

Minutes of DUAG Meeting

11th September 2009, Birmingham

Attendance

Apologies:

Mark Endacott Emma Ward Elizabeth Yates

Members in attendance:

Annette Bell	Tony Doherty	Peter Edwards	Peter Fairbairn
Rachel Hebditch	John Marshall	Robert McKnight	Ian MacLellan
Peter Rogers	Lesley Wilkin		

In attendance:

Wendy Baird (am) Peter James Gillian Thompson

1 Notes of the Last Meeting

- 1.1 These were accepted as a true record of the meeting.
- 1.2 It was accepted that for these and all subsequent notes of meetings it would be helpful to have an executive summary at the beginning to make the document easier to read when they are circulated (eg on dafneonline).
- 1.3 An executive summary for the current minutes was drafted after the meeting and reads as follows:

At the inaugural meeting of DUAG (DAFNE User Action Group) a mission statement, core set of aims, roles and ways of working was established. The mission is to improve the life of people with Type 1 diabetes in the UK and Ireland by allowing the Users' voice to promote the use and development of the DAFNE structured education programme. The four main activities included being a 'critical friend' within DAFNE structures (Executive, Research and Educator groups), increasing awareness about the potential of DAFNE, lobbying for greater funding for DAFNE and increasing the involvement of DAFNE graduates in all these activities.

2 News of Members

- 2.1 It was noted that for health reasons Tony Ball was unable to continue as a member of the group. It was agreed that a response was needed. A signed card, a letter from the Chair and a book token would be hand delivered by Lesley.
- 2.2 Ian was welcomed and introduced to the DUAG team as this was his first meeting.

- 2.3 The potential to recruit or co-opt was noted as an option for the future.

3 Overarching Issues and Ways of Working

- 3.1 It was noted that the first meeting had achieved a great deal of direction, but it was noted that this needed to be tempered by realistic expectations for future work.
- 3.2 It was noted that the four 'work streams' A-D were probably better being renamed as 'Groups'

A - rewritten as Liaison Group
B - rewritten as Awareness Group
C - rewritten as Lobbying Group
D - rewritten as Involvement Group

- 3.3 It was agreed that the convenors of these groups would be referred to as Leads

- 3.4 It was agreed that the email trail could become very confusing. Therefore in all email correspondence the sender would address it to the Lead (perhaps copied to the members of that work group) with the Group's Name being included in the heading.

- 3.5 Ways to prioritise the various activities were discussed since the group had limited resources (financial and time). A lengthy discussion explored the merits of focussing on Involvement at the expense of Awareness and or Lobbying. On balance it was thought that all needed to proceed in parallel, that each was conducive and overlapping with each other. However as work progresses decisions may need later prioritisation.

- 3.6 It was acknowledged that DUAG activities may create a demand for DAFNE which could not be met in the short term. However to be consistent with the underlying mission it was necessary to make people aware that DAFNE was available (if resources were allocated), that this was the only quality assured structured education programme for Type 1 diabetes which met NICE guidelines, AND USERS WOULD RECOMMEND IT AS A LIFE CHANGING WAY TO CONTROL THEIR DIABTES.

- 3.7 It was noted that the 'stakeholders' who impacted upon DAFNE uptake ranged from Commissioners (each making their own decision rather than any National directive) Specialist Services (especially Diabetologists), Health Professionals more generally (GPs and Practice Nurses), people with Type 1 diabetes, DAFNE Graduates and DUG members. Therefore the task would be a long haul rather than a quick fix!

- 3.8 It was observed that the DUAG members needed to know more about DAFNE, and how the work of the two dovetails so as not to replicate or complicate

work patterns. It was agreed that Gillian would provide updates to help induct DUAG members (as she did at this meeting).

- 3.9 It was noted that there was overlap between the work groups and that a Communication/Media expertise would be needed across all groups. Similarly resources might be shared. For this reason it was envisaged that the Chair would extract the shared issues across the work groups and ensure effective coordination. This might include an overall coordinated approach to groups such as Diabetes UK.

4 Development of Roles

- 4.1 Ian has an interest in research and was able to fill the vacant position in 'Five versus One' research programme.
- 4.2 Since John can not attend the Audit and Database meeting on 13 October 2009, Lesley agreed to attend this meeting along with Annette.
- 4.3 All members took part in an exercise with Wendy Baird to establish a 'Job Description' for attendees at all Research meetings. She will produce a copy this for circulation within a working week. It included reporting back to the DUAG on meetings and issues.
- 4.4 It was noted that 'Research Liaison' roles would be greatly enhanced if the research groups could produce an 'Executive Summary'. It was agreed these summaries should also be made available for dafneonline, and would be a way of getting more DUG members involved.
- 4.5 It was agreed that a Vice Chair would be a helpful role to have in addition to the Chair to provide cover and additional help.
- 4.6 It was agreed that the two representatives at the Executive would be the Chair and Vice Chair of DUAG. These roles would be for three years with the proviso that circumstance might change and the term may need to be shorter.
- 4.7 A set of Chair desirable 'Criteria' to aspire to, which double's up as expectations that the DUAG members could, were identified. These were:
- Time for the role, willing volunteer and committed to the task
 - Be experienced and comfortable in the role
 - Be inclusive (first amongst equals) and open minded (without own agenda)
 - Be able to understand the issues, summarize, and move decision making forward
 - Be efficient with time, be precise, be concise
 - To be approachable personally, and be accessible to communications
 - Be able to encourage and coordinate Group Leads, and liaise with Gillian/DAFNE
 - Promote tact, compromise, consensus and conflict reducing
- 4.8 It was agreed that Brian would take on the Chair role, Peter Rogers would take on the Vice Chair role, and Tony would provide back up and support as an additional resource given the magnitude of the task.

5 Brand Updating

- 5.1 In general DUAG views were that major rebranding of DAFNE was unlikely to yield enough benefits for the money involved.
- 5.2 It was noted that to the non diabetes initiated there was no reference made to diabetes or type 1 in the title, logo or strap line. DUAG believed that it would be advantage to get words like 'type 1 diabetes' in somewhere.
- 5.3 "Eat what you like, like what you eat" and the orange biscuit logo were seen as fine. The group also liked the notion of 'more control' (i.e. more control with Type 1 Diabetes).
- 5.4 There were no strong views about colour or layout of paper, especially as in the next ten year lifespan fashions will have changed again.

6 Initial Plans for Awareness Group – Lead Rachel Hebditch

- 6.1 It was noted that there was overlap with the work of DAFNE Central. However the distinguishing feature was the DUAG had the Users message to emphasize. However Central DAFNE probably couldn't promote DAFNE in the way DUAG can because the former would raise resistance and negative press from other services.
- 6.2 The key messages that DUAG had to express were:
 - We've used DAFNE
 - It works.
 - It changes lives for the better
 - We want to recommend it
 - We think it unacceptable that it isn't widely available.
- 6.3 The group had written a brief piece for Balance to announce the arrival of DUAG.
- 6.4 The group were going to seek an invitation to a larger piece in Balance – eg a day in the life of a DUAG role....
- 6.5 The main task of the group will be to organise a press release for November to raise awareness of DAFNE and its potential to make a difference.
- 6.6 Rachel will continue to play around with a flyer for use in health settings, taking into consideration the feedback and reflecting that this is an evolutionary process.

7 Initial Plans for Lobbying Group – Lead Tony Doherty

- 7.1 Since Brian is taking on the DUAG Chair role he stood down as workstream lead for Lobbying. Tony was voted in as the new Lobbying lead.
- 7.2 The group had identified a rich source of patient stories to use.

- 7.3 The group felt satisfied that all the scientific evidence for DAFNE, including German data, was available via Central DAFNE.
- 7.4 Wendy Baird agreed to provide a lay summary of the Health Economics paper that was published.
- 7.5 The initial groups targeted for lobbying were Cross Party MPs who could be accessed via Diabetes UK.
- 7.6 A second group of key people were the 'Diabetes Leads' in the various commissioning groups around the country. The viability of approaching these would be explored.
- 7.7 The key messages would be distilled, and 'World Diabetes Day' would be used as media opportunity.
- 7.8 Lessons would be learned and links made with Diabetes UK User Group expertise on lobbying processes.

8 Initial Plan for Involvement Group – Lead Mark Endacott

- 8.1 It was agreed that by the next meeting a plan would be produced to clarify the best message to deliver to the Educators and Health Care Professionals via the Regional Educator Network meetings and the National Collaborative, and then the best mechanisms to deliver the message would be suggested.
- 8.2 It was noted that there were excellent examples where dafneonline had provided a forum for helpful support and learning. It was noted that this was a message to pass on to the HCPs – that their patients are potentially missing out. Testimonial to this effect could prove useful as part of the message.
- 8.3 It was reiterated that the promotion of DUG and dafneonline was very patchy. Other quick approaches to lobby HCPs would be constantly sought.
- 8.4 The group also would establish some quick and simple ways to establish more two way communication with existing DUG members via dafneonline by posting minutes, research, ways to be helpful etc.
- 8.5 The group would continue to liaise with Gillian to take all reasonable opportunities to promote DUG: new Handbook, audit, links printed on diaries, making diaries quickly available from dafneonline to DAFNE Central.
- 8.6 The idea of contacting pump manufacturers to have a dafneonline link on their diaries/literature was raised as another way of reaching people. Gillian raised caution as the national DAFNE programme is independent from industry and needed to retain this independence; any such ventures with regard to national programme resources would need to be approved by the national Executive group.

9 Cycle of Liaison Work

- 9.1 As Brian could not attend the next Executive meeting, Tony Doherty as reserve, would attend along with Peter Rogers. Peter Rogers agreed to provide the summary for Professor Amiel (Chair of Executive group), this would be forwarded to Gillian who would forward to the Executive group.
- 9.2 It was noted that the DUAG members (Liz and Emma) who attended the Educator meeting would be raising the problem of Health Care Professional finding it difficult to promote DUG and dafneonline.
- 9.3 It was agreed that when members attended a 'Liaison' meeting they would write a brief summary that could go to DUAG members and dafneonline. They would determine what issues needed exploration at the next DUAG meeting and communicate with the Chair.

10 Next Meeting

- 10.1 It was agreed to hold the next meeting on Friday 15th January 2010.
- 10.2 It was noted that Birmingham remained the best venue, and the Holiday Inn facilities were seen as fine.
- 10.3 It was noted that Brian would need to talk to Gillian and produce an agenda for this meeting with at least two weeks notice for circulation to members.
- 10.4 Brian would chair the next meeting and would clarify with Gillian what sort of support he needed.

Minutes by: Peter James 11th September 2009.