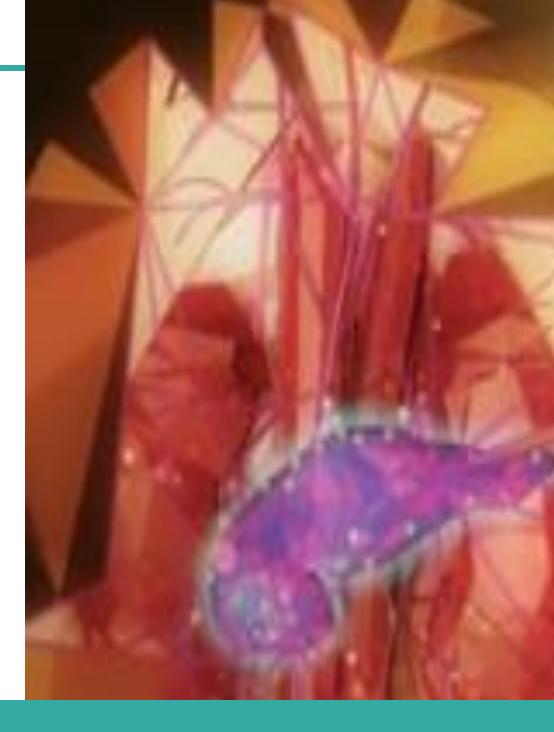
Pocket Medic Review Diabetes



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BCUHB

2019

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Reviewing resources

(Pocket medic / videos & written resources)

Engagement sessions undertaken – East Area

This piece of work, has been specifically aimed around Learning Disability, Autism and Diabetes to be reported to 'The All Wales Diabetes Implementation group', which will hopefully benefit from the testing of these resources (pocket medic/written resources) with the patient groups outlined in this report.

Elaine Jennings the Community Dietitian for BCUHB had asked the Engagement Officer to target groups in order to review the Pocket Medic Videos and ask specific questions to gauge understanding and ease of use.

Three groups were selected to view and discuss the Pocket Medic videos:

- The BAME Youth Group in Wrexham age ranges from 7 to 25 (male and female)
- Flintshire Disability Forum age range 50+ (male and female)
- KIM Inspire Wrexham Mental Health group 25+ (female)

Questions asked:

- Does anyone in the group have diabetes or pre diabetes or if they have any family members with diabetes? (if you are happy to share)
- How easy did you find navigating the films? (perhaps you could try and find the videos yourselves)
- Did you understand the messages? (can you say what you understood to be the key messages?)
- Did you find the pace too fast or too slow?
- How easy were the presenters to understand?
- What did you like about the films?
- What could be improved?

Engagement sessions:

First engagement session held with the BAME Youth Group in Wrexham – supported by the Engagement Coordinator for the All Wales BME Engagement Programme

Engagement Officer visited the Youth group to show the Pocket Medic videos in order to discuss and gain feedback.

Twenty members of the Youth group attended the session to learn more about the Pocket Medic videos. They watched an introduction to Diabetes and a selection of other videos on T2 and listened to patient stories.

The group were asked if anyone had a family member with Diabetes and all in the group had a school friend that had Diabetes who often needed support at school. One youth had a parent (father) with Diabetes.

Group held a discussion around the symptoms of Diabetes and what they already knew. They knew that thirst was a symptom, that people with Diabetes had to test their blood regularly for sugar levels, that the immune system was compromised and that the body did not make enough Insulin.

They were not aware that carbohydrates in bread turned to sugar and that it was not just 'Sugar' that they had to be aware of; neither did they know that eyes could also be affected.

One of the films discussing amputation and losing limbs caused concern to the younger members of the group – they had heard of toes being removed but not limbs. One younger member asked what 'limbs' were – it was felt that the

terminology used in some of the films was difficult for the younger ones to comprehend.

They all felt that they could navigate their way around the Pocket Medic website and felt there was a good choice of topics; but they also felt that the films were not very representative i.e. more BAME patients and also more younger patient examples. <u>http://www.diabeteswales.org.uk/en/pocket-medic.htm</u>

Key messages from the films noted by this group were 'threat of losing limbs', 'watch what you eat' and 'symptoms' such as being 'thirsty' all the time.

The group felt that the pace of the videos were ok and that the presenters were easy to understand.

Everyone in the group liked that there was lots of information in the videos and agreed that they would like more time to meet and watch more videos and perhaps discuss further – they asked if someone could attend their group again should they have any additional questions – this has been agreed and will be arranged by the Engagement Officer.



"Can anyone get diabetes?"

Second engagement session held with the Flintshire Disability Forum group at Llys Jasmine in Mold – supported by Jan Thomas from FDF Members of the group were asked, if they were able to access the internet for information. Out of the 17 present only 3 were comfortable with using technology and 1 that was internet aware, others relied on family and friends for information.

As the group did not feel they would access the Pocket Medic site fully, the Engagement Officer gave the group a quick glimpse of the site and showed how easy it was to click on the videos to view, so that they could direct their family and friends. The individual in the group who used the internet felt that she would certainly use this site and was keen to look at the other topics i.e. CPOD video; she also agreed to feedback to the Engagement Officer once she had reviewed the videos at home.

Elaine Jennings had provided information booklets on Diabetes from Diabetes UK – booklets used to discuss Diabetes symptoms.

Most members of the group had partners, family or friends who had either T1 or T2 Diabetes; and between them had lots of knowledge on the symptoms in some form – each were able to contribute to the conversation.

Discussions from their knowledge included....

Symptoms – if you have low blood sugar you can feel shaky, feel sweaty, feel tired and even grumpy (one said her partner got quite grumpy at times with his Diabetes). If you had high levels of blood sugar you could feel tired, would get up in the night to pass water and feel very thirsty – they all recognised these symptoms.

They also discussed other symptoms such as 'Slow Healing Wounds', 'Thrush' and 'losing weight'.

Complications – the group knew a bit about complications and discussed how Diabetes could cause different types of complications such as damage to limbs and major organs; heart, eyes, feet & kidneys. One member of the group had a

partner who had lost a limb (below the knee) – this had also put a strain on her health and caused her other problems i.e. putting on weight.

Diet & Food – they were all very knowledgeable on the types of food to eat; they were aware of carbohydrates in bread turning to glucose that sugars and other food such as potatoes and sweets.

Exercise – the group discussed the importance of keeping active and described ways they used; walking, swimming, dancing being the most popular – they also felt that getting out to their social group was an important part to 'getting them moving'.

T1 & T2 – a question was raised as to the difference between the different types of Diabetes; members of the group had in-depth knowledge of T1 & T2 which they shared with the group – the Engagement Officer also directed them to the booklet for further clarification (there was also an ex nurse supporting the group who supported the conversations).

Risk Factors – following the topics in the Diabetes UK booklet, the group were asked what they thought the risks were and discussions noted their knowledge regarding 'being overweight', 'smoking', 'family history', 'blood pressure', 'alcohol', 'not moving enough' and 'not getting enough sleep' – there was good recognition around risks.



"thank you so much for coming, I really learnt a lot - will you come again?"

Third engagement session held with Kim Inspire – Mental Health group in Wrexham – supported by Arianne Caloe at Luke O'Connor House

This group consisted of females over 25 – who receive regular support from Kim Inspire with any Mental Health and Anxiety Issues.

The Engagement Officer asked the group if they had any members of the family or friends with Diabetes – two said they had relatives with Diabetes (one elderly mother had just passed away) and one member of the group was a retired nurse.

Group watched a selection of the videos and opened up discussions with the questions presented on the information sheet by the Engagement Officer.

All members of the group were familiar with using technology and accessing the internet for information. They all felt they could access the videos once shown how to access the site.

They were all keen to look at more in their own time and felt that information presented in this way was good as information was presented by 'real people' and 'simplified the medical words' for everyone – they felt that Drs in Hospitals used 'big' words which they did not understand.

Key messages from the videos were discussed, and the group were asked to identify them. They all felt that one of the key messages was to watch what you eat but also that Diabetes could be controlled if you were careful, and monitoring your blood sugars and medication would put you in control; making it less scary.

They felt that the presenters were easy to understand, really good at explaining the different things associated with Diabetes – endorsing that they could 'definitely' be understood.

When asked what they liked about the films they said that using 'real people' made it more 'real' for them; they felt that the videos were short (in a good way) and very informative.



"Diabetes is serious, but you can keep it under control if you're careful"

All groups were informed that - "PocketMedic is a series of videos designed to help people understand what is happening to them and how they can start to work with health staff to play a greater part in managing their own health. Sharing of experiences along with explanations from medical staff, are to help engage the audience. Language is easy to understand and very straight forward, the environment and style is relaxed and homely, and graphic illustration is clear – and sometimes even make patients smile!"

Links to Pocket Medic Videos used.....

The introduction to Pocket Medic for Patients <u>www.medic.video/patients</u>

Diabetes Taster www.medic.video/diabetes

Diabetes – Recognising DKA Please click here for <u>DKA</u>

Diabetes – Type 2 – subtitles – What is Type 2 Diabetes www.medic.video/ko-wit2 Diabetes – Type 2 – subtitles – Jill's Story www.medic.video/ko-jill

Diabetes – Type 1 – subtitles – Carb Counting www.medic.video/ko-carb

Diabetes – Type 1 – subtitles – Living with type 1 www.medic.video/ko-lwt1

Promoting Pocket Medic Videos at BCUHB - Bite Sized Health in the Workplace sessions & also at public events:

The Pocket Medic information has also been distributed at all public events that the Engagement Officer has attended, and more recently opportunities to promote have arisen at the newly launched BCUHB 'Bite Sized Health in the Workplace' (BSH) sessions.

BSH sessions held:

- Health & Wellbeing BSH launch at Redwither Tower, Wrexham
- Mold Magistrates Court 30 people attended
- Tomlinson's Dairies 50 people attended
- Hoya Lens UK 60 people attended

Future promotion:

- XPO Logistics 152 employees 2nd July
- Holywell 999 Day 27th July
- National Eisteddfod 3rd to the 10th August (Llanrwst)
- Plas Madoc H&Wellbeing day 21st August (Wrexham)
- Mold Food Festival September
- XP Logistics September (night shift workers)
- Llangollen Food Festival October







Autism and Diabetes:

We have also looked at ways to implement the ASD autism awareness training, which was identified as being a useful 'online tool' to provide staff with an introduction to 'Autism Awareness' for all Health Care Professionals.

For further information and links to the online training – click on the link below:

https://asdinfowales.co.uk/working-with-autism-professionals - Working with Autism & Autism Aware Certification



Some of our teams within BCUHB have also received further training from the Integrated Autism Service (Nathan Smallwood) and individuals have undertaken 'Champion' training.

A calendar invite to access the ASD online training module distributed to the Diabetes team, the Dental team and the Children's Services team – in the East Area. First pilot October 2019.

As part of the awareness raising, we asked staff to capture photos of their service teams displaying their certificates, for promotional purposes.

Further work will be undertaken to gain feedback on this following the October pilot to gauge progress – the training will also be directed at GP and primary care staff.

Cancer Patient story.....

Experience of the difficulties an autistic person underwent whilst facing cancer treatment:

Being autistic and dyslexic makes it very difficult to communicate via the written word so it would be better to have a chat with an individual over the phone. However, it may be possible to use an advocate, relative or friend to pass on or discuss thoughts, concerns and ideas via email.

- An individual had an appointment recently; he had no idea what was going to happen, as the letter he received from the hospital gave no indication what it was about.
- The first major obstacle for him was to orientate himself in the car park, and then find the entrance to the hospital. This does not get easier despite him going there numerous times. When he eventually finds the entrance, his heart would start to pound and his body would be in a state of very high anxiety.
- Entering the hospital, he was confused and disorientated, not knowing where to go or where the reception desk was. The cacophony of sounds, movement and lights would make walking down corridors or approaching the reception desk almost impossible. The verbal instructions given to him by reception were not understood in this present state.
- Whilst walking to the area he is trying to find, he felt as if his legs will not work properly, his heart was pounding and his sight became affected. People are hurtling towards him, coming from all sides and the noise deafening and alarming.
- Someone who recognised him eventually showed him to the waiting room. The challenge of sitting in a confined space with a lot of people was overwhelming. The person who helped him (a friend) told him where there was a quieter place to sit.
- By the time he was seen by the consultant he was in a state of high stress. He needed to
 undergo two procedures, one for his shoulder (unrelated to his cancer) and another for his
 tumor. He refused the recommended anesthesia because he did not understand what it
 would entail. He thought he was going to be 'put under' and not be able to go home.
 Therefore, the surgery for both the shoulder and the tumor were done under a local. It was
 when they had finished that he discovered that the anesthetic he had originally been offered
 would only have frozen the left side of his body for 6 hours. He had suffered all the
 discomfort and pain because he had not understood, and probably because he was in such a
 heightened state of stress. This individual had no idea that any of this was going to happen.
 He felt that the appointment letter had not given him any details.
- He was also given a whole pile of drugs (medication) to take, but he didn't take any of them because he didn't understand what they were for; negotiating the passage of time between doses is very difficult and there was no clearly laid out explanation of how and why to take them. He still has the unopened boxes.

Patient recommendations.....

Patient came up with some simple recommendations, which would alleviate much of the stress involved in getting to a hospital appointment. This was THE most distressing part of his treatment. He had no problem with the biopsies, surgery or treatment.

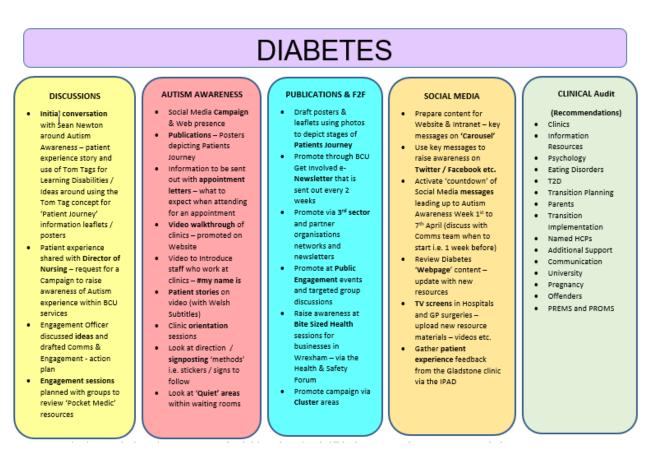
- A simple map of the hospital layout; the clinic he needed to go to, clearly marked.
- A photograph of the reception area, so that he would be able to recognise where to go as soon as he entered the building.
- A quiet place to wait. (Some opticians are already providing this for autistic people.)
- Appointment letters to give an outline of what is going to happen. The map and photos could be included so that the patient could prepare everything in advance. This is crucial for the autistic brain.
- An understanding that undressing in front of strangers is not just an embarrassment for autistic people, it is traumatic.

"My friend has a scan coming up soon in Ysbyty Gwynedd; I hope to meet him there to walk him to the reception area, then to the clinic. I will wait with him in the busy waiting area because I know he will struggle to go the short distance between the clinic and the scan waiting room. It would make all the difference if someone could just walk with him to show him where to sit (the small quiet space opposite the entrance to the scanning room.) It would be so good if there was an alert on his records for this to be offered. He is so stressed by the time he gets there, that to ask for this would be impossible. My son is the same.

My friend, who is attending for the scan, runs a very successful business, which is both dangerous and highly skilled. He is the most qualified person in his profession in the country, yet going to hospital is the most traumatic experience he presently has to cope with.

We hope that putting some simple procedures in place will help other autistic people negotiate the obstacles that arise while having cancer treatment."

Communication outline for Diabetes, Autism and Learning Disabilities.....



Acknowledgements with regard to reviewing Pocket Medic Films.....

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