Minutes of DUAG Meeting
7 May 2010, Birmingham

Attendance

Apologies:

Rachel Hebditch Robert McKnight

Members in attendance:

Annette Bell	Tony Doherty	Peter Edwards	Brian Trench
Peter Rogers	Mark Endacott	George Bridgeman	Emma Ward
Peter Fairbarn	Ian MacLellan		

In attendance:

Gillian Thompson Clare Swift

1 Welcome and Introduction

Brian formally introduced GB, a new volunteer co-opted onto DUAG to replace the losses we have experienced. BT explained that we meet 3 times a year as the DAFNE User Action Group and then are also involved as patient representatives on national groups, plus workstreams.
BT explained that RH has been persuaded not to resign, although she may not be able to attend meetings for a while due to pressures of work. He confirmed the resignations of John Marshall and Lesley Wilkin, both for health and/or family reasons.

2 Minutes of the Last Meeting

2.1 The minutes of l5 January were agreed to be an accurate reflection of the meeting.

3 Actions arising:

3.1 Wendy Baird had prepared a summary of the role of a DUAG member, but not for the role of a DUAG representative sitting on other national groups. We agreed that putting this in writing would be unnecessarily bureaucratic and no longer relevant. Instead, it was agreed that experienced members would take the time to explain the format to new volunteers.

GT asked if DUAG members felt integrated when attending meetings? AB mentioned that she sometimes found the database meeting difficult as a patient representative because it seemed very technical. Should the chair make more effort to explain? It was recognised that there are pressures on the time of the chair. TD suggested that one delegate at each meeting should take on role of explaining/mentoring. GT encouraged DUAG to ask questions at meetings and not to feel they were interrupting proceedings.

BT made the point that healthcare professionals seem welcoming and delighted to see patient representatives at meetings.

3.2 The lay summary of the Health Economics Paper (which puts in simple terms how DAFNE is cost-effective) has been distributed to DUAG and is on our website: http://www.dafne.uk.com/downloads/shearer_lay_summary.pdf

3.3 ME, for the Involvement Group, had produced a template for DUAG members to work from when attending promotional/patient recruitment evenings for DAFNE.

3.4 At the last meeting, DUAG had requested that minutes of the DAFNE Executive Meeting be distributed to all members and perhaps also to DUG and dafneonline. GT explained that they were not for general distribution because - for example - unpublished data is often discussed at these meetings and it could jeopardise the related research programmes if said data were circulated before time. GT believed that the agreed procedure was for those on the relevant sub-group to produce an executive summary of every meeting. ME explained that this simply isn't happening. TD added that the requirement to write a lay summary is creating extra work – unnecessarily? PF countered that a brief précis could be far more helpful, bearing in mind that minutes can run to 14 pages.

TD suggested that the minutes could be stored online so that whoever wanted to, could access them. ME reasoned that he respected GT's point regarding the necessity for data to be kept confidential until formally published.

It was agreed that an effort would be made to produce executive summaries in future. PF asked if the summary should be constructed after the minutes had been approved or after attendance at a meeting? GT suggested that because some minutes take a lengthy time to be produced, a summary after attendance would be preferable. This was agreed, with the stipulation that a summary of a few lines would suffice.

Action: All

3.5 Following the last meeting, names and contact details for Network Leads were distributed to DUAG; because of data protection, we were unable to issue the names of all lead educators.

ME had approached network leads to ask for permission to access contact details for leads, but had received no response. EW reported that the educators at her local network meeting (3&4) had refused permission to distribute addresses, which surprised GT; however, she suggested that this reluctance would be due to a large workload and the pressure of emails, rather than a lack of support for DUAG. IMc said the same question was raised at his meeting (5) and the educators there were amenable to providing their contact details. GT suggested that the

Collaborative Meeting would present an ideal opportunity to raise this issue and seek consent.

Action: DUAG reps to raise issue at Collaborative.

Action: GT to raise issue at next Educator Group meeting.

3.6 ME had contacted RH who had given her permission for the press release to be posted on dafneonline. This was duly actioned.

3.7 At the last meeting, PR volunteered to produce some bullet points of topics to raise at the next round of network meetings. This had not been actioned. GT pointed out that agenda items for networks are set at Educator Meetings, so if DUAG wished to have input, they should forward suggestions before the next meeting of this group on 21 May.

Action: All

3.8 CS had re-issued list of which DUAG reps are on each network.

3.9 Contact was made with two prospective volunteers to join DUAG. One had been unable to make the time commitment, but GB had accepted the invitation and was now on board.

3.10 AB had written a letter to her PCT about her move to a new area without a DAFNE centre, to ask what provision was made for patients with Type 1 Diabetes. (Covered in 4.3)

3.11 TD has made a start on collecting the names of key stakeholders. Work continues.

Action: TD

3.12 CS had not written to the members of DUG who had registered their postal address, inviting them to provide an email address in order to facilitate ease of contact. This was because the newsletter to accompany this had not been produced (AB had liaised with RH, but not produced a version). It was agreed that BT would now produce and distribute this letter. He would include a description of DUAG, which could perhaps make use the Collaborative presentation as a base/springboard.

Action: BT to write letter. CS to circulate on his behalf

3.13 CS had distributed an updated list of the dates of DAFNE meetings and is able to do so again following this meeting.

Action: CS

3.14 Activity Masterclass. GT explained that this will take place on 22 October in Manchester. It had been mentioned that DAFNE graduates should be represented (who are actively involved in sport, though not necessarily part of DUAG). An agenda has not yet been produced, but will be discussed at the Educator Meeting. **Action continues**

3.15 DUAG had queried whether the ‘Dictionary of DAFNE terms’ should appear in the handbook or on dafneonline. GT questioned its relevance to

a larger group, as it was designed to describe specific terms and acronyms to DUAG.

Action: CS to issue dictionary to GB and any other new members as they come along, but it was agreed that it would not be reproduced elsewhere.

3.16 The group discussed possible funding issues for DAFNE Centres following on from the last meeting.

BT has been in touch with one lead educator. He has offered to draft a letter (based on AB's) in support of her centre. The educator had thanked BT for his support, but would not progress the issue at the moment.

GT asked how DUAG felt – a service appears to be in danger and yet healthcare professionals seem unwilling to involve patients. TD said that he has found clinicians can be protectionist and he feels patients should become more involved.

GT pointed out that the two centres which withdrew from DAFNE in 2009 had only informed Central DAFNE when it was a 'done deal'. Patients had not been informed prior to the decision being made by either centre. Why be wary of involving the user in general? Should we talk to healthcare professionals about this and coach them about how to make use of the patient?

4 Action Group Members' News, including a review of current membership status.

4.1 TD pointed out he no longer has a role with DUK and therefore less access, certainly to the campaigners. His own ill health has also impeded progress.

GT mentioned that Richard Lane, the President of Diabetes UK had responded positively to our invitation to attend a DUAG meeting. He hoped to be able to attend in September. This may be an opportunity to restore links with Diabetes UK.

Action: CS to notify RL of date

4.2 IMc had been unable to attend the most recent 5x1 day meeting due to flight disruptions.

4.3 AB had circulated the response to her letter to her PCT (see item 3.10). This was discussed by the group. It was agreed that the data the PCT had provided, indicating their outcomes were better than DAFNE, was misleading. It was more than likely to be QoF data (Quality outcome Framework, which GPs generate and is linked to their funding). In which case, the data includes both types 1&2 diabetes and is therefore misleading. We should also bear in mind that outcomes in affluent areas are generally (at a baseline) favourable compared to inner-city, less affluent areas. DAFNE data is rigorously audited.

Where is the evidence for cost-effectiveness? TD says we're entitled to challenge this. AB said she would like to respond to the letter, but was not sure how to go about it. TD and GT offered support in the drafting of a response.

IMc mentioned that funding is key. We seem to have a postcode lottery and there should be a standardised, evidence-based treatment for Type 1 Diabetes care.

GT explained there is a toolkit to meet the requirements of a structured education programme. Why, in these financially challenging times for the NHS, would a PCT be using public money to fund a service that did not meet the required national standards and was not providing value for money in terms of cost versus effectiveness? As mentioned at the previous meeting, DAFNE has been recognised by QIPP as a programme which is capable of releasing funds due to its effectiveness and is the only programme for Type 1 Diabetes recognised by QIPP on the NHS evidence database.

TD also suggested using PALS (Patience Advice and Liaison Service). ME agreed that he always recommends that complaints are put to PALs as they can liaise with a PCT to get answers. TD added that complaints are categorised and logged and that it is important we use PALS as our patient right.

Action GT and TD to provide assistance to AB. (TD pointed out that this could be a template for future cases).

Action: GT to discuss letter at Executive Meeting.

4.4 DUAG Numbers. So far, 4 members have resigned, RH is on sabbatical, and GB has joined.

BT pointed out we need to identify vacancies on national groups. There are no holes within the Executive, but we currently have only EW on the Educator Group. Nobody now sits on the Audit and Research Database. Only PF sits on Research Group. IMc and EW sit on the '5 day vs 5 week' Group.

IMc sits on the psycho-social research programme, and BT is on the trial steering group for the REPOSE study, but there will also be a trial management group. GT will check if this group requires a user representative but she expects the answer to be yes. PE expressed an interest in becoming involved and asked for dates of meetings. GT explained that some would be in the form of conference calls (we appreciate that travelling from Devon to Sheffield for 2 hours will be difficult).

Action: GT to liaise with REPOSE study group and PE

TD volunteered to step in for the Educator Group. GB volunteered to take on the Audit and Research Database pending further information.

Action: Central DAFNE to provide information to GB

In order to make up numbers for DUAG, it was agreed that we should approach the remaining six people who participated in the first vote, plus a DUG member from Birmingham who had noted his willingness to become more involved with DAFNE on his application form.

Action: BT to write letters of invitation and CS to circulate

GT raised the issue of training new members. It was agreed this should be 'on the job', as long as new members were happy with this. (IMc pointed out that he had missed the initial training sessions but that he has picked it up quickly; in addition, other groups have been welcoming so attendance at meetings had never been a daunting prospect).

Action: CS to send terms of reference, past minutes and dictionary of terms to GB and any new members as they come along, and re-issue list of members on other groups.

PR mentioned that that UCH is holding an upcoming gathering of patients and that more graduates might come forward at this and similar events. GT also suggested we should ask educators at the Collaborative to put us in touch with willing patient volunteers.

5 Review of Group Activity since the last meeting against Agreed Targets

5.1 BT mentioned he believes that not much has been done in last 4 months. The exception is Mark's template for a progress report. He recognises that we bit off more than we could chew last time – each group had a whole list of bullet points to tend to.

5.2 ME had published RH's press release on dafneonline. He asked for guidance from GT about what to make public. GT confirmed that DUAG minutes can definitely be published on dafneonline, but that minutes from other groups should not appear.

5.3 ME distributed his leaflet explaining DUAG. BT suggested DUG should also be mentioned on the front. GT asked who the target audience was. ME explained it was 'DUAG explained by DUAG' rather than defined by DAFNE. GT mentioned costs. DUAG have around £7k left in their budget and it is up to the group to decide how to spend it. Is this the best use of funds? If Collaborative is the audience, then should we tell them what we need from them/provide a targeted message?

TD explained that DUAG are trying to raise awareness and ask front-line workers to help them, so he believed the leaflets would be a useful tool. GT suggested we should also give out DAFNE User Group leaflets plus application form. She explained that these leaflets are provided free of charge to centres and are given to graduates at end of course or follow-up. We also advertise DUG with posters.

TD wondered if there was perhaps too much information in the flyer for a patient in clinic; however, PF felt that repeating information can work well and helps reinforce a message. BT believes the leaflet supports PR's presentation at the Collaborative. GT asked the group to re-define the message they give to Collaborative and make most of the opportunity.

5.3a PE raised the issue of branding. Should DUAG totally align with DAFNE or highlight their separate voice? PE voted to be separate. TD recommended that the DAFNE logo should become smaller. (PR added that he has removed DAFNE logo from the presentation in light of recent email discussions).

5.3b It was agreed that the DAFNE logo should stay on ME's leaflet but only on the first page. **Action: ME**

5.4 IMc provided a brief feedback from his local educator meeting (Network 5). Next meetings are 10 November and 15 April, both at King's. IMc agreed to write summary of network meeting in future.

6 Collaborative Meeting, 10 June 2010 in Manchester

6.1 DUAG is to present a plenary on the first year of the DAFNE User Group at the above meeting. PR explained that he, EW, PE and BT had worked on the powerpoint presentation. Simon Fisher's dafneonline presentation would be included.

6.2 PR ran through the presentation, which lasted just over 17 minutes. This excluded Simon's contribution and therefore significantly overran. The overall time for the presentation must be 20 minutes maximum.

6.3 GT explained that the format for the collaborative is to allow the audience a 5-minute table discussion following a presentation and then to harvest the questions which arise from this. GT asked PR if he was happy to take questions, which he confirmed. GT suggested he could also direct questions to the coffee area, where a table will be manned by other DUAG members, for further discussion.

GT asked that PR give his presentation to Sharon Walker at least the evening before the meeting. **Action: PR**

6.4 TD suggests that we need to challenge the healthcare professionals more, and mention regional differences. Ask them how we can engage patients and show them there's a different way to treat diabetes. Encourage HCPs to look at long-term conditions and look ahead at the way they treat patients.

PR asked for ideas of how to include pictures in the presentation (GB offered his camera and a photo was taken of the group at the end of the meeting). **Action: GB to give photo to PR**

6.5 All agreed to the content of the presentation, with the proviso that PR should find a way of shortening delivery time to ensure that the overall timing, including dafneonline, does not exceed 20 minutes.

Action: PR

6.6 It was agreed that the DUAG table should include leaflets and some form of banner/poster. Two tables side by side, one for dafneonline and the other for DUG/DUAG.

GT offered to print posters if DUAG mocked one up. Would the existing DUG poster be sufficient? It was agreed to make use of an LCD projector and the existing DUG poster. (In the future, we will aim to produce a pop-up, when we have had time to give content due consideration).

Action: SW to ensure provision of projector and poster.

6.6a Both DUG and DUAG leaflets should be available.

Action: Central DAFNE to provide 100 leaflets.

6.7 TD suggested asking for contact details at Collaborative (from all those who approach us).

6.8 EW, PF, BT and obviously, PR, confirmed that they will attend the Collaborative. In his absence, CS reminded the group that RMcK had been very keen to attend. GB remains undecided but will notify Central DAFNE soon. All other members present that day would be unable to attend. PR's attendance would be funded by Central DAFNE, whereas remaining delegates would book their own travel and, if necessary, accommodation. They can reclaim this from the DUAG budget via Central DAFNE on the provision of receipts and a completed expenses form.

6.9 GT explained that a company will video all presentations so that non-attendees can have access to them. The company will also be interviewing some delegates.

7 Proposals for Group Goals within the next 4 months

7.1 GT expressed fear that members were taking on too much work in their volunteer capacity and she was worried that more people might resign as a result of this overload.

PF pointed out that a lot has been achieved and there is no shame in having taken so long. Should we reapportion goals rather than attempt to achieve them? September should act as a strategic planning opportunity for next year, especially as we hope to have more members on board by then.

7.2a GT informed the group that there are matters arising from the Executive Minutes into which members would like input from DUAG. For example, there was a desire to link with DUAG to progress public relations work. GT had intended to work with RH to identify key roles and raise the profile of DAFNE – this is now not appropriate given her sabbatical. TD volunteered to step in.

Action: GT to liaise with TD

7.2b Another area for discussion is: what do graduates want from follow-up? Poor attendance suggests their needs are not being met. Centres have varying formats for follow-up.

7.3 PR suggested putting Awareness Group on hold till September, especially as Mark had already achieved their goal of producing a pamphlet. (Representatives on this group had been AB, RH, TD and ME and LH).

8 Update from Central DAFNE:

8.1 GT explained that the DAFNE Carbohydrate Portion Booklet is being updated. One of the educators developing the CP Guide had suggested that colour inserts be added to it for ease of reference. GT asked the group if they found the CP Guide hard to read, but their answer was no. GT was relieved to find this, as she pointed out that one aim of the DAFNE re-branding had been to save money by limiting colour print, and the proposed inserts would have added to the production costs.

ME requested updated copy of the CP Guide as soon as possible, as he would then upload it for dafneonline.

Action: Central DAFNE to provide copy to ME once new CP Guides have been finalised.

8.2 GT reported that only 4 new members signed up to DUG in April. She pointed out that to generate interest we need to communicate with the group. DUAG need to give graduates a reason to sign up. We are not generating new members and we are not communicating with those we have.

It was suggested that at the Collaborative, we ‘name and shame’ those centres which are not generating DUG and dafneoline members, (such as the traffic light system for audit).

Action: Central DAFNE and ME to provide figures to PR before Collaborative Meeting

GT pointed out that DUG and dafneonline will form part of the new curriculum and that centres will be monitored and audited on their participation.

8.3 ME reported he is regularly generating new dafneonline members so he knows that the message is getting out there.

IMc pointed out that he personally didn’t get a code for dafneonline when given the leaflet about it. If you don’t receive this code when you graduate or at follow-up, then the likelihood is you will go away and forget about it. GT can tell that many centres are running courses and yet not generating codes.

GT pointed out that at the last Collaborative Meeting, as well as at some network meetings, lead educators were signed up to dafneonline and

shown how to generate codes (which is a simple process, taking 3 minutes to achieve).

8.4 GT described a new research programme, led by Professor Wendy Baird, which will evaluate the impact that users have on research. Dr Bootle will sit in on research meetings and observe interactions, then interview the user representatives plus some healthcare professionals. Results would be fed back to national user involvement conference. Nobody would be identified but participants would have to consent. They would sign up to be interviewed over a 3 year period – these interviews could be performed over the telephone. The point was raised that DUAG members have 2 years term of office remaining, so what would happen in the third year of this research? Would the group consider staying with research groups for this purpose?

GT will ask the NIHR Project Office to send a copy of the Patient Information Sheet and consent form to IMc, PF and EW for comment back to the NIHR Project Office.

Action: GT, IMc, PF and EW

8.5a GT requested clarity about how dafneonline, DUAG and DAFNE sit together. DUAG are part of the national programme as they are funded by DAFNE (but we need to look at DUAG's use of the DAFNE logo – it could sometimes be used on publications which the national programme hasn't approved).

ME pointed out that dafneonline are not bound by NHS rules, whereas Central DAFNE are and, to a lesser degree, so are DUAG because they are a sub-group of the national programme.

Everyone was happy to maintain links but boundaries should be clarified as confusion does arise. For example, some people look for the diary on dafne.uk.com, whereas it only appears on dafneonline. Likewise, ME sometimes gets enquiries about patients missing their follow-up appointment.

Some independence can be very useful and allows for freedom of expression, unfettered by protocol. PF suggested there's a partnership between DUAG and DAFNE, whereas an association between DUAG and dafneonline, which is not so clearly defined. (DAFNE pay the hosting costs for dafneonline).

8.5b dafneonline is a vehicle for communication for DUAG – but is this appropriate, bearing in mind that dafneonline are an independent body and furthermore, a third of DUG haven't provided an email address? It was agreed that this is a convenience and cost issue (Refer to 3.12).

BT pointed out that the association between these groups will be made by the fact that both DUAG and dafneonline are linked in the Collaborative presentation.

DUAG and DUG are people living with diabetes. Central DAFNE administer a course for patient education for people with Type 1 Diabetes. dafneonline is ‘an online community of DAFNE Graduates, Health Care Professionals, Management and friends and family of those with Type 1 diabetes’. It was agreed that they do all come together.

8.5c GT asked what would happen to the links with dafneonline and DUAG when ME stood down at the end of his term of office? This would further complicate the status of the relationship between dafneonline, DUAG and DAFNE.

8.5d TD mentioned www.realitycheck.org.au, an online network run in Australia. The Australian Diabetes Association provides expert updates and forum masters manage the website. TD suggested it would be worthwhile approaching the Australian team and asking how this is run.

Action: All of the above issues (8.5a-d should be ratified at the September meeting)

9 Any Other Business

9.1 Formal thanks were offered to the group who wrote the Collaborative presentation.

9.2 PR mentioned that Professor Simon Heller had expressed an interest in attending a DUAG meeting.

Action: PR and BT to invite informally when they see Simon at the next Executive Meeting.

9.10 It was agreed that Sky news presenter, Steve Dixon, should be invited (care of his lead educator) to join DUAG. He was featured on the cover of the March/April 2010 issue of Balance and was interviewed about the support he receives from his (DAFNE) Diabetes Specialist Nurse.

Action: BT to write letter and Central DAFNE to forward.

10 Date and location of next meeting

The group agreed to meet in Birmingham on Friday 17 September.

Action: CS to book Radisson hotel, if available