6. PATIENT RECRUITMENT

6.1 Suitable patient criteria
Not all patients will benefit from a DAFNE course. At this stage we do not have evidence to help us decide who would and who would not benefit from a DAFNE course. However a programme of research, funded by the National Institute for Health Research, commenced in January 2008, utilising psychological and sociological expertise in a combined quantitative and qualitative approach to:

- Establish which components of DAFNE determine success.
- Identify predictors of ‘success’ or ‘failure’.
- Learn why some cannot sustain intensive self management.
- Implement and evaluate further interventions.

We anticipate results will be available late 2012.

In the meantime the criteria overleaf are used to identify patients from clinics, who may be suitable/benefit from a DAFNE course. You may find it useful to distribute the criteria to your colleagues (or place in clinic rooms) to help recruit suitable patients onto your DAFNE courses.

It is recommended that you create a simple database (eg using Excel or Access) to keep track of all referrals and whether or not the referred patients go on to attend a course (refer to section 4.2). If you would like further help with the creation of a referral database please contact Central DAFNE.

All referrals should be entered into such a database if possible, as this will make it easier to contact patients later.
Identifying people who may be suitable and/or could benefit from DAFNE

The DAFNE programme is for adults (>17yrs) with Type 1 diabetes for at least 6 months, or post-honeymoon.

Potential participants need to understand that DAFNE involves MDI therapy (4+ injections/day) and relies on frequent capillary BG monitoring (4+ tests/day), therefore those who currently use a twice daily insulin regimen or are infrequent testers must be motivated and prepared to make these changes when they attend the course.

They also need to be able to attend the full 5 days of the course, plus follow-up (supporting information for employers is available)

Whilst there are no absolute ‘exclusion criteria’, we recommend that decisions about recruitment of patients with specific issues should be considered by the whole team; the Lead DAFNE Doctor has an important supporting role to play in this process:

- **HbA1c >110mmol/mol (~12%)** – may indicate a patient who is omitting insulin. Discuss how committed they are to a MDI regimen; how motivated are they to improve their glycaemic control?

- **End-stage complications:**
  - **Retinopathy** – how well can they independently manage essential skills such as CP estimation, BG monitoring, injections etc. (some resources may be available / reproduced locally in large print)
  - **Nephropathy** – whilst insulin action may be affected in ESRF, motivated patients should not be excluded. Those on haemodialysis should try to arrange evening / weekend sessions during the DAFNE week so as not to miss any of the course. Educators may prefer to have experience of delivering DAFNE and the support of diabetes / renal medical colleagues before taking on these participants
  - **Gastroparesis** – participants unable to eat normally due to nausea and vomiting, or requiring artificial nutrition for severe gastroparesis may not benefit from the DAFNE course

- **Pregnancy** – pregnant Type 1 ladies can attend a course but will need adapted advice re frequency of monitoring and BG targets. Educators may prefer to have experience of delivering DAFNE and the support of diabetes / obstetric medical colleagues before taking on these participants

- **Eating disorders** – patients may be unwilling to discuss dietary / CP intake with Educators or within the group, making dose adjustment very challenging. Educators may prefer to have experience of delivering DAFNE and the support of eating disorder / mental health colleagues before taking on these participants

- **Communication** (ability to hear/speak/understand/read English) – use of translators / signers may result in incorrect information being relayed and increase time required to deliver sessions

- **CSII pumps** – it is recommended that those on pump therapy receive the specific DAFNE CSII curriculum (additional Educator training and resources are available through Central DAFNE)

- **Type 2 diabetes; Cystic Fibrosis; Pancreatic diabetes; MODY; Secondary diabetes** – although not Type 1, DAFNE principles may be applied. Educators may prefer to have experience of delivering DAFNE before taking on these participants as advice and information in the curriculum and Workbook will need to be adapted and clarified. We recommend a limit of 1 ‘non-Type 1’ participant on any course. **Participants must be flagged accordingly on the DAFNE databases.**
6.2 Inviting patients onto a DAFNE course – Recruitment Meetings

Time frame: >12 weeks prior to patient course

Once course and recruitment meeting dates and venues have been arranged, patients on the database can be invited on to courses. This is done via a letter of invitation to a recruitment meeting.

This letter is sent to patients from your referral database (refer to sections 4.2 and 6.1) along with a DAFNE information leaflet ‘Do you have Type 1 diabetes?’ (refer to section 9.1) and a stamped addressed envelope for responses.

Below is an example of a 2-page letter of invitation, a copy of which can be found in Appendix VII. You can either use this letter as it stands or as a basis to create your own letter.

Example letter 1

Dear

Last time you attended the diabetes clinic, someone may have mentioned a DAFNE course that could be available to you in the near future.

DAFNE stands for Dose Adjustment For Normal Eating. It is a way of managing your diabetes by working out how much insulin you need to take for what you would like to eat.

We are one of a limited number of diabetes centres in the UK capable of offering DAFNE courses as part of our diabetes service.

We appreciate that you, and your family, will require more information before you can make the final decision on whether or not you want a course place.

In order to provide this and give you an opportunity to ask any questions you may have, we would like to invite you and your partner to an evening meeting on ---------- at -------. The meeting will begin at ------- until ------.

Light refreshments will be provided. There will be members of the DAFNE team available to speak to during the evening as well as people who have already completed the course.

Please return the enclosed slip in the pre-paid envelope as soon as possible.

We look forward to hearing from you soon,

Yours Sincerely

I am able to attend the above meeting

I would like further information about the DAFNE course. I would like someone to contact me by telephone.

I do not wish to be considered for any future DAFNE training courses. Please remove my name from the waiting list.

Name:………………………………………………………….
Address:…………………………………………………..…………….
………………………………………………..……………….
Contact telephone no (daytime)……………………………
(evening)……………..……………

Any other comments:

Once you have completed DAFNE courses at your centre you may have patients who are willing to attend the recruitment meetings to give a patient’s perspective of DAFNE.

Until you have such patient volunteers, please ensure that you remove any reference to this in your letter (highlighted section above).
Example letter 1 includes a response form for the patients to complete and return to you. The patients are given three options as detailed in the table below.

<table>
<thead>
<tr>
<th>Option</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Able to attend the meeting.</td>
<td>Add name to recruitment meeting attendees list.</td>
</tr>
<tr>
<td>2. Would like further information about DAFNE via a telephone call from a DAFNE Educator.</td>
<td>Contact patient via phone (refer to section 6.9 for further details).</td>
</tr>
<tr>
<td>3. Not interested in DAFNE and would like their details removing from the DAFNE referral database.</td>
<td>Update patient records and database to this effect and contact your colleague who made the referral to inform them of the patient’s decision.</td>
</tr>
</tbody>
</table>

The number of patients you need to send letters to will depend upon how many courses/ places you are trying to fill.

From experience roughly 50% of those patients receiving a letter of invitation will turn up at the recruitment meeting and virtually everyone who attends will sign up for a course.

For example if you are trying to recruit for 5 patient courses (40 patients), you would need to post letters of invitation to around 100 patients, you may expect 45-50 patients to attend the recruitment meeting.

It is important that each centre keeps an up-to-date record of the number of patients to whom letters of invitation are sent (refer to sections 4.2 and 6.1).
6.3 **Non responders**

If a patient does not respond to the invitation letter, their details remain on your referral database until letters of invitation are posted for the next recruitment meeting.

If no response is received to this 2\textsuperscript{nd} mailing, these patients are posted invitations to the next recruitment meeting. If no response is received to the 3\textsuperscript{rd} invitation, the patient details are removed from your referral database, their records marked to reflect this and your colleague who made the original referral informed of the outcome.

It is important that each centre keeps up-to-date records of the number of patients who do not respond to letters of invitation (refer to section 4.2 and 6.1).
6.4 Recruitment meeting
Time frame: ≥8 weeks before course

Recruitment meetings are an opportunity to provide patients with sufficient information about DAFNE and for patients to ask relevant questions in order for them to decide for themselves if DAFNE would be suitable for them.

These meetings usually last for about 2 hours, starting around 6.30pm – 7pm, as this will allow people to attend from work. However, the actual timing is not critical and this can be altered to fit in with your service. Refreshments should be available for patients on arrival (refer to the section 5.3.2).

It is worth pointing out that this exchange of information could take place over the telephone (refer to section 6.9). However, the benefit of a recruitment meeting is that you can have this exchange with 50 or more patients at once.

From experience we have found that most people who attend the recruitment meeting will then go on to sign up for a DAFNE course – the vast majority will do this on the evening.

A standard PowerPoint presentation - DAFNE Recruitment Presentation 2004 - is provided on the CD accompanying this manual. This presentation can be used/amended for your centre needs, or can be printed on to acetates for use on an overhead projector, if required.

Once you have started to run your own patient courses, it may be possible to have 1 or 2 of your patient graduates attend the recruitment meeting to provide a patient perspective.

Alternatively, if you have internet access in your meeting room, you could log onto the DAFNE website and play the videos of interviews with graduates which can be found in the patient section of the site.

A list of expected attendees should be available at the recruitment meeting. This will act as a ‘register’ to make it easier to record attendance/signed up. It will also help to follow-up and record the number of patients who do not attend (refer to section 4.2 and 6.1). Follow-up of non-attendees is usually by telephone, to determine why they did not attend and what they would like to do now. There are three options available to them:

- Conduct telephone recruitment (refer to section 6.9).
- Go back on the referral database and wait for an invitation to the next recruitment meeting.
- Have their details removed from the referral database.

If the patient decides to remove their details from the referral database (refer to sections 4.2 and 6.1), their records should be marked to record this and your colleague who made the original referral should be informed of the patient’s decision.
Each attendee should be provided with a form to complete at the recruitment evening. This form should provide details of the available course dates, so that the patient can list their course preferences. In addition the form should provide the patient with the choice of taking no further part in DAFNE, and removing their details from your waiting list.

An example of such a form is provided below. This form can either be used as it stands or amended to meet your local needs. A copy of this form can be found in Appendix VI.

Example form 1

<table>
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<th>Name:</th>
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<tr>
<td>Telephone (Evening):</td>
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</tbody>
</table>

Do you wish to be considered for a course on:
(Please indicate preference, ie, 1st, 2nd, 3rd, 4th)

**LIST OF AVAILABLE COURSE DATES HERE**

Could you attend at short notice, eg if there is a cancellation from another course?
Yes/No

If yes, when is it best for us to contact you to arrange an appointment?

If you no longer feel DAFNE is for you, would you like your name removed from the waiting list?
Yes/No

If attendees complete this form at the recruitment meeting they should hand this to a member of staff before they leave.

Patients who decide to take the form home to complete, should be provided with an SAE and asked to return the form within the next week. They should be informed that course places are allocated on a first come first served basis and the longer they take to decide will obviously reduce their chances of getting a place on the course of their choice. However patients should not be forced into making a quick decision without giving it sufficient thought or being offered the opportunity to ask further questions.
It is important that each centre keep up-to-date records of the number of patients expected to attend the recruitment evening and the actual numbers attending. It would also be useful to record, if known, the reason why patients failed to attend (refer to sections 4.2 and 6.1).
6.5 Employers letter
Occasionally a situation arises where a patient wants to attend a course but is concerned that their employer will not provide them with paid leave/or is having difficulty obtaining time off work. On such occasions a letter can be sent to their employer.

Below and overleaf are examples of two different employers’ letters, providing varying levels of detail. Copies of both letters can be found in Appendix VII.

Example letter 2

Dear

I am writing to ask you to help your employee --------------------------------- take part in a new education programme for diabetes. The programme, developed in Europe and introduced into the UK in 2000, radically improves flexibility in daily living for the person with diabetes, helping them to eat what and when they want and enhancing their ability to run their own diabetes. It also delivers improved diabetes control, with major gains for both immediate and long-term health.

Education programmes to enable individuals with diabetes to self manage their condition is now part of routine diabetes management in the UK.

People with diabetes in the UK often have better employment records than others. This new method of diabetes management is expected to improve this still further. When it was introduced in Germany some years ago, days lost from work were halved. The results were so impressive that the German Health Insurance firms not only demand that their clients with diabetes go on appropriate training courses but they pay the health insurance to enable them to take part.

This programme has to be taught to the person with diabetes. This involves a five-day training course with a ½ day follow-up around 8 weeks later. In the long term the course can help the person with diabetes become more independent of professional medical help.

Your employee has been advised and invited to attend this programme. I am writing to ask whether you would allow ------------------ to have paid leave to attend. The one-week course will commence on --------------------------------.

If you have any questions regarding this programme, please contact --------------------------- on ----------------------------.

Thank you for considering this request.
Dear

**DAFNE Training Course**

I understand your employee ----------------------------- has discussed with you that he/she has been offered a place on a training course at ---------------------- between --------------------- and ------------------------ as part of their diabetes management plan.

The course will teach new skills to manage his/her diabetes. Evidence suggests this will have immediate benefits for himself/herself, will improve his/her long-term health and help their employers.

I hope this is satisfactory.

Yours sincerely
6.6 Allocating places on courses
Time frame: ≥ 4 weeks before course

This is usually done on a first come first served basis, although occasionally there may be a patient with mitigating circumstances (e.g., planning pregnancy) whose need may warrant them being allocated a place on the next available course.

Once a patient has been allocated to a course you need to confirm the course date and venue with them via letter. This letter should also mention that an Educator will make telephone contact a few weeks before their course to arrange a suitable time for the patient to attend a baseline data collection clinic. All patients should attend such a clinic no more than 6 weeks before they commence their DAFNE course (refer to section 7).

Below is an example of such a letter, a copy of which can be found in Appendix VII.

It is suggested that the patient’s GP is also sent a letter to inform them that their patient is about to attend a DAFNE course, as a matter of courtesy.

Example letter 4

Dear -------

I am writing to confirm your place on the DAFNE course starting on ------------ in the ------------ at ------------ .

In preparation for the course, one of the DAFNE Educators will contact you a few weeks prior to the course, to discuss final details and arrange a convenient date for you to attend a clinic to collect some baseline measurements such as HbA1c and weight.

Yours sincerely
6.7 Over-subscription to courses
If you find that you have more patients signing up for a course than you have places (minimum 5, maximum 8 is recommended), those patients who cannot be allocated to a course need to be notified of this fact. Again this should be done by letter, such as that shown below.

Example letter 5

Dear -------

I am writing to let you know that unfortunately you have not been allocated a place on any of the DAFNE courses you selected. As you are aware demand is high.

Your name will be placed on a waiting list for future courses, or if a place becomes available due to cancellation.

Yours sincerely

A copy of the above letter can be found in Appendix VII.

Patients who go back on to the waiting list obviously will not need to attend a further recruitment meeting. These patients will simply need to be informed of new dates and sent a further copy of the form listing available course dates (refer to section 6.4 for an example of such a form).
6.8 Patient course information letter

Time frame: 1 - 2 weeks before course

Around two weeks prior to attending a course, patients should be sent a letter providing further details of the course date, times and venue (including a map if deemed necessary).

The letter should also contain details regarding car parking/transport links, what they need to bring along with them to the course, and a copy of a course timetable (timetable examples available in Appendix XIII).

An example of a patient course information letter can be seen below and a copy can be found in Appendix VII.

Example letter 6

```
Dear

DAFNE Course - Information

The purpose of this letter is to provide you with information required to participate in your DAFNE course and to list items which you will need to bring along with you. We hope this information is helpful in preparing yourself for your DAFNE course and we look forward to seeing you on the morning of Monday monary.

1. Course start date and venue
   Your course starts at time on Monday MMM, in the MMM at MMM. A copy of the course timetable is attached to this letter. There is a public pay and display car park situated MMM. Car parking charges are £-- per hour or £-- per day. Parking costs are not refundable.

2. Lunch/Refreshments
   Lunch will be provided (free of charge) daily during the course. Hot and cold refreshments will also be provided throughout your course free of charge.

3. Insulin/Blood monitoring equipment
   It is essential for you to bring along your insulin and blood glucose monitoring equipment to the course. You will have a chance to discuss different meters as part of the course and can choose a new meter (free of charge) if you wish to.
   It may be necessary to implement changes to your current insulin regimen. This may have already been discussed with you, but if not it will be discussed with you on the first day of the course. If you currently keep a monitoring diary, please bring this along with you.

4. Questionnaires
   If you were given them at your pre-course appointment, please bring along the completed questionnaires on the first day of your course.

5. Observers
   You may notice one or two observers in the room during the course. These people will be observing our teaching methods and not your participation. We hope you do not feel restricted by their presence.
   We would appreciate, and we will encourage, group input during the course, as we can all learn from each other's experiences, please ask questions at any point.
   This is an opportunity for you to learn this new approach for the management of your diabetes and we feel confident that you will continue to use this approach after the course has finished.

   My colleagues and I hope that you find your DAFNE course informative, but most of all we hope it is enjoyable.

   Yours sincerely

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This letter could be given to the patient when they attend their baseline data collection clinic (refer to section 7).

This, perhaps more than any other of the example letters provided, will need to be changed the most to reflect the facilities at your hospital (eg arrangements for lunch, car parking facilities etc).

If you have any queries regarding any aspect of recruitment, please contact the Central DAFNE.
6.9 Telephone recruitment
Time frame: ≥8 weeks before course

Telephone recruitment is an alternative to running recruitment meetings. Much of the process remains the same as that detailed in sections 6.1-6.8.

Patients are referred directly from diabetes clinics. A letter (example 7 below) is sent to suitable patients, along with a ‘Do you have type 1 diabetes?’ leaflet (refer to section 9.1) and a stamped addressed envelope.

This letter would be sent in place of the invitation letter discussed in section 6.2

Example letter 7

Dear

You will have had discussions with your diabetes doctor about attending the DAFNE (Dose Adjustment for Normal Eating) course.

This letter is to invite you to attend the DAFNE course and inform you of the next available dates for you to attend.

I would be pleased to discuss the course with you in more detail. Could you please ‘phone or write and leave a daytime phone number so that we can be in contact and you can have your questions answered.

The DAFNE course dates available are:

**Insert course dates here**

Could you please fill in the form on the next page and post it back to me.

Unfortunately it will not always be possible to give people their first choice of dates because numbers are limited to eight people per course.

I look forward to speaking with you

Yours sincerely

Please indicate your first or second choice by putting number 1, 2 or 3 beside the dates.

**Insert course dates here**

Comments

Name:
Daytime Phone Numbers:
Address:

Reply to: Insert name, address and telephone number of where forms are to be returned to here.

This letter may be used as it stands or used as a basis for your own letter.

A copy of this letter can be found in Appendix VII.
Once patient responses are received, the patient should be telephoned and the following points covered:

- What they understand about the DAFNE course, and give an explanation of the DAFNE programme.
- Explain what is involved in a DAFNE course. ie 5-day commitment, plus a follow-up session no more than 12 weeks post course, being willing to inject at least 5 times per day, being willing to carry out blood glucose testing 4 times per day
- Check that they meet the ‘Criteria for people who could be suitable/benefit from DAFNE’ (refer to section 6.1).
- Patients should be given the opportunity to ask further questions.

This conversation is likely to take about 10-15 minutes.

At the end of the phone call, if the patient decides that they would like to attend a DAFNE course you can confirm their place on, and date of the course. You can also explain the need for a baseline data collection clinic and arrange the date and time for this clinic with them (refer to section 7).

About 4 weeks before the data collection visit, the patient should be contacted (phone or post) to remind them that they are expected on the next course, to provide details of the time/venue/date and what to bring, for the data collection visit.

Either at the data collection clinic or 1–2 weeks before their course the patient should be sent a patient course information letter (example letter 6) as outlined in section 6.8.
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