

## Introduction

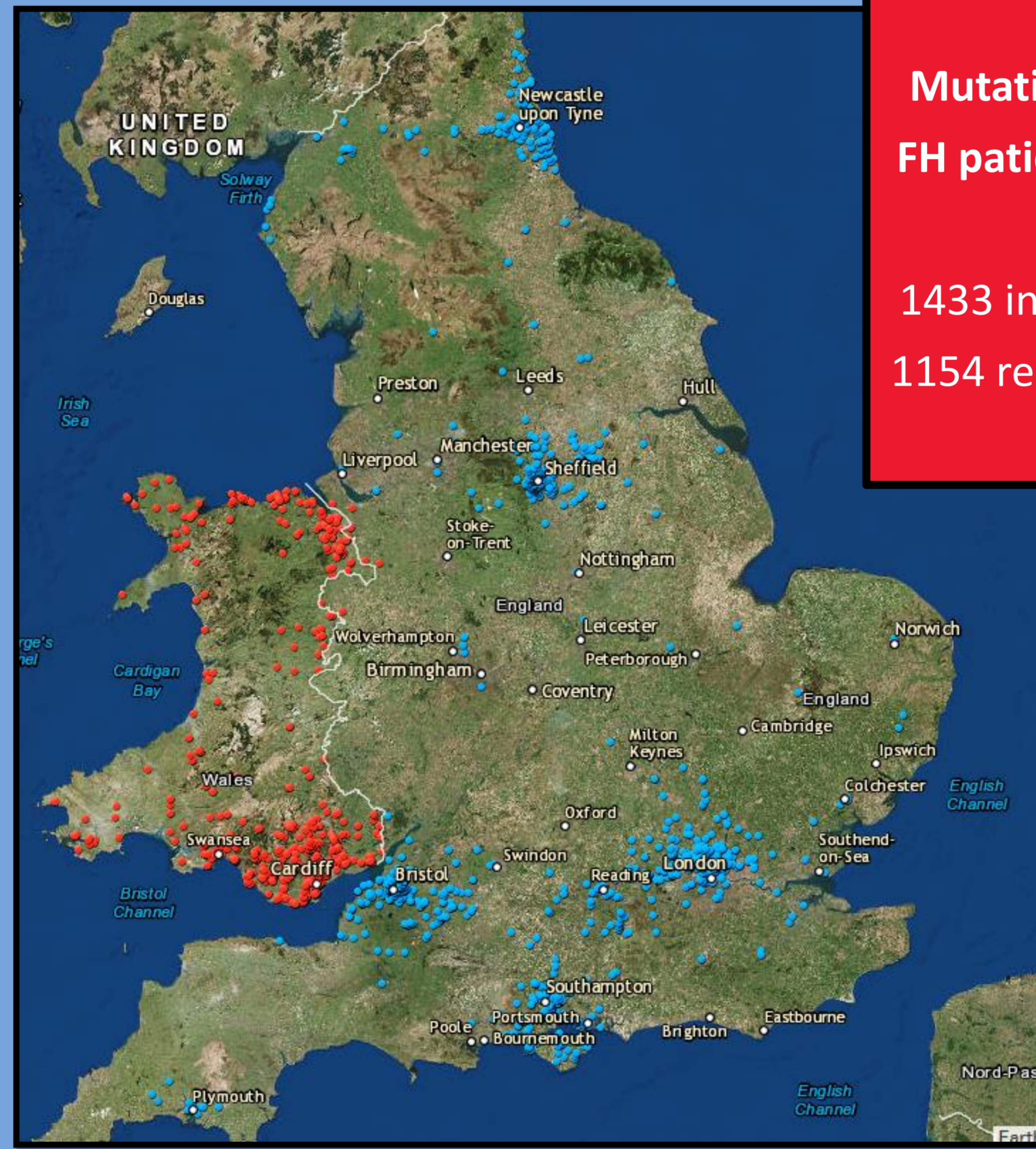
- FH is an autosomal co-dominant condition that leads to high blood cholesterol from birth.
- PASS software developed for NHS Wales and adapted for NHS England.
- Purpose is to register FH patients/families and manage FH services, particularly family cascade testing.
- Genetic test results added directly onto the system via participating labs (Bristol & Newcastle genetics laboratories).
- PASS standardises clinical and operational data collection between centres and allows services to be evaluated locally and nationally.
- Geographical Information System (GIS) software can be used to map FH diagnoses.
- Data presented in this way allows visualisation of regions where FH services are yet to be established and may help identify areas for future clinical development.

## Who uses PASS?

- WALES: used nationwide, managed by All Wales Genetics Service.
- ENGLAND: 75 licenses funded through HEART UK. Used by BHF funded FH services in 23 NHS Trusts & non-BHF funded FH services in 3 NHS Trusts. Hosted on N3 network.
- SCOTLAND: Use a different system.
- NORTHERN IRELAND: About to start using PASS.

## Key Features of PASS

- Pedigree drawing function
- Workflow management
- Template letters and archiving
- Multisite working
- Audit, research & reporting
- Integration with FH genetics labs.



**Mutation positive FH patients in PASS**  
1433 indexes (261 VUS)  
1154 relatives (135 VUS)

- Wales**  
529 indexes (152 VUS)  
494 relatives (91 VUS)
- England prior to BHF investment**  
427 indexes (36VUS)  
249 relatives (9 VUS)
- England post BHF investment**  
(from start dates of BHF nurses)  
477 index (73 VUS)  
411 relatives (35 VUS)

## Heat maps illustrating FH genetic diagnoses before and after BHF investment



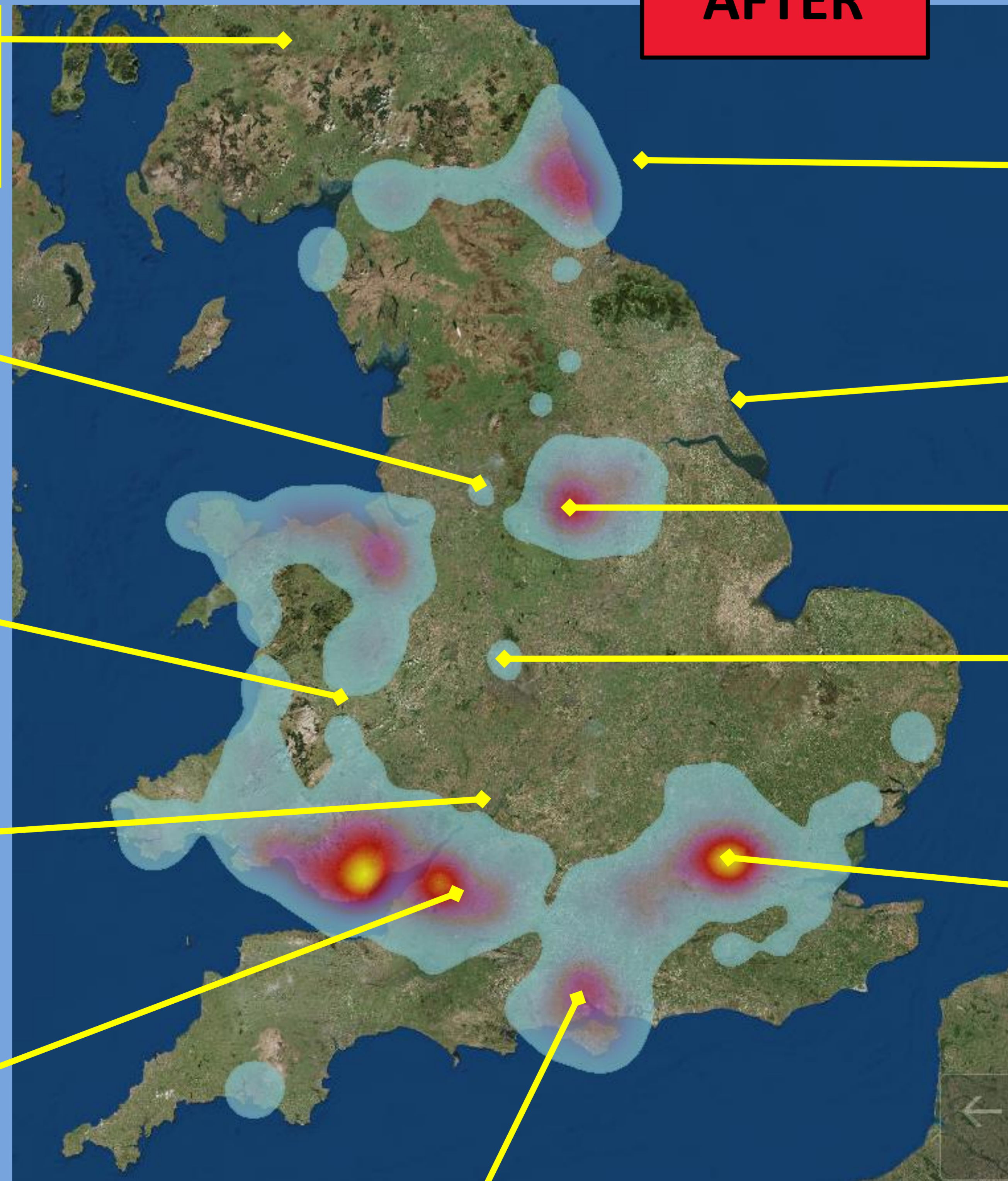
**Scotland**  
3 x BHF nurses  
2 in Grampian:  
05/2015  
1 in Western Isles,  
02/2015  
DON'T USE PASS

**Manchester**  
1 BHF funded nurse  
09/2014  
To commence using  
PASS summer 2016

**Wales**  
3 BHF funded nurses:  
09/2010 – 09/2013

**Gloucester**  
1 BHF funded nurse:  
02/2016  
To commence using  
PASS July 2016

**Bristol & Bath**  
1 BHF funded nurse:  
07/2014



**North East**  
2 BHF nurses: 03/2015

**Yorkshire and Humber**  
4 BHF nurses  
Will be in post prior to  
10/2016

**Sheffield**  
2 BHF nurses: 09/2014

**West Midlands**  
5 BHF nurses  
Will be in post prior to  
10/2016

**London**  
6 BHF nurses  
2 at Royal Free:  
12/2014  
4 at Brompton &  
Harefield  
- 2 started 09/2014  
- 2 started 05/2016

**Wessex**  
2 x BHF funded nurses: 06/2014

**KEY**

- Non-BHF Service using PASS
- BHF Funded Service Not currently using PASS
- BHF Funded Service using PASS
- BHF Funding Agreed Nurses not yet in post

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