



**National Children and Young People's  
Diabetes Network  
National Delivery Plan - Aim 1  
Patient Education Subgroup Meeting Minutes  
27 September 2021  
Via Microsoft Teams**



Attendees	<table border="1"> <thead> <tr> <th>Aim 1 Core Group Members</th> <th>Role</th> <th>Network/Organisation</th> </tr> </thead> <tbody> <tr> <td>Piyusha Kapila (PK)</td> <td>Clinical Support</td> <td>London/SEC</td> </tr> <tr> <td>Margot Carson (MC)</td> <td>Manager</td> <td>North West</td> </tr> <tr> <td>Emma Savage (ES)</td> <td>Manager</td> <td>Yorkshire and Humber</td> </tr> </tbody> </table>			Aim 1 Core Group Members	Role	Network/Organisation	Piyusha Kapila (PK)	Clinical Support	London/SEC	Margot Carson (MC)	Manager	North West	Emma Savage (ES)	Manager	Yorkshire and Humber											
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Agenda:	<p><b>Welcome and Introductions - All</b> All delegates introduced themselves to the group.</p> <p><b>The Aim of the Subgroup</b> By 2025, we can ensure that every child with diabetes has equal access to the same level of diabetes care and education that allows effective self-management through the delivery of a national standard programme supported by diabetes teams that include psychologists and social workers.</p> <p><b>MC and ES</b> have broken the aim into 6 subgroups.</p> <p>This subgroup will look at Education.</p> <p><b>MC</b> encouraged units to send information of what education packages are being used through to the subgroup. The best way to collate this may be through the regional network managers.</p> <p><b>Discussion: Existing Education Packages etc</b> <b>MC</b> shared the variation of education packages used within the North West region. Most units have based their packages around Goals of diabetes (GoD) with teams using various sets of</p>																									



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resources e.g DEAPP/SEREN/DigiBete to support this.

Felt that education starting at time of diagnosis is associated with best outcomes.

Wales using SEREN nationally. Timeline from diagnosis up to 6 weeks post diagnosis. Unit dependant on which topics to prioritise.

East Kent using SEREN since 2019. Over 18 months adapting the programme to needs in terms of when to provide what training. JB auditing results and produced SOP on this. **Action: ES asked whether JB could present on this to the group at a future meeting.** Previously using GoD but comments from CYP they were 'bored' with standardised education. Now looking at SEREN Connect.

Majority of the North East have been using GoD but are beginning to roll out DEAPP regionally. Found issues with sections being in a specific order and only unlocking once another is complete. This will be changed in an update based on feedback.

A lot of the South West are now using DEAPP. Found it has been very useful for re-education of patients that have fallen off the radar. Also using to teach ward and school staff.

Some units in Yorkshire and Humber have developed checklists which may be useful in developing a timeline (Huddersfield, Scarborough and Rotherham). Other units basing education around GoD but adapting into unit specific packages.

**PK** asked how many units are starting newly diagnosed on pumps. Some units in Wales do with some under 5s. Plymouth aim to start under 5s quickly after diagnosis. **PK** stressed importance of getting this age groups training right as they will have diabetes for a very long time and it being difficult to change habits.

Discussion around producing a timeline of education outlining at what point during the CYP care, specific training is given. Felt a timeline would be a good idea but with flexibility required for teams differing practices.

**Action: Units to send any timelines/checklists currently being used through to the group**

**Action: ES and MC to discuss with network managers working on aim 2 about when they will introduce education into the technology side of things to look at a potential cross-over**

**Discussion: Topics to consider: languages, patient engagement of structured education, linking patient education with technology**

Aim 4 are working of patient and family engagement so potential to feedback to them with any information we have on any groups of CYP that are difficult to engage in education.

In Wales the language barrier can be an issue with SEREN (Only in Welsh and English). East Kent have introduced a planner into their education programme used in conjunction with SEREN. At first appointment the expectations of the next 6 weeks are discussed and noted. This has seemed to help with engagement. Discussion around extending this timeline to perhaps a year, so they are fully aware of what to expect. **Action: JB to share planner with group**

Influx of patients with ASD in South West and stressed importance of networking and sharing work done to support these groups.

**PK** asked about chance of CYP representation in the working group. **MC** stated the group will be



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	<p>looking to adopt stakeholders following this initial meeting where required.</p> <p>In Wales all staff delivering training are quality assured to ensure all training is the same nationally. Feedback is also obtained from the families following education.</p> <p><b>PK</b> suggested creating a feedback form to obtain information on how CYP and families view the quality of education provided.</p> <p>Concerns over reinventing a package already out there.</p> <p>The aim of the group is to look at creating supplementary documents to support education packages already available. For example, a timeline of training and a planner as discussed. We would need to look at getting any work done translated into multi languages to support engagement.</p> <p>It was suggested to use the network website to congregate all documents already available nationally.</p>
<b>Actions</b>	<ul style="list-style-type: none"> <li>❖ All units to send details of standard education package used locally to their network managers/ES/MC</li> <li>❖ JB to send planner resource to ES/MC</li> <li>❖ Look at developing a timeline with milestones/key stages rather than a period of time</li> <li>❖ ES/MC to feedback to schools' group on assessment criteria and evidencing what is being taught</li> <li>❖ ES/MC to feedback to technology and engagement groups for potential cross-over work in the future</li> <li>❖ Look to share library of resources on the national network website</li> <li>❖ Look at doing user feedback survey. Look initially at PREM and then look to utilise the units of group members for feedback. MC stated need to link with FWDNN to develop survey. ES to pull together a draft survey for review at next meeting</li> </ul>
<b>Minutes</b>	<p>Minutes kindly taken by Jonathan Maiden and signed off by the Aim 1 Core Group Members namely: Margot Carson, Emma Savage and Piyusha Kapila</p>
<b>Date and time of next Meeting</b>	<p><b>Time:</b> 10:00 - 11:30 <b>Date:</b> 29th November 2021 <b>Venue:</b> Virtually - via MSTEams</p>