

NCMH

National Centre for Mental Health
Canolfan Iechyd Meddwl Genedlaethol



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

2015-16
Annual Report



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Foreword

The National Centre for Mental Health entered into a new chapter of collaboration and innovation in 2015 when it was funded as a Health and Care Research Wales Centre.

Through new partnerships with colleagues at Swansea and Bangor Universities we have opened up a range of new avenues for research that we believe will eventually lead to better diagnosis and treatment for mental health problems.

Thanks to the fresh talent and expertise of our partners, we have broadened our expertise and been able to take on new areas of study such as learning disabilities, social care and social determinants.

We've also made the first important steps towards embracing 'big data' through the Secure Anonymous Information Linkage (SAIL) Databank which promises to be a powerful tool for mental health research.

Aside from this, we have continued to build on our previous success in recruiting a cohort of members of the public with experience of mental health problems to take part in research. The current total stands at approaching 6000 individuals.

We've also continued to work towards improving the Welsh public's understanding of mental health issues, and to reduce the stigma that so often surrounds mental illness.

Our efforts have taken many forms, from the delivery of high profile collaborative events such as our Movember Launch Party to appearances in the media to simply telling the powerful real-life stories of our volunteers.

As I write this NCMH will be entering into its second year of funding. As always, the year ahead will be filled with challenges and opportunities.

We will continue striving towards a better future for those affected by mental health problems and in putting Wales on the map for mental health research.



Professor Ian Jones
Director, National Centre for Mental Health

Introduction

Aims

The key aims of the new phase of NCMH are to:

- advance mental health and learning disability research in Wales – to support areas of excellence and develop capacity in new areas of excellence;
- engage with patients, their families, the wider public and third sector organisations in Wales to increase understanding of mental illness and learning disabilities and the need for research in these areas;
- change the research culture in health and social care services in Wales with the ultimate goal of all individuals accessing care being invited to participate in research.

To achieve these aims we will focus activity in two interlinked core areas:

- i) expanding and developing the NCMH Cohort and
- ii) increasing the involvement and engagement of patients, carers, health and social care professionals and the wider public.

This annual report will discuss our progress in achieving these aims, and in particular our work in 2015-16 to develop the cohort and improve engagement with our stakeholders.



Who's Who

The NCMH team is made up of academics and clinicians from three of Wales' leading universities - Cardiff, Swansea and Bangor.



Professor Ian Jones
NCMH Director



Professor James Walters
NCMH Deputy Director

NCMH Board

- Professor Michael Owen
- Professor Keith Lloyd
- Dr. Michael Jackson
- Professor Mike Kerr
- Dr Debbie Cohen
- Professor Nick Craddock
- Professor David Ford
- Dr Elizabeth Forty
- Professor William Gray
- Professor Jeremy Hall
- Professor Peter Holmans
- Dr Ann John
- Professor Meng Li
- Professor David Linden
- Professor Michael O'Donovan
- Professor Catherine Robinson
- Professor Anita Thapar
- Professor Rob Poole

Administration Team

- Karin Alderson
- Janet Robinson
- Deborah Watkin
- Rebecca Lynch
- John Tredget*
- Lee Eynon*
- Paul Gauci*
- Megan Baldwin*

Laboratory Team

- Kiran Mantripragada*
- Bozo Lugonja
- Ganna Leonenko
- Craig Joyce*
- Alex Evans

Phenotyping Team

- Dr Catrin Lewis
- Lawrence Raisanen
- Andy Bethell*
- Kali Barawi
- Christine Fraser
- Holly Pearce
- Holly Howe
- Jenna Markham
- Hannah Bowker
- Natalie Richards
- Katie Wilkinson
- Sophie Andrews
- Emma Liddiard Williams
- Jenny Thomas

SAIL Team

- Marcos del Pozo Banos
- Niren Basu

** Not directly employed by NCMH, but part funded in some cases*

Partners

- Cardiff University
- Swansea University
- Bangor University
- Abertawe Bro Morgannwg University Health Board
- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff & Vale University Health Board
- Cwm Taf University Health Board
- Hywel Dda University Health Board
- Powys Teaching Health Board



Work packages

Our work is organised into 6 core categories, known as work packages. Our progress in each work package is discussed below.



Working to involve and engage the public in mental health research while combatting mental health stigma is a key part of NCMH's role.

Involvement, engagement and knowledge transfer

NCMH does this in a variety of ways from running events and engaging with the media to recruiting members of the public with lived experience to act as champions.

Highlights

- Over 20,000 views on social media for Clive Norling promotional video
- Delivered 4 high-profile public engagement events including a men's mental health event in partnership with the Movember Foundation and a University Mental Health Day event featuring 5 live music acts
- Secured 20 press appearances across outlets including The Western Mail, The Daily Mail, ITV Wales, BBC Wales and S4C
- Increased number of Research Champions to 20.



NCMH's remit now includes learning disability research, with a focus on mental health and challenging behaviour in people with learning disability.

Learning disabilities

This work is led by Professor Mike Kerr of Cardiff University.

Highlights

- Produced learning disability information leaflet and online resources to aid recruitment, alongside a learning disability specific recruitment leaflet
- Established a Learning Disability e-cohort
- Held a Learning Disabilities Training Day to engage with LD clinicians and raise awareness of NCMH's research in this area.



NCMH acts as a biobank. We store the biological samples that our researchers collect in a secure and anonymous repository.

Biobanking and biological samples

Relevant research studies can then apply to use these samples in their work.

Highlights

- Over 2,050 samples received in 2015/16 for a grand total of 8,636
- Applications to access over 1300 NCMH cohort samples have been received over the last 6 months, a significant increase on previous years
- NCMH was recently nominated by Cardiff University as a representative for external audit with the Human Tissue Authority - a vote of confidence in the centre's tissue handling expertise. NCMH also successfully passed the audit.



Research which considers the social determinants and social effects of mental health play an important role in NCMH's work.

Social care and social research

The centre works closely with researchers from Bangor University's Centre for Mental Health and Society (CFMHAS).

Highlights

- Questions, which consider social factors, have now been added to the menu of questionnaires used by NCMH field researchers in our assessment interviews.
- The centre welcomed the establishment of the School of Social Care with strong links to CFMHAS and other centres and units.
- A research development forum Methods and Research in Service Settings will shortly be relaunched to include social care organisations.



NCMH cohort

One of NCMH’s main purposes is to build a cohort of thousands of people who have participated in our study and agreed to be contacted about future research opportunities.

Highlights

- 1,361 volunteers recruited during 2015-16 for a grand total of 5,841
- Developed a web-based assessment system to allow volunteers to take part online (to be launched over the next year)
- Piloted the Development and Well-being Assessment for 5-17 year olds, which will be rolled out across CAMHS in the near future.



SAIL Databank

NCMH is working with partners at Swansea University to connect with the Secure Anonymised Information Linkage, or SAIL databank.

It will link up the patient information routinely collected by clinicians all over Wales to support NCMH research.

Highlights

- Approvals for linking NCMH and SAIL have been secured
- A test project linking the PsyCymru psychosis database to SAIL has been completed.

2015-16 in figures

The infographic below highlights some of the key figures across our work packages during 2015-16.

5841



Total volunteers as of 31.03.16

£29.5m+

Value of grants awarded in 2015/16

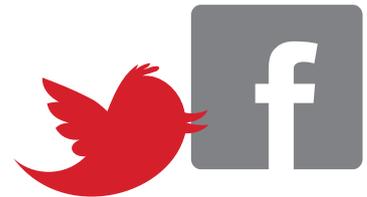
1361

Participants recruited to the cohort

9



New Research Champions recruited



2400+

Social media followers



20

Media appearances

250+

Scientific papers published



403

Online orders for information leaflets



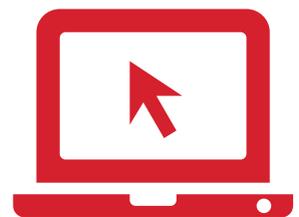
2050

Biological samples collected



20,000

People viewed latest NCMH promo video



21455

Visitors to our website

Key Achievements: Involvement and Engagement

Research Champions

Our Research Champions are people who have taken part in NCMH research and agreed to help promote the centre and its messages.

In 2015-16, NCMH built upon its already successful Research Champions programme by recruiting 9 new members of the public.

From providing case studies for the media to speaking at events and appearing in promotional videos, our champions have become a key component of NCMH's public engagement and involvement work.

A number of our Research Champions have also taken on a more active role in planning and overseeing the centre's work.

For example, Zoe has taken up a seat on the NCMH Stakeholder Liaison Group, which feeds into key decisions at the Centre, and Laura addressed Health and Care Research Wales' Involving People Conference in February 2016.

Involving service users

NCMH recognises the value of people with lived experience having involvement in mental health research programmes and studies by supporting a Service User and Carer Partnership. Professor Catherine Robinson has recently taken on the role of academic lead for the partnership, on behalf of the NCMH.

The main aims are to support opportunities for service users and carers to be actively involved in mental health research in Wales across the range of research activity from design to dissemination and for researchers in Wales to benefit from the unique perspectives of service users and carers in developing and undertaking their research.





Blowing the whistle on mental health

NCMH launched a promotional video featuring former international rugby referee Clive Norling in February 2016. Clive suffered with severe depression that led to him leaving his role as head of refereeing for the Welsh Rugby Union.

Now, as an NCMH Research Champion, Clive works to promote the centre's research and fight mental health stigma.

We released the video, which was filmed at the Principality Stadium, to coincide with the start of the RBS Six Nations rugby tournament. Since then it has been watched more than 20,000 times on social media.

Raising our profile

NCMH appeared in the national and local press more than 20 times in 2015-16.

NCMH director Professor Ian Jones has appeared discussing NCMH on *BBC 1 Wales News*, *ITV Wales News* and *S4C's Newyddion*, as well as appearing in a Channel 4 documentary on bipolar disorder.

The centre has also featured on WalesOnline, the country's most popular news website, as well as in national publications such as the *Daily Mirror*, the *Daily Mail* and the *Guardian*.



Innovative events, unexpected locations

NCMH attended more than 40 awareness raising events in 2015-16, and delivered four of its own. These events took place in unusual locations, and were designed to have a strong element of fun alongside the key messages. Here are some of the highlights:



It's a Man Thing 5th May 2015

Our men's health event at Swansea's Liberty Stadium aimed to raise awareness of mental health issues among a younger male audience.

It featured talks from various men's health charities and an appearance from Ospreys and Wales rugby players. Over 70 people attended.

Mums, Babies and Bumps Coffee Morning 2nd March 2016

This event aimed to raise awareness of perinatal mental health issues and featured baby massage and baby yoga classes.

The rain may have forced us indoors but it didn't damp our enthusiasm. The feedback from the attendees, as well as the NCT instructors, was very positive.





Movember Launch Party *30th October 2015*

Following on from our successful men's health event, we held a more ambitious event in partnership with the Movember Foundation.

The launch event, held at Cardiff's DEPOT warehouse venue offered guests the chance to sample the city's fashionable streetfood scene while learning more about how to help both the Movember campaign and NCMH.



Over 150 people attended the evening which included an appearance from broadcaster and singer Wynne Evans.

Lunchtime Live *2nd March 2016*

Our student mental health day event at Cardiff University Students Union featured 5 live music acts and offered NCMH with a chance to connect with Cardiff's sizeable student population.

Over 60 people attended.

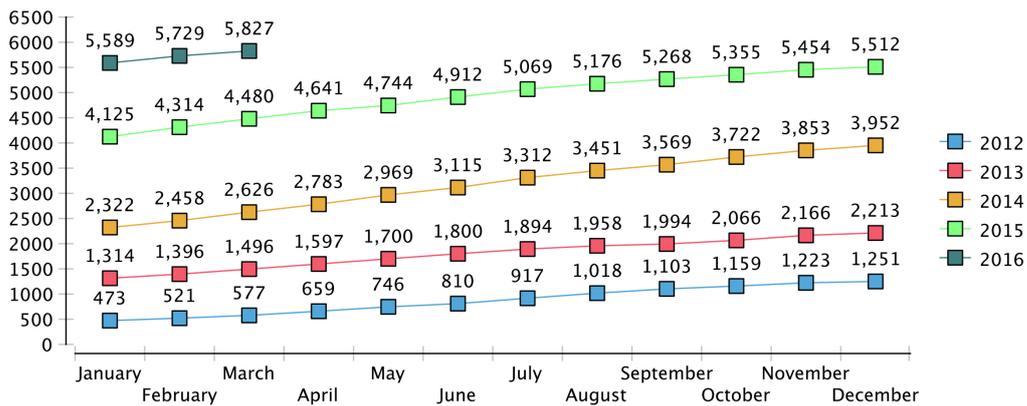


Key Achievements: Developing the NCMH Cohort

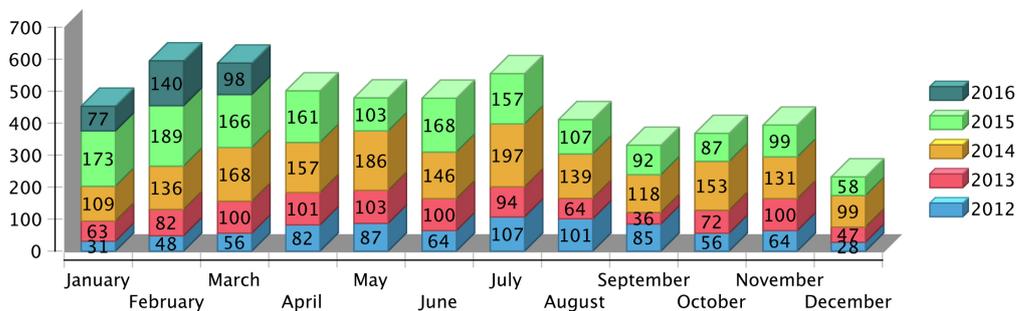
Continuing to do what we do best

NCMH recruited a further 1300 volunteers in 2015-16, for a grand total of almost 6000 - well on the way towards our next target of 8000 people by 2018. Recruiting large numbers of people allows us to draw more accurate conclusions and comparisons from the data we collect.

Cumulative Recruitment by Year



Monthly Recruitment by Year



Researching the next generation

In 2015-16 we have worked with CAMHS services in Wales to increase the numbers of child and adolescent participants in NCMH

We will be working with teams to offer all 5-17 year olds in contact with services the opportunity to take part in research through NCMH. We will be using the online Development and Wellbeing Assessment, or DAWBA, tool which we hope will provide research data as well as being a useful tool for clinical teams.





Streamlining our process

Traditionally, the process of recruiting volunteers and gathering data has been resource intensive for NCMH. A large amount of staff time is taken up with contacting people who have registered an interest to ensure that they understand the process, obtaining official consent and arranging visits, and then our field researchers have to visit each volunteer in person to complete assessments and take biological samples.

NCMH operates across Wales, so the time and travel costs of this are significant, particularly as volunteer numbers increase. That's why we've been exploring new ways of collecting data.

During 2015-16 we have been in talks with software developers and web design companies to devise a new online assessment tool which will allow us to obtain consent and collect some data online. While this will never replace our face-to-face visits, it will help us use our resources more efficiently and make taking part even more accessible to the public.

We expect this new system to be launched in the near future.

More targeted recruitment

We successfully launched our first condition-specific recruitment leaflets in 2015-16, as well as a number of online landing pages geared towards particular audiences.

By targeting people with specific conditions more effectively we believe that we can boost recruitment in key areas.

NCMH
National Centre for Mental Health

Perinatal mental health research:
Help us change lives

We are looking for women with experience of mental health problems during pregnancy or after childbirth to take part in our research. By taking part, you can help us understand the causes of these problems and develop better ways to help women affected in the future.

Find out more about taking part

Name

Contact number

Email

Anytime

Learn more

NCMH
National Centre for Mental Health

Take part in post-traumatic stress disorder (PTSD) research

Together we can make a difference

www.ncmh.info

Enhancing the data we collect

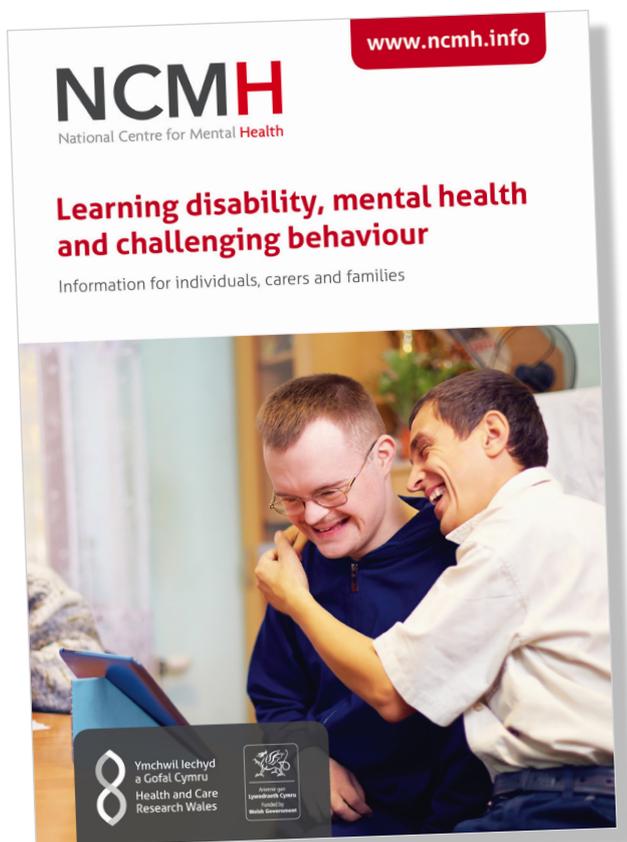
Originally, our interview was designed to be as brief as possible as we expected most participants to take part in a medical setting such as a clinic. In practice, however, most of our interviews now take place in volunteer's own homes. This means that we have more time available at interview than previously thought.

In 2015-16 we set about redesigning our assessment questionnaire to reflect this, while ensuring the process would still last around one hour in most cases. We took into account feedback from our field team researchers, comments from volunteers, the expertise of our new academic colleagues and the results of our 2014-15 #TellNCMH public involvement campaign to write the new assessment. As a result, it will take in new topics including:

- self-harm and suicide
- social deprivation
- mental health stigma
- childhood events
- work and employment
- alcohol smoking and drug use

A number of our questions have also been rewritten to harmonise with those asked in Health and Care Research Wales' HealthWise Wales major population cohort project, and will allow us to better compare data from people with and without experience of mental health problems.

The new assessment is currently being tested and we expect to roll out the new questionnaire in 2016-17.



Exploring new avenues

In 2015-16, NCMH broadened its scope to take in research on learning disabilities (LD). Led by Professor Mike Kerr of Cardiff University, this element of our work will focus on how mental health problems and challenging behaviour in people with LD

We aim to recruit around 150 individuals with learning disabilities into our cohort by 2018.

In 2015-16 we laid the foundations for achieving this target, delivering a training day for LD clinicians to help raise awareness of our work and producing LD specific information and recruitment leaflets, including Easy Read editions.

Understanding the importance of sleep

In recent years, wearable technologies such as fitness trackers have opened up new possibilities for research.

In 2015-16 NCMH began exploring the potential of wearable tech, working with colleagues at the Bipolar Disorder Research Network (BDRN) to develop a new study into sleep and bipolar disorder.

The study will use actigraph watches that record activity and movement to monitor the sleeping patterns of people with bipolar disorder.



By combining data collected using the actigraph watches with volunteers' self-reported data on their moods, the study aims to better understand the link between sleep loss and the symptoms of bipolar disorder.

Embracing 'Big Data'



During 2015-16 NCMH has taken major steps forward in linking the anonymised data we collect to Swansea University's Secure Anonymised Information Linkage (SAIL) Databank, obtaining essential clearances and permissions.

SAIL is an ambitious project to connect the information that is routinely collected by GPs, hospitals, the police and others in a secure and anonymous format so that researchers can make use of these very large datasets (sometimes referred to as 'big data').

Connecting with SAIL will allow us to broaden the scope of our studies to include information about contact with health services, accident and emergency admissions, educational history and more. This data can then be analysed to look for trends and patterns in the development of mental health problems.

NCMH has also been involved in a major collaborative project with the University of North Carolina in the United States and industry partners to develop a perinatal mental health research app.

The iPhone app, which aims to collect data from many thousands of women with experience of postnatal depression and postpartum psychosis has been launched in the US and an NCMH branded UK version is due to be launched in the coming months.

Achieving impact

BEP-C & Beating Bipolar: an NCMH success story

NCMH has delivered the Bipolar Education Programme Cymru (or BEP-C) psychoeducation course throughout 2015-16.

The programme was developed based on the work of the mood disorders research group at Cardiff University and funded by The Big Lottery.



BIPOLAR
EDUCATION
PROGRAMME
CYMRU

It aims to improve the quality of life for people with bipolar disorder by helping them better manage their condition through an understanding of triggers and symptoms.

Research has shown that psychoeducation can be very effective in bipolar disorder treatment, leading to reduction in symptoms and the need for hospital stays. It has also been found to make patients more likely to follow treatment advice.

Across Wales and beyond

Courses have taken place throughout Wales, and an estimated 570 people have benefitted from taking part, including 65 in 2015-16. The model has also been adopted internationally, with healthcare providers as far afield as New Zealand, the Netherlands and Turkey running courses based on BEP-C.

The course has also been adapted into an online version called Beating Bipolar featuring video clips and interactive elements. This version of the course allows anyone, anywhere to benefit from bipolar disorder psychoeducation.

Sharing good practice and influencing policy

The BEP-C/Beating Bipolar suite also includes free to access online training aids for both midwives and GPs on diagnosing and treating patients with bipolar disorder.

Our module for midwives is incorporated in the Welsh Government's ten year strategy for mental health and wellbeing in Wales, *Together for Mental Health*.

A screenshot of the 'Beating Bipolar' online training interface. At the top left is the logo for 'BeatingBipolar' with a stylized head icon. To the right of the logo, it says 'Module 1: What Is Bipolar Disorder?: Topic 3: Symptoms I'. Below the logo are three 3D cubes labeled 'Feelings', 'Thoughts', and 'Behaviours'. To the right of the cubes is a video player showing a woman with long dark hair. At the bottom of the interface is a navigation bar with icons for 'Home', 'Resources', and a progress indicator with five numbered circles (1-5), where circle 3 is highlighted. Below the navigation bar is the footer text: 'Healthcare Learning: Smile-on Treasure house | 19 - 21 Hatton Garden London | EC1N 8BA Tel: +44 (0)20 7400 8989 Email: support@healthcare-learning.com'.



BEP-C: a participant's viewpoint

NCMH Research Champion Julie Murray tells her story and talks about how BEP-C helped her.

"I first became unwell in my 20s and I was diagnosed with anxiety and depression. It was the start of a very difficult time in my life where I really struggled with my illness. There were times when I was self-harming, and I felt suicidal on several occasions."

"I also experienced what I now know were manic episodes, which could be just as devastating as my episodes of depression. I've gotten into very dangerous situations and the aftermath can be terrible"

"I was diagnosed with bipolar disorder following the birth of my son, and the medication has been helpful although my mood still fluctuates and I can become very unwell. My psychiatrist told me about BEP-C and recommended I try it"

"The day I started the programme I was really nervous, but the facilitators really made me feel at ease. I found it amazing to meet people with the same diagnosis as me - all from different walks of life, different cultures and ages experiencing the same struggles."

"I learned about managing my lifestyle, relapse prevention and early intervention through being aware of triggers and early warning signs. I also completed a manual as we went through the course which was tailored to my needs. I still use it today and it forms the basis of my care plan - I call it my bible"

"This programme changed my life and I'm almost certain it has saved my life. I have gone from coping to managing my bipolar disorder."

Conclusions

Over the last twelve months, NCMH has continued to build upon the success of the previous funding period.

Our cohort has gone from strength to strength, with recruitment averaging at well over 100 individuals per month. We have branched out into new areas such as learning disabilities and social determinants of mental health and are linking with the SAIL databases.

We have also developed an enhanced assessment questionnaire that promises to provide us with a deeper insight into the causes of mental health problems, and we look forward to implementing in the near future. Our work to create an online assessment is also beginning to bear fruit, and will allow us to extend our reach even further.

Our work in engaging and involving the public has enjoyed similarly positive results. We have continued to deliver innovative awareness raising events in unique locations, raise the profile of mental health research through the Welsh media and involve members of the public in both decision making and engagement activities.

Changes and challenges ahead

But 2015-16 has not simply been 'more of the same' - we have experienced many changes. For example, traditionally most of our volunteers came from systematic recruitment through NHS services. However, over the course of the last year we've seen a shift - almost half of our volunteers now originate from non-systematic sources such as advertising, social media or press appearances.

We have also faced administrative obstacles - obtaining the clearances we need to give our field team the freedom to work across all of Wales has been challenging, and this is a process that we must work to streamline.

Looking forward

We enter the second year of this funding period full of ideas and ambition.

We have plans for more industry collaboration, increased public involvement and improving our links with colleagues at other Health and Care Research Wales funded centres so that we can share experience and best practice.

We will also continue to do what we do best. We aim to improve our recruitment levels and enhance the quality and depth of data that we collect from our volunteers.

NCMH will also continue its work to educate people in Wales on mental health issues. We will combat stigma around mental illness with the help of our ever expanding team of Research Champions, spreading the word through engagement events, the media and online.

As we begin a new chapter, our dedicated and talented team are more experienced and more focused than ever before. With their help, NCMH will continue moving mental health research in Wales forward once more in 2016-17.



NCMH

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