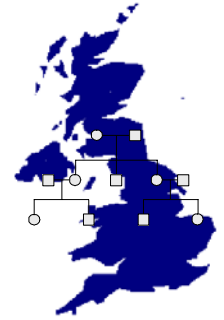


FH01 Winter News



February 2004 Issue 1

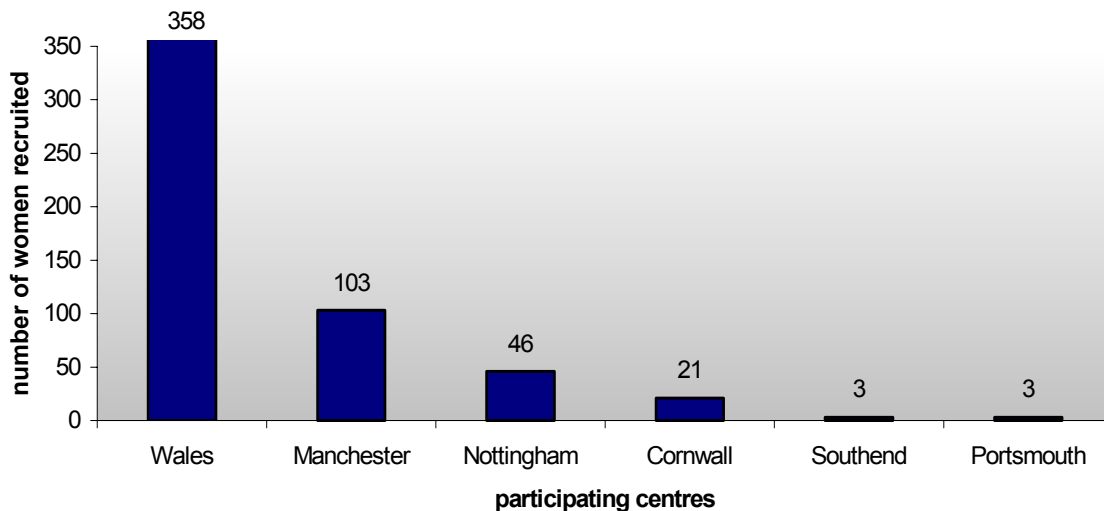
Recruitment has started

The first centres have now started recruiting women.

‘The Evaluation of Mammographic Surveillance Services in Women Under 50 with a Family History of Breast Cancer’ (FH01) is up and running and has begun recruiting women in England and Wales. Manchester led the way being the first centre to start recruiting, closely followed by Frenchay Breast Unit in Bris-

tol. The Mermaid Centre in Truro, Nottingham City Hospital, the Breast Unit at Southend, and The Patricia Massey Breast Unit in Portsmouth are also entering women into the study. There are a further 4 centres who have started recruiting. Wales was already undertaking an evaluation of the service they offer and hence women being offered mammography fulfilling the study criteria have been in-

cluded since January 2003. The chart below shows the numbers recruited and the table indicates where the other centres are in terms of readiness to start recruiting. To be registered as recruiting, copies of consent forms need to be sent to the study’s co-ordinator enabling NCRN accrual data to be recorded.



Other Centres Recruiting	Ready to start recruiting		Awaiting R&D/Ethics approval	
Frenchay	Derby	Telford	Brighton	Macclesfield
Basildon	Bury St Edmunds	Coventry	Colchester/Chelmsford	Burnley
Royal Marsden	UCLH	Addenbrookes	Chester	Worthing
Royal Free	St Bartholomews	Hope Hospital	Crewe	Burton
Charing Cross	Jarvis Centre	Trafford	Hinchingbrooke	Milton Keynes
	Northwich Park		Prescott	West Midlands RGS

Data Collection

Requests have been received from many centres to have a database provided for them. The equipment and support available within the centres was assessed and it was decided to provide web based data collection.

As a result a database has been developed by the software developers at Breast Test Wales in Cardiff to serve the needs of the study. This will be the master study database and contain all the data from the participating centres. It will be housed and maintained by Breast Test Wales in Cardiff.

The participating centres who have access to the NHS Net will be granted an account on the Family History Project web database. This will allow initial entry and update of data via a web browser. There will be 3 levels of security: each user account will be 'strong password protected'; data transfer will have 128k SSL encryption; and the whole system will be behind the NHS NET firewall.

For those centres unable to use the web based system, a local database with user interface could be developed.

Those centres that are using a locally developed database will be able to transfer their data to the master study database. Arrangements will be made with these centres for an appropriate trans-

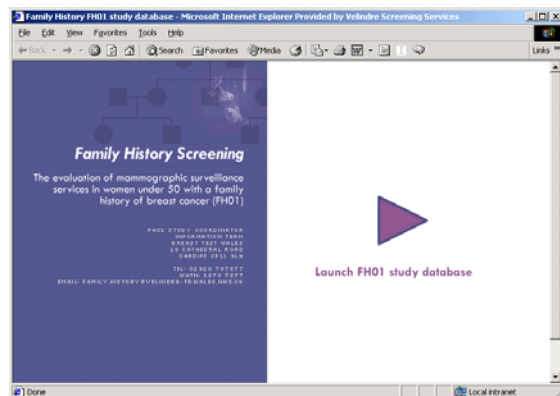
fer mechanism.

There are six centres entering data onto the database and no problems have been reported with accessing the database or with data entry. Feedback to those centres will begin shortly with the production of error reports.

The study's intranet website and database can be found at:-

<https://familyhistory.wales.nhs.uk/>

To access the database users will require a user id and password from the study co-ordinator. Access will then only be gained to their centre's data.



Reminders!!

1. Consent forms

Please can all recruiting centres send me a copy of the consent forms of women they have recruited at the end of each month. (I need this to be able to submit accrual data).

2. LREC and Trust R&D approval letters

Please can I have copies of these documents once you have received them?

3. Recruiting??

Please remember to tell me when you start recruiting!

Documentation

The following documents have been produced to support the study:

Study Protocol	September 2002
Study Guidelines	08/05/2003 (updated 07/07/2003)
Database User Guide	16/12/2003

Proforma for data collection

An A4 Handout, summarising the study

Promotional Poster for display in clinics

If anybody requires any of these please contact Sue Thomas

For more information, please contact: Sue Thomas, study co-ordinator.
Information Team, Breast Test Wales, 18, Cathedral Road, Cardiff. CF11 9CH
Phone: 02920 787877
Email: Susan.Thomas@velindre-tr.wales.nhs.uk