

REPORT OF THE BSP PATIENT FORUM MEETING

7 JUNE 2019

Grassmarket Community Centre, Edinburgh

PRESENT: Ian Needleman (IGN)
Penny Hodge (PH)
Shauna Culshaw (SC) – Senior Lecturer, Hon Consultant Glasgow Dental School
Tom Ferris (TF) – Interim Chief Dental Officer
7 Patients (members)

APOLOGIES: Representative from GlaxoSmithKline (GSK)

WELCOME: PH welcomed the patient forum members by thanking them for attending the first Scottish Patient Forum. Special welcome was given to Tom Ferris, Interim Chief Dental Officer for Scotland. PH also thanked the sponsors GSK and explained that without their support the Patient Forum meetings would not be possible.

BSP Patient Forum: Background and Progress:

IN thanked **PH** for the initiative of setting up a Scottish Patient Forum in relation to what had so far been a South centric forum. He explained that although the Patient Forum has received part funding from GSK this is not enough to be able to extend the patient forum widely across the country. The ideal would be to run more forums and to demonstrate the value of patient forums. There has been a significant input into the BSP's gum health initiatives from the Patient Forum, and **IN** is hoping that the Forum will provide a 'voice' for gum health. He addressed the members by saying that he is looking for patients' opinions and thoughts on healthcare policy – what works and what doesn't, to help the BSP become more outward-looking - which is important in improving periodontal health in the UK.

IN gave an overview of the previous 3 patient forums in London:

- At the first patient forum in June 2017 the question was raised as to whether there was any value in the Patient Forum to which there was a very enthusiastic and positive response from the members. It was evident that the Forum should continue and should develop and be able to rely on support from the BSP. Action was needed in the form of measurable outcomes, projects and engagement with the BSP.
- Patients identified problems sourcing information about gum disease on the internet.
- whyaremygumsbleeding.com – a new patient domain has been created. It is as yet not active as there are currently ongoing issues with the BSP website, which are being addressed.
- Raising awareness of gum health – **IN** commented that although public awareness is important it is very difficult to implement due to lack of funding.
- Podcasts – The London patient forum have volunteered to take part in the production of podcasts and have put forward the following topics:
 - Causes and stigma of gum disease

- Importance of gum health
 - Developing good habits
 - Professional care
- Three members of the Patient Forum have chaired a session at the last three BSP conferences and did not shy away from asking the speakers some difficult questions.
 - The Patient Forum has made a considerable contribution to the production of leaflets and infographics – breaking down the language into ‘layman’ terms with less clinical jargon.
 - The BSP Patient Forum has been invited to meet with NHS England, the Office of the Chief Dental Officer and to engage on the gum health/diabetes project.
 - The initiative needs to generate income in order to expand and despite the support of companies such as GSK, funding remains an ‘uphill battle’.

One of the members posed the question, ‘How does what you do influence research?’

IN responded; BSP are involved in an ambitious journey; how to work with the NHS to make research work, how do we find patients? What would interest people to keep them in the study? The patients who have met with NHS England are having a striking impact on research.

IN showed part one of the film ‘The Sound of Periodontitis’ (www.bsperio.org.uk/periodontal-disease/soundofperiodontitis.html) and invited the forum members to share their views:

PT #1: She could relate to the patient who had been a regular attendee at the dentist and was only diagnosed years later with gum disease by a specialist.

When questioned if they would recommend the film to other people the general response was that it didn’t demonstrate the seriousness of the disease or the effects of gum disease.

PT#2: ‘Not very relatable for patients who have not had the disease’.

PT#3: ‘Does not send out a strong enough message of the consequences of gum disease, a stark message needs to be put across – it needs a quicker way of grabbing attention’.

PT#4: ‘Used the Corsodyl advert as a good message – very convincing’.

PT#5: ‘Marketed at the older generation – should also be directed at the younger generation’.

IN reinforced the view with a presentation in which he demonstrated that gum disease is a public health problem and that the proportion of people with the most severe disease is not decreasing.

Recently published Scottish data revealed that the oral health of the population and people attending dental clinics vastly underestimates the reality of the disease.

IN discussed how the various health providers have a role to play in early diagnosis and prevention of gum disease and in identifying the risk factors, which can increase the chance of gum disease such as in patients with diabetes. Getting all healthcare workers involved is the practical idea, the realities however are more difficult, as is the case with general medical practitioners.

The public need to be empowered to be more aware of the early signs of gum disease and the implications if left untreated.

The forum were asked to discuss the importance of gum health and the following ideas/comments were raised:

Is gum health important to you?

- Yes, it highlights the fact that gum health is linked to general health – this appears to be overlooked.
- Gum health is not viewed as important enough – until something goes wrong – then the shock is overwhelming.
- Enforce the fact that you can't enjoy your food without your teeth!
- Gum health has always been important to me, but I didn't know how important until I was referred to a specialist.

Is gum health important to the community?

- It is not given the priority it should be given and there is a general lack of public awareness regarding gum disease.
- Unaffordable treatment – NHS cannot accommodate the numbers requiring treatment.
- Early intervention and prevention.

Whose responsibility is gum health?

- You can only take responsibility when you know you have a problem.
- Majority thought it was the responsibility of their doctor to check oral health as part of the general MOT.
- Grass roots education needed as it is a 'silent' disease.
- Government and NHS need to do more to prevent gum disease impacting on other diseases.
- Self-management – knowledge and informed support required.
- Generational factors – old – young – highlight the misinformation that it is an old person's disease.
- UK reputation for poor dentistry. Has this view normalised the situation for people?
- Fear of the dentist.

How could gum health be improved?

- Link information websites to NHS / Government health platforms.
- Improved access to periodontal treatment and assistance with paying for treatment.
- Equity/funding and health promotions.
- Improve communication between public health, GPs, dentists, schools, parents – ante and post-natal visits.
- 'How to' modules at school (sexual health as an example).
- Raise awareness of the importance of gum health through children's social media.
- More support from dental suppliers to help with public health campaigns across social media.
- Means testing – support the hygienist in socially deprived areas.
- Learn from other countries who manage oral health better than we do.

IN: in summary, the overall message is that oral health is part of general health and that people need to take responsibility for their own health, as long as they are informed and empowered to do so, unfortunately gum health is positioned as separate to general health.

Members were adamant that doctors should play a bigger role in creating awareness of gum health if it is compromised by present health conditions i.e. Diabetes.

TF: evidence is 80% of people go to a dentist – dentists see a range of patients who are well – doctors only when unwell.

IN: there is a different form of alignment – it could be that dentists are taking a clearer role in general health management.

TF raised the example of the pharmacists who conduct general health checks – he had posed the question about doing the same in a dental clinic – which was met with mixed reviews from GPs.

IN: Research has shown that dentists are concerned that patients are not happy for their dentist to ask about general health concerns, but the research also shows that patients are happy to be asked.

IN: regarding social media, in 2016, as part of the Gum Health Awareness Day campaign, mouth card selfies were shared on social media – but the BSP need to understand the target market and we haven't designed a target group as yet.

IN summarised the group's feedback and thanked them for their striking comments – adding the importance to individuals of gum disease in those who already know – raising awareness in people who don't know might be challenging.

PH addressed the group on 'Gum health and general health'.

Gum health is linked to an increasing number of health conditions:

Diabetes, cardiovascular diseases, cancer, chronic kidney disease, rheumatoid arthritis, cognitive impairment including Alzheimer's.

In 2017 BSP collaborated with Diabetes.co.uk to raise awareness of the increased risk of gum disease in people living with diabetes.

Out of 700 people, 50% had not heard about the link and one third were unaware that it could affect them. BSP in collaboration with diabetes.co.uk produced 2 infographics, one for people with diabetes and one for healthcare professionals, illustrating the link between diabetes and gum disease and giving advice about prevention and treatment. These were disseminated through social media, at the Dentistry show in Birmingham and at the Diabetes Care Event in London.

The information was very well received, and there have been requests from other organisations looking after patients with diabetes to use the infographics or link to the BSP website.

PH explained to the members that treatment of gum disease can improve blood sugar control which can reduce the amount of medication a patient with diabetes requires, (which impacts on the NHS). Conversely, gum disease can increase blood sugar in people who don't have diabetes.

One member mentioned her son who has a heart condition and was advised to look after his teeth, illustrating the link between general and oral health.

A campaign in 2018 'A lifetime of smiling' reinforced the message that it is never too early to develop good oral health habits. European Federation of Periodontology (EFP) graphics were used and modified for a British audience and were distributed via social media, Oral b and the dental shows.

PH highlighted the importance of prenatal check-ups and informing women about possible gum problems during pregnancy and of the relationship between gum disease and tooth decay. These diseases share a common cause – the bacteria found in dental plaque. A high sugar diet contributes

to plaque formation and tooth decay and also increases inflammation in the body, including in the gums.

Gum disease affects half the world's population – If children were taught this at school it would make a world of difference!

Members broke into groups to discuss the following:

Should the links between gum health and general health be promoted more widely?

- Yes, it is the responsibility of all health professionals to promote links on social media etc.
- Greater use of dental nurses to spread the message about gum health and general health.
- GMP screening tools for risk factors to include a trigger for gum health questions to be asked.
- Share media platforms with other support organisations e.g. heart, stroke and chest charities; Alzheimer's Scotland.
- Put pressure on the Govt to invest in oral health.
- Links to include stats for effect.

One of the members asked if dentists have access to the Patient Information leaflets – **IN** replied that they are available to download for anyone and hard copies have to be paid for.

How can the Patient Forum help?

- Speak up and raise awareness – share information with all healthcare professionals from different departments.
- Enlist celebrities to promote awareness – specifically those with the disease - **IN** replied that this initiative has been previously considered and is risk averse. It is expensive and there is a risk that the celebrity could do something that does not reflect well on BSP. At the forum in March it was mentioned that mental health have done it successfully – and we should ask them for advice.
- Forums should include non-patients and the younger generation – patient forums to invite their 'friends' to a forum.
- NHS and dental clinics could hold their own forums on an annual basis – offer hygiene kits as an incentive in partnership with companies
- Rebranding of the condition i.e. 'cervical smear' changed to a more acceptable term 'cervical check.'
- Unspoken disease – stigma – **IN** suggested the patient forum act as ambassadors.
- The importance of terminology – important to strike a balance between keeping it real and the shock impact.

IN: The use of the term 'gum health' rather than 'gum disease' is slowly evolving and is widely used. Need to keep the momentum going – hit hard and often.

IN played a you-tube video on oral health produced by Health Education England and asked for feedback from the group. He added that the piece is easily accessible and should be easy to promote.

One of the members questioned how influential this video could be if shown to health ministers.

IN: commissioning standards for diabetes and gum health – one of the influences is that providing gum treatment for patients with diabetes can save a substantial amount of money.

TF questioned whether there was any 'paper' on it – **IN** replied that it is an on-going project.

There was a mix of views re the video – some thought it was too in-depth for the general public, others thought it would appeal to those who do not have gum disease.

This raised the question of how to get the message out about gum health to those who do not suffer from the disease.

TF summarised what is needed from the NHS – more stringent health risk assessments and personalised care plans. Dental team should take control of the smoking and alcohol assessment – there needs to be protected time to have discussions with clinicians and a more effective means of documenting what has been discussed with the patient.

He suggested commissioning the Scottish Health Council to encourage the various health sectors to link in.

IN posed the question ‘should the forum continue?’ and if so how?

PH: how can we target children with the gum health message? At the moment social media from BSP is going to the professionals instead of opening up all social media platforms to attract the younger population.

IN discussed the success with diabetes and gum health – commented that disadvantaged people’s buy-in from communities has been remarkable, identifying roots in these communities as a way to get the message across to people who are resistant to these messages.

SC explained the benefit of students listening to a patient’s account of their experience of gum disease and the issues they face – emphasised the benefit of having patients attend undergraduate lectures as a powerful education tool - and asked the question as to whether they should invite patients to lectures.

One member asked whether a patient video account would be of any benefit to student learning.

SC replied that she has made videos of patients speaking about their experiences, but the patient’s perspective may be biased (because of being a patient of SC’s) and they may be reluctant to tell the truth.

Another patient member said they thought having a patient in a lecture would be more powerful because the patient could interact with the students and answer questions.

SC suggested an annual visit by patients to lectures – members of the patient forum agreed with this idea and volunteered their assistance.

IN suggested patients could also attend CPD sessions with dentists and other professional bodies to share their experiences.

Ian Needleman and Penny Hodge concluded the meeting by thanking the members of the Forum for their valuable input and Dr Tom Ferris and Dr Shauna Culshaw for their attendance.