Minutes of DUAG Meeting
15 January 2010, Birmingham

Attendance

Apologies:

John Marshall, Peter Fairbarn, Lesley Wilkin, Rachel Hebditch, Gillian Thompson

Members in attendance:

Annette Bell, Tony Doherty, Peter Edwards, Brian Trench, Peter Rogers, Mark Endacott, Robert McKnight, Ian MacLellan, Emma Ward

In attendance:

Clare Swift

1 Welcome and Introduction

BT welcomed everyone and thanked them for travelling to the meeting under adverse weather conditions.

2 Minutes of the Last Meeting

2.1 These were accepted as a true record of the meeting with one omission; BT's attendance was not noted. **Action: CS to amend**.

2.2 It was noted that LW had hand-delivered a book voucher to Tony Ball, which was to thank him for his contribution to DUAG following his resignation due to ill health. BT read out the thank you letter he had received from TB on 7 November. Tony had purchased 'The Oxford Companion to Music' with the voucher and he informed us that he had recently had a letter published in Balance.

2.3 BT informed the group that he had also written to Liz Yates (who resigned from DUAG due to family reasons) to thank her for her contribution.

2.4 Wendy Baird should have produced and circulated a job description for DUAG members which was to focus on their role when attending other DAFNE meetings/ 'liaison meetings'. This had not been received. **Action: Central DAFNE to approach WB**

2.5 WB was to produce a lay summary of the Health Economics paper (item 7.4 from last minutes) but this is still outstanding. **Action: Central DAFNE to approach WB**

2.6 At the last meeting, it was agreed that when members attend a 'Liaison' meeting, they would write a brief summary for distribution to other DUAG members (and perhaps also to DUG and dafneonline). This has not happened to date. BT clarified that all that is required is a simple summary of any issues which have a direct relevance to DUAG.

3 News from Members of Action Groups

3.1 RMcK reported that he had met with Dr Sean Dinneen (a DAFNE doctor from Galway) at Diabetes UK Northern Ireland in November. Dr Dinneen had invited RMcK to attend meetings of the Irish DAFNE Study Group. Although RMcK was unable to attend the most recent meeting in Galway because snow made travelling impossible, he hopes to attend meetings in future and will keep us posted.

3.2 ME told the meeting he has attended 2 promotional evenings for DAFNE in South East Kent, where he spoke about DUG and dafneonline. Perhaps other members of DUAG could do same? IM revealed he had already attended a DAFNE recruitment evening at St Thomas' and EW had attended one in West Essex (she had also offered patient input during a one-day Diabetes conference). The meeting discussed which group should carry this forward and create a consistent template to work from? It was decided this should fall to the Involvement Group.
Action: Involvement Group to produce template

4 Review of Group Activity since last meeting

4a.1 Liaison Group

PR reported on the Executive Meeting which he attended with TD in September. He said the item which stood out was that Professor Simon Heller had been approached by Abbott to see how they could work together with DAFNE on a glucose monitor. Three doctors were to write a proposal by October and then send to DAFNE. ME mentioned this might tie in with data dafneonline is collecting.

4a.2 The group asked if all members of DUAG could receive the minutes of the Executive Meetings and whether, with the permission of GT, they should be distributed to dafneonline and DUG. **Action: Central DAFNE**

Awareness Group

4b.1 RH was unable to attend this meeting, but had provided a report.

4b.2 As far as we are aware, the press release was not picked up by anyone. It was agreed we should continue to send them and to look at how we can pitch them to magazines and to radio. It was suggested we send future press releases to healthcare professionals and PCTs. BT agreed; press releases should be used as part of the general DUAG toolkit via liaison with RH.

4b.3 RH's report covered the feasibility of advertising. All agreed this would be too expensive. TD mentioned that all health boards produce their own freesheets. Perhaps we should approach them?

Lobbying Group

4c.1 TD produced a report. He apologised to the group, saying that because of illness and the threat of redundancies at Diabetes UK where he works, he had been unable to speak to everyone he needed to and to achieve everything he set out to do.

4c.2 TD identified 2 main areas of focus for the lobbying group; To get the support needed to increase DAFNE Graduate User Group membership; and to develop an engagement strategy with service commissioners.

4c.3 As there are 4 different models for the PCTs (Northern Ireland and Ireland; England; Wales; Scotland) TD advised that we should work through the DAFNE networks. He will coordinate so we can identify the funders by asking the DAFNE centres themselves.

Action: Central DAFNE to provide names and contact details of all Regional Network Leads and a list of DAFNE centres (because of data protection, we are unable to provide a list of contact details for all lead educators).

4c.4 Regarding campaigning on local issues/delivery; we could ask patients on waiting lists and also DAFNE graduates to give testimonies and identify problems within PCTs. Again, this covers the issue of a co-ordinated response/core template for DUAG.

4c.5 BT summarised; we now understand the job, but we need to know how to move the programme forward. We realise there will be problems – there is a mountain to climb. BT said TD had a good basis for progress.

Involvement Group.

4d.1 ME produced a report and reiterated that dafneonline is separate from DUAG – they are keen to work together, but it is an independent entity.

4d.2 Dafneonline has 2,216 members; 1,175 of whom are DAFNE graduates (the remainder are made up of 181 healthcare professionals and the rest are non-graduates). ME needs more information from everyone (public information) to post on dafneonline. PR suggested adding the press release. **Action: ME to contact RH to get her agreement to this**.

4d.3 ME reported he had advertised the DAFNE User Group to dafneonline. Current DUG membership is 623.

4d.4 ME suggested that a leaflet about DUAG should be produced, as a means of publicising DUAG in our own way, our own voice. We need to clarify the benefit of joining DUG.

Educator Group.

4e.1 TD attended with JM. He reported that the educators had been very welcoming and had assured them they did want the input of those living with diabetes.

4e.2 It emerged that a difficulty with quality review and quality assurance in DAFNE is the shortage of auditors and peer reviewers available to monitor the many DAFNE centres. The meeting had also discussed developing 5-day and 5-week pump courses and had asked for DUAG's input into this and also into re-shaping the patient quiz. They also assured TD and JM that they were extremely keen for DUAG to participate in network meetings.

Research Steering Group

4f.1 LW was not in attendance at this DUAG meeting, but produced a report from the Research Steering Group Meeting, which BT read out.

Audit and Research Database Group Meeting

4g.1 AB attended this meeting. She reported that the DAFNE post-course questionnaire was discussed and that there are difficulties with the database, which Central DAFNE are looking to address.

5-day vs 5-week Research Group

4h.1 IM went to Sheffield in October to a Research Meeting (5 day v 5 week). He was able to give input from the point of view of a patient and felt he made a positive contribution. He found it was a very professional, joined-up, positive meeting.

4h.2 After the meeting, the research proposal and invitation letter were finalised and are to go to a central research committee, then to individual health authorities (of which there are 4) for approval.

Educator Networks

4i.1 Various DUAG members had attended the latest six network meetings throughout the country to promote the DUAG message, which all found to be well-received.

4i.2 PR asked whether an effort should be made to produce a consistent DUAG message. He volunteered to produce some bullet points of topics to raise at the next round of network meetings. **Action: PR**

Action: CS to re-issue list of which DUAG members represent which networks

5 Review of Work Group Membership and Forward Activity

5a BT pointed out that DUAG has now lost 2 members and is down to 13 in number. How do we continue with fewer representatives? BT had discussed this issue with Gillian Thompson. GT explained the first option was to approach DUG – but this would involve an election and would be a lengthy process. BT preferred to offer quick fixes. When DUAG's first minutes were sent out to DUG, we had interested responses from other DUG members keen to become involved. Could we approach them in between elections? RMcK pointed out that the DUAG terms of reference give us the authority to co-opt new members.

IM, PE and EW mentioned that they feel under-utilised at present, but BT assured them there would be more work to do in the coming months. The group therefore voted to fill this hole rather than carry on as 13.

Should we approach those who were next popular in the original vote? CS pointed out that DUG had been given the option to automatically select all the original volunteers, but that they had voted to be able to choose only 15 (ie: they had wanted the right to veto). Furthermore, the original vote did not include any members who have joined since May 2009.

It was decided that we should aim to include those DUG members who had put their head above the parapet. These include a volunteer whose name had been given to PR by Anita Beckwith, the lead educator at King's College Hospital.

Action: BT will approach the volunteers and invite them to reassert their interest. CS and PR to provide contact details.

5b Group Goals for delivery within the next 4 months:

5b.1 Executive group

PR and TD are happy to proceed as they have been.

5b.2 Awareness group

AB raised the issue of the best way to make use of press releases. It was agreed that their use in local areas is a more effective way to get to PCTs. Our goal is to make entry at local level in everyone's area to make them aware of DUG/DAFNE.

AB does not have a DAFNE centre locally. How should she go about approaching her PCT? What is the message we are going to put across? That everyone who wants DAFNE should have access to it. It has changed my life, my doctor says I should have it. Why is it not available in my locality?

We should concentrate on creating a database of personal stories/case histories because currently, there is no new research relevant to DAFNE/Type 1Diabetes which we can forward. PR pointed out that we need to tailor the stories and give local stories to the relevant local papers.

We could approach network leads and/or DUG for patient stories. BT suggested someone in the Awareness Group should lead on this and produce a letter. TD suggested AB write a letter about moving to a new area where there is no DAFNE follow-up. She could raise the question of how she should proceed and in this way, put the ball in the court of her PCT. **Action: Awareness Group**

We need to recognise that every area is different and that local knowledge is the key. DUAG needs to get a feel of what is going on at each centre. How can we find out? It was agreed that the group should email/speak to lead educators. We will need to co-ordinate and pinpoint who will lead in each region. **Action: ME will lead on this. Central DAFNE to provide email addresses of all lead educators.** [Note from Central DAFNE, added post-meeting: Because of data protection issues, we cannot provide these contact details. However, DUAG will be re-issued with contact details of network leads, and we hope that continued representation by DUAG at network meetings will give them a picture of regional activity]

5c Lobby Group.

5c.1 TD's aim is to get on top of engagement strategies. He will need to find out key stakeholders for each area (one for England, one Scotland, one Wales, one NI and the Republic). Dr Sue Roberts mentioned at the Executive Meeting that Commissioning Managers are the key and TD intends to discover these names via the networks. **Action: TD**

5c.2 TD may require a database from DAFNE, if possible – how should we hold this information? PR asked if we should tackle this region by region? TD said a perfect scenario would be Hull which could provide a template model; 2 PCTs side by side, one with DAFNE, one without.

It was agreed we can still gather the necessary contact details while building the template. This template should be ready by next meeting. **Action: TD**

BT raised the issue that the lead for each group should farm out work to other members. (However, TD unsure if there is anyone else in his group).
Action: CS to send table of members of each group to all DUAG.

5d Involvement Group

5d.1 Leaflet explaining DUG and DUAG is seen as the key aim. It could be placed in the new DAFNE handbook (which will incorporate the DAFNE User Group leaflet and information about dafneonline). A final version should be produced within the next 4 months – or at least an agreed outline.

5d.2 TD asked if each DUAG group should put a question to DUG. We need to communicate more with the larger group. **Action: CS to write to all the post contacts and ask them to provide email address, if possible, in order to facilitate ease of contact. Aim to send newsletter to them at the same time (see item 7b).**

5e DUAG would like an updated list of all DAFNE meetings. **Action: CS**

6 Collaborative Meeting: 11 June 2010 in Manchester.

6.1 PR gave a powerpoint presentation, explaining what is involved in the Collaborative Meeting and how many people attend (usually 150). DUAG have been invited to present in the first session of the day for 40 minutes. It was unanimously agreed that this invitation should be accepted. The suggested title is 'Plenary on first year of the DAFNE User Group, with discussion time'. ME informed us that dafneonline had also been invited to participate in this presentation.

6.2 BT pointed out that in addition to the presentation, we have also been offered a table for DUAG and one for dafneonline (This would be situated in the coffee area and would need to be manned throughout the day).

6.3 It was agreed that the presentation should take the form of an introduction, body, a summary of dafneonline, and then open up to questions. 30 minutes will be allotted for the presentation and 10 for discussion.

What do we want to achieve? TD sees it as a positive challenge to the healthcare professionals. What systems have you got in place in your place of work to promote DAFNE, DUG and dafneonline?

BT added we should point out we've been operating for 12 months. Explain how we were set up, what we see is our role and function, a description of the sub-groups. Describe what we've worked on and what we aim to achieve. Tell them what we want from them. Then lead into dafneonline as one of our key supporting activities.

We want more take up from graduates. We also want more people to do DAFNE.

DUAG should also pose questions to the audience and gain their feedback/support. Explain that we appreciate the limitations on their time and their lack of administrative support. TD suggests putting across that we don't want it to be like DAFNE in Germany – you do your course and then the patient seems to be forgotten. Follow-up is key. IM mentioned that although the initial week-long course is well-organised, follow-up seems lacking. There are usually 3 sessions in the initial year (although this varies centre by centre), then you drop off and get on with your life. Some centres run refresher courses. Should this be formalised? We would like a model of best practice for all DAFNE centres.

6.4 It was agreed that the presentation would be powerpoint. BT volunteered to give the introduction. PE, PR, EW and BT would write the body of the presentation. All 4 would produce their own first draft, then share and present to group for feedback. ME said he and Simon Fisher would give sight of their dafneonline presentation as soon as it is written.

PR suggested that a dry run of the presentation be given at next meeting. A set of deadlines was agreed:

Initial draft	15 February
Review and final first draft	28 February
Feedback from DUAG	30 March
Final version	30 April
Dry run	7 May

IM volunteered to co-present, as did PR. Reserves are PE and EW.

6.5 TD suggested we should invest in our presentation equipment. Pop ups might cost around £200 but would be an investment and could be re-used. Likewise, posters. **Action: TD will liaise with GT**

We need literature about DUG and dafneonline – will Central DAFNE be able to provide plenty of application forms? **Action: Central DAFNE**

ME's leaflet explaining the work of DUAG should be available on the day (therefore will need to be produced in time. Format to be agreed by GT).

All DUAG members present on the day expressed their desire to attend the Collaborative Meeting (apart from AB, who has another engagement on the day). We appreciate that places are not yet available for all.

7 Central DAFNE Topics

7a Diabetes UK 3-5 March in Liverpool

Would DUAG like to be represented? TD explained the exhibition is open to healthcare professionals, not members of the public, to attend. (The presence of Pharmaceutical companies precludes members of the public/patients) TD told the group he thought it would be worthwhile for a member of DUAG to be present and mentioned that Thursday would be the busiest and therefore best day. IM volunteered to attend for one day – he will be available on Wednesday 3 March.

7b DUAG to prepare a newsletter for DUG

This should explain DUAG's activity to date. Up to now, DUG have only ever been given minutes and voting information.

PR suggested that the newsletter should replicate in some way the collaborative presentation. It was agreed that AB should liaise with RH regarding the production of the newsletter and position it around the timings of this

presentation to the Collaborative. Ideally, it would be ready by mid-February. RH has the option of simply using material from the press release. (And also the option to turn down this task, which was assigned to her only informally in her absence). **Action: AB to liaise with RH**

7c Activity Masterclass.

Central DAFNE would like 7-8 DAFNE graduates to become involved (although not necessarily from DUAG). The Educator group will note this and will provide feedback from their next meeting on 27 January. **Action: Educator Group.**

7d Collaborative Meeting

Already covered.

7e Feedback from Glossary of Terms

All agreed that they found this 'dictionary' of DAFNE terms extremely useful. Would it appear in the DAFNE handbook? Should it appear on dafneonline? **Action: GT to decide.**

8 Any Other Business

8a North East constitution

National Health Service Constitution (the northeast version was received, as it had been forwarded from Central DAFNE which is based in North Tyneside. However, TD pointed out there will be others to cover the whole of England and Wales).

BT explained he has emailed the constitution to offer feedback (beyond the deadline of 15 February, but they confirmed they would accept this). However, the questionnaire is geared to an individual replying. Plus, an address required. Is it appropriate for someone outside the region to reply? BT volunteered to respond as a representative of the group, taking a broad brushstroke approach and explaining this to the constitution.

TD suggested that as this is a national process, another response would be to inform DUG of the existence of the questionnaire and encourage them to complete it.

Action: It was decided that BT would complete as a DUAG representative.

8b East Riding

Sharon Cassidy, lead educator for the Hull Diabetes Network, had written to ask for the support of DUG. There are 2 PCTs in the Hull and East Riding Diabetes Network, one of which does have a service specification and adequate funding to deliver DAFNE and train 3 new educators. The other has never had

formal funding ring-fenced for DAFNE and now SC is very concerned that she may not be able to deliver DAFNE to the 200 patients on her referred list.

It was agreed that the best approach would be to encourage Hull graduates listed on DUG and dafneonline to write and that we should also write as DUAG (including press release). We should also attempt to interest a local journalist.

Pose this question to the PCT: Where is your quality control for the people living in Hull without access to DAFNE?

Action: CS to find out from SC the appropriate person to write to within East Riding PCT.

Action: BT to write letter on behalf of DUAG.

Action ME to inform dafneonline.

Action: CS to acquire names of Hull graduates from SC [Note from Central DAFNE post-meeting – this cannot be done because of data protection]

Action: CS to inform DUG – Hull graduates only.

When and if Hull graduates respond to us, we could ask if they would be prepared to sign a letter to a local MP (the letter would carry more weight if it came from a constituent). We could also look at creating a story in the local press.

PR raised question of DUAG stationery. BT explained he had already created a template for this.

8c Gillian Thompson's Paper

QIPP, the next stage of the Darzi report, stands for Quality, Innovation, Productivity and Prevention. Representatives were invited to complete a template and supply evidence to show that their programme or intervention met the criteria. More than 200 papers were received, and DAFNE was one of only around 50 accepted. Currently, it is the only evidence-based, structured education programme for Type 1 diabetes recognised by QIPP, although a second phase will be rolled out this year and more programmes of every kind should be added.

As part of this programme of work, a database has been set up to be used by commissioners and others working in the health service. TD emphasised the importance of this as a form of validation - a barrier so far has been that all healthcare professionals and PCTs ask 'where's the evidence?'

The paper can be reviewed at http://www.library.nhs.uk/qualityandproductivity/, under long term conditions.

8d Rebranding of DAFNE

Nine new examples of possible new DAFNE logos were presented to the group for their opinion. They unanimously decided on example one, which was simple, recognisable and not a radical change from the current logo (but will be cheaper to reproduce/print as it uses less colour).

A new strapline was suggested by the group ‘Eat what you like, when you like’ (as an improvement on ‘Eat what you like. Like what you eat’).

9 Date and Location of Next Meeting

9.1 It was agreed to hold the next meeting on Friday 7 May. (Unfortunately, RMcK will be unable to attend).

9.2 It was noted that Birmingham remained the best location, and the Radisson the best venue.

9.3 BT asked that reports from Action Groups be issued to DUAG a week before each future meeting so we all have a chance to give them consideration.

Minutes by Clare Swift January 2010