

## Original Article

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# Improving skin-tone inclusivity in patient information leaflets for radiotherapy skin reactions: a literature review

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## Abstract

**Introduction:** Radiotherapy is a common treatment modality for cancer patients. Unfortunately, the treatment can result in skin reactions that may affect their quality of life and clinical outcomes. PILs can provide guidance on managing early symptoms and reduce unscheduled treatment breaks. Evaluating PILs is not frequently evidence-based, and research into evaluating PILs' inclusiveness for radiotherapy skin reactions does not exist. This study aims to contribute to the knowledge base to better serve the whole radiotherapy population.

**Methods:** A constructivist methodology was developed to evaluate skin-tone inclusivity in the author's local PILs, and a literature review was conducted to assess the knowledge base and facilitate providing recommendations for improvement.

**Results:** Publication, diagnostic, language and educational bias were identified in the literature. The content analysis found the author's departmental PILs were not inclusive of medium and dark-skinned patients.

**Conclusions:** Further research into radiotherapy PILs inclusivity is warranted. The creation or amendments to existing radiotherapy skin reaction diagnostic tools are needed to cater for the whole population. Diverse educational resources are needed to contribute to the reduction of health inequalities faced by radiotherapy patients.

## Introduction

Radiotherapy is a common treatment modality for cancer, with up to 40% of patients receiving curative treatment.<sup>1</sup> Unfortunately, radiotherapy often causes skin reactions, affecting up to 95% of radiotherapy patients.<sup>2</sup> Skin reactions include dryness, itchiness, erythema, desquamation and necrosis.<sup>2</sup> These radiotherapy-induced side effects can affect a patient's quality of life and may interrupt treatment schedules if intolerable. The importance of PILs is highlighted by Garner *et al.*,<sup>3</sup> they state health information facilitates empowered decision-making for patients. Additionally, the Royal College of Radiologists (RCR)<sup>1</sup> recommend all patients receive PILs to manage early side effects of radiotherapy before starting treatment. The RCR's guidance<sup>1</sup> states an absolute reduction in local control for certain cancers is between 1 and 4% in patients who missed one fraction of radiotherapy. PILs can facilitate symptom management enabling patients to remain well enough to attend radiotherapy sessions—preventing unscheduled treatment breaks.

The study aimed to evaluate the authors' departmental PILs to assess the inclusivity of the skin care advice provided. A literature review was conducted to assess the current knowledge base.

## Methods: Literature Review

### Databases and search terms

The literature review utilised PUBMED and CINAHL for searches between March and April 2023. The following search terms were used to find dermatology-focused peer-reviewed articles published in the last 10 years:

(radiotherapy [Title] OR skin reaction [Title] OR dermatolog\* [Title] OR erythema [Title] OR desquamation [Title]) AND (diversity [Title] OR inclusiv\* [Title] OR col?r [Title] OR black [Title] OR brown [Title] OR dark\* [Title] OR white\* [Title])

### Inclusion and exclusion criteria

*Inclusion criteria (and justification):*

- Articles from the past 10 years from peer-reviewed journals (to get a picture of current dermatology issues)

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- Articles that cover the key themes of the dissertation (language bias, assessment bias, management/treatment issues (due to delays in diagnosing), educational bias, other biases related due to lack of skin-tone inclusive advice)
- Relevant grey literature (lack of peer-reviewed articles means the review may benefit from the literature in which the primary focus is not peer-reviewed publications)
- The literature covering skin reactions such as erythema or desquamation—common radiotherapy reactions (not enough literature directly related to radiotherapy in this area)

#### *Exclusion criteria (and justification)*

- The literature linked to dermatology which cannot be extrapolated to radiotherapy-specific issues (is beyond the scope of this review)
- Non-English (lack of money, time and resources for translation services)
- Articles around the workforce population = beyond scope of the literature review

#### **Data collection**

A data collection table was created to record studies, information and identified themes that were explored in the discussion section. The PRISMA tool was used to detail the number of articles included and excluded in the literature review. The SIGN tool was utilised as part of the critical appraisal of the articles included in the study (Figure 1).

#### **Methods: Content Analysis**

A single reviewer evaluated 13 PILs from one UK radiotherapy department between April and May 2023. The evaluation of inclusiveness was based on the written content of leaflets to assess language, grammar (e.g. order of ideas) and the suitability of skin care advice for patients of all skin tones. Constructivist methodology was used due to the subjective nature of the analysis. The content was qualitative, and findings were influenced by the reviewer's own experiences. The purpose of the analysis was to give specific recommendations and examples to increase the quality of skin-tone inclusive advice in radiotherapy PILs.

#### **Inclusion and exclusion criteria for PILs**

##### *Inclusion criteria (and justification)*

- Authors departmental patient information leaflets aimed at providing skin care advice (the detailed methodology can be used by radiographers in other departments to analyse theirs)
- English language leaflets
- The most up-to-date version

##### *Exclusion criteria (and justification)*

- Leaflets not produced by the author's department
- Duplicate text
- Working documents that are not yet released (may still be a work in progress and therefore not in a state ready for analysis and dissemination of results)
- Non-English translations of the leaflets

#### **Data collection**

The author obtained permission from their NHS Trust and departmental manager to use the leaflets as part of the study. The

relevant PILs were found electronically and copied and pasted into a Word document for content analysis. The analysis included highlighting relevant text with green for inclusive and yellow for less inclusive and utilising the comments feature on Microsoft Word for the author's comments and codes. The content analysis evaluated the sentence structure, language, and order of ideas regarding skin tone using a code book (see Figure 2).

#### **Codes**

The author used priori coding, so the content analysis methods produced transparent and reproducible findings. Initial coding was the first step so the authors could familiarise themselves with the patient information leaflets. Any additions, subtractions or changes in codes are made at this stage. Afterwards, line-by-line coding is used to extract all relevant information. Information was condensed for coding, categorised and grouped into themes. Finally, conclusions were drawn based on the outcomes.

#### **Results: Literature Review**

The literature review section identified four main categories of discussion: educational, publication, diagnostic and language bias.

##### **Educational bias**

Foreman *et al.* (2022)<sup>4</sup> focused on nurse practitioner knowledge of dermatology for all pigmentations. The study noted that for those with dark skin tones, erythema was not routinely 'red' as it is frequently described. If visual changes were to be seen, it is much more likely that hyperpigmentation would be present. The article states, '... recognition [of racial bias] alone cannot resolve biases'.

Hijab *et al.* (2022)<sup>5</sup> conducted a thematic content assessment of a one-week dermatology course for medical students at a single institution. The authors aimed for 35% of the educational images were skin of colour (Fitzpatrick skin type FST 4–6) to reflect their local population. Two trained reviewers assessed the images and classified them into non-skin of colour (FST 1–3) or skin of colour (FST 4–6). The study found that 21.2% of images were classified as skin of colour, failing to reach the 35% target. Additionally, an optional pre- and post-lecture (on cultural humility and diseases that disproportionately affect dark skin) survey was handed out to the medical students. 88/107 first-year and 49/107 third-year students completed the pre- and post-surveys. Results were that the course covered diversity, inclusion and cultural competency ( $p > 0.001$ ), and students who attended were more likely to agree that dermatology needs emphasis on cultural competency ( $p < 0.001$ ) and to agree on the importance of the role of culture in dermatology ( $p = 0.0022$ ). The article provided a blueprint or 'roadmap' on how to analyse the diversity of curriculums.

Belliscoso *et al.* (2021)<sup>6</sup> audited their curriculum to assess the diversity of skin tones represented in educational materials. Two authors independently reviewed the images used in the university, classifying FST 1–3 as white skin and FST 4–6 as skin of colour (SoC). The audit identified that only 19 out of 513 images from teaching materials and 12 out of 198 images from online learning materials depicted SoC. In addition to the audit, a survey was conducted among first- and third-year medical students to evaluate their self-rated diagnostic confidence in identifying dermatological conditions on different skin tones. Out of 269 first-year students, 101 responded, and out of 261

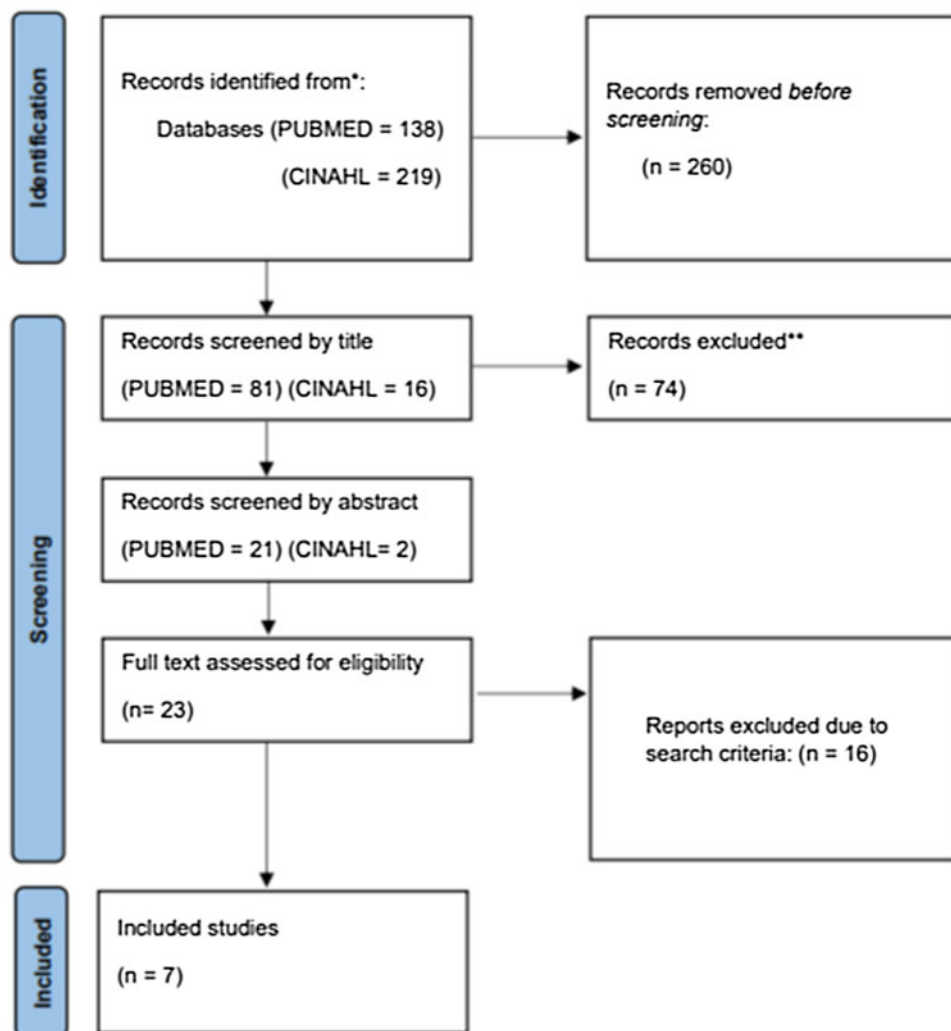


Figure 1. Prisma flow diagram detailing search results for the literature review.

Code	Description	Inclusion Criteria	Exclusion Criteria	Example
^	Sentence structure & Order of ideas biased toward dark-skinned radiotherapy patients?	-Text where skincare advice is being given	-Text where skincare advice is not being given	<ul style="list-style-type: none"> <li>Having advice for light-skinned patients in the main body of the text and having advice for dark-skinned patients in a separate section</li> </ul>
+	Language concerning skin tone bias biased toward dark skin radiotherapy patients?	-Text where skincare advice is being given	-Text where skincare advice is not being given	<ul style="list-style-type: none"> <li>Referring to patients that are not light-skinned as other</li> <li>Referring to light skin as "light skin" but dark skin as "darker" suggests that light skin is the medical default</li> <li>Using phrases such as 'your skin may go red, for dark skin patients' skin may go darker'.</li> <li>Only giving advice suitable for light skin (e.g., for erythema, using the word red but not mentioning skin darkening)</li> </ul>

Figure 2. Table showing code book author used for PILs content analysis.

third-year students, 76 responded. The survey aimed to determine if there was a difference in diagnostic confidence between identifying conditions on white skin and SoC. The results indicated that first-year students had a mean confidence score of 18.75 for diagnosing white skin and 17/75 for SoC (on a scale of 25). Third-year students had a mean score of 17.75 for white skin and 15.79 for SoC. This significant difference in confidence levels ( $p=0.0002$ ) suggests that students felt less confident diagnosing conditions on SoC compared to white skin, highlighting the need for a more diverse representation of skin tones in medical education.

A 2021 study by Gregersen and Elsner<sup>7</sup> carried out a systematic review (of 17 textbooks) to see how diverse German dermatology textbooks were and how important diversity was. They found out of 5,354 images the FST 1/2 = 4,892.11, FST 3 = 344.10, FST 4 = 51.33, FST5 = 23.5 and FST 6 = 1. The authors concluded that there is an educational bias in Germany towards dark tones, which is increasingly becoming problematic with their diversifying population.

### Publication bias

A 2020 systematic review by Bray *et al.*<sup>8</sup> focused on the diversity in dermatology publications between January 2016 and July 2019. Twenty-five publications focusing on diversity were identified. A single-factor ANOVA and two-group *t*-tests were used. The mean number of dermatology publications was 6.25, with results dropping as low as 1.75 for general surgery topics ( $p=0.02$  dermatology vs general surgery). The authors concluded that diversity in clinical trials and research articles needed to be improved to adequately represent or inform medical decisions for patients with dark skin tones.

An article by Wilson *et al.*<sup>9</sup> reviewed 50 dermatology-based journals between January 2018 and October 2020. The authors developed 'the first-ever prespecified criteria for assessing SoC and diversity in the dermatologic literature'. The authors created multiple criteria, including 'Title specifically addresses issues regarding diversity and inclusion within dermatology', to assess if the literature focused on diversity issues. The mean percentage of articles focusing on diversity and SoC was 16.8% (2.04–61.81%). The results for Western journals, such as those in Europe, dropped below 5%. Rates seen in Western publications must accurately reflect the population these journals serve. The Toronto study by Bellicoso<sup>6</sup> 2021 showed their curriculum was not diverse even though Toronto is one of the most multicultural cities in the world, with nearly half of the people identifying as non-white.

### Diagnostic bias

Diagnostic bias was seen for dark skin tones in all areas of the aforementioned themes (educational/publication bias). A 2021 UK-based study by Ooi, Lim, Ooi & Bennett<sup>10</sup> addresses it directly. The authors utilised a mixed model methodology with a paired *t*-test, showing skin tone diverse online learning resources improved participants' confidence with dark skin tone management (1.76 vs the post-course mean of 2.82,  $p=0.0001$ ). A feedback form of 50 doctors found that nearly all (42) reported improved knowledge of skin issues for dark skin patients. A focus group of 10 doctors found that 70% expressed a 'further need for BAME representation in dermatological teaching'. The authors concluded that a lack of exposure to dark-skinned in training results in diagnostic uncertainty, with a lack of appropriate

diagnostic tools for dark skin tones leading to poorer outcomes. The authors said that some skin issues are underdiagnosed in dark skin as most diagnostic tools rely on visual aids.

### Language bias

Language bias was identified as a theme and is mainly covered by the content analysis and discussion sections.

### Results: Content Analysis on Author's Departmental PILs

The analysis (see supplementary materials) found the PILs did not give adequate skin care advice to patients of medium or dark skin tones. The following paragraphs summarise the content analysis findings with the literature to facilitate recommendations for improvement.

The Radiotherapy for Brain Tumours leaflet states that skin 'may become red, dry and itchy and feel sensitive'. Using the word 'may' is a good choice as it means the target audience is patients with a wide variety of skin tones. However, the literature review shows that erythema on dark skin can be associated with hyperpigmentation, so this should also be mentioned to improve inclusiveness. Additionally, on light skin tones, erythema could become pink or purple. Wounds UK<sup>11</sup> stated that diagnostic tools are focused on visuals, which are harder to see on dark skin. Therefore, the leaflet mentioning diagnostic tools focusing on touch, for example, skin feeling sensitive, is suitable for patients with dark skin tones.

Additionally, Wounds UK<sup>11</sup> argue that 'white' or light skin patient care is the norm. The radiotherapy for bowel or anal canal cancer states, 'skin will start to look pink and then red', only giving advice suitable for light skin tones. The target audience could be perceived to be patients with light skin tones. However, the same leaflet continues, 'skin becomes red or feels sore', the wording 'or' could be perceived as being inclusive as it suggests skin may not change colour (relevant to darker skin tones). It also focuses on non-visuals ('sore') and, therefore, increases relevancy to dark-skinned patients in which skin reactions are more difficult to visualise.

The radiotherapy for mouth or throat cancer leaflet states, 'Your skin in the treated area will gradually become red and may feel dry and itchy'. Alternatively, the word choice could change from 'will' to 'may' for more inclusive grammar. Furthermore, alternatives to red should be given (darkened, purple, and pink).

Telangiectasia is mentioned, and the leaflet states, 'A few people may notice tiny blood vessels visible under the skin in the treated area'. With dark skin tones, it is more difficult to visualise, so the leaflet could mention the other telangiectasia symptoms, such as pain and itching.

The radiotherapy leaflet for localised breast cancer states, 'The skin of the breast can start to look pink and may become red'. However, dark skin tones can effectively hide visual changes in erythema.<sup>11</sup> The leaflet does go on to say, 'Some people find that it feels tender, sore or itchy', which are skin tone-inclusive effects.

The localised cancer of the larynx leaflet says, 'Your skin in the treated area will gradually become red'; however, it goes on to focus on how the skin feels or behaves. For example, the skin 'may feel dry and itchy' or '... may crack or peel'. Again, replacing the word 'will' with 'may' and including a broader range of colours the skin may change to would make the leaflet more inclusive.

The generic radiotherapy information for patients' leaflets states, 'Radiographers look at your skin each day and advise you to



keep it as comfortable as possible'. Dermatology education is biased toward visual tools (see Diagnostic bias section), and radiographers should ask patients how their skin feels and perform a skin review. Radiographers could touch the skin to aid in assessing skin reactions. However, the Society and College of Radiographers<sup>12</sup> identified that therapeutic radiographers lacked confidence in SoC, and this is something that needs to be improved.

A total skin electron treatment (TSET) radiotherapy leaflet states that late side effects could include 'skin pigmentation changes'. The phrasing is inclusive and covers patients with all skin tones, not just those with light skin whose skin can go red. However, it can be argued that patients may not understand skin pigmentation changes, so a full spectrum of examples (red, pink, purple and darker brown) may be helpful.

## Discussion

### Education bias

Educational institutions need to ensure that their learning materials are inclusive of different skin tones. The need for appropriate materials can limit learning opportunities for healthcare professionals. A recent study by Bellicoso *et al.*<sup>6</sup> discovered that out of 513 dermatology teaching materials used by a university, only 19 featured patients with skin tones other than white. This highlights the need for improved educational materials.

A recent study by Gregersen and Elsner<sup>7</sup> revealed that only 1 image classified as type 6 on the Fitzpatrick Scale was found out of 5,354 images in dermatology textbooks; 23.5 images were classified as type 5. This highlights the lack of SoC in educational resources. Diversity in skin tones included in textbooks would enhance the number of resources healthcare professionals could access for educational purposes.

Regarding language bias, Wound UK<sup>11</sup> highlighted the importance of not defaulting to white as the 'medical norm'. Educationally, this could look like lecturers being mindful in their practice—Hijab *et al.*<sup>5</sup> found that most medical students agreed that more cultural teaching in dermatology is needed. When teaching skin care, SoC would be incorporated into the main section, not as an 'other' section. Furthermore, care should be incorporated into teaching when referring to the full range of skin tones, for example, using the words light and darker when referring to skin tones (either light skin and dark skin or lighter skin and darker skin).

### Diagnostic bias

Diagnostic tools are biased towards light skin and are not adequate for dark skin patients<sup>10</sup> due to the focus on visual aids, which can negatively affect clinical outcomes. For example, the RTOG scale,<sup>15</sup> arguably one of the most utilised radiotherapy tools, focuses on visual changes. Finding non-white dermatology pictures is a challenging task (however, this has been helped along with initiatives such as the Mind the Gap textbook).<sup>16</sup> A study by Zenda *et al.*<sup>13</sup> based in Japan collected pictures of 118 radiotherapy head and neck patients with different severities of skin reactions based on the Common Terminology Criteria for Adverse Events (CTCAE) Japanese version (see journal article for the collection of images). Studies such as this increase the knowledge base, and the images collected could be used and utilised in UK Radiotherapy departments. The associated text described acute erythema as 'salmon pink' while describing erythema in the recovery stage as

'light brown'. This difference in language from what is typically described in the medical literature (based on light skin, the medical norm) highlights the importance of inclusion to better educate patients and professionals.

The text used in diagnostic tools is also aimed at light skin; for example, RTOG 0 is when 'no visible changes to skin'. However, patients with dark skin could have no visual changes but still have a radiotherapy reaction scoring higher than a 0. This is misleading to some patients and may result in them only seeking assistance when the skin is markedly worse.

To combat the difficulties in identifying skin reactions on patients with SoC, a 2022 article by Verdugo-Naranjo *et al.*<sup>14</sup> studied 23 women undergoing breast cancer radiotherapy. The researchers used an RGB camera to objectively measure treatment skin reaction changes. An RGB camera utilises red, green and blue light channels to capture and analyse these colour changes in skin. It was theorised that changes in red, green, and blue channel intensities would indicate a skin reaction which would be more accurate than a clinical skin assessment. The patients were categorised into light, medium and dark skin tone groups using the Fitzpatrick Scale (light was FST 1 and 2, medium was classified as 3 and 4, and dark was classified as 5 and 6 on the scale). While most utilised diagnostic tools result in the underdiagnoses of skin reactions in dark skin patients,<sup>17</sup> Verdugo-Naranjo *et al.*<sup>14</sup> found dark skin patients had significant changes in all three colour channels between RTOG 1 and 2. This has clinical significance as patients, who may feel that their skin feels different, may not have this validated by therapeutic radiographers who cannot see a change. However, this objective way of measuring skin reactions allows for timely and accurate management of skin. For example, lifestyle advice such as not swimming or using deodorant if the skin is having a moderate or severe reaction to the radiotherapy treatment. Medications such as topical creams or expensive dressings that are reserved for later stage reactions due to cost can be implemented into treatment management sooner.

### Publication bias

Evidence-based practice is critical to radiotherapy, enabling patients to have innovative, high-quality care. Despite the importance of research-led practice, Western journals had a mean percentage of articles on SoC or diversity of less than 5%.<sup>9</sup> The lack of radiotherapy publications included in the literature review is another example of the gap in research. This article will go towards filling the gap in knowledge for skin colour and skin care advice. It may also inspire others to investigate this under-researched area, further contributing to the gap in the knowledge base.

### Limitations

The papers found for the literature review were dermatology and not specifically radiotherapy-focused. This is due to the limited literature available, which highlights the need for further research. The content analysis was done by a single reviewer on a single department PILs. This limits the validity of results to other departments in the UK and further afield. The use of patient-reported outcome measures could be utilised in future studies to highlight areas of improvement from a patient's perspective. This is not something this study did.

The PILs were converted into a Microsoft Word document at a single point in time. Since the leaflets are reviewed every 2 years at different dates, not all the PILs analysed may be the most up-to-date at the time of analysis.

## Conclusion

In conclusion, the literature review highlighted that publication, diagnostic, language and educational biases exist for brown and black radiotherapy patients with radiotherapy-induced skin reactions. The lack of inclusivity in related PILs may mean they are an inadequate resource for patients with medium and dark skin tones. These issues contribute to health inequalities for these patients; to address these issues, we recommend the following:

- Emphasis on SoC is needed in publications, for example, participant skin tone being reported in dermatology studies so it is clear who the findings are applicable for. Additionally, specifically recruiting a diverse group of participants to a study would widen the applicability of findings. Those involved in creating new resources must be mindful of the language they use, ensuring it is inclusive to all skin-tones.
- Current diagnostic tools do not adequately cater for medium and dark skin tones leading to suboptimal care. The creation of a tool that is diverse enough to cater for patients of all skin tones is essential for these patients to get optimal care. Alternatively, existing tools such as the RTOG scale could be amended with inclusivity in mind.
- Educational materials should appropriately reflect the diverse population of radiotherapy patients. Educational workers could utilise content analysis (as used in this study) to assess the inclusiveness of their curriculum and educational resources. Appropriate changes could be implemented.

The implementation of these recommendations would improve patient experience and clinical outcomes. They would contribute to reducing health inequalities for medium and dark-skinned patients. Future research where patient and public involvement was utilised would add valuable insight.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1460396924000220>

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