Mental Health Research Network Cymru

Full network application

on behalf of the

Wales Collaboration for Mental Health

September 2005

Mental Health Research Network Cymru
Rhwydwaith Ymchwil Iechyd Meddwl Cymru

"As someone who has been a service user for much of my life, a psychiatrist in Wales for a quarter of a century, and a senior officer of my professional body for a decade or more, I know how vital it is that all agencies work together for better mental health care. I am delighted to see that the proposal for a Mental Health Research Network Cymru would bring together the voice of patients, their carers and those trying to help them through all ages and all subspecialties. This is exactly the collaboration between clinical and research components that is needed to take policy forward across the Principality. "

Dr Mike Shooter
President, Royal College of Psychiatrists

"This network will be very important in helping to identify and promote good practice and drive standards of care for mentally disabled people upwards."

Phil Fennell
Hafal Carers Group

"The Mental Health Research Network Cymru will significantly improve the connectivity of academic research to service development and improvement. It will therefore have a direct positive impact upon the quality of mental health services provided to service users and their carers."

Phillip Chick
Director for Mental Health
Welsh Assembly Government

"It has been made clear to both the Health and Social Services Committee and the All Party Group on Mental Health that the commissioning process for mental health services requires substantial improvement. We need to know what services are demanded by patients and carers; which treatments work most effectively; and where the biggest gaps in services exist. I believe that a mental health research network would do much to strengthen the evidence base on which good commissioning depends."

David Melding
Chair of the National Assembly's All Party Mental Health Group

"I very much welcome the efforts of the WCMH in attempting to establish an all Wales mental health research network. Much is still to be done to properly support people living in Wales with severe mental illness. This network would help identify the areas of greatest need and help input better services."

Richard Mayes
Hafal Client and Media Volunteer

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Crynodeb Gweithredol

Mae hwn yn gais am statws rhwydwaith llawn gan Rwydwaith Ymchwil Iechyd Meddwl Cymru (MHRN Cymru). Os caiff ei gyllido, bydd MHRN Cymru yn gweithio gyda CRCC Cymru a phartneriaid allweddol eraill er mwyn darparu rhwydwaith ymchwil ar gyfer Cymru gyfan i hybu ymchwil o ansawdd uchel ar raddfa fawr ym maes iechyd meddwl a gofal cymdeithasol, sydd â goblygiadau o safbwynt gwasanaethau a thriniaethau a fydd yn helpu i godi safon gwaith ymchwil ym maes iechyd meddwl a gofal cymdeithasol ar draws Cymru. Mewn partneriaeth â Chydweithrediad Cymru dros Iechyd Meddwl (WCMH), bydd MHRN Cymru yn fan gwybodaeth ac yn fan cyfeirio canolog a fydd yn cysylltu defnyddwyr gwasanaeth a gofalwyr ag ymchwilwyr a gweithwyr proffesiynol ym maes iechyd meddwl. Un o flaenoriaethau cyntaf MHRN Cymru fydd gweithio gyda'r James Lind Alliance i sefydlu partneriaethau rhwng cleifion a chlinigwyr a datblygu cronfa ddata ar gyfer Cymru a fydd yn cofnodi'r elfennau o ansicrwydd sy'n bodoli ynghylch effeithiau triniaeth ar gyfer sgitsoffrenia. Bydd MHRN Cymru yn ymateb i bolisi'r llywodraeth, ond bydd hefyd yn helpu i lywio dulliau gweithredu a chyfrannu at y ddealltwriaeth a geir o salwch meddwl a'r cynnydd mewn achosion sy'n ymwneud ag iechyd meddwl yng Nghymru. Byddai'r rhwydwaith yn gweithio'n agos gyda Rhwydwaith Ymchwil Iechyd Meddwl y DU, ond byddai'n ymateb i faterion Cymreig hefyd. Os bydd rhwydweithiau cysylltiedig eraill yn cael eu cyllido, megis rhwydweithiau'n ymwneud â chlefyd Alzheimer neu anhwylderau niwro-ddirywiol, rydym yn cyflwyno cynlluniau sy'n amlinellu sut y gallai'r rhwydweithiau hyn gydweithredu. Yr opsiwn a gaiff ei ffafrio yw'r un a fyddai'n arwain at yr arbedion maint a gaiff eu cynnig gan rwydwaith iechyd meddwl unigol sy'n cael ei gyllido'n briodol ac sy'n ymwneud â'r holl grwpiau cleientiaid a'r holl feysydd o ran afiechydon sy'n gysylltiedig ag iechyd meddwl ac anabledd dysgu.

Pwy ydym ni

Mae'r cais hwn yn gynnig cydweithrediadol gan Brifysgol Cymru Abertawe ar ran Cydweithrediad Cymru dros Iechyd Meddwl (WCMH). Ein bwriad yw sefydlu a rhedeg Rhwydwaith Ymchwil Iechyd Meddwl cynhwysol ar gyfer Cymru gyfan, a fydd yn sicrhau bod gan ymchwil iechyd meddwl le canolog ar draws y GIG, gofal cymdeithasol a sectorau gwirfoddol yng Nghymru. Mae WCMH wedi bod yn gweithio tuag at sefydlu'r rhwydwaith hwn ers dros 12 mis. Yn ystod yr amser hwnnw, rydym wedi gosod y sylfeini ar gyfer rhwydwaith sy'n gweddu'n glir i flaenoriaethau Llywodraeth Cynulliad Cymru a blaenoriaethau Cydweithredu ar Ymchwil Glinigol y DU (UKCRC). Rydym wedi cymryd camau pwysig tuag at sefydlu partneriaeth gynhwysol ar gyfer Cymru gyfan, y mae'r claf a'r gofalwr yn chwarae rhan amlwg ynddi, gan dorri ar draws ffiniau sectoraidd, proffesiynol a daearyddol traddodiadol. Rydym wedi dechrau llunio cynllun dichonadwy ar gyfer symud tuag at gyllid allanol cynaladwy, ac rydym bellach mewn sefyllfa i ddatblygu rhwydwaith ymchwil iechyd meddwl o safon ryngwladol a fydd wedi'i leoli yng Nghymru.

Mae defnyddwyr / cleifion, gofalwyr, y sector gwirfoddol, y GIG a'r sector gofal cymdeithasol yn ymwneud â'r WCMH mewn modd cynhwysfawr, a chaiff hyn ei ategu gan brofiad academaidd o bob cwr o Gymru sydd o safon ryngwladol ac sy'n cwmpasu'r gwyddorau sylfaenol, epidemioleg, treialon clinigol ac ymchwil ansoddol yn ogystal â gwaith datblygu a gweithredu polisïau.

Aeth y Cydweithrediad ati i noddi a threfnu cynhadledd yng Nghaerdydd ym mis Ebrill 2004 er mwyn archwilio'r posibilrwydd o sefydlu rhwydwaith ymchwil iechyd meddwl yng Nghymru, a chafwyd anerchiadau gan yr Athro John Williams o WORD a'r Athro Til Wykes, sef Cyfarwyddwr Rhwydwaith Ymchwil Iechyd Meddwl Lloegr fel yr oedd bryd hynny. Mae'r ymateb cryf a chadarnhaol a gafwyd i'r gynhadledd honno, lle'r oedd nifer dda yn bresennol, ynghyd â'r ymateb i'r ymarfer hwn i bennu hyd a lled y gwaith wedi annog y Cydweithrediad i fynd â'r cynnig presennol yn ei flaen. Caiff Llywodraeth y Cynulliad ei chynrychioli ar gr_p llywio'r WCMH gan y cyfarwyddwr iechyd meddwl sy'n mynychu'r cyfarfodydd er mwyn darparu cyngor.

Pam iechyd meddwl?

Mae prosiect Sefydliad Iechyd y Byd ar faich afiechyd y byd wedi dangos bod salwch meddwl, gan gynnwys hunanladdiad, yn gyfrifol am dros 15 y cant o'r baich afiechyd mewn gwledydd megis y DU. Mae hyn yn fwy na'r baich afiechyd a gaiff ei achosi gan bob math o ganser. Gan ddefnyddio dull o fesur y blynyddoedd o fywyd a gaiff eu heffeithio gan afiechyd, anabledd a marwolaeth (DALY), dim ond isgemia'r galon oedd yn uwch nag iselder ysbryd difrifol mewn rhestr o'r prif gyfranwyr i faich afiechyd economïau marchnad sydd wedi hen ennill eu plwyf. Roedd sgitsoffrenia, anhwylder deubegynol, anhwylder obsesiynol cymhellol, anhwylder panig ac anhwylder straen ôl-drawmatig hefyd yn cyfrannu'n sylweddol at yr holl faich salwch y gellir ei briodoli i anhwylderau meddyliol (Murray et al, 1999).

Mae iechyd meddwl yn un o flaenoriaethau'r llywodraeth yng Nghymru a Lloegr. Mae Llywodraeth Cynulliad Cymru wedi gosod iechyd meddwl ymhlith y tair blaenoriaeth uchaf o ran iechyd yng Nghymru. Mae Llywodraeth y Cynulliad hefyd wedi mabwysiadu strategaeth 10 mlynedd ar gyfer Gwasanaethau Iechyd Meddwl Oedolion er mwyn gwella, moderneiddio a datblygu gwasanaethau iechyd meddwl yng Nghymru fel eu bod yn darparu'r gofal gorau posibl ar gyfer y rheiny sydd â phroblemau iechyd meddwl. Mae'r strategaeth wedi'i seilio ar bedair egwyddor: Tegwch – gwasanaethau sydd ar gael i bawb ac a gaiff eu defnyddio yn ôl angen yr unigolyn; Grymuso – integreiddio defnyddwyr a'u gofalwyr yn y gwaith o gynllunio gofal a gwerthuso gwasanaethau; Effeithiolrwydd – darparu triniaethau ar gyfer symptomau ac achosion, atal dirywiad a lleihau'r niwed posibl er mwyn gwella ansawdd bywyd; Effeithlonrwydd – gwerth gorau ac effeithlonrwydd wrth ddarparu gwasanaethau. Caiff y gwerthoedd a'r pedair egwyddor hyn eu hadlewyrchu yn ein cais i ddarparu rhwydwaith ymchwil iechyd meddwl ar gyfer Cymru.

Beth rydym yn ei gynnig

Nod ein cynigion ar gyfer Rhwydwaith Ymchwil Iechyd Meddwl Cymru yw: (i) gwella'r modd y caiff ymchwil ei gydlynu yn Llywodraeth Cynulliad Cymru ac mewn maes a gaiff flaenoriaeth yn y GIG; (ii) gwella cyfranogiad defnyddwyr gwasanaeth; (iii) cynnal a gwella ansawdd ymchwil; (iv) gwella'r modd y caiff ymchwil a gofal cleifion eu hintegreiddio; (v) darparu gwybodaeth o ansawdd uchel sydd wedi'i seilio ar dystiolaeth ac sy'n cynyddu mynediad i'r driniaeth a'r gofal gorau; ac (vi) ehangu cyfranogiad mewn ymchwil, a hynny drwy gyfrwng cysylltiadau a thrwy rwydweithio â gweithwyr proffesiynol ym maes iechyd a gofal cymdeithasol sy'n gweithio mewn lleoliadau trefol a gwledig, a defnyddwyr gwasanaeth sy'n adlewyrchu amrywiaeth y boblogaeth. Oherwydd rhesymau gweinyddol, cafodd y cais hwn ei gyflwyno o Brifysgol Cymru Abertawe. Fodd bynnag, dylid nodi bod y sefydliadau cydweithrediadol yn bartneriaid cyfartal yn y cynnig hwn, ac y bydd cyfrifoldebau'r bartneriaeth reoli yn cael eu rhannu.

Credwn y dylai'r rhwydwaith ymwneud â phob gr_p o gleientiaid a phobl o bob oedran sy'n cael eu heffeithio gan faterion yn ymwneud ag iechyd meddwl ac anabledd dysgu, gan gynnwys pobl h_n. Bydd y rhwydwaith yn parhau i ddefnyddio dull cynhwysol o ennill ymrwymiad a dod o hyd i atebion i'r tasgau yr ymwneir â hwy wrth ddarparu rhwydwaith ymchwil iechyd meddwl trosfwaol ar gyfer Cymru.

Credwn fod y cais hwn yn ymwneud â budd-ddeiliaid ar raddfa eang iawn gan ei fod yn adeiladu ar sylfeini cadarn y WCMH. Rydym yn ymwybodol o gynigion perthnasol eraill, er enghraifft, ym maes anabledd dysgu a chlefyd Alzheimer. Byddwn yn parhau i archwilio cysylltiadau â rhwydweithiau arfaethedig eraill sydd naill ai'n mynd i'r afael â gwahanol grwpiau o gleientiaid / meysydd o ran afiechydon (megis pobl ag anabledd dysgu neu glefyd Alzheimer) neu wahanol gyfnodau bywyd (megis pobl h_n neu blant a phobl ifanc yn eu harddegau). Byddwn yn parhau i hwyluso'r gwaith o ddod â'r rhain at ei gilydd i greu un Rhwydwaith Ymchwil Iechyd Meddwl ar gyfer Cymru gyfan sydd â chynrychiolaeth dda o bawb sy'n ymwneud â'r maes, ond a fydd yn parhau i ganolbwyntio'n ofalus ar orchmynion yr UKCRC a chydweithio'n agos â'r Rhwydwaith Ymchwil Iechyd Meddwl sydd eisoes wedi'i sefydlu yn Lloegr. Un o flaenoriaethau cyntaf MHRN Cymru fydd gweithio gyda'r James Lind Alliance i sefydlu partneriaethau

rhwng cleifion a chlinigwyr a datblygu cronfa ddata ar gyfer Cymru, y byddem yn ei hehangu i weddill y DU yn ddiweddarach, a fydd yn cofnodi'r elfennau o ansicrwydd sy'n bodoli ynghylch effeithiau triniaeth ar gyfer sgitsoffrenia.

Er mwyn ymateb i'r cwestiynau a osodwyd gan WORD, rydym yn disgrifio sut y byddem yn sefydlu Rhwydwaith Ymchwil Iechyd Meddwl Cymru a fyddai'n rhychwantu gwahanol grwpiau oedran, gwahanol grwpiau o gleientiaid a gwahanol feysydd o ran afiechydon. Rydym yn ymwybodol o gynigion eraill mewn meysydd sy'n gysylltiedig ag iechyd meddwl, megis anabledd dysgu a chlefyd Alzheimer. Gall pob un ohonynt gyflwyno achos cryf dros gadw eu statws unigol. Fodd bynnag, os nad yw adnoddau'n caniatáu i hynny ddigwydd, byddem yn dadlau mai'r WCMH all gyflwyno'r achos cryfaf dros rwydwaith thematig trosfwaol a all ddwyn ynghyd ystod eang o bobl sy'n ymwneud â'r maes a sicrhau bod gan bob un ei le a'i rôl benodol mewn rhwydwaith o'r fath. Rhoddir disgrifiad yn y cais o'r arbedion maint y gellid eu hennill yn y modd hwn. Rydym hefyd yn egluro'r berthynas â CRCC Cymru a rhwydweithiau thematig eraill, gan ddangos sut y byddem yn cydweithio er mwyn darparu isadeiledd ar gyfer treialon clinigol ac astudiaethau eraill sydd wedi'u cynllunio'n dda, sydd â goblygiadau o safbwynt pobl, gwasanaethau a thriniaethau.

Y ffordd ymlaen

Credwn y dylid sefydlu Rhwydwaith Ymchwil Iechyd Meddwl ar gyfer Cymru gyfan. Dylai'r Rhwydwaith gael cyllid digonol er mwyn adlewyrchu ei rychwant daearyddol a thematig, a dylai gael ei gysylltu'n briodol â Rhwydwaith Ymchwil Iechyd Meddwl y DU er mwyn sicrhau bod pobl Cymru yn elwa ar ragoriaeth y gwaith ymchwil a wneir ym maes iechyd meddwl yng Nghymru a gweddill y DU.

Yr Athro Keith Lloyd
Prifysgol Cymru Abertawe
Ar ran Cydweithrediad Cymru dros Iechyd Meddwl
Medi 2005

Summary

Here is an application, in response to a call from the Welsh Office of Research and Development, for full network status on behalf of Mental Health Research Network Cymru (MHRN Cymru). This report builds on the case set out in our earlier scoping study report submitted to WORD in May 2005 (Lloyd et al 2005). A copy of that report can be downloaded from: www.word.wales.gov.uk/content/networks/mentalhealth-e.pdf. If funded, MHRN Cymru will work with CRCC Cymru and other key partners to provide an all Wales research network with a dedicated research professional network to support large scale, high quality research in mental heath and social care which has implications for services and treatments which will help to raise the standard of mental health and social care research throughout Wales, the UK and internationally. In partnership with the Wales Collaboration for Mental Health and the James Lind Alliance, MHRN Cymru will act as a central point of information and reference, connecting service users and carers to researchers, mental health professionals. The network would work closely with the UK Mental Health Research Network but also be responsive to Welsh issues. If other related networks, for example, in Dementia and Neurodegenerative disorders are funded, then we set out plans for how the networks could collaborate. The preferred option is for the economies of scale offered by a single, appropriately funded, mental health network inclusive of all client groups and disease areas in mental health and learning disability.

Who we are

This application is a collaborative bid by the University of Wales Swansea on behalf of the Wales Collaboration for Mental Health (WCMH). We propose to set up and run an inclusive all Wales Mental Health Research Network that will embed mental health research across the NHS, Social care and voluntary sectors in Wales. WCMH has been working towards setting up this network for over 12 months. In that time we have laid the ground work for a network with a clear fit to WAG and UKCRC priorities. We have taken significant steps towards establishing an all Wales inclusive partnership with clear patient carer involvement; cutting across traditional sector, professional and geographical boundaries. We have begun to set out a viable plan for moving towards sustainable external funding and are now in a position to develop a world class mental health research network based in Wales.

WCMH has comprehensive user / patient, carer, voluntary sector; NHS and social care involvement backed up by world class all Wales academic experience from basic sciences through epidemiology, clinical trials and qualitative research to policy development and implementation.

The Collaboration sponsored and organised a conference in Cardiff in April 2004 to explore the possibility of establishing a mental health research network in Wales, addressed by Professor John Williams, of WORD, and Professor Til Wykes, Director of the, then, Mental Health Research Network for England. The strong and positive response to that well-attended conference and to this scoping exercise has encouraged the Collaboration to proceed with the current proposal. The Assembly government is represented on the steering group of the WCMH by the director of mental health who attends in an advisory capacity.

Why mental health?

The World Health Organisation's global burden of disease project has revealed that mental illness, including suicide, accounts for over 15 percent of the burden of disease in countries such as the UK. This is more than the disease burden caused by all cancers. Using the Daily Adjusted Life Years measure, major depression ranked second only to ischemic heart disease in magnitude of disease burden in established market economies. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contributed significantly to the total burden of illness attributable to mental disorders (Murray et al 1999).

Mental health is a Government priority in Wales and England. The Welsh Assembly Government has made mental health one of the top 3 health priorities in Wales and has adopted a 10 year Strategy for Adult Mental Health Services to improve, modernise and develop mental health services in Wales to a position where they provide the best possible care for those with mental health problems. Four principles underpin the Strategy: Equity - services that are available to all and allocated according to individual need; Empowerment - users and their carers are to be integrated into care planning and evaluation of services; Effectiveness - the provision of treatment of symptoms and causes, the prevention of deterioration and reduction of potential harm to improve the quality of life; Efficiency - best value and efficiency in service provision. These four principles and values are reflected in our bid to provide a mental health research network for Wales.

What we propose

Our proposals for the Mental Health Research Network Cymru seek to: (i) improve the co-ordination of research in a Wales Assembly Government and NHS priority area; (ii) improve service user participation; (iii) maintain and enhance the quality of research; (iv) improve the integration of research and patient care; (v) provide high quality evidence-based information which increases access to the best treatment and care; and (vi) widen participation in research through links and networks with health and social care professionals covering urban and rural settings, and service users reflecting the diversity of the population. For administrative reasons this application has been submitted from the University of Wales Swansea. However, it should be noted that the collaborative organisations are equal partners in this proposal, and that the responsibilities of the managing partnership will be shared.

We believe the network should cover all client group and lifespan areas of mental health and learning disability including old age. The network will continue to take an inclusive approach to gaining commitment to, and finding solutions to, the tasks involved in providing an overarching mental health research network for Wales.

We believe that this application has very wide stakeholder involvement as it builds on the well established foundations of the WCMH. We are aware of other related bids in, for example, learning disability and Dementias and Neurodegenerative Disorders. We will continue to explore cross-linkages with other proposed networks addressing either client group / disease areas (such as learning disability or Dementias and Neurodegenerative Disorders) or life phases (such as old age or childhood and adolescence) and to facilitate their coming together to make a single All Wales Mental Health Research Network with good representation of all interests whilst still retaining a tight focus on UKCRC imperatives and working closely with the already established Mental Health Research Network in England. One of the first priorities for MHRN Cymru will be to work with the James Lind Alliance to set up patient-clinician partnerships and develop in Wales, and then extend to the whole UK, a Database of Uncertainties about the Effects of Treatment (DUETs) for Schizophrenia.

In response to the questions set by WORD, we describe how we would set up Mental Health Research Network Cymru spanning age groups, client groups and disease areas. We have worked closely with other bids in mental health related areas such as learning disability and Dementias and Neurodegenerative Disorders disease. Each can make a strong case for its stand-alone status. However, if resources do not permit, then we would argue that WCMH can make the strongest case for an overarching mental health network that can bring together a wide range of interests while ensuring that each has its identified place and role in such a network. The economies of scale that could be achieved in this way are described. We also clarify relationships with CRCC Cymru and other thematic networks indicating how we would work together to provide the infrastructure for clinical trials and other well designed studies that have implications for people, services and treatments.

The way forward

We believe that an All Wales Mental Health Research Network (MHRN) should be established that is adequately funded to reflect its geographical and thematic scope and is appropriately aligned with the UK MHRN to ensure that the population of Wales benefits from the excellence of mental health research in Wales and the wider UK.

Professor Keith Lloyd
University of Wales Swansea
On behalf of Wales Collaboration for Mental Health
September 2005

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Wales Research and Development Networks

Section A

Application for full network status by

Rhwydwaith Ymchwil Iechyd Meddwl Cymru

Mental Health Research Network Cymru

Mental Health Research Network Cymru
Rhwydwaith Ymchwil Iechyd Meddwl Cymru

1. Name, address and institution of lead applicant

Professor Keith Lloyd, School of Medicine, University of Wales Swansea, Wales SA2 8PP.
k.r.lloyd@swansea.ac.uk

On behalf of Wales Collaboration for Mental Health.

2. Names, addresses and institutions of any co-applicants

MHRN-Cymru has broad stakeholder involvement across the voluntary sector, Social Care, the National Health Service, professional bodies and the university sector. Our academic co-applicants are drawn from Bangor, Cardiff Glamorgan and Swansea Universities. They are drawn from many disciplines and are of the highest quality. We have also already established strong working links with the UK Mental Health Research Network. With the James Lind Alliance we are proposing to establish the first ever database of uncertainties about the effects of treatments (DUETs) for Schizophrenia.

Voluntary Sector:

- *Awetu:* All Wales Black and Minority Ethnic Mental Health Group: Suzanne Smith, Director;
- *Hafal:* John Abbott, Public Affairs Manager;
- *MIND Cymru:* Ms Lindsay Foyster* and Ms Ruth Coombs, Policy Manager.

Social Care:

- *Association of Directors of Social Care:* Helena Thomas.

NHS & Professional Bodies:

- *All Wales Senior Nurse Advisory Group:* Mandy Rayani*, Swansea NHS Trust. Mr Mervn Townley, Gwent Heath Care NHS Trust;
- *Local Health Boards:* Andy Williams, Chief Executive, Powys LHB;
- *National Public Health Service for Wales:* Dr Lyn Harris, Professor Ronan Lyons, Professor David Fone;
- *NHS Trusts Chief Execs. Group:* Tom Woods, Corporate Support Manager;
- *Learning disability services:* Dr Val Anness, Consultant in Learning Disabilities Psychiatry, Bro Morgannwg NHS Trust, Regional Adviser for Wales for the Royal College of Psychiatrists and Chair of the Specialist Training Committee for Psychiatry in Wales; Dr Helen Matthews, Consultant in Learning Disabilities Psychiatry, Pembroke and Derwen NHS Trust, and Chair of the Faculty of Learning Disability Psychiatry of the Royal College of Psychiatrists in Wales;
- *Medical Directors Group:* Dr Stephen Hunter, Gwent HC NHS Trust;
- *Pontypridd and Rhondda NHS Trust:* Paul Davies, Deputy Director of Nursing and Quality;
- *Psychiatry:* Professor Richard Williams*, Consultant Child & Adolescent Psychiatrist, Gwent Healthcare NHS Trust;
- *Royal College of General Practitioners' Wales Mental Health in Primary Care Network:* Dr Huw Lloyd*, Core Group Lead;
- *Royal College of Psychiatrists:* Dr Mark Winston* (representative of the Welsh Division's Executive Committee); Dr Val Anness (Regional Adviser); Dr Helen Matthews, Chair of the Faculty of Learning Disability Psychiatry of the Royal College of Psychiatrists in Wales.

University Co-applicants:

Cardiff University:

Professor Nick Craddock*, Professor of Psychiatry;
Professor Frank Dunstan, Professor of Medical Statistics;
Professor David Fone, Professor, Centre for Health Sciences Research;
Professor David Felce, Professor of Learning Disability Research;
Professor Mike Kerr*, Professor of the Psychiatry of Learning Disability;
Professor Mike Owen, Professor of Psychological Medicine;
Professor Anita Thapar, Professor of Child & Adolescent Psychiatry;

- Forensic Mental Health:

Dr Nicola Gray, Reader, School of Psychology, Cardiff University;
Professor Bob Snowden, School of Psychology, Cardiff University;
Professor Pamela Taylor, Professor of Forensic Psychiatry, Cardiff.

- North Wales Department of Psychological Medicine, Bangor:

Professor David Healy, Professor of Psychological Medicine;
Dr Richard Tranter, Senior Lecturer in Psychological Medicine.

- North Wales Section of Psychological Medicine, Wrexham:

Professor David Menkes*, Professor of Psychological Medicine;
Dr Seren Roberts, Research Officer.

University of Glamorgan:

Dr Anne Fothergill*, Principal Lecturer and Mental Health Field Leader;
Professor Ruth Northway, Professor of Learning Disabilities Nursing;
Professor Jonathan Richards, Professor of Primary Care;
Professor Paul Rogers, Professor of Forensic Nursing;
Dr Gill Salmon, Senior Lecturer in Child and Adolescent Mental Health;
Mr Mervyn Townley, Consultant Nurse, Child and Adolescent Services, Gwent Healthcare NHS Trust and University of Glamorgan; Professor Richard Williams*, Professor of Mental Health Strategy.

University of Wales Bangor:

Mr Gareth Morgan*, Project Manager, Wales Collaboration for Mental Health;
Dr Catherine Robinson, Director (N.Wales) & National Convenor, AWARD;
Professor Ian Russell, Professor of Public Health;
Professor Bob Woods*, Professor of Clinical Psychology of Older People.

University of Wales Swansea:

Professor Paul Bennett, Professor of Health Psychology;
Dr Lesley Griffiths, Reader in Medical Sociology;
Professor Keith Lloyd, Professor of Psychological Medicine;
Professor Andy Parrott, Professor of Psychology;
Professor Ceri Phillips, Professor of Health Economics;
Professor Gary Rolfe, Professor of Mental Health Nursing;

Helen Snooks, Director (Mid & West Wales) & National Chair, AWARD;
Professor Johannes Thome*, Professor of Psychiatry;
Professor Rodger Wood, Professor of Psychology.

*Individuals marked with an asterix form the management steering group.
Many other individuals and organisations contributed to the production of this report by attending events and meetings or by sending in written comments.

Other Collaborators

In addition to the formal co-applicants on our bid, we have established a number of collaborations and intentions of close working with applicants on other full network status, with applicants for infrastructure support grants, and with the Welsh consortium bid for CRCC Cymru. We already have close working links with the UK Mental Health Research Network (UK MHRN) as Professor Lloyd is a member of the UK MHRN adoptions committee. Additionally, we have begun to work with the James Lind Alliance to set up a Database of Uncertainties about the Effects of Treatment for schizophrenia.

3. What theme or sector will your proposed network cover?

A Mental Health Research Network Cymru would cover all client group, lifespan phases and disease areas of mental health and learning disability including old age, as does the UK MHRN. We believe there are strong cases for thematic networks in Dementias and Neurodegenerative Disorders, and in learning disability. However, we also set out strategies how related networks not separately funded could be managed within MHRN-Cymru.

This application has very wide stakeholder involvement as it builds on the well established foundations of the WCMH and the work conducted for the scoping study report. We are aware of other related bids in, for example, learning disability and Dementias and Neurodegenerative Disorders. We have explored cross-linkages with these other bids. Indeed, the leads from each of those bids are also co-applicants on this submission. In this document we set out a range of options, offering varying economies of scale between separately funded thematic bids for mental health, learning disability and Dementias and neurodegenerative disorders. We also discuss how the proposed risk assessment network could be incorporated into MHRN-Cymru if it is not separately funded as an infrastructure bid. In summary, we contend that many of the aims of the above networks could be achieved through an enhanced mental health research network.

We will continue to develop cross-linkages with other proposed networks addressing either client group / disease areas (such as learning disability or Dementias and Neurodegenerative Disorders) or life phases (such as old age or childhood and adolescence) and to facilitate their coming together to make a single All Wales Mental Health Research Network with good representation of all interests whilst still retaining a tight focus on UKCRC imperatives and work. The way in which we will achieve this is set out in an indicative 3 year work plan. That work plan is informed not only by research imperatives, but also by the priorities and targets set out in *Designed for Life* (WAG 2005).

In our application for the Mental Health Research Network Cymru we set out proposals to: (i) improve the co-ordination of research in Wales Assembly Government and NHS priority areas; (ii) improve service user participation; (iii) maintain and enhance the quality of research; (iv) improve the integration of research and patient care; (v) provide high-quality evidence-based information which increases access to the best treatment and care; and (vi) widen participation in research through links and networks with health and social care professionals covering urban and rural settings, and service users reflecting the diversity of the population. This application for full network status has been submitted from the University of Wales Swansea. However, it should be noted that the collaborative organisations are equal partners in this submission, and that the responsibilities of the managing partnership will be shared.

We would work closely with the UK MHRN. Details of the UK MHRN's research groups are given in Appendix A. The projects listed there illustrate the way in which whole life cycle and client group coverage has been achieved there. In this way we would align ourselves on UK wide basis with the UK MHRN that also covers mental health problems from childhood to old age, learning disability and forensic psychiatry. In England there is a separate thematic network for Dementias and neurodegenerative disorders.

4. What experience and expertise do you bring to this area?

This application for full network status is a collaborative bid by the University of Wales Swansea on behalf of the Wales Collaboration for Mental Health (WCMH) and other stakeholders. We bring together the voluntary sector, users and carer organisations, health and social care organisations and professional bodies. This is backed up by the highest quality academic input from Bangor, Cardiff, Glamorgan and Swansea. In Wales we have major strengths in basic and clinical research. These strengths provide excellent opportunities to benefit the population of Wales by early translation of findings from "bench to community" as well as through policy research and service evaluation. We have also already established strong working links with the UK Mental Health Research Network. With the James Lind Alliance we are proposing to establish the first ever database of uncertainties about the effects of treatments (DUETs) for Schizophrenia.

Wales Collaboration for Mental Health

WCMH has comprehensive user / patient, carer, voluntary sector, NHS and social care involvement backed up by world class all Wales academic experience from basic sciences through epidemiology, clinical trials and qualitative research to policy development and implementation. Whilst retaining a focus on Welsh priorities and needs we would also build on existing close links with the UK Mental Health Research Network. Professor Lloyd was deputy director of Westhub of the English Mental Health Research Network when it was first established and is now a member of the UK MHRN adoptions committee.

WCMH has been working towards setting up this network for over 12 months. In that time we have laid the groundwork for a network with a clear fit to WAG and UKCRC priorities. We have taken significant steps towards establishing an all Wales inclusive partnership with clear patient carer involvement; cutting across traditional sector, professional and geographical boundaries. We have begun to set out a viable plan for moving towards sustainable external funding and are now in a position to develop a world class mental health research network based in Wales.

The Collaboration sponsored and organised a conference in Cardiff in April 2004 to explore the possibility of establishing a mental health research network in Wales, addressed by Professor John Williams, of WORD, and Professor Til Wykes, Director of the, then, Mental Health Research Network for England. The strong and positive response to that well-attended conference and to this scoping exercise has encouraged the Collaboration to proceed with the current proposal. The Assembly government is represented on the steering group of the WCMH by the director of mental health who attends in an advisory capacity.

Mental health research in Wales

As part of the scoping study completed in May 2005 a review of current research activity in mental health and related fields was conducted (available at www.word.wales.gov.uk/content/networks/mentalhealth-e.pdf). Several approaches were used. The first step was to consult the National Research Register (NRR). This is a database of ongoing and recently completed research projects funded by, or of interest to, the United Kingdom's National Health Service (NHS). Data is supplied to the NRR by some 350 organisations (NHS Trusts, national and regional funding programmes, universities, charities) in England, Scotland and Wales.

A trawl of the NRR revealed approximately 60 projects listed under Wales and mental health. The majority of these give no record of the source of funding. This is at odds with the clear evidence of considerable research activity within the field in Wales. Full details of NRR Projects identified are given at appendix B of the scoping study report available from www.word.wales.gov.uk/content/networks/mentalhealth-e.pdf

We then approached the R&D offices of individual Trusts. It was not possible to get a full return of this data within the timescale required for the report. Nonetheless, it seems likely that at Trust level this data is held with reasonable efficacy. However, individual trusts and LHBs do not use compatible common databases to capture this information.

Finally, we approached individual universities. These held good records of their own staff's activity but this did not cross reference well with NHS records. The research activity that was returned by of the various academic centres is summarised below. Once again, there are omissions and inconsistencies but the overall picture is of considerable and vibrant activity of world class standard.

Cardiff University

The Department of Psychological Medicine (www.cardiff.ac.uk/medicine/psychological_ medicine/) is one of the largest departments of Psychiatry in the UK and has an outstanding international reputation in clinical and basic research. The annual research income exceeds £3.5m (with £5m awarded in the last year) and there are over 80 contract research staff. Principal investigators within the Department hold funding from US, European and UK funding bodies and industry, including programme grants for the genetic epidemiological investigation of schizophrenia (MRC); bipolar disorder (Wellcome Trust); Alzheimer's disease (MRC) and child psychiatry (MRC).

There is extensive expertise in large-scale, collaborative multi-site projects involving recruitment and detailed clinical assessment of large samples of patients, together with the management of the resulting datasets. There is rapidly expanding expertise in forensic psychiatry.

The long-established and internationally renowned Welsh Centre for Learning Disabilities has £500-800k annual research income from Government Departments, NHS, HTA, Wellcome Trust, European Union and charities.

The Department of Psychology is internationally recognised for its work on risk assessment and dual diagnosis offenders. The Centre for Health Sciences Research, and the Department of Epidemiology, Statistics and Public Health, have a major research focus on the common mental disorders in the general population together with Swansea.

North Wales Section of Psychological Medicine (NWSPM)

Together with IMSCaR colleagues Professor Russell (Director and Clinical Trialist), Dr Hughes (Acting Director of Centre for the Economics of Health), there is particular expertise in drug trials, and are actively developing links with academics and clinicians across Wales.

There is an active R&D link between WCMH and the Wales Mental Health in Primary Care (WaMH in PC) network. Current project aims are to attract research funding for clinical trials relevant to WAG priorities, for example assessment and treatment of depression in vulnerable populations.

University of Wales Bangor

University of Wales Bangor has a strong track record of research related to mental health and psychological disturbance across the life-span - from cognitive neuroscience approaches to psychological therapies - in the internationally renowned School of Psychology and Institute of Medical & Social Care Research.

Recent randomised controlled trials include mindfulness for relapse-prevention in depression, intervention for conduct disorder in children; comparison of psychological interventions for alcohol abuse, CBT for psychosis, and reminiscence therapy for people with dementia and their carers. Research on family care-giving in the context of mental health problems is also on-going.

Projects have been externally funded by the MRC, Wellcome Trust, Department of Health and the Wales Office of Research and Development.

The School of Psychology, which currently hosts the Centre for Mental Health Services Development for Wales, is co-located with AWARD in North Wales. www.bangor.ac.uk/research

Glamorgan University

The School of Care Sciences, together with the Welsh Institute for Health and Social Care within that school, has world-class strengths, experience and a good research record in the mental health arena. These include:

- A strong academic focus on developing and researching evidence-based and values-based policy, strategy and service design;
- Extensive experience in applied and both qualitative and quantitative research methods and expertise in conducting systematic reviews;
- A portfolio of forensic nursing research;
- A highly successful Unit for Development in Intellectual Disabilities;
- Considerable expertise in the arenas of corporate, clinical and research governance.

University of Wales Swansea

Swansea University's new School of Medicine has seen extensive investment from the Welsh Assembly Government with the appointment of 15 Professors in the last 12 months and a recent successful bid for an Institute of Life Sciences bringing £50 million funding to create a truly world class research facility with unique supercomputing capabilities. In the School of Medicine research is encompassed within two broad groupings: Bio Medical Research (BIMR) and population based science & epidemiology (CHIRAL). The emphasis is on high quality intra- and cross-disciplinary research which reflects the post-genomic era and that seeks interactions with other researchers in Swansea, the local NHS Trusts, nationally and internationally. Research funding comes from the UK research councils, National Institutes of Health (USA), the EU, charities, the Government, the NHS and industry. Co-location with AWARD South and West Wales. Within the school the social and epidemiological psychiatry group works closely with the molecular psychiatry and psychopharmacology group to conduct truly cross disciplinary research of international quality in the field of psychiatry.

Within the School of Health Science there are strong academic foci on mental health nursing practice development and qualitative methods, communication, social care delivery and team working; health economics and ethics.

Within the School of Psychology there is a major focus on health psychology and drug abuse. This research is currently exploring a range of issues in the area of health psychology. This includes a focus on drug addiction and applied research which aims to help individuals and communities tackle drug misuse and its consequences. Professor Rodger Wood is known internationally for his work on the impact of orbito-frontal brain injury on cognition and social functioning.

Professor Lloyd is a member of the adoptions committee of the UK Mental Health Research Network. Prior to moving to Wales 12 months ago, he was deputy director of the Westhub of the UK Mental Health research network. As director of R&D for Devon Partnership NHS Trust he demonstrated his network building skills by creating a unified research

governance system for all the mental health trusts in SW England covering a population of 1.75 million and working with NHS , social care, voluntary sector and academic partners.

Database of Uncertainties about the Effects of Treatments (DUETs)

A further development currently in progress would see the network, HAFAL and MIND CYMRU working with the James Lind Alliance to identify and publish patients' and clinicians' questions about the effects of treatments that cannot be answered by referring to up-to-date systematic reviews of existing research evidence. See appendix B for details of the first meeting of a group to develop the DUETs project in Wales with Sir Iain Chalmers.

The James Lind Alliance

Much has been written about how to find the evidence to practise evidence based medicine. Far less is known about what to do when there is uncertainty about a treatment or course of action. The James Lind Alliance (JLA) has been established to help identify and confront uncertainties about the effects of treatments considered important by patients and clinicians. The JLA will promote two principles: first, that addressing uncertainties about the effects of treatments should become accepted as a much more routine part of clinical practice; and second, that patients and clinicians should work together to agree which, among those uncertainties, matter most and thus deserve priority attention.

Specifically, the JLA will facilitate the identification of research priorities shared by patients and clinicians, hence its strapline – 'tackling treatment uncertainties together'. This approach to identifying research priorities remains very rare. Most funding bodies consult professionals when they decide which areas of research to support, and sometimes patients and/or the public are involved in the design of particular projects. But few actively seek to establish which areas both professionals and patients agree require further investigation.

The JLA wishes to promote such a joint approach for two reasons. First, identification of uncertainties about the effects of treatments deemed important both by patients and by clinicians is important in its own right, and second, because those who fund and support therapeutic research should take particular notice of these shared priorities.

The James Lind Alliance will:

- establish a network of affiliate organisations and individuals who support and wish actively to promote the principles set out above.
- help to develop a Database of Uncertainties about the Effects of Treatments (DUETs) containing questions about the effects of treatments being asked by patients and clinicians which cannot currently be answered confidently.
- foster the evolution of working partnerships of patients and clinicians, to identify and prioritise their shared uncertainties about the effects of treatments, and then to press for systematic reviews of existing evidence in areas where these are needed, or to influence priorities for additional research.
- provide a setting as free as possible from major biases (distorting factors) and competing interests, in which patients and clinicians can meet to identify and promote shared priorities for addressing uncertainties about the effects of treatments.

Working with Asthma and Schizophrenia in Wales

Two early priorities for the James Lind Alliance in the development of a Database of Uncertainties about the Effects of Treatments (DUETs) are asthma and schizophrenia. Uncertainties about the effects of treatments are reflected in the questions that patients and clinicians bring to question answering services such as NHS Direct, Hafal, Mind Cymru) and ATTRACT. Some of their questions can be addressed by reference to up-to-date, systematic reviews of reliable research studies. For many other questions, however, information is not readily available. Sometimes this is because no systematic

reviews of the relevant evidence have been prepared; sometimes it is because existing systematic reviews have not been kept up to date; and sometimes it is because systematic reviews have shown that uncertainties about treatment effects will not be reduced without further research.

The proposed networks in respiratory medicine and mental health therefore propose to collaborate in giving Wales a UK lead in the establishment of DUETs in these respective areas. Work is also proposed in primary care with NHS Direct Wales to use information gleaned from routine calls to that service, to generate questions about treatment uncertainties.

In the mental health field, Hafal and Mind Cymru are two national organisations that regularly field calls from people with schizophrenia. Both are members of the Wales Collaboration for Mental Health and are co applicants on the Mental Health Research Network Cymru network application.

It is proposed to seek funding for a researcher to work with these organisations to populate the DUETs databases in these areas. In the case of mental health we would then seek external funding to run this project UK wide on the UK MHRN.

We would also seek to pilot in Wales the patient-clinician working partnerships proposed by the James Lind Alliance. In mental health the partnerships would be with the Wales Collaboration for Mental Health and the Welsh Psychiatric Society (www.wps.swan.ac.uk).

5. Why do you believe that this theme or sector needs to enhance its research and development activity?

Although mental health problems account for over 15% of the burden of disease in the UK, less than 5% of the trials on the Cochrane collaboration are indexed under mental health. That literature is dominated by short term trials of medication. Many studies are too small to answer important questions and are often hospital, rather than community, based. There is a lack of research funding, or lack of creativity, or capacity, or all three even though mental health is a priority policy area for the Welsh Assembly Government, as it is in England. The UKCRC has recognised the need to get more clinical research into practice in mental health through the establishment of a MHRN in England. We set out the case for establishing a Mental Health Research Network Cymru.

The burden of mental illness

Mental health is a Government priority in Wales and England. Internationally, The World Health Organisation's global burden of disease project has revealed that mental illness, including suicide, accounts for over 15 percent of the burden of disease in countries such as the UK. This is more than the disease burden caused by all cancers. Using the Daily Adjusted Life Years measure, major depression ranked second only to ischemic heart disease in magnitude of disease burden in established market economies. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contributed significantly to the total burden of illness attributable to mental disorders (Murray et al 1999).

Mental health problems in Wales

Adults of working age

The Welsh Health Survey provides information on the prevalence of some specific conditions amongst the people of Wales. In May 1998, self-completion questionnaires were sent to over 50,000 adults (aged 18 and over) across Wales. By the middle of June, almost 30,000 people had returned completed forms providing information on their use of the health service, their satisfaction with the service provided and complaints about it, their general health and specific illnesses for which they had been treated as well as aspects of their lifestyle. The questionnaire included the Short Form 36 (SF-36) - a standard set of health status questions - the answers to which can be combined to give summary measures of physical and mental well-being. Respondents were asked if they currently had any of the following mental or nervous illnesses and had had them for three months or more: depression, anxiety, Alzheimer's disease, schizophrenia, another mental or nervous illness.

The main findings were as follows:
One in seven adults who took part in the survey reported being treated for some kind of mental illness. Amongst non-responders, only around 10% reported a mental illness suggesting that this and the estimates given below overstate true prevalence in the population.

- across Wales, 14% of adults reported a mental or nervous illness;
- the areas making up the Gwent health authority area reported the lowest and some of the highest rates of mental illness in Wales - Monmouthshire residents reported the lowest rate (8%) whilst three of the four highest rates were in Blaenau Gwent, Torfaen and Caerphilly (19%);
- 22% of adults in Merthyr Tydfil reported a mental illness, the highest in Wales.
- women were more likely than men to report a mental or nervous illness;
- the difference between the sexes was most pronounced for those aged over 75.

Children and younger people

In 2000, the Office for National Statistics published the results of enquiries conducted in Britain (England, Scotland and Wales) on the '1999 cohort'. Repetition of that survey is presently under way. The study that was carried out for ONS indicates that the rates overall are similar for England, Scotland and Wales. This was based on a survey of 5 to 15 year old young people (10,438 young people were interviewed) in which 10% were found to have at least one of just three groups of disorders studied.

The survey was designed to select only those young people who have a mental disorder of such a nature and severity that they met the diagnostic criteria for research using the ICD-10 Classification of Mental and Behavioural Disorders with strict impairment criteria and to exclude children who had more minor mental health problems even though they may well have caused significant distress or impairment. It showed that in that whole population cohort, of children aged 5 -15 years, 5% had clinically significant conduct disorders; 4% were assessed as having emotional disorders – mainly anxiety and depression - and 1% were rated as hyperactive. As their name suggests, the less common disorders (autistic disorders, tics and eating disorders) were attributed to half a per cent of the sampled population.

There were no significant differences in the prevalence rates of any mental disorder or the three broad groups of mental health problems neither between England, Scotland and Wales nor between the metropolitan and non-metropolitan areas of England - rates ranged from 8% in Scotland to 11% in London. When the data were re-analysed by ACORN classification of neighbourhood types, associations were found by area type. Prevalence figures ranged from 5% in "thriving" areas (characterised by wealthy achievers, suburban areas; affluent rural communities; prosperous pensioners, retirement areas) to 13% in areas classified as "striving" (characterised by

older people, less prosperous areas; council estate residents, high unemployment; council estate residents, greater hardship, people in multi-ethnic, low-income areas). These findings support a strong association with socioeconomic deprivation.

The overall rate of 10% includes many children who showed co-morbidity (i.e. they had more than one type of disorder) and the percentages with more than one condition grow as children move from the general population and into the specialist mental health services. Surveys by the Audit Commission that were published in 1999 have shown that children and young people who attend specialist clinics have 4 or more problems and later work conducted by the University of Durham for the Department of Health confirms the direction of these findings.

The numbers of children with special educational needs provides its own picture. The recent ONS survey showed that 1 in 5 children had special educational needs (SEN) that was formally recognised by the education authorities. The prevalence of mental disorder increases with the level of SEN: 16% at Stage 1; 18% at Stage 2; 36% at Stage 3; and 43% at Stages 4 and 5.

Forty nine percent (49%) of children identified with a mental disorder were recognised as having special educational needs. The different types of mental disorders are associated with differing prevalences of SEN: 37% of young people with emotional disorders had SEN; 57% of those with conduct disorders; 71% of those with hyperkinetic disorders and 68% of young people with the less common disorders.

The ONS survey showed that a specific learning difficulty was found in 12% of children with a mental disorder and 4% who had no disorder.

Twenty five percent (25%) of children with emotional disorders had been absent from school for 11 days or more in the past term compared with 21% with serious conduct problems and 14% with hyperkinetic disorders. Predictably, the rate was highest for children with problematic conduct (44%).

Forty seven percent (47%) of children assessed by the ONS as having a mental disorder had a parent who scored 3 or more on the GHQ 112 (a measure of mental health problems for adults). This was approximately twice the proportion of the sample of children with no disorder (23%).

Mental disorders are three to four times more common in children with learning disabilities than the general population. The range of disorders found is similar to that found in children in general. Conduct and emotional disorders are both increased by about the same proportion. Some disorders occur much more frequently, notably hyperactivity, pervasive developmental disorders and stereotypes and self-injurious behaviour. The rate of disorder is higher in more profoundly affected children.

Demand on social services departments gives another proxy measure of the scale of the challenge. The primary healthcare, paediatric, dental, educational, social and mental health needs of children who are clients of those services are substantial.

There were 3,313 children 'looked after' by local authorities on 31 March 1999. Seventy six percent (76%) were in foster placements and 7% were in Wales 28 registered homes. Two thousand, four hundred and thirteen (2,413) children were on child protection registers and 344 were offered respite care. In the same year, 2,867 children were on learning disability registers, 692 supervision orders were made and there were 56 admissions (1.8 per 10,000 of the 10 to 17 year old population) to secure units.

In the ONS survey, the proportion of children with a rating of fair, bad or very bad general health was 20% in those who also had a mental disorder compared to 6% of those without a disorder.

Looking at the prevalence of mental disorders by particular physical complaints, children with neurological problems - epilepsy (37%) and co-ordination difficulties (35%) - were more frequently assessed as having a co-morbid mental disorder. Among children with co-ordination problems, there is a preponderance of children with hyperkinetic disorders.

Other physical diagnoses associated with a high frequency of mental health problems were: muscle disease or weakness (30%); speech or language problems (29%); obesity (22%); stiffness of deformity of foot (22%); and kidney or urinary tract problems (20%). Around 1 in 6 children who had a life threatening illness were found to have a mental disorder. Twenty five percent (25%) of children who had suffered accidental poisoning had a mental disorder.

Overall, the prevalence of all mental disorders in community surveys is reported to be around 20-30% of school-age children (Fonargy et al 2000) and there is reasonable agreement that around 15% may have a disorder of more serious nature and/or degree. The prevalence rates for specific disorders of child and adolescent mental health are shown in Table 1. This is taken from a table that appears in a piece of work that was undertaken in Wales for Iechydd Morgannwg Health (IMH) and published by that authority in a report in 2001 (Iechydd Morgannwg Health, (2001)).

Substance use by adolescents in Wales is endemic (Gilvarry 2000) and the rate of misuse is predicted to be higher than in England as it, too, is related to indicators of deprivation, alienation and exclusion. Binge drinking by teenagers is now one of the most worrying aspects of recent changes in patterns of substance use.

In 2002, the National Assembly for Wales commissioned a report for its Health and Social Services Committee on 'Mental Health in Childhood, Children and Young People who have Mental Health Problems and Mental Disorders and Mental Health Services for Young People'. That report drew attention to:

- The evident significance of deprivation, social exclusion, lack of affluence, poverty and alienation as powerful risk factors for mental disorders and mental health problems;
- The huge toll on society now and in future generations that stems from unresolved mental health problems and disorders in childhood;
- The high volume of pertinent research evidence that is available, yet the need for very much more research;
- The enormous potential possibilities for health promotion and early intervention that are now opening;
- The growing and very real potential of services to offer interventions that are presently, or are likely to be effective in the future;
- The considerable health economic advantage that could accrue from early intervention prior to adolescence, but also the key importance of supporting our young people through adolescence;
- The growing gap between the potential for intervening and the capacity of our current services, which are under huge pressure; and
- The vital importance of enabling further service developments coupled with research into their effectiveness to guide the direction of travel.

In 2000, the National Assembly for Wales set up a Review of Safeguards for Children and Young People Treated and Cared for by the NHS in Wales chaired by Lord Carlile. That review reported in March 2002 after conducting its own evaluation of the emerging CAMHS Strategy as well as devoting a considerable volume of its effort to practical matters impacting on policy and strategy for and delivery of child and adolescent mental health services (CAMHS).

Parent's mental health

In summary, children with parents who screened positive on the GHQ12 were three times more likely to have a mental disorder than those whose parents had sub threshold scores -18% compared with 6%.

Older adults

Dementia currently affects over 750,000 people in the UK. The number of people with dementia is steadily increasing. Over 18,000 people with dementia are aged under 65 years. Dementia affects one person in 20 aged over 65 years and one person in five over 80 years of age. It is estimated that by 2010 there will be about 870,000 people with dementia in the UK. This is expected to rise to over 1.8 million people with dementia by 2050.

Dementia in people under the age of 65 is comparatively rare. There are over 18,000 younger people with dementia in the UK.

The proportion of older people from an ethnic minority in the UK is small, but increasing steadily as this section of the population ages. There are about 14,000 people with dementia among ethnic minorities. However, many services for people with dementia remain inappropriate and inaccessible.

People with learning disabilities may experience a higher risk of dementia because of premature ageing. Also, people with Down's syndrome have an increased genetic risk of developing dementia. Additional specialist support and services need to be provided to meet their increasing needs.

People with a learning disability

People with intellectual disabilities have an increased risk of early death compared to the general population, although the life expectancy of this population is increasing over time and, for people with mild intellectual disabilities, approaching that of the general population (Hollins et al 1998). People with Down's syndrome have a shorter life expectancy than people with intellectual disabilities generally, although the life expectancy of this group is increasing particularly quickly (Puri et al., 1995).

Like people with severe mental illness, people with learning disabilities die young from common causes. Respiratory disease is the leading cause of death for people with intellectual disabilities.

The prevalence rate of epilepsy amongst people with intellectual disabilities has been reported as 22% (Welsh Office, 1996). People with intellectual disabilities are between 8.5 and 200 times more likely to have a vision impairment compared to the general population and around 40% are reported to have a hearing impairment, with people with Down's syndrome at particularly high risk of developing vision and hearing loss (Carvill, 2001).

Although people with intellectual disabilities visit their GP with similar frequency to the general population, they are less likely to receive regular health checks (Kerr et al., 1996).

Learning disability and mental health

Prevalence rates for schizophrenia in people with intellectual disabilities are approximately three times greater than for the general population (3% vs 1%; Doody et al., 1998), with higher prevalence rates for South Asian adults with intellectual disabilities compared to White adults with intellectual disabilities (Chaplin et al., 1996).

Reported prevalence rates for anxiety and depression amongst people with intellectual disabilities vary widely, but are generally reported to be at least as prevalent as the general population (Stavrakaki, 1999), and higher amongst people with Down's syndrome (Collacott et al., 1998).

Children with intellectual disabilities are more likely to experience anxiety disorders (8.7% vs 3.6%) and conduct disorders (25.0% vs 4.2%) than children without intellectual disabilities, although rates for depression are similar (1.5% vs 0.9%) (Emerson, 2003 in press).

Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%-15% of people with intellectual disabilities, with age-specific prevalence peaking between ages 20 and 49 (Emerson et al., 2001). People with mental health problems and borderline intellectual functioning are particularly difficult to treat (Hassiotis et al., 1999) and people with intellectual disabilities are at risk of receiving no mental health service, due to the lack of communication between mainstream psychiatry services and intellectual disability psychiatry services (Hassiotis et al., 2000; Moss et al., 1996; Roy et al., 1997).

A very high proportion of people with intellectual disabilities are receiving prescribed psychotropic medication, most commonly anti-psychotic medication (40%-44% long-stay hospitals; 19%-32% community-based residential homes; 9%-10% family homes; Branford, 1994; Clarke et al., 1990; Robertson et al., 2000b). Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects (Emerson, 2001).

Special groups

In preparing this report we have met with other scoping study groups. Some have highlighted other important overlaps with the proposed mental health research network. Other themes have emerged form the stakeholder consultation. Key themes that we have identified through this process are:

- Black and minority ethnic mental health
- The mental health needs of asylum seekers
- Mother and baby mental health
- Social deprivation and mental health

The policy context

Mental health is a Government priority in Wales and England. The Welsh Assembly Government has made mental health one of the top 3 health priorities in Wales and has adopted a 10 year Strategy for Adult Mental Health Services to improve, modernise and develop mental health services in Wales to a position where they provide the best possible care for those with mental health problems. The adult mental health services National Service Framework (NSF) was published in 2002. The principal aim of the NSF is to drive up quality and reduce unacceptable variations in health and social services provision. It establishes the practical guidelines that will ensure consistent and comprehensive implementation of the strategy's vision across Wales. Four principles underpin the Strategy: Equity - services that are available to all and allocated according to individual need; Empowerment - users and their carers are to be integrated into care planning and evaluation of services; Effectiveness - the provision of treatment of symptoms and causes, the prevention of deterioration and reduction of potential harm to improve the quality of life; Efficiency - best value and efficiency in service provision. These four principles and values are reflected in our bid to provide a mental health research network for Wales.

Stronger in Partnership was published in 2004 and highlighted the need to effectively involve people who use mental health services and their carers in the design, planning, delivery and evaluation of those services. The Assembly Government's aim is for people with mental health difficulties and their carers to be genuinely and constructively involved in all aspects of mental health services, and this is a fundamental principal of the adult mental health strategy. Similarly we would make user and carer involvement an integral part of the design, commissioning and provision of a mental health research network.

In 2004 WCMH was commissioned by WAG to conduct a review of mental health services in Wales. The literature review highlighted the pressure currently faced by mental health services across the age range in Wales. Areas of good practice and excellence were identified also.

A House of Commons cross party committee has recently identified that major challenges still remain for mental health services in Wales and that the proposed mental health bill would not be implantable in Wales. At a time when the Assembly is investing in mental health services a responsive research base becomes even more relevant.

Welsh Assembly Government policy has been further clarified in *Designed for Life*. Published in May 2005 it sets out a new National Health and Social Care strategy focusing on:

- identifying clearly the needs of different groups;
- clarifying what should be done at different levels;
- ensuring that care is streamlined and integrated within a well-run network of services.

A series of 3 year targets are set for the NHS, many of which are directly related to mental health services in adults of working age, young people and older adults. As part of this process, the document reports, Mental Health Services will be remodelled over the next three years to meet any new legislative requirements, the Adults of Working Age Mental Health National Service Framework and the Mental Capacity Bill. This will include action on workforce reconfiguration, provision of low secure beds, risk management skills, substance misuse, psychological therapies, eating disorder services, perinatal mental health services, comprehensive rehabilitation facilities, court diversion schemes, a liaison psychiatry service, day activity services, work entry programmes and strengthened primary care. There will be significant capital investment in modernising mental health services over the next three years. Such developments will require evaluation in a Welsh and broader UK context.

Existing research activity

In Wales we have major strengths in basic and clinical research within mental health. This provides excellent opportunities to benefit the population of Wales by early translation of findings from "bench to community" as well as through policy research. There are currently shortcomings with the dissemination and implementation of the findings from research. Our review identified that currently no single data base or resource captures the range of mental health research in Wales. Later in the report we set out plans to remedy this.

There is evidence of considerable research strength in Wales in the mental health and learning disability fields. For maximum NHS and social care benefit, and above all benefit to the patient and carer, that activity requires co-ordination through a mental health research network.

As part of the earlier scoping study (Lloyd et al 2005), a review of current research activity in mental health and related fields was conducted. Several approaches were used. The first step was to consult the National Research Register. This is a database of ongoing and recently completed research projects funded by, or of interest to, the United Kingdom's National Health Service (NHS). Data is supplied to the NRR by some 350 organisations (NHS Trusts, national and regional funding programmes, universities, charities) in England, Scotland and Wales.

A trawl of the NRR revealed approximately 60 projects listed under Wales and mental health. The majority of these give no record of the source of funding. This is at odds with the clear evidence of considerable research activity in within the field in Wales. Full details of NRR Projects identified are given at appendix B of the scoping study (Lloyd et al 2005).

We then approached the R&D offices of individual Trusts. It was not possible to get a full return of this data within the timescale required for the report. Nonetheless it seems likely that at Trust level this data is held with reasonable efficacy. However, individual trusts and LHBs do not use compatible common data bases to capture this information.

Finally we approached individual universities. These held good records of their own staff's activity but this did not cross reference well with NHS records. The research activity that was returned by of the various academic centres is summarised below. Once again, there are omissions and inconsistencies but the overall picture is of considerable and vibrant activity of world class.

Within Wales there is both quality and quantity of research but not coordination for the benefit of patient care. For maximum NHS and social care benefit that activity requires co-ordination through an appropriately funded single network across lifespan phases, client groups and disease areas. The importance of mental health area is reflected in it's being a Welsh, UK, and WHO policy priority area. In England and many other countries thematic mental health networks already exist. Now is the time to establish a MHRN-Cymru that is both internationally competitive and responsive to Welsh questions and issues.

6. Please explain how you believe your proposed network will enhance research and development activity in this field?

The UK Mental Health Research Network has shown how a network can enhance research and development activity in mental health within England. By working with them and CRCC Cymru, we can bring that added value to Wales and take a UK lead in existing and emerging areas of strength whilst maintaining a focus on Welsh questions.

Aims of MHRN Cymru

The principal aims of MHRN Cymru will be:

- To organise and deliver large-scale research projects to inform policy and practice as it develops, and to help services implement change.
- To broaden the scope and capacity of research, including full involvement of service users and carers in commissioning and delivering research.
- To help identify the research needs of mental health (particularly in health and social care), working with frontline staff, service users and carers.
- To develop research capacity through a range of initiatives at a local, regional and national level.

Ways in which these aims will be achieved are set out in response to this and succeeding questions.

The UK example

Wykes (2004) has reviewed the need for a mental health research network in a UK context. She noted that until the establishment of the UK MHRN, mental health research had not led or supported practice development. Reliance on small, localised studies has prevented researchers from drawing valid general conclusions. To date there has been little or no active involvement of those at the front line, the service users and carers.

As a result, research has failed to inform policy, lacking coherence, relevance and crucially credibility with users and professionals. Without an efficient infrastructure, research findings suffer poor dissemination. Poor integration of resources, experience and expertise has meant that mental health research has been unable to attract the valuable support from major funding bodies that it deserves. (Wykes 2004). Since it was set up, the UK MHRN has been highly successful in attracting external funding, building in meaningful user involvement, and in making a difference to the NHS. The UK MHRN has no sites in Wales. Now we have the opportunity to create a Mental Health Research Network Cymru to enhance the research and development activity from a Welsh context.

The UK Mental Health Research Network currently brings together 20 Universities and 38 NHS Trusts. It covers a population of 29.7 million which is approximately 60% of the population of England. The contract for managing the Network was awarded to Institute of Psychiatry / University of Manchester by the National Institute for Mental Health in England on 1 January 2003 following a competitive tender. The MHRN's Mission is 'To provide the infrastructure to support large scale, high quality research in mental health and social care which has implications for services and treatments.' As well as helping to raise the standard of mental health and social care research nationally. The MHRN acts as a central point of information and reference, connecting service users and carers to researchers and mental health professionals.

Achievements 1 January 2004 – 31 December 2004 are very impressive and are listed in the annual report as :

- The official launch of the Network which was held in June 2004.
- Continuation of funding for the MHRN infrastructure from the Department of Health (DH) for a further five years, with annual funding increasing progressively to £4.2 million from 2006.
- National infrastructure of Hubs increased from five to eight, chosen through a competitive process.
- Hubs becoming fully operational with the appointment of key staffing.
- Further development of MHRN Coordinating Centre structure including formalisation of the Network Executive to lead on MHRN operation and future development.
- MHRN name changed to UK MHRN, to reflect the planned expansion of the Network to Scotland, Northern Ireland and Wales.
- Service User Research Group in England (SURGE) formally appointed to support service user input into the MHRN.
- Industry Relations Associate Director appointed to explore and develop relationships between the Network and industry.
- Discussions with the MRC have contributed to increased funding for mental health projects, specifically in the area of capacity building for large trials.
- A total of 16 projects adopted on the MHRN in 2004. These have already secured external funding and are currently running on the Network.
- Considerable support has been provided to Chief Investigators (CIs) in the set up of studies across the Network, including completion of research governance requirements on behalf of the C.I.
- Mapping of services by hub coordinators initiated, developing a full picture of the services and demographics available within the Network.
- National research groups have been set up in;
    - o Early intervention in psychosis (A number of successful grant applications were generated by this group including one project which has received £400K from the Department of Health)
    - o Treatment of depression
    - o Self help
- Scoping groups have been set up in:
    - o Child & Adolescent Mental Health Service (CAMHS)
    - o Social Research in Mental Health

- Mental Health in Older Adults
- Further groups are planned for carers

- Development of a formal ongoing marketing strategy which has included displays at key conferences, presentations to clinical and academic organisations, papers in professional journals (BPS, RCPsych, RCN and OT), and production of MHRN and Hub leaflets and other promotional materials.
- Development of MHRN website (www.mhrn.info).
- Development of a secure data system which allows the remote collection of individual data for studies running on the MHRN.

The Welsh Context

- Mental health has been identified as a Welsh Assembly Government priority area and is well suited to the development of a thematic network due to its uniquely interagency nature.
- A national infrastructure for mental health research has already been set up in England (Wykes T 2004).
- Now there is a clear need to establish a corresponding network in Wales to answer Welsh questions and to participate in UK / international studies of relevance to service development and the delivery of effective, evidence and values-based interventions. WAG priorities in mental health are very similar to those in other European countries.
- The proposed network will be a springboard for research creativity and for attracting research resources spanning basic sciences, mental health services and social care research in synergy with the user carer perspective.
- *The Wanless Review* highlighted the need for a continuing emphasis on evidence-based approaches at both policy and service level and, with an imminent revised mental health NSF, there is an acute need for evidence to underpin service development and address policy questions.
- WCMH has recently undertaken a risk review of adult mental health services for the Assembly, underlining the need for novel models of service delivery and client centred approaches to the delivery of mental health care.
- Implementation of the *All Wales Adult Mental Health Strategy* (The National Assembly for Wales, 2001) and the *National Service Framework for Adult Mental Health Services* (Welsh Assembly Government, 2003) and *Designed for Life* (2005) explicitly requires a broadening of the concept of mental health away from a disease-focused approach to one that also addresses the links between the individual and the wider social and economic environment.
- WCMH has had a heavy involvement in developing and implementing Wales' policies across the lifespan, including those for eldercare services and child and adolescent mental health (in *Everybody's Business*, National Assembly for Wales, 2001 and in the *National Service Framework for Children, Young People and Maternity Services*, Welsh Assembly Government, 2004). WCMH is, therefore, well acquainted with the policy and strategic drivers for service change, the need for a relevant evidence base and the development of the required research agenda.
- Local joint planning for action on mental health inequalities between local government and the NHS will include neighbourhood renewal and policies on education and training, housing, employment and social inclusion. Since there is considerable variation in mental health status between the 22 unitary authority areas in Wales, further understanding of the contribution of composition and context to this geographical variation in mental health status is required to provide an evidence basis for national policy and local planning.
- There is a need to provide the evidence base for implementing in this client group *Health Challenge Wales* and Better Health Better Wales and to ensure that all work done is compatible with and mapable onto the emerging statutory healthcare standards for Wales.
- Evaluating new models of service delivery requires high quality research. In order to deliver policy-relevant research, large-scale studies are often needed. Such studies must be powerful enough to answer the complex questions posed for mental health care, yet few large-scale mental health trials of direct relevance to the NHS are available. One reason is the lack of quality mental health grant applications arising from a lack of capacity competence across the country. This proposed network would redress that and establish an inclusive all Wales network of international quality.

Enhancing R&D

The MHRN Cymru will generate research ideas in priority areas through the establishment of multidisciplinary research groups that develop capacity and widen access to the Network. Those groups would also work closely with the UK MHRN where there are currently there are research groups in Early Intervention in Psychosis, Self Help and Anti-depressants.

The principal aims of MHRN Cymru will be to:

- To organise and deliver large-scale clinical trials and other well designed studies that have implications for people, services and treatments.
- To organise and deliver research projects to inform policy and practice as it develops, and to help services implement change.
- To broaden the scope and capacity of research, including full involvement of service users and carers in commissioning and delivering research.
- To help identify the research needs of mental health (particularly in health and social care), working with frontline staff, service users and carers.
- To develop research capacity through a range of initiatives at a local, regional and national level.
- To act as a unifying network for related disciplines and emerging thematic networks.

Types of research that the network will host

Projects that requires multiple sites because of:

- A large sample size,
- Participants with a rare condition, or
- Participants from a particular group or lifestyle.
- The project is a cluster-randomised trial that requires multiple centres or units of randomisation.
- The project requires multiple centres in order to establish that a finding or an intervention is generalisable across different settings or is applicable in specific settings (for example rural areas).

Pilot studies can be adopted if they have the potential to develop into large scale studies.

Driving Research Creativity

Mental health research has made great advances but it has not been able to answer some important questions because often studies and clinical trials have been too small. The reliance, on small, localised studies has prevented researchers from drawing valid general conclusions and as a result, research has failed to inform policy, and has lacked coherence, relevance and credibility with users and professionals.

There is a shortage of research capacity and competence across Wales and a concentration of research in only a small number of key research centres. Consequently there have been few chances for interested clinicians from the rest of the country to gain experience in carrying out large scale projects.

Poor integration of resources, experience and expertise has meant that mental health research has been unable to attract the valuable support that it deserves from the major funding bodies. The Mental Health Research Network Cymru will provide an infrastructure across Wales with a range of demographic and cultural differences together with specific service configurations which enables it to host large-scale research projects in mental health. Researchers using the MHRN Cymru will be able to access the valuable high-level expertise within the network and can benefit from a coordinated approach to patient recruitment. In addition, researchers are relieved of much of the administrative burden of setting up research projects through UK MHRN central support for governance and financial arrangements. It is hoped

the UK MHRN will create a culture of large-scale studies relevant to key problems in mental health and that the knowledge within the Network will become a useful resource for less experienced researchers.

Until now mental health research has not led or supported practice development. Reliance on small, localised studies has prevented researchers from drawing valid general conclusions. To date there has been little or no active involvement of those at the front line, the service users and carers. As a result, research has failed to inform policy, lacking coherence, relevance and crucially credibility with users and professionals. Without an efficient infrastructure, research findings suffer poor dissemination. Poor integration of resources, experience and expertise has meant that mental health research has been unable to attract the valuable support from major funding bodies that it deserves.

Building research capacity

It is vitally important to develop new researchers and expand capacity for research within the NHS and social care. As part of our proposal we set out plans for mid career fellowships that will offer opportunities for NHS staff to gain research experience. As a network we would be in a strong position to bid for high prestige training fellowships from the NHS, charities and research councils.

7. Who else do you propose to involve in your network and how will your network be structured?

We describe plans for the coverage, structure and function of MHRN Cymru. These plans are based on a detailed option appraisal as part of the scoping study. We also take into account relationships with other potential related thematic networks, CRCC Cymru and the UK MHRN. Specifically, MHRN Cymru would work with CRCC Cymru and have a dedicated research professional network. The proposed mental health research network will provide the infrastructure to support large scale, high quality research in mental health and social care which has implications for services and treatments in Wales and beyond.

Scoping study option appraisal

As part of the scoping study we conducted extensive consultation with stakeholders in all relevant sectors. An option appraisal was conducted in which a range of possible network structures was assessed against the criteria of appropriateness, inclusiveness, sustainability, accountability and fit with UKCRC priorities (Lloyd et al 2005). Four options were considered:

- No mental health research network but a single all embracing generic network,
- Wales becomes a hub of the UK MHRN,
- There should be a stand alone MHRN in Wales,
- A MHRN Cymru closely aligned with UK MHRN.

In total almost 100 responses were received from a broad constituency reflecting the composition of the group. The clearly preferred option was for a mental health research network Cymru that is closely aligned with the UK MHRN in terms of coverage, structure and function. This would create a network with the flexibility to respond to assembly priorities in health and social care and the ability to compete at a UK and international level in clinical research.

Since that exercise was conducted two things have become clearer. Firstly, there are economies of scale to be gained

from working closely with other related networks in areas such as Dementias and Neurodegenerative Disorders and learning disability, provided such collaborations are appropriately funded. Secondly, it has become clear that there are also considerable benefits to developing close links with the proposed CRCC Cymru.

Who would be involved

Co-applicants

The main partners from the voluntary sector, social care, NHS, professional bodies, universities and charities are set out in response to question 2.

Wales Collaboration for Mental Health

Although this bid is led by the University of Wales Swansea, the umbrella organisation is the Wales Collaboration for Mental Health (WCMH). The WCMH is a non-statutory collaborative partnership of stakeholders in the mental health field, which developed in 2003 with a commitment to the "Stronger in Partnership" principles of involving users and carers at all levels. The Centre for Mental Health Services Development for Wales has been a core component of the collaboration, with other partners drawn from service users and carers, the voluntary sector, NHS, social services and the Royal Colleges of Psychiatrists and General Practitioners, and the academic community. The Welsh Assembly Government recognises the collaboration as its Director of Mental Health, Phil Chick, attends its meetings and management meetings in an observer capacity.

WCMH has the potential to place mental health high on the public agenda and to demonstrate that mental health receives at least as much support in Wales as in any other part of the UK and Europe. Meeting the need of service users and carers is the main priority of WCMH. In particular, the interdependence of service delivery, education and training, research and policy development are explicitly recognised and provides the basis for mutual development.

Linked research networks

Working relationships are already well developed with some other proposed networks namely:

- CRCC Cymru
- Dementias and neurodegenerative disorders
- Learning disability
- Primary Care
- Respiratory disease

Explicit intentions to collaborate have been shared with a number of other proposed infrastructure and thematic network bids specifically:

- Black and minority ethnic groups
- Children and young people
- Emergency/intermediate care
- Epilepsy
- Health economics
- Health information
- Nursing midwifery and health visiting
- Risk assessment and harm to other people

This list is not exhaustive. Further collaborations are envisaged. Our main UK collaboration will be with the UK Mental Health Network.

The James Lind Alliance

One of the first priorities for MHRN Cymru will be to work with the James Lind Alliance to set up patient-clinician partnerships and develop in Wales, and then extend to the whole UK, a Database of Uncertainties about the Effects of Treatment (DUETs) for Schizophrenia. See response to question 4 and appendix B for more details.

Association of British Pharmaceutical Industries Cymru Wales

The network has begun to explore constructive relationships with the Association of British Pharmaceutical Industries (ABPI). ABPI Cymru Wales has offered their continued support for the Mental Health Research Network bid for WORD funding. Similar discussions have taken place within the UK MHRN and a code of practice and guidelines have been drawn up for adopting commercial studies onto the UK MHRN. Welsh Assembly Government has also issued guidance on working with the pharmaceutical industry (Welsh Health Circular). Industry collaboration, although advocated by UKCRC, remains a challenging issue for some of our collaborators and further discussion will be needed to take this forward.

AWARD

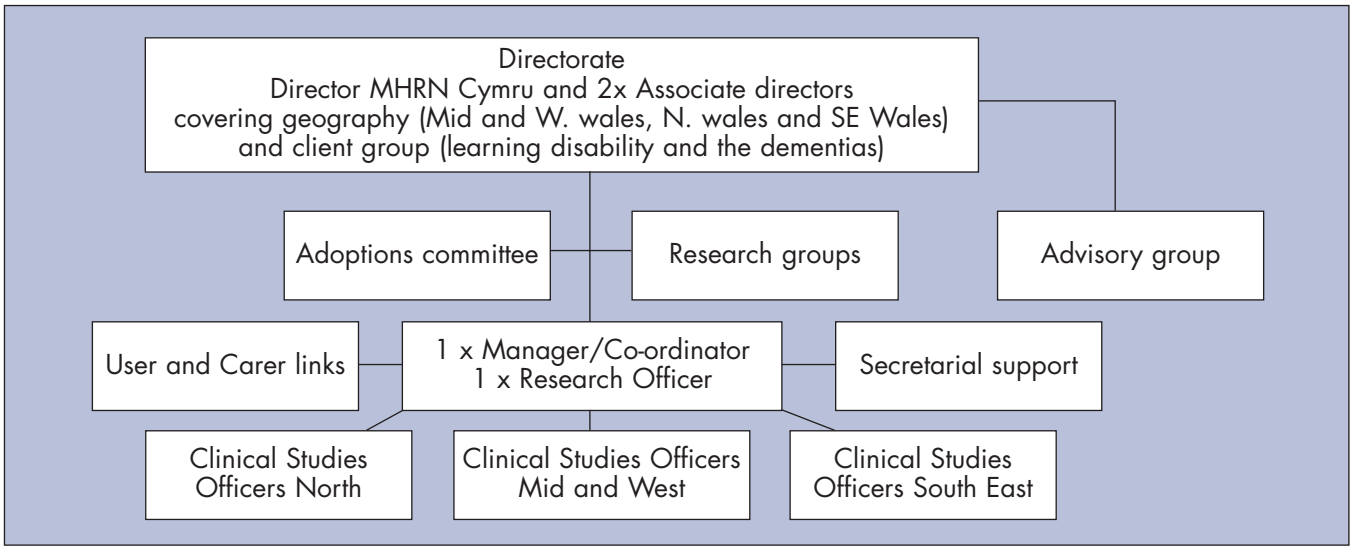
We propose a similar geographical distribution fo resources to AWARD. Discussion with CRCC Cymru supports the concept of AWARD providing methodological expertise to research professionals in some aspects of their work.

Structures and Organisation of MHRN Cymru

Geographical and thematic coverage

We propose a thematic network with a dedicated research professional network that reflects the geography of Wales and matches other initiatives such as the NHS regions in Wales and AWARD. There would be a presence in North Wales, Mid and West Wales and South East Wales. In terms of population Wales is similar to a large hub of the UK MHRN in England. However, there are greater complexities of geography demographics and policy formations in Wales.

Figure 1: Structure of MHRN Cymru



Client group and disease area coverage

If a single mental health bid is funded, but bids in learning disability and the dementias are not, the preferred option is for MHRN Cymru to be inclusive of all client groups and disease areas. However, if those related bids in learning disability and Dementias and Neurodegenerative Disorders were to be funded, then we would seek to work closely with them. If there were only one Mental Health R&D Network in Wales, there would need to be a corresponding increase of funds to support activity in each distinct area.

User carer representation

The UK Mental Health Research Network has a Service User Representation Group for England (SURGE). We would explore the potential for expanding that to Wales. The steering group is fortunate in having strong representation from HAFAL and MIND Cymru that could form the basis for such involvement given the national profile and role of that grouping. Similar stakeholder representation will be sought from other client groups and disease areas represented within the network and will be a priority task for the network.

Involvement in the DUETs initiative through the James Lind Alliance would further increase the level of user and carer input through the use of routinely collected data to identify and publish patients' and clinicians' questions about the effects of treatments that cannot be answered by referring to up-to-date systematic reviews of existing research evidence.

Management group

We would propose setting up a management group with both geographical and client group / disease area representation. There would be clear representation of users and carers on that grouping. Links would be identified with

other relevant networks for example primary care or methodology base groups such as health informatics, trials or qualitative methodology. The UK MHRN has indicated that, were this network to be funded, the management group would have a place on the hub leads committee of the UK MHRN. The group would relate to both WORD and CRC Cymru.

Research Groups

The UK MHRN is currently establishing research groups that supplement the research hubs. They have a non-geographical basis and reflect cross-cutting areas of research expertise and activity across institutions. The UK MHRN has research groups in early intervention in psychosis; self help; anti-depressants; mental health in the elderly; mental health in children; social care and carers. A Welsh network, if established, would seek to develop a distinctive portfolio reflecting national needs and research strengths. The purpose of the research groups is to provide the creative drive for the network. In some instances groups in Wales will want to be part of, or lead, research groups across the UK network. In other cases the group may be within Wales. Each research group is expected to submit two protocols to the adoptions committee in the first 8 months of their life. A protocol will contain (i) one or more hypotheses; (ii) a structured abstract; (iii) a power calculation (if necessary); (iv) a summary of MHRN resource implications including any resources to help develop a full grant application; (v) intended submission date with details of the body to which the full application will be submitted; (vi) an estimated schedule for the recruitment of participants. Each research group is expected to demonstrate how it will continue to liaise with stakeholders who are active in the area covered by the group.

Adoptions committee

Like the UK MHRN it is proposed that the MHRN Cymru would have an adoptions committee to consider all studies wishing to run in the network. Professor Lloyd is a member of the UK MHRN adoptions committee. It is proposed to adopt the same terms of reference for the MHRN Cymru adoptions committee. The UK MHRN will be offered a place on MHRN Cymru's adoption committee.

A typical project that would be suitable to run on the network would be one that:

- Has evidence of service user /patient input its development;
- Is in line with national mental health policy;
- Is free from major ethical and design flaws;
- Would be feasible to run on the network;
- Requires multiple centres because of sample size, recruitment;
- Is a cluster randomised trial;
- Requires multiple centres in order to establish whether a finding or intervention is generalisable across different settings or is applicable in specific areas or for comparative purposes.

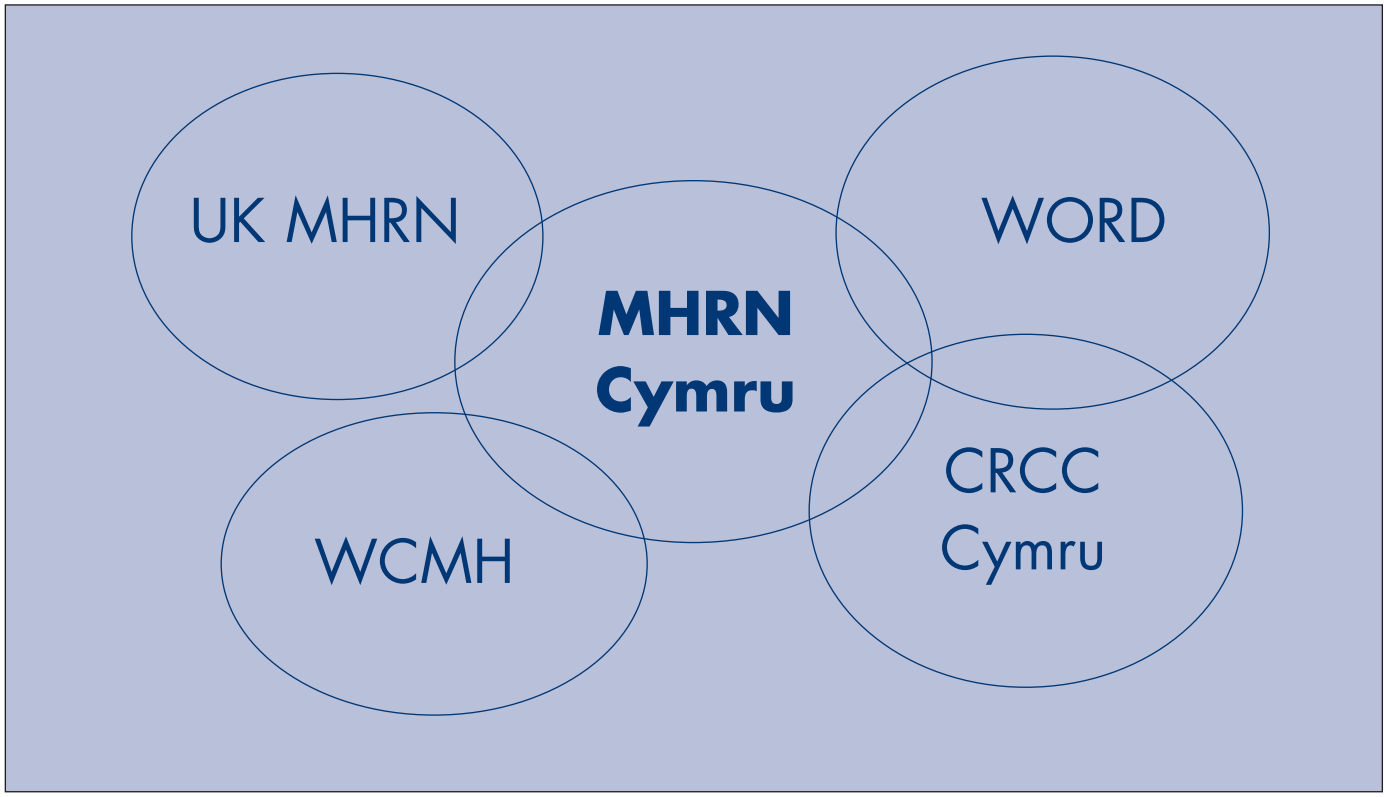
Research professional network

The scoping study option appraisal indicated strong preference for a dedicated research professional network (RPN). The case for a dedicated RPN is made in section 15. We also describe how that network would work closely with the generic RPN proposed for CRCC Cymru.

Relationship with CRCC Cymru & WORD

The network would be accountable to WORD and would work closely with CRCC Cymru with cross representation on respective management structures.

Figure 2: Relationships with WORD, CRCC Cymru and UK MHRN



Proposed Functions

- To organise and deliver large-scale research projects to inform policy and practice as it develops, and to help services implement change;
- To broaden the scope and capacity of research, including full involvement of service users and carers in commissioning and delivering research;
- To help identify the research needs of mental health;
- (particularly in health and social care), working with frontline staff, service users and carers;
- To develop research capacity through a range of initiatives at a local, regional and national level;
- To maximise opportunities for translational research across all relevant environments.

How the proposed network will address Welsh Assembly Government priorities

The proposed network will address a Welsh Assembly Government stated priority area, mental health with the following aims:

a) To organise, deliver and implement large-scale research projects to inform policy and practice as they develop and help services implement change;
b) To broaden the scope and capacity of research, which includes full involvement of service users and carers in conceiving, planning commissioning and delivering research;
c) To implement a specific strategy for service user / patient involvement;
d) To help identify mental health research needs (particularly in health and social care, working with front line staff, service users and carers);
e) Develop research capacity through a range of initiatives at local, regional, national and international levels;

f) Link and coordinate with the UKCRC and European initiatives to maximize the value to Wales, the wider UK and Europe;
g) Participate in the UK PsyGrid initiative;
h) Develop a Wales-wide sampling frame for basic and translational clinical research;
i) Establish large, representative cohorts of patients that can be followed longitudinally through their illness career;
j) Attract funding through collaborative tending across the institutions involved to add to that available from WORD to develop the mental health research infrastructure in Wales;
k) Attract major external funding to allow the above aims to be achieved and sustained.

Rationale for these structural arrangements

Appropriateness

The network would be able to be responsive to WAG priorities in health and social care for Wales and be able to address research questions that require at least a UK wide base. There would be scope to build research capacity within a priority area. The broader the coverage of the network the more it would facilitate this, providing funding matched coverage.

Inclusiveness

Good geographical coverage could be achieved within Wales by mirroring aspects of the AWARD structure. Similar coverage of client groups and disease areas could be achieved through a management structure mirroring the UK MHRN. There is good multidisciplinary, patient / user, carer and stakeholder sign up to this structure.

Sustainability

The broader the client group and disease area coverage the greater the critical mass, providing this is matched by proportionate incremental funding. Close alignment with the UK MHRN would enhance the sustainability of the network and facilitate common work programmes and increase access to external funding sources. Research creativity could be enhanced further by mirroring UK MHRN plans to set up research groups in areas of interest and expertise that will provide the creative drive for the network.

Accountability

By close alignment with the UK MHRN we would be able to specify and address both Welsh and broader UK outcomes. There would be good fit with existing structures in Wales and the UK through membership of relevant Welsh structures and, within the UK, the relevant committees of the UK MHRN.

8. Please provide an indicative 3-year work plan (with measurable outputs against current baselines) for your proposed network.

This work plan builds on earlier work in the scoping study report. Clear milestones and performance indicators with target dates and a clear reporting cycle are given.

Work plan

In drawing up a three year work plan we have developed further the work plan first set out on page 30 of our scoping study report (Lloyd et al 2005). That development work has been informed by three subsequent steering group meetings. We paid particular attention to the performance of the UK MHRN in it's first year so as to base our projected activity in some already validated reality. We have also introduced outcome as well as process measures that reflect WAG

priorities. We would seek to develop targets that reflect already existing policy targets in mental health so that evidence can lead and evaluate policy. For example appendix 3 of Designed for Life gives key milestones for mental health services such as "Health communities to put in place mental health crisis resolution and home treatment services by March 2006" Although this particular deadline may be too short for the network, future horizon scanning would enable us to identify mutually beneficial initiatives to evaluate.

Figure 3 Indicative work plan for years 1-3

	Calendar year											
	2005		2006				2007				2008	
Task	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2
Liaise with related bids that are not progressing to ensure inclusivity	X	X										
Liaise with key partner networks	X	X	X	X		X	X	X	X	X	X	X
Liaise with CRCC Cymru to confirm relationship with generic RPN	X	X	X									
Set up management group	X	X										
Finalise key performance indicators with WORD & CRCC Cymru	X	X										
Produce annual report and stakeholder event				X				X				X
Set up geographical sites like AWARD	X	X	X	X								
Set up user / patient reference group	X	X	X	X	X	X						
Set up adoptions committee	X	X										
Set up research groups in phased way			X	X			X	X			X	X
Adopt funded projects onto network			X	X	X	X	X	X	X	X	X	X
Recruit staff and identify KPIs	X	X	X	X	X	X						
Set up DUETS database for schizophrenia in Wales	x	x	x	x								
Maintain DUETS database & extend to UK					x	x	x	x	x	x	x	x
Liaise with UK MHRN	X	X	X	X	X	X	X	X	X	X	X	X
Liaise with CRC Cymru	X	X	X	X	X	X	X	X	X	X	X	X
Baseline survey of activity	X	X	X	X								
Dissemination	X	X	X	X	X	X	X	X	X	X	X	X
Set up mental health patient level data base					X	X	X	X	X	X	X	X
Marketing & working with NHS , social care, voluntary and independent sector		X	X	X	X	X	X	X	X	X	X	X

Performance indicators

Generic performance measures that will be set and will reflect upon the quality of the network are as follows:

- Activity and international standing of the research portfolio;
- Number of research projects developed by a thematic network for external funding;
- Number of research projects funded;
- Publications from thematic network members, related to network based projects;
- Production of an annual report;
- Disemination.

Performance against those targets will be detailed in our first annual report. Outcome measures will be developed in the first three months of activity.

Figure 4 Performance and outcome indicators

Task	Outcome measure	Target date
Liaise with related bids that are not progressing to ensure inclusivity	Inclusion of relevant bids	End Q4 2005
Liaise with key partner networks	Extent of collaboration agreed	Quarterly reporting
Liaise with CRCC Cymru to confirm relationship with generic RPN	Formal agreements made and maintained	Quarterly reporting
Set up management group	Appointed, convened, met.	End Q4 2005
Finalise key performance indicators with WORD & CRCC Cymru	Axtivity and international standing of research portfolio.	End Q4 2005
Produce annual report and stakeholder event	Annual report produced	Annually
Set up geographical sites like AWARD	RPN and management structure set up in N, Mid & W and SE Wales	End Q2 2006
Set up user / patient reference group	Established and maintained	Quarterly reporting
Set up adoptions committee	Established and maintained	End Q4 2005
Set up research groups in phased way		Start Q1 2006
Adopt funded projects onto network	Externally funded studies adopted	End Q2 2006
Recruit staff and identify KPIs	All in place by end 2006	Start Q3 2004 end Q4 2006
Set up DUETS database for schizophrenia in Wales	Research fellow appointed and contacts made with partners	End Q2 2006
Maintain DUETS database & extend to UK	UK extension	End Q1 2007
Liaise with UK MHRN	Cross representation on structures. Projects adopted	End Q2 2006
Liaise with CRC Cymru	Reciprocal attendance at meetings	Ongoing
Baseline survey of activity	Completed	End Q3 2006
Set up mental health patient level data base	Liaise with health information Wales and begin to set up database	End Q2 2008
Marketing & working with NHS , social care, voluntary and independent sector	Meetings, user, carer, staff feedback. New partners added	Quarterly reporting
Dissemination	Number & type of outputs	Quarterly reporting

9. Please provide an indicative research portfolio for your network.

MHRN Cymru will work with CRCC Cymru provide the infrastructure for running large scale trials and other well designed studies. In addition to studies originating in Wales, there is an existing portfolio of studies already active on the Uk MHRN that we can apply to extend to Wales so that recruitment can begin as soon as staff are in place.

MHRN Cymru will provide the infrastructure for running large scale trials and other well designed studies.
The types of study that will be run on the MHRN Cymru are projects that requires multiple sites because of:

- A large sample size,
- participants with a rare condition,
- or participants from a particular group or lifestyle.
- The project is a cluster-randomised trial that requires multiple centres or units of randomisation.
- The project requires multiple centres in order to establish that a finding or an intervention is generalisable across different settings or is applicable in specific settings (for example rural areas).

Pilot studies can be adopted if they have the potential to develop into large scale studies.

There is a portfolio of work already up and running on the UK MHRN. One of our first actions would be to examine this portfolio and see which projects could be extended to Wales. In this way there is activity that can be adopted onto the network from very early on in it's life.

We will also ask all researchers to identify projects they are submitting for funding that could be run on the network.

Projects already adopted by the UK MHRN

There are currently fourteen projects hosted by the UK MHRN:

Involve – Outcomes of Involuntary Hospital Admissions - Prof. Stefan Priebe

MIDAS – Motivational Interventions for Drug and Alcohol Misuse for Schizophrenia – Prof. Christine Barrowclough

EDEN – Evaluating the Development and impact of Early Intervention Services in the West Midlands – Dr. Helen Lester

National study of mental health professionals' information sharing practices with carers of persons with mental health problems – Prof. Peter Huxley

Feasibility study of enhanced relapse prevention by key workers for people with bipolar disorder – Dr. Fiona Lobban

PSYGRID – e-science to Facilitate Clinical Trials and Longitudinal Studies in First Episode Psychosis – Prof. Shôn Lewis

Randomised Trial of fluoxetine and CBT versus fluoxetine alone in adolescents with persistent major depression – Prof. Ian Goodyer

The impact of treatment foster care on the outcomes for young people looked after by the authorities – Dr. Stephen Scott

GENPOD – Genetic and Clinical Predictors of Treatment Response in Depression – Prof. Glyn Lewis

A collaborative study to identify genes associated with susceptibility to anorexia nervosa – Prof. Janet Treasure

NACHBID – Neuroleptics in Adults with Aggressive Challenging Behaviour and Intellectual Disability – Prof. Peter Tyrer
A randomised controlled trial of adolescent anorexia nervosa including assessment of cost effectiveness and patient acceptability – Prof. Simon Gowers

What in-patient alternatives to traditional in-patient care exist, and how effective, cost effective and acceptable to users and carers are they? – Prof. Graham Thornicroft

Primary prevention of cardiovascular diseases in people with severe mental illnesses: Development and feasibility of complex interventions in both primary and secondary care – Dr. David Osborn

Evaluation of the Threshold Assessment Grid (TAG) as a means of improving access from primary care to mental health services – Dr. Mike Slade

Improving social recovery in early affective and non-affective psychosis: a randomised controlled trial of Social Recovery oriented Cognitive Behaviour Therapy (SRCBT) – Dr. David Fowler

SuperEDEN – A National Evaluation of Early Intervention for Psychosis Services: DUP, Service Engagement and Outcome – Prof. Max Birchwood/Dr. Helen Lester

TREAD – A pragmatic randomised controlled trial to evaluate exercise as a Treatment for Depression – Prof. Glyn Lewis

BECCA – Befriending and the Costs of Caring – Prof. Shirley Reynolds

How do patterns of risk predict the evolving nature of psychopathology in post-pubertal adolescents? – Prof. Ian Goodyer

MHRN Cymru indicative projects

The following are examples of specific projects, that the steering group has identified, that could be conducted by the proposed network:

a) Large pragmatic randomised trials of complex interventions such as suicide prevention; early intervention in psychosis or collaborative models of disease management across the primary secondary care interface;
b) Opportunities would exist to collaborate with the English MHRN on UK wide studies;
c) The establishment of large cohorts of patients with the major psychiatric disorders (eg. psychoses, mood disorder) for longitudinal investigation to allow both basic and translational research from bench to community;
d) Linking with the All Wales Birth Cohort to explore the potential for longitudinal research;
e) Conducting policy relevant research into black and minority ethnic mental health;
f) Research to support policy development systems, national, regional and local development of strategy across the sectors to support evidence-based mental health and mental health service development and commissioning of the services required;
g) Providing responsive research to support policy initiatives and examine Welsh priority areas within mental health and learning disability such as Better Health Better Wales and Health Challenge Wales.

Here is an indicative list of projects that could be adopted giving details of actual or proposed funding:

• Improving the physical health of people with severe mental illness (NPRI short listed)

- FOLATED A RCT of folate augmentation in depression (HTA short listed)
- Genetic epidemiological investigation of risk factors for psychosis (MRC).
- Treatment trial of atypical antipsychotic medication for prophylaxis of puerperal (postpartum) psychosis (US Stanley Foundation).
- Identifying clinically relevant predictors of postnatal mood disorders (Wellcome Trust).
- Longitudinal study of adolescents at high risk of mood disorders and psychosis (MRC).
- Service implications of molecular advances in neuropsychiatric genetics (DoH).
- Development of a clinically useful dimensional diagnostic system for psychiatric practice (Wellcome Trust).
- A RCT of folate supplements in the management of depression in primary and intermediate care (HTA)
- BALANCE study in bipolar disorder (Stanley Foundation)
- Development of a substance misuse, mental health and physical health screening and assessment tool (youth justice board)

We have the expertise, interest and population base to contribute to existing English projects including GENPOD (in which Cardiff is already providing the genetic input), PsyGrid and studies of first episode psychosis and relapse prevention in bipolar disorder.

Commercial studies for adoption by the network

The UK MHRN is considering adopting it's first commercial study. We will monitor this closely to see if it is appropriate to extend this to Wales.

10. How will your proposed network address Welsh Assembly Government priorities?

Mental health is a WAG priority area. Designed for life 2005 contains more targets for mental health than almost any other clinical area. MHRN Cymru will embed clinical research in the mental health services.

The proposed network will address a Welsh Assembly Government stated priority area, mental health with the following aims:

- To organise, deliver and implement large-scale research projects to inform policy and practice as they develop and help services implement change;
- To broaden the scope and capacity of research, which includes full involvement of service users and carers in conceiving, planning commissioning and delivering research;
- To implement a specific strategy for service user / patient involvement;
- To help identify mental health research needs (particularly in health and social care, working with front line staff, service users and carers);

- Develop research capacity through a range of initiatives at local, regional, national and international levels;
- Link and coordinate with the UKCRC and European initiatives to maximize the value to Wales, the wider UK and Europe;
- Participate in the UK PsyGrid initiative;
- Develop a Wales-wide sampling frame for basic and translational clinical research;
- Establish large, representative cohorts of patients that can be followed longitudinally through their illness career;
- Attract funding through collaborative tending across the institutions involved to add to that available from WORD to develop the mental health research infrastructure in Wales;
- Attract major external funding to allow the above aims to be achieved and sustained.

The following are examples of specific projects, that the steering group has identified, that could be conducted by the proposed network:

- Large pragmatic randomised trials of complex interventions such as suicide prevention; early intervention in psychosis or collaborative models of disease management across the primary secondary care interface;
- Opportunities would exist to collaborate with the English MHRN on UK wide studies;
- The establishment of large cohorts of patients with the major psychiatric disorders (eg. psychoses, mood disorder) for longitudinal investigation to allow both basic and translational research from "bench to community";
- Linking with the All Wales Birth Cohort to explore the potential for longitudinal research;
- Conducting policy relevant research into black and minority ethnic mental health;
- Research to support policy development systems, national, regional and local development of strategy across the sectors to support evidence-based mental health and mental health service development and commissioning of the services required;
- Providing responsive research to support policy initiatives and examine Welsh priority areas within mental health and learning disability such as *Better Health Better Wales* and *Health Challenge Wales* and *Designed for Life*.

11. How will your proposed network support UKCRC objectives?

UK CRC has already invested in a UK MHRN for England, reflecting the priority given to this area. This proposal would create a MHRN in Wales.

The proposed network will:

a) Develop & consolidate the mental health research infrastructure in Wales;
b) Build up the research workforce in Wales and broaden the research culture;
c) Provide a vehicle for the organisation, delivery and implementation of coordinated and streamlined mental health services research in Wales;
d) Work very closely with the MHRN for England to address UK wide priorities in mental health services research. Specific examples of this are:
   i) The Network would participate in the First Episode Psychosis Study being undertaken by the MHRN for England.
   ii) Establishment of the first longitudinal study of mental health in the UK with small area contextual measures of social capital, income deprivation.
e) Through achievement of these objectives the network would contribute to the UKCRC vision of the UK as a world leader in contributions to clinical research by harnessing the power of the NHS.

12. Please set out your plans for achieving the long-term sustainability of your proposed network.

In its first year the UK MHRN achieved 16 externally funded research projects running on the network. There is scope in Wales to replicate that success. By having a dedicated MHRN Wales will be highly attractive to external funders from all sectors. Research groups will provide the creative drive for the network and enhance sustainabaility.

Success of MHRN Cymru depends on the availability funds for mental health R&D. Unlike many disease areas such as cancer or heart disease there is no large dedicated mental health research charity comparable with Cancer Research UK or the British Heart Foundation. The UK MHRN is involved in a Funder's group chaired by Professor Claire Chilvers to increase mental health spend in research.

We will identify niche markets in which Wales can take a UK and international lead. In our programme of work we have set ourselves what we believe to achievable targets for sustainable growth. Like the UK MHRN we will continue to explore links with ABPI Cymru Wales. If central funding cease then the capacity to conduct clinical trials will be central tour survival. We will develop our sustainability strategy in the first year of activity. The best guarantees of sustainability will be our close links with UK MHRN and our unique position to offer a strong research environment in Wales.

In the scoping study option appraisal we asked respondents about sustainability strategies. A thematic MHRN with its own RPN was identified as the best option for sustainability for the following reasons:

Generic networks can offer additional support in trial methodology or qualitative research. They would be well placed to support thematic or domain specific networks such as a mental health network. However, without a network in a priority area such as mental health it is unclear to whom the generic methodology network would be providing support in the first place. A generic network would lack expertise and experience in both the design and conduct of clinical trials with this patient group and access to the people who would need to be recruited into studies from community and social care settings. The English MHRN has been very successful in attracting external funding and recruiting people to studies. In a competitive environment for network support mental health rarely fares well against other specialties. This is especially likely to be the case when the proposed generic trials resource is so heavily based in the cancer trials network.

With a thematic network with a dedicated RPN the network can address a broad client group. The broader the client group and disease area coverage the greater the critical mass, providing this is matched by proportionate incremental funding. Close alignment with the UK MHRN would enhance the sustainability of the network and facilitate common work programmes and increase access to external funding sources. Research creativity and sustainability could be enhanced further by mirroring UK MHRN plans to set up research groups in areas of interest and expertise that will provide the creative drive for the network.

13. Please provide a full breakdown of your anticipated costs. (You may apply for a grant of up to £80,000 a year for a period of 3 years.)

Based on an October 1st 2005 start date all costings have been itemised as far as possible All relevant direct costs have been included. Indirect costs have been charged at 40% of staff costs. Economies have been achieved by sharing administrative costs with the Dementias and learning disability networks

14. Use of additional funding

Two initiatives are proposed. The first is to employ a research fellow on a part time basis to establish with the James Lind Alliance a DUETs database for schizophrenia. The second is for a shared capacity building fellowship across MHRN Cymru, Learning disability and the Dementias.

The James Lind Alliance research fellow

It is proposed to seek funding for a researcher to work with these organisations to populate the DUETs databases in these areas. In the case of mental health we would then seek external funding to run this project UK wide on the UK MHRN.

We would also seek to pilot in Wales the patient-clinician working partnerships proposed by the James Lind Alliance. In mental health the partnerships would be with the Wales Collaboration for Mental Health and the Welsh Psychiatric Society (www.wps.swan.ac.uk).

This fellowship would be shared with the respiratory medicine network for whom this individual would work on a DUETs database for asthma. Two early priorities for the James Lind Alliance in the development of a Database of Uncertainties about the Effects of Treatments (DUETs) are asthma and schizophrenia. Uncertainties about the effects of treatments are reflected in the questions that patients and clinicians bring to question answering services such as NHS Direct, Hafal, Mind Cymru) and ATTRACT. Some of their questions can be addressed by reference to up-to-date, systematic reviews of reliable research studies. For many other questions, however, information is not readily available. Sometimes this is because no systematic reviews of the relevant evidence have been prepared; sometimes it is because existing systematic reviews have not been kept up to date; and sometimes it is because systematic reviews have shown that uncertainties about treatment effects will not be reduced without further research.

The proposed networks in respiratory medicine and mental health therefore propose to collaborate in giving Wales a UK lead in the establishment of DUETs in these respective areas. Work is also proposed in primary care with NHS Direct Wales to use information gleaned from routine calls to that service, to generate questions about treatment uncertainties.

In the mental health field, Hafal and Mind Cymru are two national organisations that regularly field calls from people with schizophrenia Both are members of the Wales Collaboration for Mental Health and are co applicants on the Mental Health Research Network Cymru network application.

It is proposed to seek funding for a researcher to work with these organisations to populate the DUETs databases in these areas. In the case of mental health we would then seek external funding to run this project UK wide on the UK MHRN.

Research capacity building fellowship

Ideally, if funding were available, the MHRN Cymru, Learning Disability, and Dementia networks would each seek to offer a research fellowship to enable a practising clinician to take time out to develop their research skills. Thus building research capacity back into the NHS. This would pump prime three priority projects focused on overlapping research interests. The request for funding below reflects this position. However, if funds are not sufficient for three research fellowships, then the three networks would undertake to share the support available (one or two fellowships) in the best way possible.

The networks undertake to establish priorities for mutual collaboration, prepare research protocols and arrange to have the proposals peer-reviewed in the first six months of their existence. Beyond the initial projects, the networks would establish a regular cycle of dialogue to identify and prepare future suitable projects with the aim of maintaining a joint rolling programme of research fellowships.

15. Using the Research Professional Network

It is WORD's preference that all established networks use the generic Research Professional Network (RPN) as far as possible. (Please see the What WORD is offering section in the supporting notes for more information.)

Clear opportunities exist for collaborating with the generic RPN for studies in primary care and secondary care. Staff from a generic network derived from a cancer trials model will lack specific skills related to dealing with the client group and the specialist RPN will be able to assist them in this.

How we would utilise staff from the RPN

In certain studies, e.g. those carried out in primary care, we can envisage that the generic RPN would be of considerable assistance in establishing links with the relevant practices, establishing potential participants and in recruitment. We would intend to develop a shared experience with other networks on the effective use of the generic Research Professional Network. We foresee using the generic RPN for recruitment in certain studies (e.g., identifying people with mental health problems, learning disabilities or dementia within general practice lists).

There will be a clear role for the generic RPN and CRCC Cymru in administrative and IT support, data handling and management of routine data, randomisation, electronic data capture, generic training in for example ICH GCP, dissemination communication.

We envisage a major role for RPN in developing a national register database and for working with local health boards and authorities on strategic dissemination of evidence-based practice. We are doubtful that this could be undertaken by

the generic resource, partly due to the sustained commitment involved, partly because of certain necessary specialist understanding and partly because of competition from other calls on the generic resource. In principle, there is great potential for using generic approaches. However, there is long-standing experience that mental heath is overlooked within generic concerns. This is evidenced by the relative dearth of funding of mental health research outside of networks compared to other disease areas. We are, therefore, cautious about the extent to which we can expect the generic RPN to be dedicated to our concerns.

A Case for a specialist RPN network

In the scoping study option appraisal we asked respondents about sustainability strategies. A thematic MHRN with its own RPN was identified as the best option in terms of appropriateness, quality, client group inclusiveness, sustainability and accountability. Economies of scale are identified from collaborating with other proposed networks.

Recruiting from the community as well as primary care and hospital settings

CRCC Cymru propose to offer RPN and clinical trials support in primary and secondary care. Many of the people to be recruited into large well designed studies in mental health are not in primary care or hospital settings they are in the community.

Specialist research skills

Generic networks can offer additional support in trial methodology or qualitative research. They would be well placed to support thematic or domain specific networks such as a mental health network. However, without a network in a priority area such as mental health it is unclear to whom the generic methodology network would be providing support in the first place. A generic network would lack expertise and experience in both the design and conduct of clinical trials with this patient group and access to the people who would need to be recruited into studies from community and social care settings.

With a thematic network with a dedicated RPN the network can address a broad client group. The broader the client group and disease area coverage the greater the critical mass, providing this is matched by proportionate incremental funding. Close alignment with the UK MHRN would enhance the sustainability of the network and facilitate common work programmes and increase access to external funding sources. Research creativity and sustainability could be enhanced further by mirroring UK MHRN plans to set up research groups in areas of interest and expertise that will provide the creative drive for the network.

User group preference

Mental health is a highly specialised field within the range of health and social care provision. We have a clear steer from user groups involved with our group that a specialist research professional network will be essential to working with this client group. This has been demonstrated in the UK mental health network.

A clinical trials model derived from cancer trials is not appropriate.

The English MHRN has been very successful in attracting external funding and recruiting people to studies. In a competitive environment for network support mental health rarely fares well against other specialties. This is especially likely to be the case when the proposed generic trials resource is so heavily based in the cancer trials network.

Different core professional RPN training

Many RPN staff have a nursing background. In clinical practice, general nurses have different professional training from

nurses working in mental health or learning disability resources of the mental health is a highly specialised field within health. That reflects the different issue in working with these client groups.

The way forward

For these reasons, we believe there is a strong argument for having a distinct research professional network for mental health. This would require four individuals across Wales. That option is costed in table 3. However, we recognise that may not be the most cost efficient solution.

We have worked with the learning disability and the dementias network to achieve economies of scale across the three networks. Details of how this can be achieved are set out in table 4.

In this model there would be two RPNs in each of N Wales, Mid and West Wales and SE Wale. In recognition of the limited resources available, we feel that professionals with a mental health or learning disability background would be able to undertake this role in relation to people with dementia and related disorders, with additional support and supervision. We therefore propose a joint RPN for learning disability, mental health and the dementias, comprising 3 posts in total, distributed across Wales, with the expectation that at least one of these post holders would have specific relevant experience and skills.

16. Declaration.

I apply for a grant of over three years to establish a mental health research and development network or over three years to establish a mental health, learning disability and dementia's network with shared infrastructure.

My institution is aware that I have applied for this grant and supports my application.

Name: Keith Lloyd
Date: 8th September 2005
Institution: University of Wales Swansea

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Appendix A: The UK Mental Health Research Network

UK Mental Health Research Network

Providing the infrastructure to support large scale, high quality research in mental health and social care.

The UK MHRN is a network designed to provide a research infrastructure. The network supports vital large-scale research which will help to raise the standard of mental health and social care research throughout England. In addition, it acts as a central point of information and reference, connecting service users and carers to researchers and mental health professionals. The UK MHRN research will not only respond to government policy but will help guide practice and contribute to the understanding of mental illness and the increase of mental health in the UK.

The Network's Infrastructure

The MHRN is managed on behalf of the Department of Health, by a partnership between the Institute of Psychiatry and University of Manchester. Professor Til Wykes is the Director, based at the Institute of Psychiatry. Professor Shon Lewis and Professor Max Marshall are Associate Directors, based at the University of Manchester and Professor Tony David is the Associate Director based at the Institute of Psychiatry.

The Network currently consists of:

- 20 Universities
- 38 NHS Trusts
- more than 40 PCTS
- research expertise in primary, secondary and social care
- many disciplines including social sciences and health economics
- 49% of the population of England

There are eight research hubs which have clinical, academic and service user components. The clinical component consists of primary, secondary and social care and the academic component is a mix of high quality multi-disciplinary researchers from universities and research consortia. In addition there is a Service User Research Group for England (SURGE) which supports service user involvement in projects run on the network.

What Types of Research Does the UK MHRN Host?

Projects that requires multiple sites because of:

- a large sample size,
- participants with a rare condition, or
- participants from a particular group or lifestyle.
- The project is a cluster-randomised trial that requires multiple centres or units of randomisation.
- The project requires multiple centres in order to establish that a finding or an intervention is generalisable across different settings or is applicable in specific settings (for example rural areas).

Pilot studies can be adopted if they have the potential to develop into large scale studies.
To date, sixteen projects have been granted final approval to run on the network following success in securing funding.
To apply to run a research project on the UK MHRN contact mhrn@iop.kcl.ac.uk

Research Creativity

The MHRN generates research ideas in priority areas through the establishment of multidisciplinary research groups that develop capacity and widen access to the Network. Currently, there are research groups in Early Intervention in Psychosis, Self Help and Antidepressants.

Mental health research has made great advances but it has not been able to answer some important questions because often studies and clinical trials have been too small. The reliance, on small, localised studies has prevented researchers from drawing valid general conclusions and as a result, research has failed to inform policy, and has lacked coherence, relevance and credibility with users and professionals.

There is a shortage of research capacity and competence across England and a concentration of research in only a small number of key research centres. Consequently there have been few chances for interested clinicians from the rest of the country to gain experience in carrying out large scale projects.

Poor integration of resources, experience and expertise has meant that mental health research has been unable to attract the valuable support that it deserves from the major funding bodies. The UK Mental Health Research Network provides an infrastructure across England with a range of demographic and cultural differences together with specific service configurations which enables it to host large scale research projects in mental health. Researchers using the UK MHRN can access the valuable high-level expertise within the network and can benefit from a coordinated approach to patient recruitment. In addition, researchers are relieved of much of the administrative burden of setting up research projects through UK MHRN central support for governance and financial arrangements. It is hoped the UK MHRN will create a culture of large-scale studies relevant to key problems in mental health and that the knowledge within the Network will become a useful resource for less experienced researchers.

What is the purpose of the Research Groups?

- To supplement the work of the Research Hubs, providing the creative drive of the Network.
- To develop a programme of research to facilitate understanding of key scientific issues, as well as developing evidence for effective practice.

UK MHRN Research and Scoping groups, June 2005

- Early intervention in psychosis Professor Max Birchwood
- Evaluation of Treatment Interventions in Adults with Learning Disability Professor Nick Bouras
- Depression/Anti-depressant treatment Professor Tony Kendrick
- MHRN Rehabilitation and Recovery Research Group Dr Helen Killaspy
- Physical and Metabolic consequences of Severe Mental Illness (SMI) Dr David Osborn
- Patient-professional Treatment Partnerships in Mental Health Professor Robert Peveler
- Self help Professor Dave Richards
- TASC: Theory and Analysis of Social Capital in Mental Health Research Professor Justine Schneider
- Employment and Mental Health Professor Graham Thornicroft
- Personality Disorder Research Group Professor Peter Tyrer
- Long-term effect of psychotropic medication in children Dr Ian Wong

Scoping groups

- Older age Professor Sube Banerjee
- Children's mental health Professor Eric Taylor
- Social care Professor Peter Huxley
- Carers Rethink

Current projects

There are currently fourteen projects hosted by the MHRN:

InvolvE – Outcomes of Involuntary Hospital Admissions - Prof. Stefan Priebe.

MIDAS – Motivational Interventions for Drug and Alcohol Misuse for Schizophrenia – *Prof. Christine Barrowclough.*

EDEN – Evaluating the Development and impact of Early Intervention Services in the West Midlands – *Dr. Helen Lester.*

National study of mental health professionals' information sharing practices with carers of persons with mental health problems – *Prof. Peter Huxley.*

Feasibility study of enhanced relapse prevention by key workers for people with bipolar disorder – *Dr. Fiona Lobban.*

PSYGRID – e-science to Facilitate Clinical Trials and Longitudinal Studies in First Episode Psychosis – *Prof. Shôn Lewis.*

Randomised Trial of fluoxetine and CBT versus fluoxetine alone in adolescents with persistent major depression – *Prof. Ian Goodyer.*

The impact of treatment foster care on the outcomes for young people looked after by the authorities – *Dr. Stephen Scott*

GENPOD – Genetic and Clinical Predictors of Treatment Response in Depression – *Prof. Glyn Lewis.*

A collaborative study to identify genes associated with susceptibility to anorexia nervosa – *Prof. Janet Treasure.*

NACHBID – Neuroleptics in Adults with Aggressive Challenging Behaviour and Intellectual Disability – *Prof. Peter Tyrer.*

A randomised controlled trial of adolescent anorexia nervosa including assessment of cost effectiveness and patient acceptability – *Prof. Simon Gowers.*

What in-patient alternatives to traditional in-patient care exist, and how effective, cost effective and acceptable to users and carers are they? – *Prof. Graham Thornicroft.*

Primary prevention of cardiovascular diseases in people with severe mental illnesses: Development and feasibility of complex interventions in both primary and secondary care – *Dr. David Osborn.*

Evaluation of the Threshold Assessment Grid (TAG) as a means of improving access from primary care to mental health services – *Dr. Mike Slade.*

Improving social recovery in early affective and non-affective psychosis: a randomised controlled trial of Social Recovery oriented Cognitive Behaviour Therapy (SRCBT) – *Dr. David Fowler.*

SuperEDEN – A National Evaluation of Early Intervention for Psychosis Services: DUP, Service Engagement and Outcome – *Prof. Max Birchwood/Dr. Helen Lester.*

TREAD – A pragmatic randomised controlled trial to evaluate exercise as a Treatment for Depression – *Prof. Glyn Lewis.*

BECCA – Befriending and the Costs of Caring – *Prof. Shirley Reynolds.*

How do patterns of risk predict the evolving nature of psychopathology in post-pubertal adolescents? – *Prof. Ian Goodyer.*

Appendix B The James Lind Alliance and DUETs

Research Networks Cymru and Database of Uncertainties about the Effects of Treatments (DUETs)

Hafal National Resource Centre, Museum of Welsh Life, St Fagan's, Cardiff, CF5 6DU

31 August 2005 at 11.30am

Notes

Present: Keith Lloyd – Mental Health
Jon Brassey - ATTRACT
Iain Chalmers – James Lind Alliance
Fiona Dennis – NHS Direct Wales
Iolo Doull – Paediatric Respiratory Physician
Adrian Edwards – Primary Care
Mark Fenton – James Lind Alliance
Colin Gelder – Respiratory Disease

Apologies: John Abbott – Hafal
Ruth Coombs – MIND

1. Introduction

Iain Chalmers opened the meeting with a brief introduction of himself, the James Lind Alliance (JLA) and the Database of Uncertainties of the Effects of Treatments (DUET) currently being developed. The purpose of the meeting was to discuss the possible ways in which the JLA and the respective networks could work together to help populate the database with relevant questions with the intention that, as well as addressing uncertainties about the effect of treatments, it become a valuable resource to promoting and directing clinical trials and other studies.

2. Mental Health Research Network – Keith Lloyd

Keith Lloyd gave an overview of the bidding processes currently happening in Wales at the moment. Earlier this year Professor John Williams, Director of WORD, gave a lecture regarding the development of R&D. Following the establishment of the UK Clinical Research Collaboration (UKCRC) as a national body with responsibly for overseeing clinical research in the UK, Professor Williams felt there should be a corresponding centre for coordination of R&D in Wales to be able to attract and coordinate studies large enough to answer important questions to specific health issues in Wales. Bids are to be received in early September. There was also a call for the creation of thematic networks and there were initially 55 bids submitted. We are now in phase 2 of this bidding process.

As an introduction to the mental health bid KL gave a brief background to the Wales Collaboration for Mental Health (WCMH). On behalf of the WCMH a bid was submitted to WORD for a Mental Health Research Network Cymru. An application for a full network is now being submitted with full collaboration from voluntary sector, the NHS, social care, universities, patients and carers across Wales, with a focus on health informatics.

3. Respiratory Disease Research Network – Colin Gelder

Colin Gelder gave the background to the proposed Respiratory Disease network application. So far research in respiratory disease has been driven by industry, and the majority of outcome measures are based on physiology rather than how the patient actually feels. This is an opportunity to redirect the way research is carried out and they are now working in collaboration with people from social sciences, general practitioners, pharmacies and patients.

4. James Lind Alliance and Database of Uncertainties about the Effects of Treatments (DUETs) – Iain Chalmers, Mark Fenton

Iain Chalmers gave a fuller background to the JLA and synopsis of what they do. Research on the effects of treatments today often fails to address questions that matter to patients and the clinicians to whom they turn for help when they are ill. Research tends to be dominated by studies on drugs, with insufficient attention given to assessing other forms of therapy. The JLA is an alliance of people who wish to help address the mismatches between what is research and the information needed by patients and clinicians, so the development of the Alliance is being guided by a steering group of patients, clinicians and others. They encourage patients and clinicians to work together to identify and prioritise questions about the effect of treatments.

Mark Fenton started by giving his background then went on to describe in detail how DUETs is structured and how the web site functions from a patient, carer and clinical point of view. He highlighted the need for identifying what research is currently being carried out or the results published. The most important thing is to ensure the right questions are being asked as the biggest problem is how do we know what is a good outcome for someone with, for example, asthma or schizophrenia. Need reliable sources to be able to identify what outcomes should be addressed in future research. The website (as it stands to date) can be viewed at: http://www.update-software.com/duets/

5. ATTRACT and the National Clinical Question Answering Service – Jon Brassey

Jon Brassey gave his background and the background to ATTRACT. ATTRACT was created in 1997 in response to a large needs assessment exercise carried out with members of the primary care team in Gwent, South Wales. Clinicians were keen to practice 'evidence-based medicine' but found that they didn't have the time and/or expertise in which to keep 'up to date'. What the clinicians wanted was rapid access to the literature via a mechanism that meant that they had minimum resource implication for them.

In order to meet these needs ATTRACT was created. Since 1997 the basic principle has been the same - clinicians contact them, and they rapidly search the evidence, appraise and summarise and then fax it back to the clinician.

The interest in DUET stems from not having all the answers. They are currently answering approx 50 questions a week. There is a fairly infrequent repeat rate of questions but in those instances DUET would provide the opportunity to take notice of where the questions are and what people want.

6. Planned work with NHS Direct Wales – Jon Brassey, Fiona Dennis & Adrian Edwards)

A pilot study has been run with NHS Direct Wales in order to understand the volume and type of questions received from callers to the service. Fiona Dennis explained the system of call handling and what information is recorded. NHS Direct Wales is happy to share the information collected with DUET.

7. General Discussion

There was some discussion about what support would be made available for the networks to work with DUET. Also, about the original bid put in by Professor Lindsey Prior for a grant of £15,000.

Both Keith Lloyd and Colin Gelder expressed keen interest in their respective bids working with DUET and discussed how they would be able to provide valuable resources and a triangulation of support to one another. KL suggested that these suggestions be included in the bids.

8. Summary of agreed Action Points

It was identified that both the Respiratory Disease and Mental Health bids are keen to work with DUET. This will be in addition to the work already being done in conjunction with NHS Direct Wales.

Keith Lloyd and Colin Gelder are to have a meeting to discuss their joint interests in working with DUET and how this should be dealt with in their bids.
Action: KL/CG

Keith Lloyd will continue to talk to John Abbott at Hafal and Ruth Coombs at MIND about possibly working with them in the same way as the pilots with NHS Direct Wales.
Action: KL/JA/RC

MF will email everyone with instructions on how to access the website live, which he stressed changes on a regular basis. He called for comments to be made to help with the weekly iterative process.
Action: MF

Notes of the meeting to be circulated to all and included in application to WORD.
Action: AL

Draft to be produced of how the JLA and proposed networks in mental health and respiratory diseases could work together.
Action: IC/CG/KL

Glossary

AWARD	All Wales Association for Research and Development
CRCC Cymru	Clinical Research Coordinating Centre Cymru
HTA	Health Technology Assessment Panel
MHRN Cymru	The Mental Health Research Network for Wales
MHRN- UK	The UK Mental Health Research Network
MRC	The Medical Research Council
NHS	The National Health Service
SDO	The Service Development and Organisation panel
UKCRC	The United Kingdom Clinical Research Collaboration
WAG	Welsh Assembly Government
WORD	Wales Office of R&D
WORTH	Wales Office for Randomised Trials for Health
WCMH	Wales Collaboration for Mental Health

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Keith Lloyd

Providing the
infrastructure for clinical
trials and other well
designed studies that
have implications for people,
services and treatments

Compiled on behalf of the
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