

Aim

The aim of the patient forum was to provide a voice for patients and members of the public to help shape periodontal health in the UK by engagement with the British Society of Periodontology. The initial forum was organised and supported by the British Society of Periodontology, however the aim is to allow the forum to grow in the way envisaged by its members.

Introduction/Background

The patient forum was held at the Wellcome Collection on the 21st of June 2017, as part of the British Society of Periodontology Conference. Professor Ian Needleman (President BSP 2017) welcomed and thanked participants and introduced the Chair of the session, Professor Simon Denegri from UCL (NIHR National Director for Patients & Public Health in Research and Chair of INVOLVE).

There were six patients who were initially split in two working groups and three observers, all of whom gave a brief introduction. They had been previously treated at their own dental practice by a private periodontist and hospital periodontology department. The group gelled and empathised from the start as individual stories were shared. To inform (but not lead) the discussion Ian Needleman asked 'Is Periodontal disease important?' There was a sharp intake of breath and murmurs as statistics showed the seriousness and extent of the disease. Throughout the morning the themes revisited most by the forum members were how to increase the public's awareness of the disease and how to get patients to take responsibility for their own health. There was a real commitment to improving the system and the outcomes for future generations.

Key findings and Results

In the first part of the discussion, topics that were discussed included:

- *Is periodontal disease important?*
- *Is periodontal disease a public health problem?*
- *Can periodontal disease be prevented?*

These questions generated a lot of active discussion. Overall, there was strong agreement that periodontal disease was important both to individuals and as a public health problem.

In the next part of the discussion, the question discussed was "what part and responsibility do you feel you have towards managing your own gum disease? What would help you fulfil this?"

The participants felt that they were 100% responsible for their own gum health. Looking after your gums is cheap and relatively easy to do. This was demonstrated by one of the participants bringing in a pack of toothbrushes costing £1.00. They questioned and discussed

whether the public knew the consequences of not looking after their gums. The participants also acknowledged that they were not perfect and required support from family and friends, GP's and the NHS and it required an overall team approach. The forum also thought that making people aware that poor gum health results in bad breath would motivate the public to improve their gum care and that young people should be made aware of the importance of gum care from a young age.

Leading on from the above, the group then discussed “*what role do you feel (a) dentists, (b) other health professionals, (c) the Department of Health and (d) toothpaste and drug companies have in managing the problem? Is anyone else missing from the list?*”

(a) Dentists

The forum believed that dentists need to take time and fully explain to patients what gum disease is and make messages really clear for them e.g. ‘because your gums are receding your teeth will fall out’ and provide really clear messages such as ‘by the time you are in your 40s you will be losing teeth’.

Some of the forum participants were not aware of having had screening done for gum disease and this resulted in a lot of discussion on the methods of recording the gum disease, how they know it has been recorded and whether they could request it. One of the participants voiced that dentists should have a secret shopper type of spot check to ensure that they are carrying out this screening. One area the forum thought was important was fostering a close relationship between the British Dental Association and the British Society of Periodontology. The participants were unsure of the exact role of the hygienist and dental therapist, however they respected the role of the dental hygienist much more than in the past and it was even suggested the hygienist could provide better treatment than a general dentist.

The participants thought that dentists should conduct more periodontal treatment and provide referrals to a periodontist more readily. The issues surrounding resources were explained and discussed and the participants believed it was important to reward dentists for providing periodontal care.

(b) Other Health Professionals

The consensus amongst the participants was that it was important to provide education in schools, especially within secondary schools and in PHSE lessons. It was felt that intervention was important in the early years and to focus on interdisciplinary care by collaborating with mental health professionals and GP's to provide advice on the impact of medication on gums (for example the effect of blood pressure medication on gums). In addition, it was thought necessary that education for and from diabetic nurses was important and expanding this education further in to the community to include gum awareness in different disciplines. The participants thought it was important to ensure full collaboration and cooperation between these different professionals.

(c) Department of Health

The participants expressed that the Department of Health and other regulatory/governing bodies had a crucial role to play. However to fully understand this, the participants believed that they needed a greater insight into the role of the Department of Health, Public Health England, the General Dental Council, the British Dental Association and the British Society of Periodontology.

The participants discussed that currently, the public sees health and teeth as separate entities but it is essential to include the prevention of 'losing teeth' in a healthy lifestyle package alongside the prevention of heart disease, obesity and diabetes. The forum participants also discussed that a contribution at a local level would have an impact and were keen to promote themselves as speakers to help local authorities spread the message.

(d) Toothpaste and drug companies

The participants said that a much stronger message on the products should be provided to encourage users to visit the dentist. According to the forum, the public are not fully aware that periodontitis is irreversible. The participants also believed that many products were masking the symptoms of gum disease such as having bad breath. The participants believed that the drug companies were tapping into the vanity side of things rather than health such as with tooth-whitening products, particularly aiming at the "young selfie generation" but were failing to deliver key health messages. Participants thought that drug companies should also deliver messages of encouraging patients to attend the dentist. One patient said the message should be 'go to the dentist early to avoid pain later'.

The commitment to increase awareness of gum disease was so strong that The Forum was not averse to, or overly concerned about, collaborating with companies to fund a role such as 'Brand X Gum Awareness Ambassador'. Other potential roles discussed were that of 'Health Ambassador' or 'Patient Research Ambassador' role who might work with patients in a hospital to identify candidates for a trial. Companies could contribute funds to, for example, produce a cinema advertisement that portrayed young people with gum disease along the lines of the film that was produced by the BSP for EuroPerio 8 '*The Sound of Periodontitis*' www.bsperio.org.uk/periodontal-disease/sound-of-periodontitis.html

The next point raised and discussed was what the most important factors are that researchers and clinicians should be thinking about from a patient's perspective when developing future treatment. The forum raised several questions about the disease including:

- *what exactly is gum disease?*
- *is it genetic and if so, what genes are responsible?*
- *is it bacterial and can it be treated with antibiotics?*
- *what is the impact of stress and other lifestyle factors?*
- *which behaviours influence and cause periodontitis?*
- *are there international differences and similarities?*
- *what about ethnicity?*

Should the Forum continue, and, if so, how would you like to see it develop? What would success look like for the forum?

The participants felt strongly about continuing the forum and agreed the draft terms of reference. The forum considered that their stories were powerful and could make a difference and they all had individual ideas on how they could make a difference. One forum member was considering volunteering herself as a speaker to a local community healthcare trust. The participants believed that by targeting particular groups they could help raise awareness further. They all felt they had a contribution to make in raising awareness and in helping the British Society of Periodontology establish a benchmark for success in raising awareness. The forum participants wanted to ensure their contribution and input was valued, useful and measurable. Their initial plan was to work on two or three specific tasks and keep in touch by email. The first task would be to provide feedback on the draft patient information leaflet. The forum participants also fed back that at this early stage they would welcome help from the British Society of Periodontology in facilitating meetings.

Summary Findings and Conclusions

From this first focus group, there were a couple of key findings which are of significance:

1. there was a strong and clear message from the focus group participants that the forum **should** continue and they believed it **can and will make** a difference to help promote awareness of gum disease.
2. there was strong feeling amongst the group that their **input needs to be valued, useful and measurable** and they were determined to be seeing to be making a difference and not staying stagnant as a talking point.

From the success of this patient forum, it is evident that patients and participants are keen to get involved to help spread awareness about gum disease and help in a variety of different ways. The group has already discussed and started to implement ideas on how to progress. They have identified the next steps which ought to be taken, initially starting as part of the British Society of Periodontology and as they grow, to become an independent body and a voice for patients.

Reaction and questions from BSP members following Julian Ekiert's Presentation to BSP Conference

Mr Julian Ekiert, one of the members of the Patient Forum delivered a short presentation the following day at the BSP conference on the 22nd of June 2017 and highlighted that he had learnt that gum disease was a much more complex issue than he had originally appreciated. He also acknowledged that there were many factors attributable to gum disease and that patient attitudes towards it are changing.

BSP delegates referred to the 'Healthy Gums Do Matter' toolkit. Public awareness should be promoted through the Health Service (rather than just being a professional message). There was further emphasis on the importance of representation of the NHS primary care service in the Patient Forum since it provided a different experience.

Professor Ian Needleman then concluded that the forum participants had shown enthusiasm and initiative to support the patient forum and it was something that must go ahead and the question for the British Society of Periodontology members was not "if" but "how".

