Finding undiagnosed Familial Hypercholesterolaemia (FH) patients in your practice

One person in every five hundred people in Wales has Familial Hypercholesterolaemia (FH) and 5 out of every 6 patients with FH are undiagnosed.

Untreated, there is a very high risk of early coronary heart disease. In treated FH patients, all-cause mortality is similar to the general population. The key is diagnosing the condition early and providing effective treatment.

**Genetic Cascade Testing**

FH is a genetic condition with autosomal dominant inheritance. If a person has FH, any first degree relative (such as a child, parent, brother or sister) has a 50:50 chance of having the condition too. Wales has the most advanced genetic FH cascade testing service in the UK. Any new patient (index patient) suspected of having FH and meeting the genotyping criteria can be offered the FH genetic test. Genetic confirmation of FH can then enable cascade testing to be done in the rest of the family.

Cascade testing is when the FH genetic test is offered to the index case’s first degree relatives, through your local FH specialist nurse and genetics service. If these relatives test positive, their first degree relatives are offered the test in a cascade fashion. On average cascade testing identifies at least 3-4 people per index case, making this system much more efficient at identifying FH than other methods.

What your local lipid clinic needs is more undiagnosed possible FH cases to be referred from primary care.

**Clinical criteria for the diagnosis of possible FH**

<table>
<thead>
<tr>
<th>Adults:</th>
<th>Cholesterol &gt;7.5mmol/L, and/or LDL &gt;4.9mmol/L</th>
</tr>
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<tbody>
<tr>
<td><strong>Plus</strong></td>
<td>Either: family history of premature MI (&lt;60 in first degree relative/50 in second degree) Or a family history of cholesterol above 7.5mmol/L in an adult 1st or 2nd degree relative</td>
</tr>
</tbody>
</table>

If your patient fulfils these criteria consider FH and refer to your local lipid clinic.

For patients already on statins

Many FH patients will already be on lipid lowering therapy with a diagnosis of hyperlipidaemia. These patients may be identified during medication reviews. If your prescribing advisor has recommended drug switches for patients on ezetimibe or more costly statins consider these patients as well before switching. If you do not have a pre-treatment cholesterol available you can use the most recent cholesterol measurement and multiply it by the factor on the LDL correction chart on the reverse of The Wales Familial Hypercholesterolaemia (FH) Cascade Testing Service Information Leaflet, which is accessible on the SWCN website (www.wales.nhs.uk/sitesplus/986/fh).

If these patients fulfil the criteria for possible FH refer them to your lipid clinic.

**Searching your database**

You can also identify patients who may have undiagnosed FH by running a search for patients with elevated total cholesterol or LDL cholesterol levels in your practice. This is straightforward and the work is suitable for submission for your appraisal folder. Details of how to do this are available on the SWCN website (www.wales.nhs.uk/sitesplus/986/fh).

Most importantly if each GP in Wales finds one patient by this process, the FH Cascade Testing service will identify the other 3 patients registered with you, and all patients with FH will have the potential of receiving optimal treatment for their condition.

**Your contacts**

Details of your local FH specialist nurse can be found below. You are encouraged to contact them for further information.

- **South East Wales** - Rhiannon Edwards
  - Rhiannon.Edwards@wales.nhs.uk
  - 029 2074 4021

- **South West Wales** - Delyth Townsend
  - Delyth.Townsend@wales.nhs.uk
  - 01696 752759

- **North Wales** - Robert Gingell
  - Robert.Gingell@wales.nhs.uk
  - 07805 667608

Contact: Armon Daniels 07768 566293
Armon.Daniels@talktalk.net
The introduction of a 24/7 region wide Primary PCI service has transformed the care of patients in South Wales with ST elevation myocardial infarction (STEMI). However, these represent only one third of Acute Coronary Syndrome cases. Currently neither Morriston Cardiac Centre nor the University Hospital Wales manage to consistently treat all Non-ST elevation ACS cases within the NICE recommended window of 96 hours. So our current “heart attack” service is optimal only for the minority of patients with STEMI. In recent years both regional Cardiac Centres have made significant improvements in the patient pathway through the extended role of cardiac nurse practitioners, electronic referral systems and dedicated ACS transfer bays. Nevertheless the annual audit by the British Cardiovascular Intervention Society (BCIS) has highlighted our poor performance in South Wales compared to our UK peer group (see figure 1 below).

Ideally all new admissions with suspected cardiac chest pain should be reviewed by a Consultant Cardiologist within 12-24 hours of admission. Following clinical risk stratification the appropriate patients need immediate referral to an interventional centre. Inevitably bed pressures and catheter laboratory capacity can become a significant rate limiting step in transfer but it is imperative that interventional centres are allowed to protect their transfer beds otherwise patients and referring hospitals face unreasonable delays and unnecessary cost pressures. A co-ordinated approach across Health Boards is now required to ensure patients receive timely senior clinical cardiology review on admission and then expedited transfer for angiography and revascularisation where appropriate.

Contact: Stephen Dorman 01792 701489
Stephen.Dorman@wales.nhs.uk

Two thoughts came into Austin’s mind when he was having his heart attack. One was that he wouldn’t get his long service award from the Royal Welsh Show. The other was that he wouldn’t make his 70th birthday.

Being fit and active is very important to Austin Davies, a family man and retired lorry driver, currently working as a store man in Builth Wells. Apart from being treated for a ‘hellish high’ cholesterol and blood pressure he had no other health problems.

Whilst in work, one Monday afternoon in April, Austin started to experience severe chest pains. His work colleagues were advised by the local GP surgery to dial 999 and after 35 minutes the paramedic team, travelling from Llandrindod Wells, promptly diagnosed a heart attack, relieved his pain and rang for an air ambulance.

Austin arrived in Morriston hospital and within 15 minutes received Primary PCI. His wife and family arrived some time later!

Back home on Wednesday afternoon he felt shell shocked but positive about his future and attended Cardiac Rehabilitation. He has consequently returned to work, received his long service medal from the Royal Welsh and is looking forward to celebrating his 70th Birthday.

Both Austin, his wife and work colleagues commented on how quickly he recovered and all drew a parallel between his recovery and the speed at which he received expert care both from the paramedics and at the Specialist Cardiac Centre.

The reorganisation of services to deliver primary PCI across south Wales over the last two years is a major success story. PPCI instead of thrombolysis is now offered to all STEMI patients in mid and west Wales and most in south east Wales. It is the result of collaboration between dedicated clinicians involved in delivering the service, Local Health Boards, the Welsh Ambulance Services Trust, South Wales Cardiac Network and the Welsh Health Specialised Services Committee.
Dial 999 - time is heart muscle

The South Wales Cardiac Network undertook the Primary Care Chest Pain Awareness project with support from the British Heart Foundation. The aim is to signpost those calling a GP practice with acute chest pain and associated symptoms to dial 999 immediately. The rationale is to expedite treatment previously by chemical thrombolysis and more recently to access primary PCI, in the knowledge that timely reperfusion preserves heart muscle and therefore cardiac function. If patients present to their GP practice, whether by telephone or in person, valuable time is wasted.

Resources were created and disseminated widely to enable a structured approach to dealing with such events, for both clinical and non-clinical staff.

Concerns were raised that this could increase the number of calls to the ambulance service. However, all chest pain calls were monitored both before and after the project. There was no increase in the total number of calls, suggesting that the call to the ambulance service would have been made anyway, it was just done in a more timely way.

The supporting resources (pictured) are available at www.wales.nhs.uk/siteplus/986/chestpain with a limited number of hard copies available to order from swcn@wales.nhs.uk.

A slide presentation can also be accessed at www.wales.nhs.uk/siteplus/986/chestpainpresentation enabling local areas to implement guidance with the supporting evidence, alongside the resources. The final project report is available in full on www.wales.nhs.uk/siteplus/986/cheastpain.

The project has also been published in two Primary Care journals: The Primary Care Cardiovascular Journal: www.pccj.eu/images/stories/CurrentIssuePdf/p115-118Turner.pdf and Management in Practice www.managementinpractice.com

For further information or support contact Alison Turner Alison.Turner@wales.nhs.uk or Marc Thomas Marc.Thomas@wales.nhs.uk.

Welsh Cardiovascular Society Male Voice Choir

A number of ‘hearty’ tuneful(ish) cardiologists in the South Wales Cardiac Network are members of the fledgling Welsh Cardiovascular Society male voice choir. The choir have already performed at two major medical functions, the British Cardiac Interventional Society meeting and the Royal College of Physicians/Welsh Society of Physicians’ joint meeting.

The choir has relied on tuition provided by four extremely patient teachers at Ysgol Gynradd Gymunedol Gymraeg Llantrisant led by Ms Lisa Veck, supported by Dr Catherine Burrell, a GP in Havefordwest.

The heterogeneous calibre of musical talent within the choir makes rehearsal an essential but sadly challenging (due to availability) task. However, it is hoped that the choir will continue and that they will perform again in the future although there are no immediate plans to compete on the Eisteddfod stage, Britain’s Got Talent etc.

Contact: Gethin Ellis 01443 443580 Gethin.Ellis@wales.nhs.uk

WCS Male Voice Choir at RCP/WCS Meeting 2011 (with their musical tutors)
BNP Testing to exclude Heart Failure in Primary Care in Cardiff & Vale UHB

Cardiff and Vale UHB has recently become the latest Health Board to offer B-type (or brain) natriuretic peptides (BNP) testing in primary care. This simple blood test offers a sensitive test for the exclusion of a diagnosis of heart failure.

Heart failure is a complex clinical syndrome in which a cardiac abnormality reduces the ability of the heart to pump blood. Chronic heart failure affects about 2% of the population. It has a substantial mortality, a major impact on quality of life and represents a very large cost to the NHS. The key to optimal management is early diagnosis and effective treatment.

Heart Failure Symptoms

Symptoms of heart failure typically include breathlessness, fatigue or oedema. These non-specific symptoms mean diagnosing heart failure by clinical means alone is difficult, and the majority of patients referred to heart failure clinics in areas which do not have primary care BNP testing do not have the condition. In patients with heart failure the peptide BNP is released by the heart into the bloodstream. BNP concentrations are therefore raised in patients with heart failure, and generally the higher the concentration, the more severe the disease.

NICE Guidance

NICE guidance specifies that doctors should arrange for people with suspected heart failure to be offered appropriate investigations. Patients who have symptoms of heart failure who have had an MI or patients with evidence of a previous MI on an ECG should be referred directly to a Heart Failure clinic for an echocardiogram and do not need to have a BNP test. Clinical assessment for symptoms and signs of heart failure, a chest x-ray to exclude chronic lung disease and blood tests to exclude conditions like anaemia should also be undertaken.

Patients suspected of having heart failure with no evidence of a previous MI should have a blood sample taken for BNP. A random SST (yellow top) sample together with a filled BNP request form should be sent to the laboratory. Request forms (PDF and Word) can be accessed via labhandbook.cardiffandvale.wales.nhs.uk or via the ‘Pathology test info’ link on the patient search page of Clinical Portal. The BNP form together with the sample can be sealed in the sample bag of a standard primary care request form, with the original form removed.

Patients with a normal BNP may be reassured that they do not have heart failure and another cause of breathlessness should be sought. Patients with a high level of BNP should be referred to their Local Heart Failure Clinic quoting the BNP level.

Cardiology Key Messages

- Careful clinical assessment for symptoms and signs of HF and other conditions which cause breathlessness, lethargy, and oedema is important.
- Patients with HF symptoms who have a history of MI or have evidence of a previous MI on an ECG do not need a BNP test - they should be referred directly to the local HF team.
- Other investigations such as blood tests, CXR and spirometry should be performed in primary care and if a cause of SOB is found this should be explored further.
- Once all these factors have been considered, a patient with HF symptoms and high BNP should be referred to the local HF team for further assessment.
- A normal BNP is great for excluding HF, and patients can be reassured that they don’t have heart failure.

For information on laboratory issues:
Contact: Dr Dev Datta 0292071 6844,
Dev.Datta@wales.nhs.uk

For information on clinical heart failure matters:
Contact: Dr Zaheer Yousef 029 2074 2972
Zaheer.Yousef@wales.nhs.uk

RESEARCH IN THE NETWORK

Running for Research Funds

James Wrench presents his cheque for the magnificent £2,500 he raised by running the London Marathon in April in aid of the Heart Research Fund for Wales.

Welsh Pharmacy Heart Health Initiative 2012 targeting high risk young patients

The aim of the Welsh Pharmacy Heart Health initiative is to determine the simplest screening tool for assessing risk and to modify those risks. It targets high cardiovascular risk young patients who do not access primary care due to deprivation and poor access, in community pharmacy setting, in order to give lifestyle advice and access to primary care for management of lifetime risk.

J Wrench GP; Prof J Halcox WHRI; Jon David, Pharmacist Milford Haven & Pembroke; Steve Simmonds WNPA lead on this work.

www.welshpharmacycvd.co.uk

Contact: James Wrench; 07875 848835;
jameswrench1@gmail.com
Breathlessness in older people — diastolic heart failure?
GPs — Can you help us with research?

Heart failure (HF) is becoming more common in Europe as the population ages. More than 50% of HF patients have normal global left ventricular (LV) systolic function and so they are presumed to have diastolic HF (DHF). Many older patients in the community with unexplained breathlessness on exertion may have DHF, especially if they have hypertension or diabetes mellitus.

In the Wales Heart Research Institute (Cardiff) we are investigating patients with DHF compared with breathless control subjects and healthy controls. The aims of our international project (MEDIA: The Metabolic Road to Diastolic Heart Failure) are to assess interactions between arterial stiffness and LV diastolic function and to refine the diagnostic strategy for DHF. We are measuring arterial function at rest, and changes in diastolic LV function from rest to exercise using tissue Doppler and speckle tracking echocardiography during semi-supine bicycle stress. The diagnostic utility of these tests will be compared against assays of serum N-terminal-pro-brain-natriuretic peptide.

A detailed protocol of our study is available upon request.

Contact: Dr Tamas Erdei - 029 2074 7747 extension 46046
dr.tamas.erdei@gmail.com

GPs you can help by sending:
- Clinical referrals of older (>60 years), breathless people with suspected diastolic heart failure to Professor Fraser or to the Heart Function Clinic (lead by Dr Zaheer Yousef Consultant Cardiologist)
- Referrals of older people (age>60 years) from your GP surgery to volunteer as healthy control subjects who have no known heart disease (offering them a very detailed screening of cardiovascular status).

We can send you an advertisement for your waiting room.

Potential cost savings to health care professionals:
- 20% of registers are labelling normotensives as hypertensives
- 20% less management required
- 90% of cases found do not need medical treatment

Cost Savings to LHBs
- 20% decrease in drug costs for hypertension and cardiovascular risk treatment.

Cost analysis beyond drug Rx
- Failure to diagnose — cost of disease burden £4700 pa

Proposed Outcomes:
- Compare differences of ‘True’ diagnoses of Hypertension, drug usage rates & costs, compliance & concordance rates between enhanced group and standard group.
- Measure morbidity data, adverse reaction rates and disease complications due to side effects of unnecessary treatment and morbidity/mortality.

References:
Systematic review: J Hodgkinson et al BMJ 2011;342:d3621
Modelling study: K Lovibond et al Lancet August 2011DOI:10.1016
NICE guidance: BMJ 2011;343:d4891
Contact: James Wrench 07875 848835
jameswrench1@gmail.com
The reorganisation of health services into Health Boards has brought together primary, secondary and tertiary care under one managerial organisation. However, even within Health Boards, communication between primary and secondary care is often sub-optimal. The complicated job plans of Cardiologists and General Practitioners as well as the working environment of the NHS often makes direct communication challenging. Reducing hospital referrals (emergency and outpatient) and refining primary care cardiac patient management decisions through specialist cardiology support may be helped considerably by providing a facility that enables General Practitioners to communicate with cardiologists promptly and effectively.

**Smartphones in Aneurin Bevan Health Board**

Cardiologists at the Royal Gwent Hospital have developed a service based on the use of a handheld smartphone to improve access of cardiologists to General Practitioners. A pilot study of the service was initially conducted and it has now been operational for over a year. The feedback on this service has been extremely positive; during the pilot study one General Practitioner’s response to the service was “…sorted out a medication query for me, very helpful”.

**Contact Details:**

Royal Gwent 07584 346747 (phone); 01633 255448 (fax); AdviceRGH.Cardiology.ABB@wales.nhs.uk;

Nevill Hall 07800 585354 (phone); 01873 732299 (fax); AdviceNHH.Cardiology.ABB@wales.nhs.uk

**E-mails at Cwm Taf Health Board**

A similar service has also started at Cwm Taf HB supported by Jon Brassey and the ATTRACT website team. Cardiologists at Cwm Taf, working with primary care leads and the ATTRACT team have developed an email-based cardiology advice service. Again, this has received positive feedback from primary care and the pilot study confirmed the effectiveness of the service. In the Cwm Taf pilot, potential referrals to cardiology were reduced (in 67% of cases an inpatient/outpatient referral was prevented).

**Contact Details:** [www.attract.wales.nhs.uk](http://www.attract.wales.nhs.uk)

Further work refining the services at Cwm Taf and ABHB continues with Cardiologists and primary care working together. A good example of joint working leading to individual patient and wider service benefit.

**Contact:** Gethin Ellis: 01443 443580 Gethin.Ellis@wales.nhs.uk

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**All Wales advice on the role of oral anticoagulants for the prevention of stroke and systemic embolism in people with atrial fibrillation**

In October 2012, the All Wales Medicines Strategy Group (AWMSG) endorsed guidance to support the safe and effective use of oral anticoagulant therapy in Wales. This was developed by a multiprofessional collaborative group with representation from Health Boards across Wales.

The guidance and statements relate to warfarin, dabigatran etexilate (Pradaxa®) and rivaroxaban (Xarelto®) for the indication of prevention of stroke and systemic embolism in people with atrial fibrillation. The statements highlight the importance of undertaking risk assessments for both stroke and bleeding and documenting the discussion between the clinician and the person about the risks and benefits of treatment. The statements cover choice of anticoagulant, prescribing responsibility, assessment of time in therapeutic range and Yellow Card reporting.

**In October 2012, the All Wales Medicines Strategy Group (AWMSG) endorsed guidance to support the safe and effective use of oral anticoagulant therapy in Wales.**

Poor adherence to any oral anticoagulant regimen is likely to be associated with increased risk of thrombosis or bleeding and it is recommended the prescriber makes efforts to understand and address the reasons for non-adherence before switching to an alternative medicine.

The full document and a summary are available on the All Wales Medicines Strategy Group website.

**Link to full document:** [www.wales.nhs.uk/sitesplus/986/awmsg-nov-2012-full](http://www.wales.nhs.uk/sitesplus/986/awmsg-nov-2012-full)

**Link to summary:** [www.wales.nhs.uk/sitesplus/986/awmsg-nov-2012-summary](http://www.wales.nhs.uk/sitesplus/986/awmsg-nov-2012-summary)


**Contact:** Ruth Lang: 029 2071 6900 awttc@wales.nhs.uk
All Wales News

CARDIAC DELIVERY PLAN and Consultation
The Cardiac Delivery Plan (CDP) is one of a growing suite of Welsh Assembly Together for Health Delivery Plans for key health conditions. It has been out for public consultation and the final version should be published well before the end of March. The aim is to reaffirm the standards set in the Cardiac Disease National Service Framework and to meet these standards by 2016. LHBS are required to take ownership and provide the services specified.

The South Wales Cardiac Network responded at some length to the consultation document applauding the aspirations, but expressing the concern that unless resourced, the CDP will remain an aspiration. It remains to be seen to what extent the final version will have taken on board consultation comments. Unfortunately, as with the rest of the NHS, there is little new funding to achieve many of these necessary service developments.

Outcome indicators and performance measures
Results Based Accountability methodology brings to NHS Wales Outcome Indicators and Performance Measures which the Assembly will use to measure the success of the Delivery Plans. The Networks and other stakeholders are working with the Assembly to ensure that what is measured will be useful to the service and the public.

NATIONAL AUDIT OF CARDIAC SERVICES 2012
The 2012 National Audit of Cardiac Services was held on 28 November in Wrexham, organised this year by the North Wales Cardiac Network. It covered secondary and tertiary services including cardiac surgery, electrophysiology, interventions including diagnostic angiography, PCI, STEMI and NSTEMI, and cardiac imaging. This was the second year a common template was used to enable easier comparison between different centres plus Liverpool Heart and Chest Hospital.

A report on the day will be produced and all presentations will be available on the Network website. (www.wales.nhs.uk/sitesplus/986/audit)

HEALTH AND WELLBEING BEST PRACTICE AND INNOVATION BOARD: CALL FOR EVIDENCE
The Minister for Health and Social Services has recently established a Health and Wellbeing Best Practice and Innovation Board. Jan Williams, Chair of the Board, is issuing a Call for Evidence, seeking to identify the levers and barriers in place that impact on innovation, adoption and dissemination of best practice across all sectors. The call for evidence will be issued in early December 2012.

British Heart Foundation Update

BHF Cymru welcomed two new team members to Wales in October and November; Joanne Oliver is the new area development manager covering Wales and will be the responsible for project managing all BHF prevention and care activity. This includes everything from the funded healthcare professional posts to Hearty Lives projects and delivery of the Healthy Hearts Kit, Health at Work, Chest Pain toolkit and schools activities – a busy time ahead! Joanne has come to us from the NHS and many will know her as she was a BHF Heart Failure Nurse specialist with Cardiff and Vale UHB.

Trish Buck is currently a Cardiac Rehabilitation nurse specialist in the Royal Glamorgan Hospital and will be seconded to BHF half time, for two years, to work with primary care; identifying training needs for staff in primary care and either signposting, or delivering training around cardiac care and service development for patients in the community with cardiac conditions.

Increasing Public Access Defibrillators
The BHF launched the ‘Saving Welsh Lives’ appeal at the National Eisteddfod this year. This appeal aims to raise funds to place public access defibrillators across Wales and ties in with the BHF funding two posts, working in partnership with the Welsh Ambulance Service, the South Wales Cardiac Network and Churches in Wales to ensure basic life saving skills and public awareness and confidence around PADs is increased. The two newly funded posts will work with a team of paramedics and WAST staff to deliver training across Wales with a view to increasing survival of out of hospital arrests and patient outcomes. These people should be in post in the New Year.

If you have any questions or would like to meet with any BHF staff please contact us directly.

Elaine Tanner 01656 648301; 07710 129411; tanners@bhf.org.uk; Joanne Oliver 07825 111371; oliverjo@bhf.org.uk; Trish Buck buckt@bhf.org.uk

Contact: Gaynor Williams 029 2050 3478 Gaynor.Williams@wales.nhs.uk
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Mel.Haworth@wales.nhs.uk

South Wales Cardiac Network
3rd Floor, 14 Cathedral Road
Cardiff, CF11 9LJ
www.swcn.wales.nhs.uk

Future Events and Conferences

Cardiac Physiology Cymru
2nd Annual Conference
“Into the Future of Cardiac Physiology”
Friday 12th April 2013
Glamorgan Conference Centre, University of Glamorgan (Treforest Campus)
For further information contact:
Angela Sims, Senior Lecturer in Cardiac Clinical Physiology
University of Glamorgan
amsims@glam.ac.uk

Electrophysiology & Device Therapy 2013
What Every Cardiologist Needs to Know
Friday 8th / Saturday 9th February
Mercure Holland House Hotel, Cardiff
For further information contact:
Peter O’Callaghan@wales.nhs.uk;
Mark.Anderson@wales.nhs.uk

All Wales Joint Heart Failure / Cardiac Rehabilitation Conference 2013
Further information to be announced in due course

Network Meeting Dates 2013

Network Board
Friday 1st February
Friday 24th May
Friday 27th September

Clinical Collaborative Group
South East Wales
Friday 8th March
Friday 19th July
Friday 22nd November

Clinical Collaborative Group
Mid and West Wales
Wednesday 16th January
Wednesday 8th May
Wednesday 11th September

SWCN Website
The website of South Wales Cardiac Network continues to develop (www.swcn.wales.nhs.uk). Please get in touch if you would like us to host any of your information or would like to contribute to the site!

Contact: Marc Thomas; 029 2019 6164; 07792 024979
Marc.Thomas@wales.nhs.uk

South Wales Cardiac Network
Rhwydwaith y Galon De Cymru
www.swcn.wales.nhs.uk