

# Minutes of DUAG Meeting 17 September 2010, Birmingham

## Attendance

### Apologies:

Rachel Hebditch          George Bridgeman

### Members in attendance:

Annette Bell	Tony Doherty	Peter Edwards	Brian Trench
Peter Rogers	Mark Endacott	David Fairbairn	Emma Ward
Peter Fairbairn	Ian MacLellan	Robert McKnight	Oratio Nelson

### In attendance:

Gillian Thompson	Clare Swift	Peter James	Richard Lane
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## Welcome and Introduction

BT introduced Richard Lane, a special guest at our meeting in his role as the President of Diabetes UK. RL thanked BT and told the meeting he was passionate about DAFNE and that he would do all he could to support it. BT also introduced David Fairbairn and Oratio Nelson, two new members of DUAG; and Peter James, who would facilitate the meeting.

## Minutes of the Last Meeting

The minutes of 7 May were agreed to be an accurate reflection of the meeting.

## Matters Arising

BT had not written to those members of DUG who had only registered their postal address.

BT and PR had invited Professor Simon Heller to attend a DUAG meeting but he was unable to join us on this occasion. It was agreed that he should be invited again.

**Action: PR and BT.**

BT congratulated PR on the successful delivery of the DUAG presentation at the Collaborative Meeting in June. The meeting also noted the excellent work of PR's co-presenter, Simon Fisher, who had spoken about dafneonline.

GB had not yet produced the DUAG photo. CS will ask him for it. **Action: CS**

TD and GT had not written a letter with AB to her PCT. AB had asked whether we should still proceed, bearing in mind the government's proposed changes to the health service and the uncertain futures of PCTs. TD feels we should – we can't simply put things on hold for this reason. **Action to continue.**

A questionnaire regarding DUAG had been distributed; these had been scanned by Central DAFNE and emailed to PR the week following the Collaborative Meeting. PR informed the meeting that he had not received them. GT to arrange to have the scanned questionnaires sent to PR, who will collate the responses. **Action Central DAFNE and PR**

There was uncertainty about whether or not ON had received the dictionary of DAFNE terms. CS will send a copy to him. RL also requested a copy. **Action: CS.**

ME asked if the additions to the CP guide which had been requested by dafneonline had been implemented. GT responded that some had, but that the dietitians had been unable to include others.

All members of DUAG were to write and circulate a summary of any meetings they attend. BT had issued a summary of the Executive meeting but no others had been seen. PF did distribute one, but will reissue. **Action: All meeting reps.**

BT explained that he hoped we would be able to ratify the essence of what we're about as DUAG, DUG, dafneonline and the crossover between them during the course of the meeting.

### **DUAG Members' News**

PR spoke about his attendance at the DAFNE Collaborative in June. He found it very worthwhile and would recommend other members attending in the future; it was informative, well attended and well run. PR encountered many healthcare professionals who had been involved in DAFNE for years and were still enormously enthusiastic about it – PR found this uplifting.

PR had attended a DAFNE reunion/party at UCLH which was very enjoyable.

PR announced he was taking part in tests on continuous blood glucose monitoring run by the King's DAFNE team. The tests involve a sensor, which has worked reliably - Peter trusts what it is doing and is not cross-checking. PR has learned a great deal. He discovered he'd been badly controlled post-breakfast but that injecting 15-20 minutes prior to eating was beneficial.

PR will miss the sensor when he gives it back. He can see that, even if the cost for long-term use could be prohibitive, it would be a good tool - as a short-term solution - to give to people when they are having problems. RL pointed out that prices will come down.

RL added that he is using a similar type of electronic sensor which reads blood sugar levels and sends a message to his pump.

RMcK reported on attending the Irish Educator Group and Research Group meetings. He also attended a follow-up at his own hospital in Lagan Valley. Two Trusts had amalgamated and although there was a fear that DAFNE would lose out, the decision has been made to offer both DAFNE and an alternative, locally-developed course.

Peter Fairbairn had attended meetings for the Research Group, where he found there was a great deal of debate about the new DAFNE database. PF was also interviewed by Dr Jonathan Bootle, who is assessing the impact of user involvement in research.

PF is participating in a local trial at his DAFNE centre (Leicester). He keeps a very tight diary, involving close glucose monitoring. He has agreed to extend this trial for a further 20 weeks as is enjoying the programme and his HbA1c is 6.18. Like PR, PF has found it hugely beneficial to inject insulin before meals – he then tests and adjusts after eating. PF has nothing but praise for what they're doing at Leicester.

Peter Edwards is taking part in research project in Sheffield via teleconferencing. The project is in its infancy.

Emma Ward has recently become involved in a new local diabetes forum for Type 1 and Type 2 diabetes.

Tony Doherty spoke about a Diabetes Action Plan 3-year rolling study. This will ask Health Boards in Scotland how many courses they provide which meet the NICE criteria. They will then have a tool which will enable them to compare what different health boards are doing; they will use this to make funding queries to the government. A diabetes education coordinator will be appointed. TD would see this as a good campaign model.

TD and DF attended the DAFNE Educator Group meeting on 9 September. TD will write and circulate a summary of this. The new workbook is almost ready to go and will be disseminated through the Educator Network meetings in October/November. TD had brought the front section to show the group. GT said she would be interested to hear feedback. **Action TD**

TD added that a new curriculum had been devised and that the CP guide had been extended – DAFNE dietitians have been working hard to verify the additions.

Annette Bell volunteered to continue to try to attend the North West Network Meetings in spite of her move to Cornwall. GT pointed out that the next network meetings will roll out the new curriculum and will take the form of a training session. Therefore, it may not be appropriate for DUAG to attend the October/November network meetings.

Mark Endacott gave thanks to DAFNE educators for getting out the message about dafneonline. This week, membership exceeded 4,000 members. There are 250 healthcare professionals registered, although some centres are still not represented. ME has set up dafneonline for Australia and has received positive feedback. He intends to do the same for Kuwait.

ME reported that his local DAFNE service has encountered funding difficulties and the whole future of DAFNE within this PCT is being re-considered. They believe DAFNE is a brilliant course, the gold standard, but were concerned that the fees doubled this year. Mark spoke to a commissioner and knows that they are seriously contemplating switching to an alternative, local programme.

GT informed the meeting that the PCT's claim that the fees had doubled was inaccurate. GT offered to give ME some accurate information to feed back to the commissioner which would support DAFNE. **Action GT.**

Ian MacLellan has taken part in 5 day v 5 week study, which is now up and running. Ian continues to be the DUAG rep for Dr Debbie Cooke's research for Patient Benefit study.

BT remarked it was good to see such a variety of activities going on and passed over to Peter James.

### **Examination of the Relevance and Achievements of DUAG to date**

Peter James reminded the group that, 14 months ago at their inaugural meeting, DUAG had said they wished to be left to function for a while and then review the way they work before setting goals for the coming year.

DAFNE is the only evidence-based education programme for Type 1 Diabetes. There are over 17,000 DAFNE graduates, of whom 750 are registered with DUG. DAFNE performs a whole range of activities and covers a massive terrain. It comprises an Executive Group, several Research groups, an Educator Group, healthcare professionals, volunteers etc.

Looking at DUAG as a group, are our targets being met? Are we making the best use of people and are they being supported, rewarded and encouraged? Does the group have cohesion?

DUAG is the executive of DUG and we are here on behalf of them. There is an overlap with dafneonline and collaboration between DUAG and dafneonline on behalf of DAFNE. We need to be clear about how best we can work.

PJ asked the group to look back at last year, to think about how it's gone and what the main issues are. The group were handed a questionnaire (Appendix 1) to complete individually (new members were to offer their first impressions), before forming small discussion groups and then feeding back to PJ. We were to decide

which elements we were happy with and to identify how we would like to develop. We might wish to alter/shift the way we work.

The group were also handed a yellow sheet which detailed the aims and purposes of DUAG and its terms of reference (Appendix 2).

### **What has gone well?**

- DUAG remain enthusiastic and committed; everyone contributes within the DUAG meetings - it's a very cohesive group.
- Had managed to sustain user representation at most of the DAFNE meetings; their views are taken into consideration and there is genuine, positive involvement – a good relationship.
- Satisfaction with, and appreciation of, the welcome given to them by healthcare professionals.
- DUAG had written a press release
- Dafneonline

### **Core Purpose of DUAG**

PJ then asked the group to think about the yellow sheet, detailing the core purpose and main aims of DUAG and working groups (refer to Appendix 2).

The group agreed that the Core Purpose of DUAG remains relevant and that no changes were required.

### **Main Aims**

#### **1 Working with healthcare professionals:**

The group agreed they had achieved this aim; there have only been one or two meetings which representatives had been unable to attend, but this was mainly due to the reduction in the number of DUAG members and, as BT pointed out, geography.

PE raised the possibility of teleconferencing, which is used a lot in the REPOSE group. It was agreed to consider this as an option, but that in cases where the DUAG representative is the only teleconferencer, they may feel uncomfortable about the loss of interface.

PR was concerned we may not have enough people to provide two representatives plus one reserve for every group. GT told the group about an ongoing project studying the impact of users on research groups. For it to work, we obviously need user representation, although we could manage with only one rep at each meeting.

TD, PR, PF, IMcL, BT, PE, EW and DF confirmed they are happy to stay on their current groups. GT informed the group GB had confirmed he would take part in the Audit and Research Database Group. There was no need for additional representatives on Debbie Cooke's RfPB study or REPOSE TSG; however there are 5 vacancies to fill.

GT told the group about a psychosocial research group which has been running for 2 years but has only just decided they would like patient representation. We don't yet know where this group will meet or even how frequently. ON volunteered to sit on the group. EW is happy to act as reserve if the venue for the meetings is Sheffield and TD would do the same if it were Edinburgh. **Action: CS** to provide ON's, TD's, and EW's email addresses to Celia Emery so she can discuss what is involved.

PE teleconferences for his group (REPOSE TMG) and is happy to continue. However, he feels it would be sensible to have support. TD volunteered to help out as a teleconferencer. **Action CS to inform Celia Emery**

PF requested another volunteer on the Research Group. GT informed the group that the next Research Group and Database Group meetings were being held on the same day (13 October); if PF could arrive early and attend the Database meeting with George, we could ask George if he could stay longer and attend the Research meeting with PF. If this works out, GT will ask Simon Heller and Celia Emery if we can continue to hold Research and Database meetings on the same day; this would mean both groups have the potential of 2 user representatives. PF confirmed he could attend the earlier Database meeting. **Action: CS to contact GB and ask if he can attend Research meeting and confirm with GT and CE; GT to contact CE re scheduling of meetings in future.**

GT explained that attending Regional Network Meetings is not a meeting requirement of DUAG on behalf of DAFNE. TD said he believes it's vital to build up relationships with the networks. GT suggested each person could discuss this with their network lead. **Action: All**

#### **Other Aims:**

- 2 Awareness Campaign
- 3 Lobbying for health funding
- 4 Represent the views of DUG

The group acknowledged that these three areas represented a dauntingly huge amount of work and that these areas had largely not been achieved. What influence, with limited resources, do we have? If we take them all on then we will fail. The group agreed that we need to refine our aims in order to achieve something; we must focus on the achievable.

IMcL pointed out that funding is going to be a huge issue in whatever we do.

RL remarked that the main problem is getting through to the people who control the money. These people seem to look at the short term, not the long term, as regards making savings; would they invest in DAFNE now to save millions in the future? RL informed us that Diabetes UK are looking at ways of providing accurate costings to encourage targeted investment.

PJ pointed out that DUAG feel the personal benefit of DAFNE, plus they appreciate its cost-effectiveness. It is hard for us to ignore the needs of those without access to DAFNE.

GT brought attention to point 4 - we've failed to engage with the DUG, who we are supposed to represent. It was noted that by communicating effectively with DUG, we not only fulfil our remit but can harness the input of hundreds of others.

PJ summarised that, in terms of purpose, the group is happy, but the aims need re-jigging. We don't want members to be overwhelmed by the demands of lobbying and awareness.

We should now think about our way of working and set new objectives.

### **Revisions and Roles for next 12 months**

PF told the group we have wonderful, laudable goals but we only have the resources to achieve but a fraction of them. This is one of the reasons why we have few concrete achievements. We either have to be ruthless in terms of our objectives or we have to increase our capacity by working more effectively and having more people involved.

PF thinks we should have a bigger forum and increase the membership of DUAG. He suggested we meet once a year over a two day period. Then, 6 months following a meeting, the individual working teams would get together and could convene regularly.

IMcL disagreed entirely as if you meet only once a year, you lose cohesion and drift. Expanding the numbers would also reduce cohesion. IMcL recognises that PR has been extremely busy but feels that the majority of DUAG haven't got enough work to do.

GT said she took on board the points of both PF and IMcL. She approved in theory of the idea of a 2-day meeting. GT pointed out that DUAG meetings are expensive and increasing member numbers would therefore be costly (whilst this is not the deciding factor, cost must be considered). GT suggested that meetings are not the only issue, we should be making more of the time between meetings to progress issues electronically - this is not always happening. PF talked about the drive between meetings; the need for someone to ensure targets are met and work is being done. GT agreed that we need structure and deadlines. ME pointed out that instead of sending lots of emails, which some people are averse to, he could set up a private forum for DUAG within dafneonline. **Action ME**

GT proposed that at future meetings, mornings could take the form of a business meeting and then the sub-groups could come together in the afternoon. PF noted that in which case, nobody could be a member of more than one group (all agreed that this might actually be a good thing).

GT suggested that we might not need the sub-groups. Instead, we could all focus on the same few objectives.

PJ suggested DUAG should consider their aims and ambitions. He invited the group to identify 2 or 3 bite-sized tasks and put them in order of priority. We would then need highly-motivated people behind these ideas to make them work.

RL asked if DUAG had any involvement with Balance. PR explained we had the impression that Diabetes UK were unwilling to get involved in DAFNE above other education programmes. RL offered to help in any way he could and the group were very grateful for this offer. RL would need a briefing and this would be dependent on which ideas DUAG came up with. RL also added that he has links with the Juvenile Diabetes Research Foundation (JDRF), which is the world's leading charitable funding body for Type 1 Diabetes research. **Action: TD and GT to provide a briefing for RL**

PF asked for likely scenarios from GT regarding budget cuts within the NHS. GT said although there was a relative increase in NHS funding this year, there would be no increase in funding in the next financial year or the foreseeable future. In addition, the NHS has to find £20 billion savings over the next 5 years and is having to look at efficiencies across the board. GT fears that funding difficulties will mean that many centres will find it difficult to sustain DAFNE.

PJ pointed out we need to work within the realities of the healthcare system. He recognises we are a small group, but what we can put across is the value of DAFNE – the improvement it makes to quality of life as well as to HbA1c. PJ remarked that there are plenty of people in DUG who also appreciate the value of DAFNE. He suggested that our strategy could be to define our message, to find ways of engaging DUG and then involving them - this could be our focus for next year. PR added we should also make cases for PCTs and then MPs. Type 1 care controlled at local level won't work – we need to find a way of influencing decisions. PJ suggested there could be a template letter to MPs which might be given to DUG and dafneonline.

GT suggested there should be a letter to DUG explaining who DUAG are, and inviting them to contact the member nearest to them (geographically). It is admirable to contact DUG, but we need to have a reason to do so.

ME feels that building relationships is the key. In this way, for example, we could find out which areas are having funding issues. (GT added that Central DAFNE is currently trying to get funding information from all centres - including the size of their Type 1 population and waiting list - via a questionnaire).

RL spoke about contact with MPs. If he can get Diabetes UK on board, they work closely with members of the House of Lords and MPs. He could even arrange for DUAG/DAFNE to be present at one of their regular meetings. GT suggested Professor Stephanie Amiel, together with a DUAG member, would make good representatives. GT will raise this at the next DAFNE Executive meeting. RL pointed out he would need to get the go-ahead from Diabetes UK. **Action: GT**

PR wondered if we should attempt to contact all 17,000 DAFNE graduates? A fundamental problem is that we don't know who they are and have no direct access to them. GT feared it could take years to contact all graduates. However, a parallel piece of work is how we get educators to work together with us to get at those graduates; the new DAFNE workbook requires educators to speak to new graduates about DUG and dafneonline.

It was agreed that our target is to engage DUG with a wider campaign – and that we could cast our net wider by delivering the same message to dafneonline. GT asked if DUAG were happy for their contact details to go out to DUG and received no objections.

PR asked whether we should first introduce ourselves and notify DUG that we'll contact them again within the following 4 months (We could put out a questionnaire asking them if they would like to be involved at a local level, what issues would they like to raise, etc).

GT agreed we can take this on board but stressed that we need to have a workstream in place (for example, encourage DUG to write to their MP). She agreed the way we communicate should be a 2-way street and would very much welcome feedback.

ME proposed we put out a newsletter and then we'll be in a position to divide up targets based on the response we receive.

GT suggested that one group create a letter. Responses would come to central office and they would provide feedback to DUAG.

DF suggested that DUG could be advertised at DAFNE refresher groups. He has been a graduate for nearly a decade yet has only just found out about DUG and dafneonline.

## **Summary of Aims**

PJ summed up that, within the next year:

DUAG wish to achieve an effective working relationship with DUG and have in place a set of outcomes they would like to achieve with them.

As a parallel task, some DAFNE graduates aren't aware of DUG, so we should look to ensure we have done all we can with healthcare professionals (and perhaps Balance) to signpost them to DUG and dafneonline.

PJ asked the group to consider the following three workstreams:

1. The preparation of initial communication (with a dual purpose of giving information and asking for feedback to engage DUG in a shared aim).

It was suggested that, within the body of the letter to DUG, we should explain who DUAG are and what we've been doing. We could tell them what we hope to do in the next year to improve communication with them. Should we attach a newsletter? Should feedback be via an open question, such as 'do you have any problems/concerns?' Should we ask for help?

TD pointed out that DAFNE is not just about the first course. It's about what happens after that – therefore we could ask the group what has happened to them since they completed DAFNE.

AB will lead on 1 with the support of EW. **Action AB to construct draft letter and circulate via DUAG forum before 1 October, for all to comment and feedback. Aim to get this letter out November 2010, which would allow for feedback to be collated by the time of our next meeting in January.**

- 2 How to relate to and engage with the national/DUG/dafneonline community. ME agreed to lead on this.
- 3 The message/roles and tools to develop to share with the DUG community. PR volunteered to take on this workstream

It was agreed there was a need to have someone co-ordinate all 3 areas, encouraging people and ensuring they were achieving their aims. TD volunteered for this role. **Action: TD**

As no further volunteers were forthcoming, PJ suggested that leads define the brief and provide further detail as to the aims and timescales of the various work areas. This should be achieved within the next 3 weeks (by 1 October) and should be posted on the DUAG forum; in this way, people can get an idea of what they would be taking on and might be more willing to put themselves forward. **Action: PR and ME to define briefs. All to log on to DUAG forum in the next 3 weeks to review briefs and consider volunteering to support leads.**

PR asked for targets for when we next meet in January 2011. GT raised her concern that not much would happen between now and the next meeting. TD reassured her that ME's online forum will help us to communicate and to meet deadlines. We should know by January what we're asking people; furthermore, issues raised by DUG might also produce work.

## **Discussion of the Roll over of Existing Members after 2 years with DUAG**

BT proposed that, due to pressures of time, we would wait until a later date to discuss the handover.

### **Any other Business**

ME asked about videos from the Collaborative. GT has not yet watched them all but will try and make the DUAG presentation available if the quality of the recording is good enough.

ME offered to put ON and DF onto the DUAG mailing list and will let them know how to get onto dafneonline. **Action: ME**

ME asked for his thanks to be passed on to Professor Simon Heller for his regular contributions to dafneonline.

ON asked about training. Although there is no formal training in place for new members at present, it was agreed that new members should have mentors within DUAG. TD volunteered to mentor ON and DF **Action: TD**

RMcK asked if could claim expenses for attendance at network meetings. GT said that since attending these meetings were not a requirement from DAFNE, expenses would not usually be covered. TD stated that patient volunteers should not be out of pocket; GT agreed and suggested funding could come out of the money set aside for DUAG if the group agreed, but GT thought that the mileage rate would be the same as the NHS rate (the usual DUAG rate is slightly higher). She will confirm. **Action:**

**GT**

RL announced that Douglas Smallwood was standing down as Chief Executive of Diabetes UK and his replacement will be Baroness Barbara Young. She is very influential and could be good for DAFNE.

### **Date of Next Meeting**

Date of next meeting is to be confirmed. Venue will be Birmingham. Central DAFNE will confirm details to DUAG asap. **Action: Central DAFNE**