



BSP Patient Forum Meeting - 22 March 2019
Faculty of Dentistry, Guy's Hospital, King's College London

This was the third meeting of the Patient Forum (PF) that was set up in July 2017. Four existing and one new member attended and there were three apologies. Ian Needleman (IGN) and Simon Denegri (SD) chaired the sessions; also present were BSP Past President Penny Hodge and current President Mark Ide (MI), who attended for part of the meeting. There were two observers from GlaxoSmithKline.

Ian Needleman brought the group up-to-date with developments since the last meeting in July 2018.

- The domain www.whyaemygumsbleeding.com had been registered.
- There had been limited improvements to the BSP website in terms of navigation and readability since it is in the process of identifying and transferring to a new provider. The transition provided an opportunity for PF members to offer suggestions which they are strongly encouraged to take.

ACTION: Paula Dunn (PD): Involve PF members in development of new website once new provider established.

- Infographics have been amended in a limited way (a more distinctive text) with an acknowledgement of the group's 'too wordy, too much jargon' feedback for the future. There was also an issue around the European Federation of Periodontology (EFP) involvement in the drafting.
- Podcasts had proved a popular suggestion for raising awareness at the last meeting and a list of topics had been compiled from their suggestions and a pilot podcast recorded for the group to watch and discuss.
- Following the successful chairing of BSP Conference sessions and providing a report to Conference on the PF meeting by PF members Julian Ekiert in London and Barbara Sturgeon in Edinburgh, a volunteer was sought for Brighton in 2019. This was a challenging role but worthwhile for the valuable inclusion of the patient perspective. Neil volunteered for this role and Julian (and Barbara) would provide support, along with the BSP.

ACTION: PD & MI to coordinate with Neil regarding BSP 2019 to include conference call with Julian and Barbara to discuss their experiences of chairing.

- A second Patient Forum is being considered for Scotland (led by Penny Hodge) to gather views from another part of the country.
- The PF suggested that six-monthly meetings would be useful, along with brief quarterly updates.

ACTION: IGN, PD to look into funding

PerioPods - BSP Patient Forum podcasts

The PF listened to the pilot podcast on research linking gum disease and dementia (Ian Needleman interviewing Mark Ide). Ian Needleman explained that it had been recorded in response to a News item, not as an example for the PF to follow. The podcast was well received

The group felt all topics on their list of suggestions were important and inter-connected. After initial discussion it was felt the key questions were 'What is gum disease?' and 'How do you spot it?' There was further discussion around the target audience and the marketing of the podcasts. Many important points were raised:-

Audience

The PF questioned whether to target those who were already interested and seeking information (i.e. the 8% with the most severe gum disease and others with some form of destructive gum disease) or to reach out to those with bleeding gums and more generally. It was agreed that to target the 8% captive audience would be most effective place to start. The group did however express its strong on-going commitment to wider awareness and prevention.

It was suggested that a 'funnel/umbrella' approach (with clear signposts) could capture those beyond the 8%. A podcast or video of an interview could be cut down into relevant segments.

Production

It was proposed that two Patient Forum members interview two periodontists with a loose script. Neil, Julian and Andy volunteered to be interviewers. An attractive background would enable it to be produced in video format as well as a podcast. Media degree students might be interested in having the podcast as a final year project.

It was noted that the costs of production had dropped significantly with the advent of YouTube. There was a general interest in getting something underway and learning from the experience rather than to undertake something difficult. The dementia podcast had not taken long to put together.

ACTION: PD to coordinate IGN, MI, Neil, Julian, Andy

Ideas of how to access/share the podcast and how to market it

- YouTube
- BSP website
- Twitter

- Dentist referral (perhaps pointing to the relevant level for the patient)
- By Googling the word 'gum'
- Establish a link with an individual's appearance
- Need to make the podcast accessible to all (i.e. languages and pictures)
- To involve the community, the National Citizen Service could be involved.
- Could GSK's marketing people help?
- Simon Denegri could share his experience of marketing and communications. And suggested to consider pursuing a public engagement grant. There might be opportunities to get locate young groups within UCL.
- The group was advised not to target a younger audience without getting a younger group together

ACTION: PD to coordinate strategy for sharing podcasts within the BSP communications strategy together with IGN and SD

Gum Health and General Health

Ian Needleman provided examples of how gum health has a broader impact on people's health and a broader significance for healthcare professionals. He described the role of (oral) bacteria and inflammation in chronic diseases and how improving gum disease can improve general health. The disease with the strongest research evidence is diabetes. Diabetes makes gum disease worse and gum disease makes diabetes worse. Other conditions linked with inflammation are cancer, cardiovascular disease, kidney disease and cognitive impairment (including Alzheimer's).

A Commissioning Standard is pending from NHS England entitled 'Dental Care for People with, or at risk of, Type 2 Diabetes (T2D). The purpose of this standard is to provide support to develop clinical care pathways with the aim of improving **both general and oral health outcomes**'.

The Patient Forum saw this as an opportunity to engage with the parties involved to help support the development of care pathways. Suggested actions included:-

- Offer engagement of the BSP PF with the NHS England London pilot which is testing the Commissioning Standard pathways (e.g. links between GP and dentist regarding diabetes diagnosis).

ACTION: IGN to contact Chief Dental Officer (CDO) and Deputy CDO

- The PF identified a cost issue if the dentist is private, which is not a factor with referrals for diabetes-related eye and foot problems. This may lead to a campaigning or lobbying role.
- Possible podcast around dementia and gum disease

- To involve 'community patient leads' in communication and prevention.
- To identify and link up with other patient groups
- To contribute to doctor and dentist education
- To share patient experiences

Other noteworthy comments

- The description 'destructive gum disease' had an impact.
- One member commented that after almost 40 years he has at last been taught how to brush his teeth properly. Parents need to know how to make sure their children are brushing their teeth properly. The Scottish Dental Clinical Effectiveness Programme has a video on how to brush. It is important that it is demonstrated in the patient's mouth (with consent) rather than just be shown.
- Interdental brushes are thought to be for people with problems, not as a preventative measure. Floss is considered to be something to get bits out from between teeth.
- The PF was shocked to hear that one doctor had only received half an hour's training in oral health.
- PF members had evidence that BPE checks were not being carried out consistently.
- The PF were interested to find out whether oral health was improving. Members were pleased to learn that oral health and tooth decay were improving. On the other hand, the situation for children and disadvantaged groups was worsening and the number of people with the most severe gum disease has not improved. The determining factors of genetics, access and awareness were discussed, along with the important message of 'don't blame yourself, take action'.

Comments from Patient Forum at the end of the meeting

"Very helpful and motivating". "It was more of a conversation".

"The best PF meeting so far".

"Very important points were made".

"Very happy that the meeting covered deprivation and joined-up care".

"The meeting had more grit". "I feel more educated; I like to learn".

Ian Needleman concluded by thanking the PF members for all their input, Simon Denegri for facilitating the meeting, GSK for their continuing financial support and Hilary Needleman for writing the final report.