

Minutes of the Cross Party Group on Diabetes

Tuesday 12th November 2013

Attendees

Jenny Rathbone AM (Chair)
David Rees AM
Julie Morgan AM
Chris Williams (Novo Nordisk)
Yvonne Johns (Diabetes North Wales Reference Groups)
C Hugh Thomas (Community Pharmacy Wales)
Wendy Gane (Diabetes Peer Support)
Dr Sarah Davies (GP Cardiff)
Penny Griffiths (Abbott Diabetes Care)
Jackie Dent (Retired lead coordinator Diabetes in Wales)
Lynne Hughes (RCN)
John Griffiths (Lay Member)
Jason Harding (Diabetes UK Cymru)
Dai Williams (Diabetes UK Cymru)
Edward Rees (Welsh Government)
Chris Dawson (Welsh Government)
Robert Wright (Lay Member)
Colette Skilling (Medtronic)
David Chapman (Representing Medtronic)
Scott Cawley (All Wales Podiatry)
Patrice Cowan (SANOFI)
Lesley Jordan (Input Patient Advocacy)
Paul Coker (Input Patient Advocacy)
Helen Cunningham (Office of Jenny Rathbone AM)
Mirriam Dupree (Office of Jenny Rathbone AM)

Apologies

Dr Lindsay George
Steve Bain (Swansea University)
David Miller Jones GP
Helen Nicholls (British Dietetic Association)
Pippa Ford (CSP)

The cross party group would like to thank the following organisations for their support:



Introductions

Jenny Rathbone welcomed attendees to the 7th meeting of the group in the 4th Assembly. Members introduced themselves and their organisations.

1. Minutes and matters arising

The group agreed the accuracy of the minutes of the meeting on April 30th 2013.

Adam Cairns has yet to report back on prescribing guidelines to GP's on glucose testing strips (Jan 29th 13 meeting). JR to follow up

2. Together for Health – a Diabetes Delivery Plan

Chris Dawson explained the Diabetes Delivery Plan was one of a series Welsh Government was developing for different conditions. The Diabetes Plan is deliberately short with a patient outcome focus and measures for tracking progress. It was developed with input from a range of stakeholders including clinicians and members. The Health & Social Care Committee recommendations were incorporated into the Plan.

Annual reports would be published on “my local health service” website which will enable the public to look at services in their area, to drive forward and add continuity to the plan.

Comments included:

Dai Williams thought health boards were still thinking in isolation; locally rather than nationally, and a named clinical lead in each HB will be vital to get LHBs working together.

Yvonne Johns reported a turnaround in North Wales since the last CPG meeting. There have been two meetings with Deloitte looking at “where we are” and “where we want to be” with a care plan. Betsi Cadwaladr HB re-thinking how to deliver diabetes care. There will be a 3 year roll out using savings made in secondary care. Yvonne added there is more work to do in primary care; she thought 2 new appointments were required.

Robert Wright: terms of reference should be handed down nationally rather than developed locally for the sake of consistency. Dai Williams responded that he understands that they are to be handed down nationally.

Julie Morgan said the Public Accounts Committee, of which she and JR are members, is currently looking at unscheduled care. JR asked how patient education could be delivered effectively when it was most needed - on diagnosis.

Chris Dawson and Ed Rees responded: Plans have to take into account patient movement across borders. The National Implementation Group will help make plans reflect national priorities and tackle cross border issues. All local delivery groups will have representation on the All Wales implementation group.

The terms of reference will be produced by the implementation group. The terms can be adapted locally but there are fundamentals that apply across the board.

Patient Education is insufficient. There's a significant backlog of people who haven't had structured education. Those who have find it useful and feel more in control and are equipped to ask the right questions. It needs to be delivered at times that people can attend. Twice weekly evening sessions delivered by Cardiff and Vale UHB in the evening were mentioned, though demand is not as high as expected. There were examples of structured education which does help to move patients forward.

Jason Harding pointed out the Minister had said that structured education is at the core of the Plan. JH questioned the effectiveness of delivering training to large groups but with so many people in Wales with diabetes there was a need to think of the best way to help thousands of patients.

Julie Morgan AM asked how would it be possible to rectify discrepancies in testing (once per year / twice per day). Ed Rees mentioned that new information leaflets were being tested through GP's to improve understanding as education reduced fear.

Penny Griffiths said that the biggest issue with testing was in type 2 patients. Many don't need to test themselves regularly, but some do. She is not in favour of all patients being tested. There needs to be education about who needs to test, when, and how often. Sarah Davies added that GP's are advised to provide 50 testing strips a month unless there are exceptions where patients require more.

Yvonne Johns: more education in food and nutrition is required as most diabetic patients do not understand carbohydrates and calories and the effect each has on blood sugar. She stated that there is a problem with some diabetic young people (particularly girls) not taking their insulin. She commented that there was a need to ensure nutrition education is reinforced, which does not have to be delivered by a specialist nurse or dietician.

Chris Williams from Novo Nordisk emphasised importance of whole population education i.e. healthcare professionals with the right standard of education. The first six months after diagnosis are crucial for a patient, so the GP, nurse, pharmacist they come into contact with before they got on a course are all important in influencing that patient.

Dai Williams: sometimes clinicians have to spend time correcting misinformation that's been given to a patient earlier on in the process.

Lynne Hughes: primary care nurses don't always have time or can't access training, even if it is online.

Wendy Gane: her organisation delivers a self-management course, the only one in Wales. There needs to be more basic education prior to structured education i.e. something to take home on the day of diagnosis. The majority of patient reference groups don't have good patient involvement, and not confident that health boards are committed to more patient involvement.

Chris Dawson: there would not be extra money to deliver this Plan. It is about using current resources to work better to deliver structured education. He acknowledged health services don't always make the best use for groups like Wendy's. Better information between community services and GP's surgeries would help doctors be more aware of what they can refer patients to in their own communities such as Communities First nutrition projects.

Bob Wright commented on the lack of patient involvement in Powys. Chris replied that it would be useful to have a single point of contact for obtaining information leaflets and a list of quality assured websites and also refer to third sector organisations.

On patient involvement, Chris said that co-production is emphasised by the Minister, that patients are experts in their care and they can help other patients. Further feedback was encouraged so it can be relayed to the implementation groups.

Paul Coker: the psychology of diagnosis can be overlooked. For teenagers and young people this is especially important. Children tend to have a good HPA1C but when they

become teenagers and manage their own diabetes, their HPA1C level deteriorates. Counselling is required for this age group as they are in denial of their condition.

3. Health & Social Care Committee Short Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction

The Chair asked David Rees AM if all the recommendations have been captured in the Diabetes Plan. DR said that there's still a question on the clinical lead. Education needs to be consistent nationally. He asked about the speed of diagnosis in both primary and secondary. Dai Williams and Yvonne Johns both agreed that diagnosis mostly takes place in secondary care but the quality is mixed.

Re recommendation 12 of the report on recommended audit of diabetes specialist nurses. Ed Rees had met the Chief Nursing Officer; they agreed to look at how Diabetes specialist nurses work and how they are used within teams. There will be an audit and guidance to follow. Health board approaches vary, eg differences between Powys and Cardiff.

Sarah Davies: Diabetes nursing needs to be brought to primary care to improve Practice Nurse education. Cardiff are looking at a community model i.e. consultants doing virtual clinics, coming to practices and reviewing patient notes

4. Diabetes Implementation Group

The All Wales Implementation Group will meet on 19 December. Chris Dawson will send the Chair the membership list for distribution

John Griffiths asked about employers being encouraged to support staff to manage their condition. He noted that the food industry has a big part to play – how can the food industry be held to account. The Chair acknowledged this was a big subject which could be an agenda item at a future meeting.

Action: Item to be added to next agenda.

5. Cross Party Group forward work streams

The Chair outlined the work that had been done on patient education and patient monitoring systems over the past year.

Wendy Gane gave an update on the retinopathy sub group. The group agreed to draft something on how the work of the sub-group could be completed

The group agreed that Insulin Pumps and inpatient care would be the two new workstreams.

Action: Insulin Pump workstream and Inpatient Care workstreams to be set up

6. New rules on the operation of cross party groups

The Chair outlined the new rules governing the work of cross party groups. These include the need for cross party support, which the group has. Both Darren Millar and Elin Jones have agreed to co-sponsor. The group will need to hold an AGM at the next meeting.

7. AOB and date of next meeting

Diabetes UK launching a report at the Senedd on 27 November. All welcome to attend.

Date of next Cross Party Group Meeting is **Tuesday 4th March 12.00-1.30pm**