

Report on the British Society of Periodontology Patient Forum meeting held at Chandler House, 2 Wakefield Street, London on Friday, 13 July 2018

Introduction/Background

The first patient forum was held on 21 June 2017 as part of the British Society of Periodontology Conference. On 13 July 2018 five members of the original group of patients confirmed their commitment by attending the second forum meeting. Four new patients had been recruited to diversify participation and bring new ideas. Unfortunately two were unable to attend on the day, but they remain keen to contribute. The new members were warmly welcomed by the forum which launched into a discussion of general (and not personal) periodontal issues before the meeting had officially started. The format for the meeting was similar to that of the initial forum with seven patients split into two working groups. Professor Ian Needleman facilitated the meeting and opened with a presentation updating the group on current developments, highlighting areas where the forum had indicated it wanted to make an impact.

Aspects that the Forum had already had an impact were highlighted and included;

- Input and change to the patient information leaflet *Periodontal health for a better life*: more than 25,000 printed copies had been distributed and many thousands more downloaded from the website
- Patient involvement in 2017 BSP Conference as session chair and reporting on Forum meeting and scheduled again for 2018 Conference
- Change in pathway for BSP patient information resources – all to have patient involvement in development
- Patient involvement in BSP new strategic plan 2020-2024

Later in the meeting Penny Hodge (President, British Society of Periodontology 2018) shared information on developments in specific areas of oral health, which again generated much discussion. Also present were three observers, one of whom was from GlaxoSmithKline (GSK). The groups were given two tasks based on their suggested topics for the day: to provide feedback on the BSP website and to consider how to raise public awareness of periodontal disease.

Feedback on the BSP website

The discussion produced much useful information, ranging from how information was presented to patients, to results from Google searches into gum disease. Both Ian Needleman and Penny Hodge encouraged and welcomed feedback, both negative and positive. Some explanations were provided which are not included in this report.

On the positive side, the forum noted that there was plenty of information available and the video and stressed-out person sketch proved to be particularly popular. The site was well-structured and navigation was easy. As patients they were pleased to see the word ‘gum’ used in preference to ‘periodontal’ disease. Indeed, they would like to see ‘gum health’ rather than ‘periodontal health’ used consistently.

Inevitably there were a greater number of negatives. Their first impression was that the site is more suited to professionals, even under the ‘Patient’ heading. Although the amount of information was praised in the paragraph above, it was also raised as a negative in that some resources and infographics could be too detailed and too wordy for some patients. It was suggested that guidelines containing ten or more bullet points should highlight the most important messages to avoid them

being lost. A suggestion to involve the BAEM community, for example in videos, echoed the views of the presenters. It was unclear to some why there was an infographic for healthcare professionals on diabetes under the 'Patient' section. It needs to explain that the information is intended for the patient to use in consultation with their doctor. Other helpful comments on text colour and font and the large banner section were noted.

In the next exercise the forum presented their views on what they would like to be included. Since they felt so strongly about raising awareness of gum disease they wanted more repetition of key phrases such as "bleeding gums are not right". Another deeply held belief they wanted represented was that patients have ownership of their treatment. One patient voiced the opinion that they would like to have been involved at an earlier stage in the website development. They recommended including a section on what to expect from your dentist covering screening for gum health, gum treatment and oral hygiene. This could include what to ask the dentist, such as the BPE (Basic Periodontal Examination) score. In terms of the organisation of the website, they favoured splitting information into two sections: adult and children, commenting that there is only one form of gum disease. More detail could be provided separately on special topics such as diabetes and pregnancy. Information on patients taking immunosuppressants would be helpful. A comment about gum disease, which was appreciated by everybody, was "No social boundaries, anyone can have it". It would be good to represent this visually.

Finally the forum discussed how to raise the visibility of the website. One group Googled "What is Periodontology?" and discovered that the BSP website was listed fifth and the European Federation of Periodontology (EFP) first. In a Google search "Why are my gums bleeding?" the BSP link didn't appear at all. It was suggested that the BSP consider a new web domain for patients, for example www.whyaemygumsbleeding.com. Other suggestions included establishing a link from NHS websites to the BSP website and also from websites for conditions such as diabetes and stress.

Raising Public Awareness of Periodontal Disease

The first part of this discussion involved identifying the topics and messages to promote to the public. The forum identified the following: patients to take responsibility for their own health and that of their children; dentists to ensure that patients understand the impact of gum disease and pregnant women to be reminded that they qualify for free dental care. Group discussions focussed on the following as priority targets: health services, BAEM, pregnant women and children.

In considering how to raise awareness, the two groups, once again, proved to be creative and committed. It was obvious that they had been contemplating the issues between meetings. The use of social media was a key factor, particularly among younger forum members. The value of blogs, podcasts, hashtags, free-to-build mobile apps and Nandos' successful campaign without advertising was discussed. Continuing the theme of using modern technology, suggestions included a QR code in GP surgeries and dental practices and in-practice screens with a link to BSP resources. In addition 'The Sound of Periodontitis' could be shown in GP surgeries (but perhaps not appropriate for nervous dental patients).

The BBC could possibly provide the opportunity to raise awareness through shareable podcasts or short conversation style resources such as the Radio 4 *Listening Project* and contributing to programmes such as Horizon (perhaps featuring Michael Mosley). One group considered the impact of celebrity endorsement and questioned whether an industry partner might have suitable contacts. It liked the idea of Harry Styles using an interdental brush.

The forum emphasised on several occasions the importance of promoting oral health to include gum health rather than just tooth brushing and mouthwash. To this end it suggested the sale of toothbrushes together with an interdental brush (and perhaps also disclosing tablets) - a pairing likened to 'gin and tonic'. The positioning of oral health products together in pharmacies and

supermarkets would also help lessen the impression that interdental brushes are an accessory. The supermarket reference led to a suggestion to man a stand similar to that used by the RAC.

Other organisations and groups that could be targeted to promote public awareness include grass root organisations, festivals in urban boroughs, faith groups and local authorities that have a remit for dental health. It was suggested that it could also be worth reviewing what action is being taken by other dental organisations.

The recent public campaign to reduce the stigma and shame of mental health should be explored for gum health. In a separate discussion the forum asked whether people talk about their gum disease with family members or at work. In particular some members felt that the word 'disease' may have stigmatising connotations and/or appear to be too serious and cause alarm. Others felt it was important to use the term to highlight its seriousness and that a subtle approach doesn't work. There is a need to reframe 'I'm going to the hygienist' into the more positive 'I'm looking after myself' or 'I'm having treatment for my gum disease'.

It was proposed that if the public were made aware of the cost of periodontal treatment received on the NHS, they might value and care about it more.

At their first meeting the forum had expressed their interest in sharing their experience and knowledge as ambassadors and several members confirmed they were still keen to do this. Also echoing views expressed in the initial meeting, the forum wanted to be able to measure increased public awareness and their own contribution.

General Comments

There were points raised during the course of the patient forum that were valuable and interesting, but did not fall into the two areas for discussion set out above.

- The forum emphasised the importance of raising awareness that general health can be signalled by gum health.
- Some forum members liked 'oral health' as a label (similar to mental and physical health) in preference to dentistry. Others felt 'oral health' was old fashioned with connotations of brushing and mouthwash only. It was suggested that a new generic name was needed for a new era and the term 'bitcoin' was quoted as an example of one that had rapidly grown represent all related products. An alternative view was that oral health is the right word but people need to understand that it includes gum health. (Ian Needleman suggested working with industries that have marketing expertise on labels and titles that might grab interest generally and to target specific demographics.)
- On several occasions concern was expressed about approaches elsewhere (not the BSP) of promoting appearance over oral health. One member considered that this might also give the impression that treatment was expensive.
- The forum wanted to see products such as mouthwashes specifically encourage people to see their dentist.
- The forum was shocked at some of the statistics presented; in particular that 50% of people with diabetes are not informed of the risk of gum disease.

Next steps

Many excellent ideas were suggested by the Forum. The Forum report with suggested action points will be presented to the BSP Council in September. The Forum members will be updated with the outcomes and with progress during the period before the next Patient Forum meeting in 2019. Professor Needleman, on behalf of the British Society of Periodontology, thanked the Forum members for their enthusiasm and commitment to the Forum and looked forward to a very productive continuing relationship. The Society is also grateful to the generous support of GSK Consumer Healthcare.

Next meeting

The next meeting will be held prior to the BSP annual conference in April 2019. The date and location are to be confirmed.