
Prevention and Treatment of Periodontal Diseases in Primary Care: focus group to co-design a patient information leaflet

Introduction

The Scottish Dental Clinical Effectiveness Programme (SDCEP) is updating the *Prevention and Treatment of Periodontal Diseases in Primary Care* guidance.¹ As part of the guidance update process, an accompanying patient information leaflet has been produced, which provides information about gum disease, including its causes, risk factors and symptoms, as well as what patients can do to improve their own gum health.

The current version of the leaflet was based on an oral health self-care leaflet produced by a citizen science participatory research project called GUIDE.² Participants in the GUIDE project were presented with a patient information leaflet about gum disease that had been developed to accompany the earlier version of the SDCEP *Prevention and Treatment of Periodontal Diseases in Primary Care* guidance, published in 2014. They then generated 36 ideas for how to improve the leaflet, which led to changes including: “adding more images and a more realistic cover image; simplification of language; (and) more focus on actions related to prevention including brushing and toothpaste choice”.²

The leaflet was further revised following the GUIDE project. The final version of the leaflet included information about the causes of gum disease, risk factors and symptoms, as well as what patients can do to improve their own gum health. To user-test the revised leaflet, and support the development of the updated SDCEP guidance, a focus group was conducted to obtain the views of members of the public, and ensure that the leaflet was providing the necessary information in an appropriate and accessible way.

Aim

The aim of this project was to get feedback from members of the public about the gum disease patient information leaflet.

Method

Sample and Recruitment

A recruitment email was sent to members of the Dental PPI group at the University of Dundee. This is a newly established group comprised of members of the public, that aims to support research involving patients and the public being conducted in the Dundee Dental Hospital and Research School. This email detailed the purpose of the focus group, the expected input from participants, and information about where and when the meeting would take place. It was sent to all members of the PPI group; those that were interested in participating were asked to complete an expression of interest form, leaving their contact information and indicating their availability.

Once a date and time for the focus group was confirmed, participants were contacted with joining instructions for the focus group, as well as a participant information sheet providing more details about the project, and a consent form to read and sign in advance of the focus group.

Data Collection

A focus group was selected as the most appropriate method to collect feedback on the patient information leaflet as it would allow participants to share their thoughts with their peers and generate discussion on key aspects of the leaflet.³

A list of questions was developed, which asked about general thoughts on the leaflet, and then specific opinions about how it looked (layout, use of images) and the content, including how understandable it was and the level of detail provided. The focus group was facilitated by LB and BG.

Data Analysis

The focus group was recorded to allow for analysis. Analysis was conducted by BG and LB, who identified common themes within the data.⁴ A summary of the key points raised in the focus group was sent to participants to ensure it was an accurate representation of the discussion.

Summary of Findings

Participants:

Eight participants (4 female, 4 male) attended the session with a range of interests and backgrounds. No participant mentioned a previous history of gum disease. One participant had a specific professional background related to oral health. The discussions in the focus group fell into five categories.

Content

Participants reported several grammatical errors, and were encouraged to send a list of such errors to LB after the focus group. Suggestions were also made to improve readability, e.g. transforming passive sentences into active ones. In the section “What can I do to improve my gum health?”, it was suggested that the bullet point about smoking was too wordy, and patronising, with one participant commenting “*people know they need to stop smoking, the challenge is how*”. Similarly, it was felt the wording about weight could be improved, with participants suggesting that the term “normal weight range” was inappropriate and should be changed.

While there was general agreement that the leaflet was prepared using plain English, it was suggested by participants that a few words were too “jargon-y”, e.g. inflammation, plaque, inflamed, abscess. As such, participants requested more information in the leaflet, specifically asking for more explanation or context about terms used within the leaflet. More information was also requested about the use of mouthwash, dental floss and interdental brushes. It was agreed that it would be helpful to include additional information, even if it is to say “we have no evidence it works”.

Suggestions were made that the leaflet address the dental access situation, acknowledging that visiting your dentist regularly may not be possible. Another participant suggested that the leaflet could signpost to resources or local contact information to access free dental care.

Format

Participants said the leaflet’s format was inconsistent, specifically regarding the use of bullet points and numbers when listing items, and the use of brackets when presenting examples. It was agreed that not everyone will read a leaflet and that the best approach to decide whether the leaflet is appropriate would be for the dentist to ask the patient directly “in what format would like to receive more information about gum disease?” or “would a leaflet be helpful?”. Participants suggested both an online version and a print version of the leaflet should be available and delivered based on patient preference.

Images

When asked about the images included in the leaflet, participants suggested they should be labelled and clearly referenced within the text so that it would be clear why they are part of the leaflet and what they are meant to tell readers.

Mixed feedback was received about the image showing the angle at which to brush your teeth (Figure 1).



Figure 1: Image showing toothbrush at 45° angle

An image showing cross sections of teeth with gingivitis and periodontitis also received mixed feedback, with some participants finding it “useless”, and others finding it helpful (Figure 2). There was general agreement that a caption and referencing in text would help. Participants also mentioned that specific parts of the image were confusing for a lay person. It was suggested that more descriptions within the image (e.g. the inclusion of arrows pointing to specific parts of the image and explaining what they represent) could help.

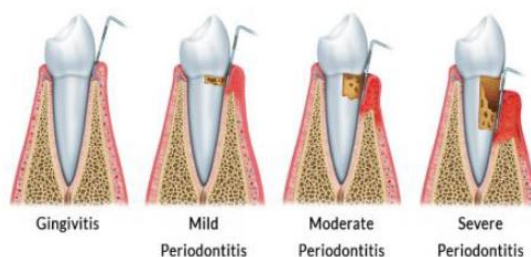


Figure 2: Cross section of teeth, showing gingivitis and periodontitis

Regarding an image in the leaflet showing the fluoride content on toothpaste packaging (Figure 3), participants found this helpful in general but suggested the image could be improved by explaining in the text what some of the terminology meant, i.e. “ppm” and “sodium monofluorophosphate”, and making it clear that the image is from a label of a toothpaste so readers understand where to look for it and what the image represents.

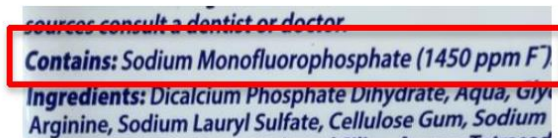


Figure 3: Image of toothbrush packaging, showing fluoride content

Participants were asked if they had suggestions for other images that could be used in the leaflet. Most participants favoured “real life” images instead of illustrations, and suggested photos that showed the symptoms of inflammation in real gums (i.e. what does it look like, how can they spot this?). Participants said this could allow people to check whether they had swollen/inflamed gums.

Suggestions for future/different leaflets

While this leaflet may have an appropriate level of detail and language for a specific group of people, some participants noted that it would exclude people with learning disabilities, or people with poorer literacy. It suggested a new leaflet with more images and less text could help these groups. Leaflets for different target groups like diabetic patients, children, people with dentures were suggested, as were alternative means of presenting information about these topics, e.g. short videos.

General comments

In general, participants felt it was unclear who the leaflet was aimed at, and what the purpose of the leaflet was. To address this, it was suggested that an initial section stating “why did I receive this leaflet?” might be helpful, especially if the leaflet is not delivered directly by the dentist.

Discussion

Following the focus group, a summary of the discussion was written by BG and LB. This summary was then shared with the focus group participants, allowing them the opportunity to ensure this was an accurate representation of the discussion and to provide any corrections or clarifications if required.

GUIDE

There were several comments from the focus group that reflected similar thoughts about the leaflet that emerged during the GUIDE project. For example, GUIDE participants questioned the target audience of the leaflet too, and had similar comments about the “stop smoking” point. GUIDE participants also asked about mouthwash, flossing and interdental brushes.

The idea of adding an image showing how to spot the fluoride content of a toothpaste came from GUIDE, so both GUIDE and focus group participants were in agreement that the addition of the toothbrush packaging image is useful. While GUIDE participants asked to have an image of how to brush your teeth so it is clearer what to do, the image included in the leaflet received mixed reviews.

GUIDE participants suggested some of the same future steps as the focus group participants, including developing leaflets for specific subgroups, and considering short videos.

Leaflet Redesign

The summary of the focus group discussion was shared with the SDCEP team. It was agreed that the leaflet should be divided into three separate leaflets, to better address the issue of who the

leaflet was aimed at: patients with healthy gums, patients with gingivitis, and patients with periodontitis.

The content and grammar were revised to take into consideration comments received from the focus group participants, e.g. wording about weight range, explaining dental-specific terms such as plaque, and adding information about oral hygiene aids.

New images were included, to reflect the suggestion from the focus group that “real life” images of gums (healthy and with gingivitis) would be beneficial. Additionally, labels were included for each image, to explain what the image shows, and text was added to the leaflet to reference the images.

The revised leaflets are available on the SDCEP website, including in a format that will allow dental practices to download, print and fold the document, resulting in an A5 leaflet.

Conclusions

The focus group with members of the public provided valuable feedback on the content, format and layout of the patient information leaflet, including identifying typos, suggestions for additional information and how to improve the images in the leaflet. As a result, the leaflet has been revised to address this feedback and reformatted into three separate leaflets, each with a different intended audience. The leaflets are now available to read on the SDCEP website.

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