the needs of patients with TMD in receiving general dental care, further work is needed to understand this across different groups of patients with TMD from a range of backgrounds and settings, including private and publicly funded health systems. Similarly, it is important to understand the specific needs of patients with TMD in accessing healthcare more generally, and how these can be addressed.

The TMJ Association intends to produce a leaflet for use by dental teams which incorporates these recommendations, in order to help patients with TMD in receiving dental care. Future translation of the recommendations into languages other than English would also increase their potential positive impact.

## 5 | CONCLUSION

It is important for all members of the dental team to understand the specific needs of patients with TMD in receiving general dental care. The guidelines derived by patients experiencing TMD and TMD clinicians during this Delphi process aim to help dental practitioners and teams to provide supportive general dental care for their patients with TMD.

### AUTHOR CONTRIBUTION

JRA, JD: Conceptualisation, methodology, formal analysis, investigation, writing-original draft, writing-review and editing; TC, DC: Conceptualisation, investigation, writing-review and editing; EO: Investigation, writing-original draft, writing-review and editing; SB, JGF, LMS, TK: Investigation, writing-review and editing; JCT, DM, DRN, AMCDP, InFORM: Methodology, investigation, writing-review and editing.

### FUNDING INFORMATION

No specific funding was received in relation to this project.

### CONFLICT OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

### PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/joor.13444>.

### DATA AVAILABILITY STATEMENT

Data available on request from the authors.

### ORCID

James R. Allison  <https://orcid.org/0000-0002-0562-4133>

Jens C. Türp  <https://orcid.org/0000-0001-9267-4317>

Daniele Manfredini  <https://orcid.org/0000-0002-4352-3085>

Donald R. Nixdorf  <https://orcid.org/0000-0003-1757-9592>

Justin Durham  <https://orcid.org/0000-0002-5968-1969>

### REFERENCES

- Slade GD, Bair E, Greenspan JD, et al. Signs and symptoms of first-onset TMD and sociodemographic predictors of its development: the OPPERA prospective cohort study. *J Pain*. 2013;14(12 Suppl):T20.e1-T32.e3.
- Schiffman E, Ohrbach R, Truelove E, et al. Diagnostic criteria for temporomandibular disorders (DC/TMD) for clinical and research applications: recommendations of the international RDC/TMD

- consortium network\* and orofacial pain special interest group†. *J Oral Facial Pain Headache*. 2014;28(1):6-27.
3. Slade GD, Fillingim RB, Sanders AE, et al. Summary of findings from the OPPERA prospective cohort study of incidence of first-onset temporomandibular disorder: implications and future directions. *J Pain*. 2013;14(12 Suppl):T116-T124.
  4. Bitiniene D, Zamaliauskiene R, Kubilius R, Leketas M, Gailius T, Smirnovaite K. Quality of life in patients with temporomandibular disorders. A Systematic Review. *Stomatologija*. 2018;20(1):3-9.
  5. Salinas Fredricson A, Krüger Weiner C, Adami J, et al. Sick leave and disability pension in a cohort of TMD-patients – the Swedish National Registry Studies for surgically treated TMD (SWEREG-TMD). *BMC Public Health*. 2022;22(1):916.
  6. Hoffmann RG, Kotchen JM, Kotchen TA, Cowley T, Dasgupta M, Cowley AW Jr. Temporomandibular disorders and associated clinical comorbidities. *Clin J Pain*. 2011;27(3):268-274.
  7. Breckons M, Bissett SM, Exley C, Araujo-Soares V, Durham J. Care pathways in persistent orofacial pain: qualitative evidence from the DEEP study. *JDR Clin Transl Res*. 2016;2(1):48-57.
  8. Ostermann AC, Dowdy JD, Lindemann S, Türp JC, Swales JM. Patterns in self-reported illness experiences: letters to a TMJ support group. *Lang Commun*. 1999;19(2):127-147.
  9. Taimeh D, Leeson R, Fedele S, Ni RR. A meta-synthesis of qualitative data exploring the experience of living with temporomandibular disorders: the patients' voice. *Oral Surg*. 2022;16:152-168.
  10. Greene CS. Managing the Care of Patients with Temporomandibular Disorders. *J Am Dent Assoc*. 2010;141(9):1086-1088.
  11. NICE. Temporomandibular disorders (TMDs) – NICE CKS 2020. <https://cks.nice.org.uk/topics/temporomandibular-disorders-tmds/>
  12. Guarda-Nardini L, De Almeida AM, Manfredini D. Arthrocentesis of the temporomandibular joint: systematic review and clinical implications of research findings. *J Oral Facial Pain Headache*. 2021;35(1):17-29.
  13. Türp J. The “problematic patient”: what is the problem? Illustrated by the example of temporomandibular disorders. *Dtsch Zahnärztl Z Int*. 2021;3:16-24.
  14. Bogaert B. Need for patient-developed concepts of empowerment to rectify epistemic injustice and advance person-centred care. *J Med Ethics*. 2021;47:e15.
  15. Safour W, Hovey R. Advice for dentists from temporomandibular disorder patients: a phenomenological study. *J Can Dent Assoc*. 2022;88:m4.
  16. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ*. 2017;358:j3453.
  17. Cintra DN, De Oliveira SAS, Lorenzo IA, Costa DMF, Bonjardim LR, Costa YM. The detrimental impact of temporomandibular disorders (mis)beliefs and possible strategies to overcome. *J Oral Rehabil*. 2022;49(7):745-753.
  18. Cramer CK, Klasser GD, Epstein JB, Sheps SB. The Delphi process in dental research. *J Evid Based Dent Pract*. 2008;8(4):211-220.
  19. Currie CC, Ohrbach R, De Leeuw R, et al. Developing a research diagnostic criteria for burning mouth syndrome: results from an international Delphi process. *J Oral Rehabil*. 2021;48(3):308-331.
  20. Durham J, Al-Baghdadi M, Baad-Hansen L, et al. Self-management programmes in temporomandibular disorders: results from an international Delphi process. *J Oral Rehabil*. 2016;43(12):929-936.
  21. Rongo R, Ekberg E, Nilsson IM, et al. Diagnostic criteria for temporomandibular disorders (DC/TMD) for children and adolescents: an international Delphi study-part 1-development of Axis I. *J Oral Rehabil*. 2021;48(7):836-845.
  22. Rongo R, Ekberg E, Nilsson IM, et al. Diagnostic criteria for temporomandibular disorders in children and adolescents: an international Delphi study-part 2-development of Axis II. *J Oral Rehabil*. 2022;49(5):541-552.

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Allison JR, Offen E, Cowley T, et al. How dental teams can help patients with temporomandibular disorders receive general dental care: An International Delphi process. *J Oral Rehabil*. 2023;50:482-487. doi:[10.1111/joor.13444](https://doi.org/10.1111/joor.13444)