

NORTHUMBERLAND, TYNE AND WEAR NHS FOUNDATION TRUST

Board of Directors Meeting

Meeting Date: 29th November 2017

Title and Author of Paper:

Simon Douglas Joint Director of Research, Innovation and Clinical Effectiveness
R&D Annual Report 2016/17

Executive Lead: Rajesh Nadkarni

Paper for Debate, Decision or Information:
Information

Key Points to Note:

Here is presented the Research and Development Annual report for 2016/17.

1) National League Table success

Financial year 2016/17 was another successful year for NTW in research terms, with particular note to be made of the Trusts improvement in position in the NIHR league table of research activity to 3rd out of mental health Trusts. Coupled with the first place for local acute Trust Newcastle Hospitals (NUTH) among acute providers this shows the strength of the region in terms of Outstanding CQC ratings is beginning to be mirrored in research strength and activity.

2) Funding application activity

The new research strategy refresh began to be implemented in 2016/17 with a range of new initiatives and the further development of academic collaborations both through, and in addition to, the Academic Clinical Collaborations (ACCs). While a range of significant new grant funding applications were developed through these collaborations during this year, we are still awaiting outcomes at the time of writing.

3) Research capacity increasing

Progress on key metrics reported to the Department of Health continued, with increases in number of large scale portfolio research studies (50 up from 45) and portfolio recruitment (1364 up from 1331) supported by input from NTW clinicians across all professions supported by the clinical research network teams.

4) Financial benefits

Financially, NTW's research income increased by nearly £400k or 16% on the previous year. While this is largely the result of increasing successes in research collaborations, or NTW clinicians and academics being funded to collaborate on other's research projects, it also shows an increase in commercial research activity, which is a key area of the research strategy. It allows us to develop a more skilled and flexible capacity for bringing still more commercial research to into NTW.

5) Impact

Although there are well-recognised benefits to being a research-active NHS trust, in particular improvements in quality of care and recruitment and retention of key staff, it is also important that we can evidence more direct benefits of being involved in research for those who use our services. Chapter 3 details some of the projects which have realised an impact in 2016/17, from dementia with Lewy-Bodies to assessment in police custody suites, and street triage to veteran's mental health.

Risks Highlighted to Committee:

None

Does this affect any Board Assurance Framework/Corporate Risks?

No

Equal Opportunities, Legal and Other Implications:

None to note

Outcome Required:

For information

Link to Policies and Strategies:

NTW R&D Strategy

NTW (O)47 Research Management and Governance policy



**Northumberland,
Tyne and Wear**
NHS Foundation Trust

Research and Development Annual Report 2016/17

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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

Financial year 2016/17 was another successful year for NTW in research terms, with particular note to be made of the Trusts improvement in position in the NIHR league table of research activity to 3rd out of mental health Trusts. Coupled with the first place for local acute Trust Newcastle Hospitals (NUTH) among acute providers this shows the strength of the region in terms of Outstanding CQC ratings is beginning to be mirrored in research strength and activity.

The new research strategy refresh began to be implemented in 2016/17 with a range of new initiatives and the further development of academic collaborations both through, and in addition to, the Academic Clinical Collaborations (ACCs). While a range of significant new grant funding applications were developed through these collaborations during this year, we are still awaiting outcomes at the time of writing.

Progress on key metrics reported to the Department of Health continued, with increases in number of large scale portfolio research studies (50 up from 45) and portfolio recruitment (1364 up from 1331) supported by input from NTW clinicians across all professions supported by the clinical research network teams.

Financially, NTW's research income increased by nearly £400k or 16% on the previous year. While this is largely the result of increasing successes in research collaborations, or NTW clinicians and academics being funded to collaborate on other's research projects, it also shows an increase in commercial research activity, which is a key area of the research strategy. It allows us to develop a more skilled and flexible capacity for bringing still more commercial research to into NTW.

Research should not happen for its own sake but to improve treatments and outcomes for those who use the services of the NHS. NTW's Annual R&D reports therefore aim to promote research that has impacted on the care we can provide, from improving treatment options for veterans with addictions to developing improved diagnostic capabilities for dementia.

The research strategy highlights the importance of partnerships, and in particular those which can provide links between our clinicians and academics. To this end we have maintained the previous year's approach to developing partnerships with all of our local HEIs, including a keynote at the annual conference from Professor Charles Fernyhough of Durham University to highlight the important Hearing the Voice project.

For the future, it is key within the refreshed strategy 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.

Simon Douglas
Joint Director of Research, Innovation and Clinical Effectiveness
August 2017

2 Progress with the NTW Research Strategy – implementing the updated strategy

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 to provide a plan for the next five years in line with the Trust strategy was completed in 2015/16, leading to a refreshed plan for implementation in 2016/17.

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. Notably we promoted an approach to engage with all local Universities within our footprint with the aim of harnessing academic expertise which would fit with the diverse service provision of NTW as a Trust.

3 Impact of NTW research in 2016/17

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 May 2017. We have further highlighted some examples of impact in 2016/17 below:

International impact in the field of Lewy-body dementia (DLB)

Newcastle, with NTW heavily involved, has played a significant role as 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 and are now used globally, and in 2013 were formally incorporated into DSM IV. The primary output from The Consortium meeting in Fort Lauderdale, Florida (2015) will be the first revision of the DLB Consensus statement in over a decade. These revised recommendations led by Newcastle and NTW authors (McKeith, Taylor) have currently been accepted in Neurology and will be published in May 2017 forming the blueprint for translational and early phase clinical trials in DLB and related disorders. Importantly the consensus report provides a framework for future research direction including development of a publically available DLB genetic database and a repository for DLB exome data, placing greater emphasis on

enhanced molecular biological interrogation of purported patho-aetiological processes and cultivating improved international harmonisation of networks of researchers and research participants that share platforms for data and biomarker collection, outcome measures for clinical-translational research in DLB, and a common terminology across language, cultures, and traditions.

Local research success in DLB

In partnership with Lilly we completed a study to determine the relationship between in vivo amyloid burden in DLB, as determined by AV-45 PET imaging, clinical features of the disease, other imaging changes and subsequent clinical course. The successful delivery of the 'AMPLE' study has the potential to determine if amyloid can be a possible treatment target in DLB. The study has established the largest amyloid imaging cohort in DLB and demonstrated amyloid to be a potential therapeutic target in half of cases. The patients are currently in follow up and will show whether amyloid deposition is associated with differences in disease progression, which could provide a significant new option for targeting treatments.

HELP PC Innovative project to help diagnose mental health issues in police custody suites

The Health Screening of People in Police Custody (HELP-PC) has redeveloped health screening and risk assessment within police custody suites. The initial stages of this project took place with the Metropolitan Police Service (MPS) in London. The redesigned screening process has been cited in a number of influential publications including Lord Victor Adebawale's 2013 "Independent Commission on Mental Health and Policing Report" and in the recently published NICE Guideline 66 "Mental health of adults in contact with the criminal justice system" (2017).

In mid-2016, Northumbria Police implemented the HELP-PC risk assessment screen and the effectiveness and impact of the new process is currently being investigated by Dr McKinnon and colleagues from Newcastle University and Northumberland Tyne and Wear NHS Foundation Trust's Criminal Justice Liaison and Diversion Team.

Street triage research demonstrates success

An on-street assessment by a specialist team has been shown to more than halve the number of police detentions under the Mental Health Act. Street Triage is a service that comprises of a mental health nurse working alongside a dedicated police officer in mobile community units. The initiative enables the police and the NHS to work collaboratively to make sure an individual gets the best care possible when concerns about their mental state are reported to officers.

A research project carried out in NTW found the annual rate of detentions under Section 136 of the Mental Health Act reduced by 56% in the first year Street Triage was introduced. In the second year of street triage the rate of detention by the police fell by more than 80% compared with the baseline, which reflected nearly 60 fewer detentions per month, and just under 700 fewer detentions per year across NTW. Street triage was particularly effective in reducing the rate at which individuals were detained multiple times in a year (greater than 90% reduction).

Street Triage linking into NTW services brings the ability to respond quickly, with the skills of police officers working with mental health professionals to provide the best care possible. The initiative had an immediate and noticeable effect with the number of detentions falling as soon as it was introduced. For every four Street Triage interventions there was one fewer detention. The research findings suggest Street Triage has the potential to transform the delivery of adult mental health services.

The research findings were published in the British Medical Journal (BMJ open, Keown et al (2016)) and generated significant national interest.

Alcohol brief interventions and interventions for well-being for armed forces personnel transitioning back to civilian life

This study was funded by the Forces in Mind Trust and was a collaboration between Newcastle University, Teesside University and Northumberland Tyne and Wear NHS Foundation Trust. The aim of the study. Led by Dr Sarah Wigham, was to review evidence for the effectiveness of brief interventions to protect the well-being of armed forces personnel including interventions to help cut down on alcohol. The study comprised two systematic reviews of the effectiveness of the preventative interventions. The alcohol component of the study has been completed and the interventions reviewed included techniques for cutting down on drinking for example providing information on the effects of alcohol on mental and physical health.

The interventions found effective for reducing drinking in soldiers and veterans were delivered online and were adapted for military personnel. For example they included information on the interaction between symptoms of PTSD and alcohol and the possible effects of experiencing combat on drinking.

The study findings have been summarized into two briefing documents for publication on the Forces in Mind Trust website and the alcohol document has been circulated to key stakeholders. The stakeholders include groups with an interest in the development of interventions to protect the well-being of serving armed forces personnel and veterans including military public health and community veteran services. Key stakeholders currently developing alcohol services have visited the university to hear about the study findings. The study is important as it has created information of interest to those stakeholders developing alcohol strategies in military and veterans' settings, by identifying which interventions have evidence of effectiveness and therefore in which interventions it may be important to invest for service development. This may help to protect the well-being of military personnel, for example using the early brief interventions to facilitate informed choices about alcohol may reduce admissions to clinical services for alcohol related difficulties in the longer term.

Project Cygnus success

117 participants with dementia from NTW, and their study partners were recruited into Project Cygnus, a study with four recruitment centres in the north of England. The study was developed to help to understand the impact of diagnosis and subsequent outcomes for patients with memory loss and those who care for them in real-world settings. The data gathered will help assess the value of interventions, evaluate data collection methods, and follow post-diagnosis progression of conditions. This will hopefully help to develop pathways of care for dementia patients in the future.

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 and despite a drop for 2015/16 we have improved again from 45 last year to 50 studies recruiting participants in 2016/17 (full list of studies in Appendix 3). This number of studies puts NTW as third in the NIHR-published league table of most research active mental health trusts for 2016/17, up from fourth the previous year.

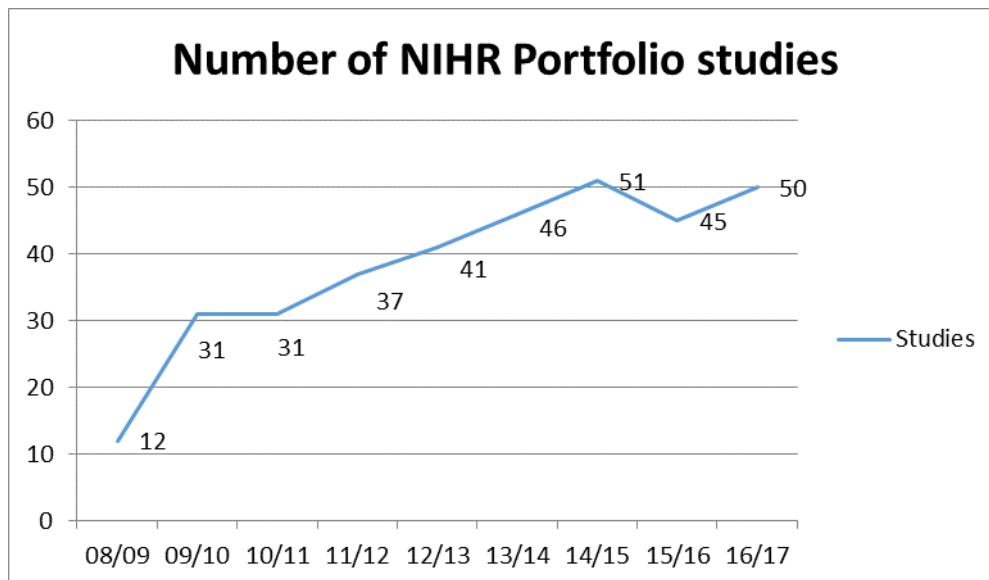


Figure 1 – Number of NIHR Portfolio Studies recruiting participants in year

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.

4.2 Portfolio recruitment

To ensure continued level of national research network funding, recruitment of participants to NIHR portfolio research remains the key measure for NHS organisations. While this measure is sensitive to a range of factors such as study complexity, availability of research funding or outliers such as single high-recruiting projects, we can in NTW point to evidence of progress over the life of the strategy (fig 2, below). The final total for NIHR portfolio recruitment in NTW in 2015/16 was 1364, above the total of 1331 in the previous year and well above the goal of 826 set with the local Clinical Research Network, placing NTW 6th in the annual NIHR-published league table of top-recruiting mental health trusts.

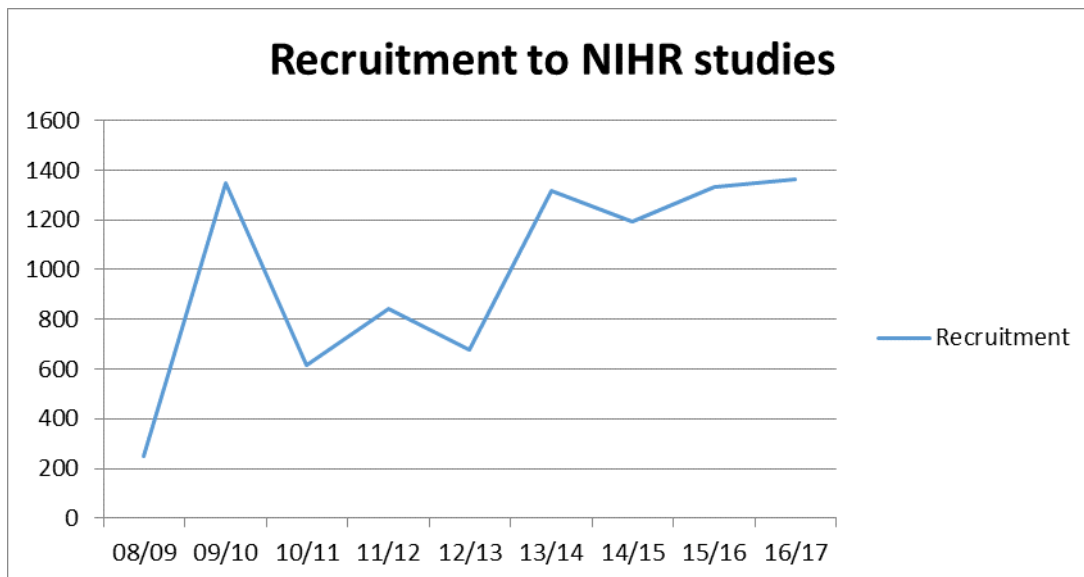


Figure 2 – Recruitment to NIHR Studies

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 2016/17, with increasing focus on research in Huntington’s Disease, for which NTW is being seen as a leader nationally.

The NTW-based DeNDRoN Speciality Group team also have recruited successfully to exciting pharmaceutical clinical trials in mild cognitive impairment and mild dementia. Huntington’s disease research has also continued to be successful in 2016/17, recruiting to time and target in several commercial trials. This success leads to further requests to take part in new trials and improves NTW’s reputation as a centre which can successfully deliver commercial research in the field.

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 Speciality 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.

In 2016/17 NTW continues to provide local leadership to the Clinical Research Network with Dr Bob Barber leading the DeNDRoN specialty Group across the north east and north Cumbria and Dr Stuart Watson doing likewise for the mental health SG. These key leadership roles give strategic direction to the research delivery teams and allow us in NTW to influence the progress of the network. In addition, Dr Adi Sharma was confirmed as Child & Adolescent Mental Health Champion (Sub Speciality Lead) to provide a similar cross regional input in what is seen as an important speciality.

NTW continues as a member 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. Further discussions with Northumbria, Sunderland and Durham Universities, with the aim of developing mutually beneficial research partnerships also continued during 2016/17.

The focus on the four Academic Clinical Collaborations (ACCs)(see table 1), which are partnerships between the clinicians in the Trust and academics, continues. 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 2016/17. 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 2017/18.

Exciting news from NTW/Newcastle University's dementia's research programme

Newcastle's new PET-MR facility, is a major investment by the MRC to support high level innovation and a tangible "step-change" in dementia imaging research. It will be part of the UK Dementia Platforms Imaging Platform forming part of a network of state of the art scanners able to support multicentre dementia trials and act as a key enabler of experimental medicine for new therapeutics development. Bringing state of the art scanners into clinical research environments across the country will facilitate translation of new diagnostic and monitoring approaches into clinical practice. The switch from PET/CT to PET/MRI will be a major advance for the field. Larger scale studies with a less cooperative, vulnerable older and early dementia population demands new approaches to scanning that put a premium on process efficiency and patient tolerability. A "one stop shop" for an integrated exam promises significant gains for both. Standard registration approaches cannot correct for subject motion during scanning, which can be substantial. A unique advantage that will be realized with MRI-PET (early methods development work already is ongoing) involves adaptive reconstruction of dynamic MRI-PET data with frequent MRI "navigators" to provide a continuous update on the precise head position from minute to minute. Improved reconstruction accuracy meant that the PET signal can be better localized particularly to smaller anatomical structures relevant to dementia pathology. Fully integrated MRI-PET also allows changes assessed by PET (e.g., neurotransmitter receptor occupancy, drug occupancy and even innate immune activation) to be related directly to functional brain activity evaluated by MRI (e.g., resting state fMRI, arterial spin labelling perfusion).

Developing research in pharmacy and medicines optimisation

The Pharmacy Department has continued to build on its research and development. The use of automated medicine cupboards on inpatient units was rolled out and assessed to show that nursing time to care was released (0.4 wte Band 5 nurse per ward) as well as a 13% reduction in drugs spend across the wards. A Senior Clinical Pharmacist helped to lead on work within medicines optimisation within learning disabilities (STOMP). This led to the production of a national CPD booklet as well as a secondment to NHS England. The Pharmacy has contributed to and been the winner at the Pharmacy Management National Forum Awards, presenting posters on the PD Hub, Medicines Management in the CMHT and the utilisation of pharmacy assistants in the medication administration process. The Department continues to support the supply of clinical trial medication within the Trust.

NTW Pharmacy has been instrumental in the forming of the Great North Pharmacy Research Collaborative. This group aims to bring together pharmacists from all sectors within the region to ensure that research and innovation within pharmacy is supported and showcased.

Improved links between the Pharmacy and local HEIs are being built and it is hoped that this will increase the levels of research significantly in the years to come.

6 Research governance

The new national system for NHS permissions, run by the Health Research Authority (HRA) was implemented fully from 1st April 2016. 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.

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 [Trust external website](#). 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 2016/17 NTW had nine trials eligible for PID reporting, of which eight were approved and recruited the first participant within the target of 70 days. Thus NTW remained one of the top performing NHS Trusts nationally on research set up and initiation, albeit from a relatively low number of studies.

The element of research approvals processes which is now devolved to the Trusts is that of “confirmation of capacity and capability”, which is the NTW process around whether the Trust has the knowledge, expertise, patient population, research team capacity and local clinical services approval for any study approved via the HRA process.

As part of providing governance and oversight in research running in NTW, the R&D team audits a sample of research studies (based on the national standard of 10%) annually. Five studies were audited in 2016/17, with no major findings. All minor findings have been corrected and signed off at time of reporting.

7 Financial report

NTW's research income for 2016/17 increased by nearly £400k or 16% on the previous year. This was largely due to two of the funding streams, NIHR grant income and commercial income. For NIHR income this is mostly the result of increasing research collaborations, where NTW clinicians or academics collaborate on funded research projects run from elsewhere but we receive funds for their time and expertise on the project. It does also show an increase in commercial research activity, which is a key

area of the research strategy. As in the previous year it has been led by the increase in Huntington’s research, and It allows us to develop a more skilled and flexible capacity for bringing still more commercial research to into NTW.

We also have recruited successfully to exciting pharmaceutical clinical trials in mild cognitive impairment and mild dementia. Huntington’s disease research has also been successful again in 2016-2017, recruiting to time and target in several commercial trials and we have been approached to participate in more studies, both commercial and non-commercial.

Income type	2012/13 £	2013/14 £	2014/15 £	2015/16 £	2016/17 £	Variance from 15/16
Grant income	430,837	521,996	720,618	921,906	1,224,400	302,494
DH funding (RCF)	297,447	288,840	240,182	298,152	295,965	-2,187
NIHR network funding (LCRN – now includes MHRN and Dendron specialties)	556,564	564,811	1,107,677	1,022,157	1,030,550	8,393
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	173,928	73,677
Total	2,314,561	2,348,582	2,150,065	2,324,466	2,724,843	382,377

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, remained stable this year, despite a decrease in funding associated with NIHR Senior Investigators (currently worth £75k of RCF each) from one Senior Investigators to none. 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 Fifth Annual NTW Research and Development Conference was held in May 2017 (but reported here as it was fully embedded in the 2016/17 funding and strategy cycle). Opened by NTW Chief Executive John Lawlor, it focussed again on showcasing the work of the Academic Clinical Collaborations and each one presented their work and future directions. In addition we saw presentations from a range of clinicians and academics who talked about their research plans, findings and ideas. We again ran a dedicated poster session, enabling presenters to speak to their posters and answer questions, which again generated a great atmosphere of discussion and discovery. The most highly rated poster and presentation was again awarded a prize, sponsored by local bookshop Blackwells. The winning poster is reproduced in appendix 3. The conference was attended by over 220 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. The keynote was delivered by Professor Charles Fernyhough from Durham University who discussed the Wellcome Trust funded Hearing the Voice project, highlighting the links between medicine, psychology, philosophy and sociology which the project is drawing on.

Developing the research workforce has been a key strand of the NTW research strategy and we have had success in 2016/17 through developing non-medical Principal Investigators (PIs). We now have a second Nurse Consultant leading an NIHR Portfolio study as a local PI, Kate Chartres, in the LP-Maestro study with the Sunderland Liaison Psychiatry team.

Since successfully completing her professional doctorate in occupational therapy, Dr Maria Avantaggiato-Quinn has led on developing the research capacity and capability of the NTW Allied Health Professional workforce within the Region, Nationally via CAHPR (the Council for AHP Research) and for NTW.

In June the Board ratified the new NTW AHP Strategy (2017-2022) with Action Plans for the new Trust Localities and Associate AHP Directors in CBUs to implement over the next five years. AHPs will help realise the Trust's Strategic Ambition Five, to be a centre of excellence for mental health and disability, through:

Leading change:

- Having an AHP research aware and active culture, supported by career pathways for AHPs in research from interested to expert research leader and supported by Trust & AHP R&D Groups. To identify AHP research champion roles in locality groups.
- Ensuring that CPD/CWD, updating via conferences/literature/audit are an embedded part of the improvement culture for services, ensuring AHPs are up to date with latest evidence.
- Forging sustainable links with Universities for academic support and networking (to increase research outputs) and to support HEIs in best AHP clinical practice (e.g. developing Honorary Contracts/Visiting Scholar opportunities).
- **Developing AHP Skills:** AHPs will extend their skills/knowledge to improve service efficiency/outcomes and develop the evidence base through evaluation and research. To utilise skills and knowledge in the use of data collection and analysis and evaluating evidence to develop and improve the delivery of services, supported by NTW Library & Knowledge Services and training.
- Develop business case for Trust wide AHP Consultant in R&D to facilitate and lead increased research activity across AHP community, to improve AHP confidence, develop clinical academic careers, successful NIHR applications and generate research income.
- **Evidence the Impact of AHP Services:** Develop a commercial research portfolio, reinvesting income generation in further research initiatives.
- Ensure AHPs involved in research, publish and disseminate findings and contribute to NTW R&D activities & that all AHP staff use HCPC recommended half day a month for CPD.

Utilising Information and Technology:

- To establish mechanisms for AHPs to respond swiftly and successfully to research funding opportunities (e.g. ACCs, Strategic Clinical Networks, AHP CPD/R&D Groups).

Sharon Dorgan, NIHR CRN/HENE Strategy Development Lead, has led on an exciting collaborative development of a Regional NMAHP (Nursing Midwifery & AHP) Research Strategy, involving Universities and a range of stakeholders including the NTW Clinical Director for AHPs, in the development of an Action Plan, aiming to build research capacity and capability across the North East and Cumbria, and Maria will be involved in its NIHR/CRN launch on 7th November 2017.

Our run of successful applications for regional research training programmes continues, Jane Bourne, a drama therapist was accepted on to an NIHR/HEE internship 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 recognition. 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.

The NTW Research Register

Since 2015 we have been working hard to develop a research register, the purpose is draw together individuals who are interested in mental health research and to build relationships to support and develop research in NTW.

The register is now established and has over 400 members who receive regular newsletters, information about current and published research and any other relevant information. Members are invited to focus groups regarding new research grants and other projects. Public engagement events are held about 4 times a year and the register enables us to reach a broad and varied audience for these events. These events increase awareness of local and national research which increases NTW capacity to conduct research through public, patient and clinician participation.

Dendron Case Register

Regionally, the Dendron Research Case register continues to be a used as an excellent recruitment tool for all our studies.

- During 2016-17 90 new participants from NTW have joined the Case Register, they are still actively available for studies.
- 23 participants from the 90 have been recruited into a research study in 2016-17
- 193 participants joined the Case Register for the year from across the region.

Peer Researcher training for a new generation of service user and carer researchers

Following the success of the previous training course, which enabled NTW-based service users and carers to develop knowledge, skills and expertise in research processes and methods, NTW once again partnered with Northumbria University to deliver a course to a new cohort. The rationale for the training was that once the skills have been developed the participants can be actively involved in research projects, thus bringing a range of lived-experience to the researcher role. This approach had been highly commended for the previous cohort collecting a variety of awards for co-production and participation.

The new Peer Researcher Training course was delivered to service users of mental health services and military veterans over eight sessions. The short course was designed to help participants to gain the skills and knowledge needed to be able to take an active and meaningful part in research projects that concern service users.

Initially, eleven participants registered to take part in the training and attended the session. On completion of the course, eight participants received certificates and provided positive feedback about their experience. During the course, participants were introduced to Northumbria University staff who have specialist knowledge of peer research in practice. Participants have been offered the opportunity to pro-actively consider, discuss and take part peer researcher opportunities in the future. Two of the military veterans who completed the course are currently supporting researcher projects as part of the Military Veterans and Families Research Hub at Northumbria University, while we anticipate that there will be a range of opportunities within NTW in the future which can be offered to the participants.

The continued success of the NTW research strategy underpins the increase in research activity over the previous year and we are confident that the implementation of the strategy will develop the foundations for continued success and improvement.

2016/17 was an important year for the NTW Research Strategy as it marked the implementation of the next iteration of the refreshed strategy which provides 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.

Once again NTW have consolidated the position in the NIHR annual league table of 3rd among mental health trusts for research activity, which is a great achievement in the face of some increasingly organised competition. South London and Maudsley Trust (SLAM) remain in first place with their association with the Institute of Psychiatry at Kings College London contributing significantly to their ability to generate grant funding and run commercial studies, while the Trust in second position was Oxford Health who have a significant new collaboration in the Biomedical Research Centre with Oxford University focussed on brain health. With the lack of current infrastructure along these lines the 3rd place for NTW is even more impressive.

The report provides details on a range of impacts which NTW research has provided and while there are frustrations around how quickly research findings can be implemented into practice, there are many more examples where research impacts will provide benefits over the longer term.

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.

Appendix 1: Final routine performance report for 2016/17 provided to NTW's R&D Committee

Table 1 – Performance on key R and D measures related to the R&D strategy (End of year 2015/16)

Strategic Objective 1 – Financial Performance, Recruitment & external relationships	2014/15	2015/16	2016/17 goal	2016/17 total
Stable infrastructure (Research Network) income *	£1,107,677	£1,022,157	+/- 10%	£1,046,329
Increase in Commercial Income	£81,588	£100,251	+ 20%	£173,928
Increase in NIHR Grant income*	£720,618	£921,906	+ 20%	£1,224,400
Increase in RCF income *	£240,182	£298,152	+ 5%	£295,965
Last ½-year spending within budget variance of 1%	0%	0%	+/- 1%	Yes
NIHR Portfolio Recruitment (NTW)	1192	1331	826	1364
NIHR Portfolio Recruitment (all network, all Trusts)	2175	2391	1700	1776
NIHR Studies recruiting in year	51	45	50	50
Commercial Recruitment	16	22	70	17
Number of NTW-hosted NIHR funding applications this financial year	6	8	10	10
*projected for 15/16 total				
Strategic Objective 2 - internal Processes Internal Relationships				
Service Approval turnaround (from receipt of service approval form)	15 days	5 days	20 days	20 days
Caldicott approval Turnaround (from receipt of valid application)	NA	NA	15 days	NA
Contract turnaround (from receipt of draft)	15 days	30 days	30 days	NA
Service User involvement in research funding bids (tbc)	NYA**	NYA**	3 bids	4 bids
Strategic Objective 3 - Learning and Development				
Number of Trust staff involved in Portfolio research	NYA**	NYA**	50	70
Number of Trust staff attending GCP training	NYA**	NYA**		NYA**
Number of staff attending Trust Research Training	134	NA	50	NYA**
Number attending PI development Group (now SG group)	89	42	60	NYA**
Communications				
Articles in The Bulletin	31	5	24	12
Articles on Trust intranet	17	17	24	14
Monthly e-bulletins on time	100%	100%	12	100%
Annual conference registrations	182	201	200	223
Annual lunchtime research seminar registrations	76	47	150	n/a
Other Operational Performance				
Research Governance				
Portfolio Approval Times	100% (23)	100% (16)	From 1 st April 2016 research governance processes were taken over by HRA – see Appendix 2 for performance figures	
Non-Portfolio Approval Times	93% (54)	91% (58)		
Commercial Approval times	100% (4)	100% (3)		
Performance in initiating Research (PID) raw	100% (7)	100% (6/6)		
Performance in initiating Research (PID) adjusted	100% (5)	100% (6/6)		
Peer Reviewed Projects		16 NIHR, 18 Uni HRA 1		


** NYA=Not yet available

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

Study	Clinical Service	Topic
The Adult Autism Spectrum Cohort - UK	Adult Mental Health	Mental Health
Recovering Quality of Life (ReQoL) Stage 4b	Adult Mental Health	Mental Health
CODES	Adult Mental Health	Mental Health
PIPP2	Adult Mental Health	Mental Health
LP MAESTRO	Adult Mental Health	Mental Health
SCIMITAR	Adult Mental Health	Mental Health
MATCH	Adult Mental Health	Mental Health
PACT G	Adult Mental Health	Mental Health
IMPART	Adult Mental Health	Mental Health
Lifestyle Health and Wellbeing	Adult Mental Health	Mental Health
Measuring quality of life in adults on the autism spectrum	Adult Mental Health	Mental Health
Use of patient experience data in inpatient mental health services	Adult Mental Health	Mental Health
ADEPT: Guided self-help for depression in adults with Autism	Adult Mental Health	Mental Health
Interpersonal art psychotherapy for the treatment of aggression	Adult Mental Health	Mental Health
Lithium versus Quetiapine in Depression (LQD study), Version 1	Adult Mental Health	Mental Health
Young offenders in transition from child to adult services	Adult Mental Health	Mental Health
Family Based Support with parents and family carers	Adult Mental Health	Mental Health
DPIM - alcoholism	Adult Mental Health	Mental Health

Evaluation of Offender Liaison and Diversion Trial Schemes	Adult Mental Health	Mental Health
NCISH	Adult Mental Health	Mental Health
Psychosis and Language study (PaLs)	Adult Mental Health	Mental Health
BLISS	Adult Mental Health	Mental Health
DPIM - schizophrenia	Adult Mental Health	Mental Health
DPIM - bipolar disorder	Adult Mental Health	Mental Health
Molecular Genetic Investigation	Adult Mental Health	Mental Health
Homicide by patients with schizophrenia: a case-control study	Adult Mental Health	Mental Health
Offender Personality Disorder Pathway – Feasibility Study	Adult Mental Health	Mental Health
Psychological Adjustment in Progressive Multiple Sclerosis	Neurological disorders	Neurological disorders
Diagnosis of Alzheimer’s disease by measuring blood proteins	Cognitive function and neuro	Dementias and neurodegeneration
IDEAL study	Cognitive function and neuro	Dementias and neurodegeneration
DIAMOND-Lewy Work Package 1	Cognitive function and neuro	Dementias and neurodegeneration
DIAMOND-Lewy Work Package 2	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
BRU VEEGStim Study	Cognitive function and neuro	Dementias and neurodegeneration
DeNDRoN 3255 Pfizer A8241021	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
SHAPED (v1.0)	Cognitive function and neuro	Dementias and neurodegeneration


What can gait analysis tell us about dementia and its subtypes?	Cognitive function and neuro	Dementias and neurodegeneration
SUPeRb	Cognitive function and neuro	Dementias and neurodegeneration
Cygnus	Cognitive function and neuro	Dementias and neurodegeneration
Dementia Carers Instrument Development:DECIDE Psychometric evaluation	Cognitive function and neuro	Dementias and neurodegeneration
What Works? in dementia training and education v1	Cognitive function and neuro	Dementias and neurodegeneration
YETI - Young people's Experiences of Transition	Health Services Research	Health Services and Delivery Research



Validation of a Quality of Life measure: Involving autistic people in research

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Background

- Quality of Life (QoL) is a subjective assessment of well-being used as an outcome measure in health interventions¹ and to highlight differences in lived experience between groups^{1,2}
- The World Health Organisation Quality of Life questionnaire (WHOQoL-BREF) is a widely used measure of QoL. It has 4 domains: Physical QoL, Psychological QoL, Social QoL, and Environment^{1,4}
- QoL is consistently lower for autistic people than the typical population². This is a trend that has been evidenced worldwide²⁻⁷
- Despite being used in several studies with autistic adults, there is very little research looking at the validity of the measure with autistic people.

Aims

- To assess how valid and reliable the WHOQoL-BREF and an associated Disabilities module are for use with autistic people using a mixed methods approach.
- Design**
- Factor analysis using a large sample of pre-existing WHOQoL-BREF data
 - Discussion groups involving autistic people seeking to answer the question:
 - Are WHOQoL-BREF/DIS items conceptually clear for autistic people?

Methods

- Participants**
- Participants for the present study were invited from the Adult Autism Spectrum Cohort-UK (ASC-UK) project and had completed a demographic questionnaire, the Social Responsiveness Scale-Adult (SRS-A), and the WHOQoL-BREF. This is a longitudinal study looking at the lived experiences of autistic adults.
 - 370 participants (mean age=41.6, SD=14.4) were included for the factor analysis: 199 males, 158 females, and 13 who reported 'other'/'would rather not say as their gender'. 18 adults could not give informed consent; these adults were represented by a relative/carer.
 - Four discussion groups were carried out in the North East of England (N=20; mean age=28.2, SD=9.0). The groups included 13 males and 7 females, and were led by the research team (including a parent of an autistic adult and a person with autism).
- Measures**
- The WHOQoL-BREF has 26 items that cover 4 domains (pre-existing data used in the factor analysis).
 - The Disabilities module has 13 items and covers 3 domains: discrimination, autonomy, and inclusion (used with the discussion groups).
- Procedure**
- Exploratory factor analysis was used with the pre-existing WHOQoL-BREF data. Internal consistency was also established for each domain that emerged from the analysis.
 - Discussion groups were audio recorded and transcribed. The transcripts were coded to look for nuances in the way autistic people understand the item, and to highlight quotes that indicated an aspect of QoL not covered by the measure or unique to autistic people.

WHOQoL sample questions

- WHOQoL-BREF:**
- Physical domain - "Do you have enough energy for everyday life?"
 - Psychological domain - "How satisfied are you with yourself?"
 - Social domain - "How satisfied are you with your personal relationships?"
 - Environment domain - "To what extent do you have the opportunity for leisure activities?"
- Disabilities:**
- Discrimination - "Do you feel that some people treat you unfairly?"
 - Autonomy - "Do you feel in control of your life?"
 - Inclusion - "Do you feel that other people accept you?"

Acknowledgements



Northumberland, Tyne and Wear  

NHS Foundation Trust

- To Northumberland Tyne and Wear NHS Foundation Trust for sponsoring the study
- To Research Autism and Autistica for funding the study

Results – Factor Analysis

Factor structure

- A 1 or 2 factor model initially emerged from the data.
- In line with recommended exploratory factor analysis practice, the WHOQoL-BREF theoretical structure (4 factor model) was also tested.
- 3 and 5 factor models were also tested.
- The final model decided upon showed item groupings that were conceptually meaningful.

Internal consistency

- Cronbach's α was computed for each subscale of each factor model
- The 5 factor model demonstrated acceptable to good internal consistency: Environment, $\alpha=.859$; Psychological, $\alpha=.650$; Social, $\alpha=.662$; Medical, $\alpha=.805$; and Physical, $\alpha=.812$.

Items have been color coded according to the WHOQoL-BREF structure

Figure 1: 5 factor model for pre-existing WHOQoL-BREF data

Results – Discussion groups

- Three items from the WHOQoL-BREF data did not load onto the same factors as in the WHO structure. One item did not reach the minimum cut point (.300).
 - The reasons for these problematic loadings were further investigated by inspecting the discussion group transcripts.
 - Quotes that suggested a different/difficult interpretation of the item were coded for analysis.
- Do some WHOQoL-BREF items have a conceptually different meaning for autistic people?**
- Item 7: How well are you able to concentrate?
 • *I can't multi-task like certain women can. And loud noises and stuff put me off. If I'm doing a task I need to concentrate. So the kids put me off...* (Male, 40)
 - Item 11: Are you able to accept your bodily appearance?
 • *Am I able to accept it? Well I can't do anything else with it, can I? I haven't got a say in the matter, I've got to. I do so because I have to, but I go to the gym* (Female, 30)
 - Item 15: How well are you able to get around?
 • *I hate that question because it's vague, 'get around' what? Get around... I just don't like the way it's worded* (Female, 39)
 - When it says able 'to get around' does that mean like physical disabilities...? (Female, 30)
 - Item 26: How often do you have negative feelings such as blue mood, despair, anxiety, depression?
 • *It's just too broad though isn't it? Going from blue mood to despair is... they're so different to be on the same piece of paper is like... I wouldn't really agree with having them together* (Female, 36)

Discussion

- The WHOQoL-BREF appears to be acceptable in terms of validity and reliability as a measure of the QoL of autistic people. However, some items are problematic, and should be interpreted with caution.
- Autistic people advising on research provide insights which are highly beneficial to furthering the quality of autism research.
- The discussion groups identified aspects of quality of life not adequately measured in a mainstream questionnaire, despite the overall acceptability of the WHOQoL-BREF.

Future research

- Given the difference in the QoL factor structure, further study of the conceptualisation of QoL for autistic people is needed.
- There may be issues relating to QoL that are unique for autistic people: this suggests that a set of 'add-on' items (similar to the WHO Disabilities module) could better assess QoL in this population.

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Appendix 4 – NTW related Publications 2016/17

Case Study

Gnanavel Sundar and **Hussain Sharafat** (2017) X-linked ichthyosis and neurodevelopmental disorders: a case report and review of literature. Asian Journal of Psychiatry [Epub ahead of print]

Critchley Simon, **Hackett Simon** and Bradbury S (2017) Case study 47: Art therapy in cultural spaces: understanding the problem. In: NHS England Allied health professions into action: using allied health professionals to transform health, care and wellbeing: 2016/17 - 2020/21, pp.123-126.

Clinical Review

Allan Charlotte L, Behrman S, Baruch N and Ebmeier KP (2016) Driving and dementia: a clinical update for mental health professionals. Evidence Based Mental Health, 19(4), pp. 110-113.

Allan Charlotte L, Behrman S, Ebmeier KP and Valkanova V (2017) Diagnosing early cognitive decline - when, how and for whom? Maturitas, 96, pp. 103-108.

Barnes TRE, Leeson VC, Paton C, Costelloe C, Simon J, Kiss N, Osborn D, Killaspy H, Craig TKJ, Lewis S, **Keown Patrick**, Ismail S, Crawford M, Baldwin D, Lewis G, Geddes J, Kumar M, Pathak R and Taylor S. (2016) Antidepressant controlled trial for negative symptoms in schizophrenia (ACTIONS): a double-blind, placebo-controlled, randomised clinical trial. Health Technology Assessment, 20(29), pp. 1-46.

Baruch N, **Allan Charlotte L**, Cundell M, Clark S and Murray B (2017) Promoting early dementia diagnosis: a video designed by patients, for patients. International Psychogeriatrics, 29(5), pp. 863-857.

Camilleri N, Newbury-Birch Dorothy, **McArdle Paul**, Stocken Deborah D, Thick Tony and **Le Couteur Ann** (2017) Innovations in practice: A case control and follow-up study of 'hard to reach' young people who suffered from multiple complex mental disorders. Child & Adolescent Mental Health, 22(1), pp. 49-57.

Cooper P and **Grace Janet** (2016) Vulnerable patients going to court: a psychiatrists' guide to special measures. Psychiatrist, 40(4), pp. 220-222.

Currie Alan and Johnston A (2016) Psychiatric disorders: the psychiatrist's contribution to sport. International Review of Psychiatry, 28(6), pp. 587-594.

McKinnon Iain G, Thomas SDM, Noga HL and Senior J (2016) Police custody health care: a review of health morbidity, models of care and innovations within police custody in the UK, with international comparisons. Risk Management and Healthcare Policy, 9, pp. 213-226.

Comparative Analysis

Bass M, Dawkin M, Muncer S, Vigurs S and **Bostock Jan** (2016) Validation of Warwick-Edinburgh Mental Well-being Scale (WEMWBS) in a population of people using secondary care mental health services. Journal of Mental Health, 25(4), pp. 323-329.

Thompson-Janes Emily, Brice Samuel, McElroy Rebecca, Abbott Jennie and Ball J (2016) Learning from the experts: a thematic analysis of parent's experiences of attending a therapeutic group for parents of children with learning disabilities and challenging behaviour. British Journal of Learning Disabilities, 44(2), pp. 95-102.

Conference Paper

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