

## Who can join the DAFNE User Group?

Everyone who has completed a DAFNE course will be invited to join the DAFNE User Group. We would like the DAFNE User Group to represent all DAFNE Users.



## Why have a DAFNE User Group?

DAFNE is a national programme currently delivered in 77 diabetes services across the UK and Southern Ireland. The number of centres increases every year. The national programme is co-ordinated by the National DAFNE team hosted by Northumbria Healthcare NHS Foundation Trust in North Tyneside. The National DAFNE team do not hold any details about the people who have completed a DAFNE course; only the individual's diabetes team keep this information.

Occasionally, we need to make contact with DAFNE Users to gain insight into their experiences or to get feedback on materials which DAFNE has developed. Historically, making contact with DAFNE Users has been a difficult process, with the National DAFNE team having to rely on DAFNE Educators from one or two centres finding the time to contact their DAFNE Users, discuss the issues and then pass back comments to the National DAFNE team. The response rate we have had in such instances has been very poor. It is a slow and time consuming process. Furthermore, by having to restrict the process to only one or two centres, the responses/feedback from Users may not represent the views of all DAFNE Users.

The DAFNE User Group will enable the National DAFNE team to keep in touch with a large number of Users and obtain their views on matters relating to the provision and use of DAFNE. Also, by obtaining the views of – we hope – hundreds of DAFNE Users rather than just a handful from selected centres, the information we receive will be more representative.

## Why should I join the DAFNE User Group?

The DAFNE User Group is a voluntary group; you do not have to join. However, by becoming a member of the User Group you can help shape DAFNE for the future and improve DAFNE for yourself and for others.

The people using DAFNE on a daily basis know what works well, what doesn't work and what needs to be changed. DAFNE users are also uniquely aware of the barriers they face. In order for DAFNE to develop and meet the needs of users, we need to encourage user involvement. We value the unique and valuable contribution DAFNE users have to make.

The DAFNE User Group will provide a means for the national DAFNE team to engage with DAFNE users and for DAFNE Users to engage with them in turn.



## How do I join the DAFNE User Group?

All you have to do is complete the registration form. This form asks where you completed your DAFNE course and your name and contact details. We also ask for your year of birth, gender and ethnicity. Giving this information is optional but it is useful, as it helps us establish just how representative the DAFNE User Group is. It also enables us to target groups of Users with specific queries which may be particularly relevant to them.

By completing and returning this form, you will be agreeing for your details to be held on a secure database and for the Central DAFNE team to make occasional contact with you.

You can obtain a copy of the registration form from the following:

- In the flap at the back of this booklet
- Your local DAFNE team at your diabetes service
- The DAFNE website [www.dafne.uk.com](http://www.dafne.uk.com)
- The Central DAFNE team:

**DAFNE Programme**  
**Central DAFNE**  
**North Tyneside General Hospital**  
**Rake Lane**  
**North Shields**  
**NE29 8NH**

**Tel:** 0191 293 4115

**Email:** [dafne@nhct.nhs.uk](mailto:dafne@nhct.nhs.uk)

You can complete this form electronically or by hand. The completed registration form should then be returned using the contact details above.

## Who will have access to my contact details?

The DAFNE User Group database will be held by the National DAFNE team on the Northumbria Healthcare NHS Foundation Trust server.

The DAFNE User Group database will only be accessed by authorised members of the Central DAFNE team who are obliged to abide by the Data Protection Act 1998 and who respect patient confidentiality as part of their terms of employment. The database will not be shared with any other organisation.

On occasion, we are contacted by healthcare professionals or organisations such as the Department of Health or Diabetes UK, asking us for information/input from DAFNE Graduates about a range of matters. For example, in the past we have been asked to:

- Provide DAFNE Users experiences of hypoglycaemia to the Department of Health National Diabetes Support Team.
- Invite a number of DAFNE Users to participate in a blog organised by NHS Choices.
- Obtain DAFNE User feedback to questionnaires developed by researchers at Universities

In such cases the National DAFNE team would contact members of the DAFNE User Group to explain the request and to give details of whom they should contact if they are interested in getting involved. Members of the DAFNE User Group are not obliged to respond to any such requests; any involvement would be completely voluntary.



## How often will I be contacted?

We will only contact you when we have a question to ask or when we need your views on certain matters. We will not make contact unnecessarily; we would not want to be a nuisance. You will be able to contact us whenever you want and raise questions for us to answer.

The DAFNE User Group is a new venture for DAFNE, and particularly in the early days, we will be informed by the DAFNE User Group as to what they would like in terms of contact.



## Will I have to attend meetings?

No. All contact with the DAFNE User Group will be either by email, phone or letter. Only members of the DAFNE User Action Group will attend meetings.

Occasionally we may wish to obtain your views by using a focus group event. If this is the case we will contact members of the DAFNE User Group to ask if anyone is interested in the subject to be discussed and whether they would be available to attend. However, attending such events is purely voluntary;.

Members of the DAFNE User Group will be asked to volunteer to join the DAFNE User Action Group. The DAFNE User Action Group will consist of up to 25 User Group members who will take on the additional role of representing the User Group at 3 meetings each year. Members of the DAFNE User Action Group will also provide 2 representatives to attend the three National DAFNE Executive group meetings each year in addition to representing Users at research meetings.

Further information about the DAFNE User Action Group and the National DAFNE Executive Group is available from the DAFNE website [www.dafne.uk.com](http://www.dafne.uk.com) or from the Central DAFNE office.



## What happens if I decide to stop being part of the DAFNE User Group?

You can decide to leave the DAFNE User Group at any time. All you need to do is contact the Central DAFNE team in writing, using the contact details below, informing them of your decision.

**DAFNE Programme**  
**Central DAFNE**  
**North Tyneside General Hospital**  
**Rake Lane**  
**North Shields**  
**NE29 8NH**

**Email:** [dafne@nhct.nhs.uk](mailto:dafne@nhct.nhs.uk)

Your details will then be removed from the database and we will not contact you again. Deciding to leave the DAFNE User Group will not affect your diabetes treatment in any way.

