Northumberland, Tyne and Wear NHS Foundation Trust

Board of Directors Meeting

Meeting Date: 23 November 2016

Title and Author of Paper: Research and Development Annual Report 2015/16 Paula Whitty & Simon Douglas

Executive Lead: Dr Rajesh Nadkarni

Paper for Debate, Decision or Information: Information

Key Points to Note:

Since the R&D strategy was approved in 2012 there has been significant progress and some clear evidence of the impacts of the strategy.

Research is generally recognised to be an important factor in high performing healthcare organisations, with a number of benefits accruing as a result of research involvement, from better outcomes for service users, more evidence of evidence-based treatment, evaluation and monitoring of outcomes, and improved staff recruitment and retention. The NTW research strategy aimed to promote the awareness and embedding of research in the Trust and increase research activity and engagement the profile of research was mentioned throughout the recent assessment report by the CQC.

The lifetime of the research strategy has seen increases in research activity through increases in numbers of research projects, numbers of service user participants, numbers of staff involved and grant income received. Further achievements have been NTW being ranked as the 3rd, 2nd and 4th most research active mental health and learning disability trust in consecutive years in terms of number of research studies. We can also point to a significant number of high profile national and international publications based on research in the Trust; significantly strengthened research collaborations across the region and further progress in successful funding applications.

We can also evidence real impacts though – research based in NTW has been influential in the recognition of dementia with lewy bodies as a discrete illness, which will have benefits for our service users in terms of diagnosis and early treatment - and should encourage more research investment which we can capitalise on. We are also involved in some pioneering work in developing treatment approached in autism, not only through working with families to develop shared approaches but also through using technology such as virtual reality to help to treat phobias – this has now started to be offered as a clinical service by NTW with the support of commissioners.

Specifically in 2015/16 there has been a slight drop in the number of NIHR research projects, although with a slight increase in participant numbers, NTW remains one of the best NHS Trusts in England to do research in mental health.

Risks Highlighted to Board : None

Does this affect any Board Assurance Framework/Corporate Risks? No

Equal Opportunities, Legal and Other Implications: N/A

Outcome Required: For information

Link to Policies and Strategies: NTW R&D Strategy 2016-21



Research and Development Annual Report 2015-16



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Glossary and Abbreviations

NIHR	National Institute for Health Research	The research arm of the Department of Health
	NIHR Portfolio	A register of large scale research projects which meet certain standards of size and quality, usually funded by NIHR
MRC	Medical Research Council	Funding Provider
RfPB	Research for Patient Benefit	NIHR funding stream
PGfAR	Programme Grant for Applied Research	NIHR funding stream
EME	Efficacy and Mechanism Evaluation	NIHR funding stream
HTA	Health Technology Assessment	NIHR funding stream
NIHR CRN	NIHR Clinical Research Networks	The research delivery arm of NIHR, represented in the North East by CRN North East and North Cumbria (CRN NENC)
PID CR	Performance in Initiating and Delivering Clinical Research	A measure of performance of NHS Trusts in approving clinical research to run in the NHS, reported by DH
RCF	Research Capability Funding	Strategic funding given by NIHR to NHS Trusts based on previous year's NIHR grant income
LCRN	Local Clinical Research Network	Local (North East and North Cumbria) regional branch of the Clinical Research Network (CRN)
DenDRoN	Dementias and neurodegenerative diseases	Specialty Group of the LCRN

The NTW Research Strategy established in 2012 has continued to be promoted throughout 2015/16 and, with the strategy being refreshed throughout this year, this report represents a marker of progress for the original strategy. The three key strategic objectives around which the strategy was designed have all seen significant progress but can be built on further in the next five years.

These ojectives are:

- Maximised opportunities for NIHR portfolio investment in the Trust, by building on local, national and international research strengths, and supported by healthy university partnerships.
- Clear evidence that R&D is an embedded, mainstream, substantial element of the Trust's core business producing demonstrable impacts.
- A workforce whose culture and behaviours demonstrate the value of R&D to improving patient care, and which demonstrates the commitment to the promotion of new talent throughout the workforce.

While the numbers remain impressive (NTW up to second in England in terms of research active mental health trusts on the basis of numbers of NIHR studies open in 2014/15 and sixth in recruitment to NIHR Portfolio research; along with increased income from commercial research), what is striking, and which is evident throughout this report, is the impact of research across NTW and the benefits that the people we serve can experience as a result of research. We have examples of research influencing practice at multiple levels within the Trust, the development of research careers for Nurses, Midwives and Allied Health Professionals (NMAHPs), further national recognition for our involvement of service users and carers in research, and national and international impact in relation to the identification and treatment of Dementia with Lewy-Bodies.

Research is also more widely recognised across the Trust with more teams and individual clinicians involved than ever before, while initiatives to develop processes to ensure the structured and routine involvement of services users and carers in research at all levels are well underway.

Partnerships are crucial to our research efforts, with key university partnerships established during the year, and the concept of developing Academic Clinical Collaborations will promote this engagement even further. For the future, it is key within the refreshed stategy that we ensure that there is a clear clinical 'pull' from services for research and evaluation expertise, placing NTW at the forefront of NHS research in mental health and disabilities.

Paula Whitty Director of Research Innovation and Clinical Effectiveness

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Head of Research Innovation and Clinical Effectiveness

The NTW Research strategy was approved by the Trust Board in 2012 as a plan for the first three years of a ten year programme. Work to refresh the strategy was underway in 2015/16 through a series of workshops and debates on how best to capitalise on progress to date and in particular how to progress even further.

The original three strategy objectives were retained but the initiatives and actions required were significantly updated and in doing so we reflected on the successes and challenges to date. These successes have seen NTW become one of the leading research active mental health and learning disability Trusts, generating and participating in increased large-scale research (NIHR Portfolio) activity, embedding research and evaluation into the Trust's service provision and developing the capability and capacity of the workforce.

The challenges which were discussed as part of the 'refresh' process were around: maintaining the value and importance of research to all stakeholders in a time of financial difficulties for the NHS; systematically involving service users and carers in the full range of our research activity; widening participation in research to a full range of health disciplines, including nurses and Allied Health Professionals (AHPs); and promoting the opportunity to take part in research for all of our service users.

A range of initiatives were continued from the original strategy document but in addition there were several new ideas which were to be developed as new streams of work for the strategy implementation plan.

3 Impact of NTW research in 2015/16

Research has been widely recognised as being an important factor in providing high quality care for healthcare organisations. Not only does organisational involvement in research improve clinical outcomes and service user satisfaction but it is also suggested in the evidence that organisations are able to attract higher quality employees, organisational culture benefits so that employees are more interested in basing care and treatment decisions on the best available evidence and on measurable improvements in outcomes. While these are benefits of NTW involvement in research there should also be a demonstrable benefit for our service users. In some areas this is clear but for others it can take several years for benefits to filter through to front line services, this is something we should aim to address in future developments of the R&D strategy.

A wide range of examples of impact of the NTW research Strategy on care and treatment for our service users were presented at the Annual Research Conference in February 2016 (see page 12 for more details). We have further highlighted some examples of impact in 2015/16 here:

Further progress on Dementia with Lewy-Bodies

Newcastle University(NTW clinical academics involved include McKeith and Taylor) was the lead partner in the International Consortium on Dementia with Lewy Bodies (ICDLB), which has over the last two decades been the key group advancing the world-wide LB dementia research agenda. Two ICDLB reports recommending guidelines for the clinical and pathological diagnosis, and treatment of DLB, have been cited >6500 times, are now used globally, and in 2013 were formally incorporated into DSM 5. The Consortium met in Fort Lauderdale, Florida in December 2015; the primary output was the first revision of the DLB Consensus statement in over a decade, led by NTW based authors (McKeith and Taylor). These revised recommendations included consideration of early and prodromal DLB, and will form the blueprint for translational and early phase clinical trials in DLB and related disorders.

Innovative research into the impact of sleep on mood disorders

The Northern Centre for Mood Disorders (NCMD) has completed a study of sleep and cognitive function in bipolar disorder. The goal of the study was to characterise the sleep disturbance in bipolar disorder and to examine to what extent such disturbance contributes to the well known cognitive dysfunction seen in the disorder. It is the largest such study ever conducted. Initial key findings are that objective assessment of patients' sleep and activity levels (using devices similar to 'FitBits') suggests that a key problem is lower levels of activity than age and gender matched healthy subjects, with an increase in time in bed though not necessarily marked lack of sleep or over-sleeping. These findings point to the potential utility of objective activity monitoring devices to help optimise the care of patients. This will be examined in future studies and also piloted within the Regional Affective Disorders Service.

Innovative autism research moves into practice

The NIHR-funded 'Blue Room' project, a virtual reality intervention for children with autism and specific phobias, has proved to be so successful that NTW has acceded to demand from local clinicians, families and commissioners and begun to accept referrals through the NTW Complex Neuro-Developmental Disorders Service (CNDS) to the treatment as a clinical service within NTW. This is an excellent example of the push in the research strategy not only to innovate but also to roll out innovation and ensure that service users can benefit.

Highlighting evidence-based treatment options in NTW

The Northern Centre for Mood Disorders (NCMD) was a partner in the largest study of ECT conducted for over 50 years in the UK, led from Manchester. This study was designed to examine if the anaesthetic ketamine reduced impairments in memory caused by ECT and speeded up beneficial responses. Unfortunately the study found that ketamine probably does not have these effects. However it has highlighted the steady decline in the use of ECT with a reduction in patients being treated being evident even over the 3 years of the study, and the study has therefore helped increase awareness of this treatment option which is included in NICE depression guidance for selected severely unwell patients.

ReQol – Recovering Quality of Life

ReQoL is a short, easy to use and self-completed generic Quality of Life (QoL) outcome measure. It covers the key aspects of quality of life and is needed to assess recovery outcomes in mental health services. The ReQoL measures were developed to meet this need for people recovering from different mental health conditions. The research was undertaken in the School of Health and Related Research (ScHARR) at the University of Sheffield by a team of researchers, service users and clinicians working together to generate the themes, items and scoring of the measure. Adopted onto the portfolio, the study ran nationally with NTW contributing 164 questionnaires. The ReQoI measure is now ready to be implemented into routine clinical practice with an official launch taking place in October 2016.

Research in Art Therapies is making a difference

Dr Simon Hackett Lead Art Therapist is in the second year of his Clinical Lectureship Fellowship as part of the Health Education England / National Institute of Health Research Integrated Clinical Academic programme. The NIHR/HEE ICA provides full funding for research training awards to nurses, midwives and allied health professionals who wish to develop careers that combine clinical research with continued clinical practice. Dr Hackett's research has been developed from his own clinical practice and PhD research in Forensic Services for people with learning disabilities at Northgate Hospital. Dr Hackett is now conducting a feasibility study of Interpersonal Art Psychotherapy in three NHS Forensic services in England, namely in Rampton Hospital, The John Howard Centre, and in Mersey Care NHS Foundation Trust. Dr Hackett was able to develop his research protocol and fellowship application as a result of NTW Research Capability Funding.

Research Strategy producing national interest in NTW and benefits for our service users

A recent project between NTW and a local self-advocacy group, Skills for People, illustrates how NTW's research strategy can produce unexpected benefits. Dr Steve Noone, a consultant clinical psychologist, received NTW Research Capability Funding to work up a proposal to evaluate the adaptation of an eight week mindfulness based stress reduction (MBSR) course for adults with learning disabilities. The grant produced a protocol that formed the basis for an application for large scale research funding from NIHR. Although the application was unsuccessful, the protocol was then used to bid for money from Health Education North East. This bid was successful and enabled NTW to run an adapted MBSR programme in partnership with a self-advocacy group. The bid also included the making of a 'fly on the wall' documentary by a local film maker who followed three of the participants across the course to produce a 40 minute film. The film was shown at a special preview at the Tyneside Cinema. The film was so well received that a special edited version was made to present at the Westminster Health Forum Keynote seminar chaired by Sir Steve Bubb. The film has also lead to special commissioning for more groups from CCGs in South Shields, Gateshead, Sunderland and a second one in Newcastle, generating the capacity to offer this potentially valuable group activity to even more of our service users. The full evaluation report is awaited.

4 Research Activity

4.1 Numbers of research studies

Research activity is an important measure of progress in the R&D strategy and one of the measures is the number of large scale research projects which have recruited participants from NTW. Objective 1 of the R&D strategy is focused on the level of NIHR portfolio activity, which encompasses those research studies which meet criteria of the National Institute for Health research portfolio, funded largely by DH/NIHR funders or national charities. This shows (fig 1 below) that the number of studies recruiting participants in NTW is generally increasing year on year but for 2015/16 there was a slight drop off in the number of studies from 51 in 2014/15 to 45 in 2015/16 (full list of studies in Appendix 4). The 2014/15 figure led to NTW being highlighted as the second most research active mental health Trust in England; at the point of writing, the league table for 2015/16 has not yet been published.

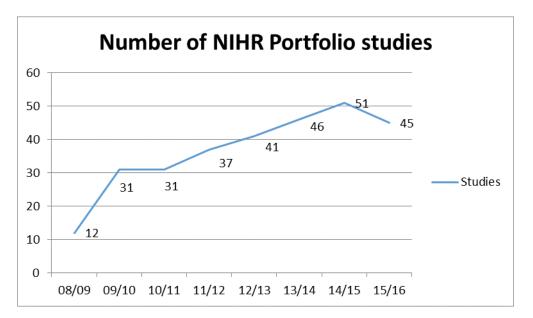


Figure 1 – Number of NIHR Portfolio Studies recruiting participants in year

While there is a focus within objective 1 of the strategy on large scale research, there is also a significant amount of smaller scale research, ranging from student research to pilot work for larger scale funding bids and service evaluation work, all of which provides evidence to develop and improve the quality of the NTW service provision.

The NTW approach to the use of Research Capability Funding (RCF) is illustrative of this. RCF is allocated to the Trust from the Department of Health (DH) based on the amount of NIHR income the Trust receives and can be used to strategically develop an NHS organisation's ability to engage in research. The approach in NTW has been to run an applications process aimed at targeting RCF to fund research or research programmes which will lead to subsequent NIHR funding bids. A NIHR Research for Patient Benefit application hosted by NTW that was developed using RCF was successful in 2015/16.

4.2 Portfolio recruitment

For national research network funding, recruitment of participants to NIHR portfolio research remains the key measure for NHS organisations. While this is sensitive to a range of factors such as study complexity, availability of research funding or outliers such as single high-recruiting projects, it does show evidence of progress over the life of the strategy (fig 2, below). The final total for NIHR portfolio recruitment in NTW was 1331 in 2015/16, above the total of 1152 in the previous year and well above the goal of 850 set with the local research network.

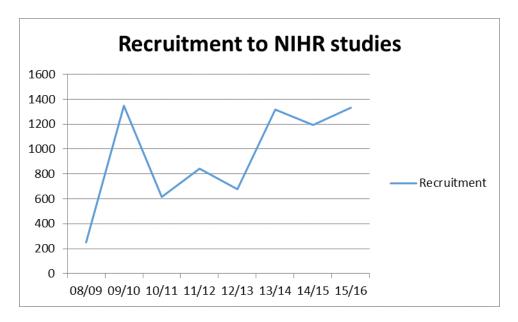


Figure 2 – Recruitment to NIHR Studies

4.3 Commercial Research

An important aspect of the NTW Research strategy was to develop the Trust's capability to compete for commercial research, usually sponsored by pharmaceutical companies. In general this is seen as a method of income generation, although this is considerably more difficult in mental health than in some acute medicine specialities due to the limited number of possible research studies. Although still relatively small scale in comparison with the non-commercial portfolio of research, from a baseline of one or two commercial studies per year the commercial portfolio has grown to five in 2015/16, with increasing focus on research in Huntingdon's Disease, for which NTW is being seen as a leader nationally.

A very successful 'Proximity to Discovery' themed week in LBD (led by NTW Clinical Academic Dr John-Paul Taylor) was held in February 2016. Proximity to Discovery is an MRC award to encourage interaction with the pharmaceutical industry. There are now a number of developing relationships with companies interested in research collaborations in LBD. Furthermore this is being used as a springboard to develop a major MRC consortium stratification proposal in LBD led by Newcastle University and supported by NTW.

5 Working in partnership

As a member of the Clinical Research Network North East and North Cumbria (LCRN NENC), NTW hosts a range of clinical research specialist staff who contribute to recruitment of participants into large scale NIHR Portfolio research. The funding received from LCRN NENC covers the costs of the Mental Health Specialty and the Dendron Speciality research teams. These teams have developed excellent working relationships with clinicians within NTW and in other local trusts to ensure that we have the capacity and resources to recruit right across the Trust geography in our speciality areas.

During 2015/16, a range of discussions were held with local universities about potential collaborations and one notable development during the year was the establishment of the Newcastle Academic Health Partners (NAHP) (http://nahp.org.uk/). NAHP is a partnership between Newcastle University, Newcastle Hospitals FT and NTW which aims to harness clinical and academic expertise to make sure patients will benefit sooner from new treatments, diagnostics and prevention strategies. Discussions with Northumbria, Sunderland and Durham Universities will continue to be progressed during 2016/17.

The creation in 2014/15 of four Academic Clinical Collaborations (ACCs)(see table 1), which are partnerships between the clinicians in the Trust and academics, have helped to focus some of the research efforts on areas which are already significant strengths. The four ACCs are situated so as to benefit from existing research collaborative strengths but with the aim of increasing the potential and outputs of these groups through widening participation and collaboration across organisations. The four current ACCs are:

ACC	Academic Lead(s)	Link Clinical Director	
Autism (including learning disabilities)	Professor Ann Le Couteur / Dr Vicki Grahame	Professor Eilish Gilvarry	
Dementia	Dr John-Paul Taylor	Dr Rebecca Courtney-Walker	
Northern Centre for Mood Disorders	Dr Hamish MacAllister- Williams	Professor Eilish Gilvarry	
Psychosis	Dr Iain McMillan	Dr Patrick Keown	

Table 1 – NTW Academic Clinical Collaborations

The ACCs have started to implement collaborative activities across the Trust but also with other Trusts and Universities and there are a range of impacts which were starting to be generated from these in 2015/16. The list of NTW related publication in appendix 4 illustrates this point as many are linked to the ACCs and we expect this to look even more impressive in 2016/17.

6 Research governance

NTW has for some years been a leading Trust in England for research governance, the process of giving permission for researchers to run their studies in the NHS. The later part of 2015/16 in research governance terms was dominated by the staged implementation of a new National system for NHS permissions, run by the Health Research Authority (HRA). The aim was to make the research approvals process simpler for researchers by ensuring that the activities which had previously been undertaken by

research departments could be done centrally. While the full new process is still bedding in there have been significant delays in approvals for some research, but this is not within the Trust's control with the new system in place.

NTW still reports directly on research approvals process for particular types of important research projects, including commercial pharmaceutical projects, to the Department of Health through the Performance in Initiating and Delivering Clinical Research (PID-CR) process. This is reported quarterly to DH and publicised by them and on the <u>Trust external website</u>. There are potential financial penalties for NHS Trusts who fail to deliver within the target timescales of 70 days from submission of valid application for NHS approval to the recruitment of the first research participant.

In 2015/16 NTW had nine trials eligible for PID reporting, of which eight were approved and recruited the first participant within the target of 70 days. The remaining trial failed to meet the 70 day target for first recruit because of staffing issues within the service. Thus NTW remained one of the top performing NHS Trusts nationally on research governance, albeit from a relatively low number of studies.

7 Financial report

Research related income remained largely stable in 2015/16 overall, with increases in both NIHR Grant income and Research Capability Funding (RCF) balanced by an expected drop in funds received from the Local Clinical Research Network (LCRN). Most local Trusts received reduced allocations from the LCRN reflecting a decrease in the LCRN's total funding received from DH. NTW's funding was reduced based on a formula which penalised the Trust for failing to increase NIHR portfolio recruitment on the previous year (despite exceeding recruitment targets). Commercial research income has been particularly boosted by some real success in recruiting participants into research in Huntingdon's Disease (HD), the Trustwide total showing an increase of 23% on the 2014/15 figure up to £100,251 in 2015/16, 80% of which was from three studies in HD. From the total of research activity in NTW any cost to the trust in terms of staff time is significantly outweighed by the financial and other benefits brought in to the trust by research.

Income type	2012/13 £	2013/14 £	2014/15 £	2015/16 £	Change from 14/15
Grant income	430,837	521,996	720,618	921,906	28%
DH funding (RCF)	297,447	288,840	240,182	298,152	24%
NIHR network funding (LCRN – now includes MHRN and Dendron specialties)	556,564	564,811	1,107,677	1,022,157	-8%
Research Network hosting income (MHRN/DeNDRoN)*	901,894	918,897	N/A	N/A	N/A
Commercial income	127,819	54,038	81,588	100,251	23%
Total	2,314,561	2,348,582	2,150,065	2,324,466	9%

Table 2 – income figures

*until March 2014 NTW hosted the Mental Health and DeNDRoN regional Research Networks under contract from DH. These networks were merged, along with six others, into a single "LCRN" network, hosted by NuTH, and the staff costs pertaining to NTW are now received as part of the LCRN funding package.

As suggested above. RCF, which is funding that NTW receives from NIHR based on the amount of NIHR Grant funding which comes in to the Trust, increased this year, despite a decrease in funding associated with NIHR Senior Investigators (currently worth £75k of RCF each) from two Senior Investigators to one. The usual annual allocations process was run with a range of very high quality applications of which 11 were funded, ranging from support to writing of grant applications to research time for analysis of scan data as background for further large-scale grant funding applications.

8 Communications

The Fourth Annual NTW Research and Development Conference was held in February 2016. Opened by Non-Executive Director Dr Leslie Boobis, it focussed on the Academic Clinical Collaborations and each one presented their work and future directions. This enabled interested clinicians in the Trust to find out where they could access the research which interested them and facilitated significant new memberships for the ACCs. In addition the poster presentations were the strongest yet with a dedicated session for the presenters to speak to their posters and answer questions and a prize for the best presentation. The winning poster is reproduced in appendix 3. The conference was attended by over 200 participants, many of them NTW staff but with the addition of a number of representatives from local universities, demonstrating the increasing research links between the Trust and academics.

9 Workforce

Developing the research workforce has been a key strand of the NTW research strategy and we have had success in 2015/16 through developing non-medical Principal Investigators (PIs), and in particular our first Nurse Consultant PI, Paul Courtney, has led a large scale portfolio study in NTW (the ReQoL study, see page 5). This is a really exciting development and there are more non-medical PIs in the process of receiving training and experience to allow them to fulfil these roles in the future.

We had two clinicians involved with successful applications for regional research training programmes, a physiotherapist, Dionne Moat, who was accepted to an NIHR/HEE internship in research and an Occupational Therapist, Lynsay Duke, who was appointed to a 12-month role to promote research after a successful application to the Local Clinical Research Network for a "developing the Research Workforce" award.

Dr Chris Smart was awarded a Royal College of Psychiatrists travel award to visit a laboratory in Munich run by the world renowned Professor Elisabeth Binder. This was to learn more about research into epigenetics. This is the study of processes that modify the functioning of an individual's DNA. There is strong evidence that, for example, early life-adversity can lead to epigenetic changes to an individual's DNA that alters their response to stress. It has been proposed that such changes may mediate the increased risk of depression seen in people who have suffered early life adversity. Dr Smart hopes to use the experience gained during the visit to help him develop a successful application to the Medical Research Council for a Fellowship to undertake a PhD and allow him to develop into a clinical academic of the future.

10 Patient and public involvement (PPI) in research

NTW has a strong track record in involving service users and carers in research, with some particular research projects having led to multiple awards and national recignition. The challenge is now to make this involvement a systematic part of all of NTW's research, as some areas have stronger and more established PPI than others.

Award for Service User and Carer Involvement

The Autism research Group in collaboration with Newcastle University have been given an award by NIHR specifically for the inclusion of 'carers' in the autism research programmes (for example ASD-UK and DasIne, and the adult and relatives cohort projects).

The Group have worked with carers and relatives of people on the autism spectrum from many perspectives. They were commended for working with both carers and relatives and also adults on the autism spectrum and received the prestigious award, made jointly by NIHR and the charity MQ (a mental health research charity) at an award lunch at Newcastle University attended by James Cusack, Autistica's Research Director.

Public Engagement in Mood Disorders Research

A major goal of the Northern Centre for Mood Disorders (NCMD) is an increase in public awareness of mood disorders and research into them, and a decrease in stigma. In this regard, NCMD was successful in obtaining a small grant from Newcastle University's Faculty of Medical Sciences to promote public engagement in July 2015. Public meetings have subsequently been held in November, January, February 2016). These have included topics such as the role of exercise and physical activity in mood, a debate around the complementarity of antidepressants and psychotherapy for depression and a review of ongoing research being conducted in NCMD. These meetings, held at Newcastle University, have been attended by between 70 and 100 people. More events are planned as well as an awareness raising event - a relay run from Carlisle to Newcastle by patients, carers, nurses, doctors and researchers.

Launch of a web-based resource to promote service user and carer involvement in research

This year saw the completion of an NIHR Research for Patient Benefit 3 year project entitled "Is there a pathway to Mental Health Recovery through Care Coordination?" (See case study on p.14) and the launch of a web-based resource to support further involvement in research (see http://www.rwire.co.uk/). This was emancipatory action research led by Northumbria University in collaboration with NTW and third sector organisations. A group of university accredited researchers with mental health experience went on to provide training on consent with psychiatrists working in NTW and presented the methodology/findings from the work at various NTWs R&D events and to the Trust Board.

Further impacts have been: work for the 'Deciding Together' consultation for the North East NHS Commissioning Support Unit; the original research was shortlisted for the NHS Bright Ideas Award for PPI and won the CCA award (http://www.cpaa.org.uk/) for promoting effective care process and standards in 2015; and workshops were conducted outlining the findings with mental health teams across the locality. In addition this work has led to the same service user and carer research group undertaking an ongoing evaluation of NTW Psychosis/non psychosis transformation services in Sunderland and South Tyneside. At the conclusion of 2015/16 they were about to start interviewing service users, carers and professionals across the three mental health teams in Sunderland.

Is there a Pathway to Mental Health Recovery through Care Coordination- emancipatory research with service users, carers and professionals?

Recovery through care coordination was an innovative and exciting project which commenced in 2011 as a partnership between the NHS Foundation Trust, Northumbria University and Northumberland Service user and carer networks; it was borne out of Dr Toby Brandon's desire to authentically engage with service users in research and blur the lines between academic researchers and service users.

The aim of the research was twofold, firstly to involve services users in the research on a much greater level than traditionally expected; the following comment made by a participant sums up this aim succinctly "Nothing about us, without us." The researcher's second aim was to explore the relationship between recovery and care coordination, these aims therefore meant that the process of the research was as important as the actual outcomes.

The study was a great example of PPI as the service users were heavily involved; their tasks included designing research tools such as questionnaires and interview guides. They also underwent an intensive training course which equipped them with the skills to conduct interviews, helped to analyse and evaluate the data from interviews and discuss the impact of learning about other research participant's stories.

"We are a community of researchers who got involved in research because the research question holds some meaning for us."

Unlike some research this study was designed by service users for service users and its impact can be seen in the following points:

- Provided service users with a platform to air their views.
- Challenged traditional research process in a positive way.
- Helped the interviewees discuss their experiences in a different way to how they would with therapists or academics.
- Offered an opportunity for service users and carers to interact and develop on a personal level.
- Improved validity of research.

2015/16 was an important year in the implementation of the NTW Research Strategy as it marked the development of the next iteration of the refreshed strategy and provided the platform for the next five years. It is therefore good to report progress on many fronts with continued increases in research recruitment and hence research opportunities for our service users, income related to research, commercial income and real progress in widening participation, significantly amongst non-medical professions.

The report provides details on a range of impacts which research has provided and, despite research which suggests the average time to implement research findings into practice is 17 years, there are many more examples where research evidence is being used much more quickly in NTW.

The challenge for us is to maintain progress across the breadth of the research strategy programmes of work, particularly in ensuring the embedding of research and research processes into the mainstream of clinical practice so that not only does every one of our service users get the opportunity to be part of research relevant to them, but we develop a culture of collecting and analysing evidence to support them in achieving the best possible outcomes.

1 – Performance on key R and D measures related to the R&D	strategy (End	of year 201	5/16)	
Strategic Objective 1 – Financial Performance, Recruitment &	2014/15	2015/16	2015/16 total	
external relationships		Goal		
Stable infrastructure (Research Network) income *	£1,107,677	+/- 10%	£1,022,157	
Increase in Commercial Income	£81,588	+ 20%	£30,861	
Increase in NIHR Grant income*	£720,618	+ 20%	£921,906	
Increase in RCF income *	£240,182	+ 5%	£298,152	
Last ½-year spending within budget variance of 1%	0%	+/- 1%	0%	
NIHR Portfolio Recruitment (NTW)	1192	826	1331	
NIHR Portfolio Recruitment (all network, all Trusts)	2175	1700	2391	
NIHR Studies recruiting in year	51	55	45	
Commercial Recruitment	16	70	22	
Number of NTW-hosted NIHR funding applications this	6	8	8	
financial year				
*projected for 15/16 total				
Strategic Objective 2 - internal Processes Internal				
Relationships				
Service Approval turnaround (from receipt of service approval	15 days	20 days	5 days	
form)			<u>s aays</u>	
Caldicott approval Turnaround (from receipt of valid	NA	15 days	NA	
application)		,		
Contract turnaround (from receipt of draft)	15 days	30 days	30 days	
Internal research awareness (tbc – annual trust intranet	NYA**	-	NYA**	
survey?)				
Service User involvement in research funding bids (tbc)	NYA**		NYA**	
Strategic Objective 3 - Learning and Development				
Number of Trust staff involved in Portfolio research	NYA**	73	NYA**	
Number of Trust staff attending GCP training	NYA**		NYA**	
Number of staff attending Trust Research Training	134	50	NA	
Number attending PI development Group (now SG group)	89	60	42	
Communications				
Articles in The Bulletin	31	24	5	
Articles on Trust intranet	17	24	17	
Monthly e-bulletins on time	100%	12	100%	
Annual conference registrations	182	200	201	
Annual lunchtime research seminar registrations	76	150	47	
Other Operational Performance				
Approval measure for researchers (post approval survey –	NYA**		NYA**	
initiated February 2015)				
Research Governance				
Portfolio Approval Times	100% (23)	100%	100% (16)	
Non-Portfolio Approval Times	93% (54)	90%	91% (58)	
Commercial Approval times	100% (4)	100%	100% (3)	
Performance in initiating Research (PID) raw	100% (7)	100%	100% (6/6)	
Performance in initiating Research (PID) adjusted	100% (5)	100%	100% (6/6)	
Peer Reviewed Projects	, <i>,</i>		16 NIHR, 18 UI	
-	1	1	HRA 1	

** NYA=Not yet available

Appendix 2 – List of NIHR Portfolio research studies which recruited in NTW in 2015/16

Study	Clinical Service	Торіс	
The Adult Autism Spectrum Cohort	Adult Mental Health	Mental Health	
- UK			
Recovering Quality of Life (ReQoL)	Adult Mental Health	Mental Health	
Stage 4b			
DPIM - alcoholism	Adult Mental Health	Mental Health	
Evaluation of Offender Liaison and	Adult Mental Health	Mental Health	
Diversion Trial Schemes			
NCISH	Adult Mental Health	Mental Health	
Psychosis and Language study	Adult Mental Health	Mental Health	
(PaLs)			
BLISS	Adult Mental Health	Mental Health	
DPIM - schizophrenia	Adult Mental Health	Mental Health	
OBSERVA	Adult Mental Health	Mental Health	
DPIM - bipolar disorder	Adult Mental Health	Mental Health	
ASPIRE Phase 2	Adult Mental Health	Mental Health	
Molecular Genetic Investigation	Adult Mental Health	Mental Health	
Focusing on Clozapine	Adult Mental Health	Mental Health	
Unresponsive Symptoms			
Homicide by patients with	Adult Mental Health	Mental Health	
schizophrenia: a case-control study			
Offender Personality Disorder	Adult Mental Health	Mental Health	
Pathway – Feasibility Study			
Ketamine-ECT Study	Adult Mental Health	Mental Health	
The ATLAS Trial	Adult Mental Health	Mental Health	
FAB: Family focused treatment for	Children and Young People	Mental Health	
Adolescents with Bipolar Disorder	children and roung People		
EIMD	Children and Young People	Mental Health	
Virtual reality intervention for	Children and Young People	Mental Health	
anxiety in children with ASD			
Diagnosis of Alzheimer's disease	Cognitive function and neuro	Dementias and	
by measuring blood proteins	-	neurodegeneration	
IDEAL study	Cognitive function and neuro	Dementias and	
	-	neurodegeneration	

DIAMOND-Lewy Work Package 1	Cognitive function and neuro	Dementias and neurodegeneration
GREAT	Cognitive function and neuro	Dementias and neurodegeneration
DIAMOND-Lewy Work Package 2	Cognitive function and neuro	Dementias and neurodegeneration
Supporting excellence in end of life care (SEED)	Cognitive function and neuro	Dementias and neurodegeneration
AMPLE	Cognitive function and neuro	Dementias and neurodegeneration
Enroll-HD	Cognitive function and neuro	Dementias and neurodegeneration
AD GENETICS	Cognitive function and neuro	Dementias and neurodegeneration
ThinkActive: Designing for Health v1	Cognitive function and neuro	Dementias and neurodegeneration
LewyPro	Cognitive function and neuro	Dementias and neurodegeneration
Quality of Life Sub-Study	Cognitive function and neuro	Dementias and neurodegeneration
Minocycline in Alzheimer's Disease Efficacy (MADE) trial	Cognitive function and neuro	Dementias and neurodegeneration
MIDAS	Cognitive function and neuro	Dementias and neurodegeneration
BRU VEEGStim Study	Cognitive function and neuro	Dementias and neurodegeneration
DeNDRoN 3255 Pfizer A8241021	Cognitive function and neuro	Dementias and neurodegeneration
LonDownS cohort	Cognitive function and neuro	Dementias and neurodegeneration
Effective Home Support Dementia Care:Patterns of Current Provision v1	Cognitive function and neuro	Dementias and neurodegeneration
BRU ACDC-Study	Cognitive function and neuro	Dementias and neurodegeneration
DeNDRoN 2748 TEVA HD	Cognitive function and neuro	Dementias and neurodegeneration
DEME 4833	Cognitive function and neuro	Dementias and neurodegeneration
DEME 4245	Cognitive function and neuro	Dementias and neurodegeneration

Visual hallucinations, visuoperceptual function and attention	Cognitive function and neuro	Dementias and neurodegeneration
Cost efficient service provision in neurorehabilitation	Health Services Research	Health Services and Delivery Research
Exploring the black box of shared decision making (SDM)	Health Services Research	Health Services and Delivery Research

Appendix 3 – NTW Research Conference 2016 – winning poster prize

Shining a light on the future

Northumberland, Tyne and Wear

Caring Hands Research Project- A Pilot Study Lynsay Duke* Lucy Gibbison** Vicky McMahon*** *Advanced Occupational Therapist **Specialist Nurse *** Health Care Assistant

Can the provision of education to paid carers improve their confidence in managing complex hands?

BACKGROUND

Following a neurological diagnosis individual's may experience spasticity, an involuntary tightening of the muscles.

This can have an impact, not only on function but also the ability of carers to support individual's in their daily routine. If a hand is affected by spasticity then opening the hand for hygiene, nail care, pressure care management, as well as the application of splints can be problematic, painful and lead to poor skin integrity It is reasonable to expect that "whoever cares for the patient undertakes all aspects of personal hygiene including nail care" (DOH 1997b 1999 2001b)

RESULTS

Staff perceived that their confidence following the Education sessions improved by 0.821 points on average (range 0 to +5 points) and their skill improved by an average of 1.96 points (range -2 to +6). They also indicated that their awareness of the problems experienced by the residents had improved.

In addition staff felt that the patients were more confident in the staff handling their hands and therefore some challenging behaviours had reduced as a result of the Education Sessions.

Duke L, Gibbison L, McMahon V (2015) Improving Hand Hygiene after Neurological Injury. Nursing Times 111, 45 12-15

METHODOLOGY

This pilot study recruited 6 carer agencies (a total of 28 carers) who were working with 7 patients who attended the Spasticity Management Clinic at Walkergate Park and had identified problems with a tight hand. Semi-structured interviews were carried out pre/post two Education sessions exploring confidence, skill narrative and impact on the patient. The first session covered issues around capacity, skin and nail care, moving and handling, challenging behaviours, splints, pain management, documentation and quality standards. In addition each carer received a practical session jointly with the patient to address issues around stretching, opening the hand, positioning and splint use and discussion about individual needs. Each patient was assessed pre and post interventions to note any benefits and provided with a hand care kit

including an emery board, nails

scissors and a Do's and Don'ts sheet.

FUTURE ACTIONS:

•Explore future partnership working with care agencies to provide education opportunities for paid carers. •Development of services to meet need.

- •Development of services to meet need.
- Influence practice within the Trust by: Provision of Education to In-patient staff
- •Discussing whether Trust Policies include pressure area care and hygiene for the upper limb and hand.
- •Publish results of study to highlight the problem in the wider population and to add to the body of evidence

•Encourage care staff to assist in hand hygiene, applying hand splints and stretching in all patients but particularly with those with complex hands.

Appendix 4 – NTW related Publications 2015/16

Case Study

Dodds Nicola, Legg Gill, Sinfield Philip, Armstrong Dale and **Cheng Wilson** (2015) The application of a positive behavioural support framework in a low secure adolescent inpatient unit. <u>International Journal of Positive Behavioural Support</u>, 5(2), September, pp.33-42.

Clinical Review

James Ian A (2015) The rightful demise of the Sh*t Sandwich: providing effective feedback. <u>Behavioural and Cognitive Psychotherapy</u>, 43(6), November, pp. 759-766.

Comparative Analysis

Dudley Robert, Ingham Barry, Sowerby K, and **Freeston Mark** (2015) The utility of case formulation in treatment decision making: the effect of experience and expertise. <u>Journal of Behaviour Therapy and Experimental Psychiatry</u>, 48, September, pp. 66-74.

Conference Paper

Adekunte Oluyemi, Owen Bruce and Burrell C (2016) Simulation training - pilot: psychiatry higher trainees' mental health tribunal report writing, oral presentation and cross-examination by tribunal panel. <u>European Psychiatry</u>, 33 (Sup), March, pp. S537-S538.

Editorial

Abed R and **Teodorczuk Andrew** (2015) Danger ahead: challenges in undergraduate psychiatry teaching and implications for community psychiatry. <u>British Journal of Psychiatry</u>, 206(2), February, pp. 89-90.

Hawkes Kevin, Jackson V and Reed A (2015) Editorial. Context, 138, April, p. 1.

Expert/Opinion

Abed R and **Teodorczuk Andrew** (2015) Undergraduate psychiatry teaching should happen in primary care: authors reply. <u>British Journal of Psychiatry</u>, 206(6), June, p. 522.

Ahuja Niraj and Cole Andrew (2015) Practical approach to management of catatonia. <u>Future</u> <u>Neurology</u>, 10(5), November, pp. 455-466.

Alakeson V, Boardman J, Boland B, Crimlisk H, Harrison C, Iliffe S, Khan M, **O'Shea, Rory** and Patterson J (2016) Debating personal health budgets. <u>British Journal of Psychiatry Bulletin</u>, 40(1), February, pp. 34-37.

Branch Alison and Denne L (2015) Positive behavioural support - a competence framework. International Journal of Positive Behavioural Support, 5(2), September, pp. 65-66. Cleare A, Pariante CM, Young AH, Anderson IM, Christmas D, Cowen PJ, Dickens C, **Ferrier I Nicol**, Geddes J, Gilbody S, Haddad P, Katona C, Lewis G, Malizia A, **McAllister-Williams Hamish R**, Ramchandani P, Scott J, Taylor D and Uher R (2015) Evidence-based guidelines for treating depressive disorders with antidepressants: a revision of the 2008 British Association of Psychopharmacology guidelines. <u>Journal of Psychopharmacology</u>, 29(5), May, pp. 459-525.

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Cohen-Tovee Esther (2015) Why bother with lean? Clinical Psychology Forum, 271, p .21.

Crooks Matthew (2015) Adaptive clothing to help with vital personal care. <u>Journal of Dementia</u> <u>Care</u>, 23(4), September, pp. 16-17.

Duke Lynsay, Gibbinson Lucy and McMahon Victoria (2015) Improving hand hygiene after neurological injury. <u>Nursing Times</u>, 111(45), November, pp. 12-15.

Goodwin GM, Haddad PM, **Ferrier I Nicol**, Aronson JK, Barnes TRH, Cipriani A, Coghill DR, Fazel S, Geddes JR, **Grunze Heinz**, Holmes EA, Howes O, Hudson S, Hunt N, Jones I, **Macmillan IC**, **McAllister-Williams Hamish**, Miklowit, DR, Morriss R, Munafo M, Paton C, Saharkian BJ, Saunders KEA, Sinclair JMA, Taylor D, Vieta E and Young AH (2016) Evidencebased guidelines for treating bipolar disorder: revised third edition recommendations from the British Association for Psychopharmacology. <u>Journal of Psychopharmacology</u>. ePub ahead of print. DOI:10.1177/0269881116636545.

Hawkes Kevin and Reed Alex (2015) Early contact family meetings in psychiatric services. <u>Context</u>, 138, April, pp. 27-28.

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James Ian A (2015) The use of CBT in dementia care: a rationale for Communication and Interaction Therapy (CAIT) and therapeutic lies. <u>The Cognitive Behaviour Therapist</u>, 8, December, pp. e31-32.

Kendall-Raynor Petra (2015) Trusts initiate programme to tackle prejudices in the NHS. <u>Mental</u> <u>Health Practice</u>, 19(2), October, pp. 8-9.

Report by Petra Kendall-Raynor (Freelance Journalist) on the Time to Change Anti-Stigma Campaign pilot being run in NTW NHS FT and 2gether NHS Foundation Trust. Includes comments from Deputy Chief Executive, **James Duncan**.

Lebert Latoya N, **Spence, Helen M** and **Turkington Douglas** (2015) Caring for relatives with schizophrenia: a role for stress reduction and CBT techniques training? <u>British Journal of</u> <u>Psychiatry</u>, July.

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