RCPsych
Issue 1
June **2017**

INSIGHT

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

Seas the day!

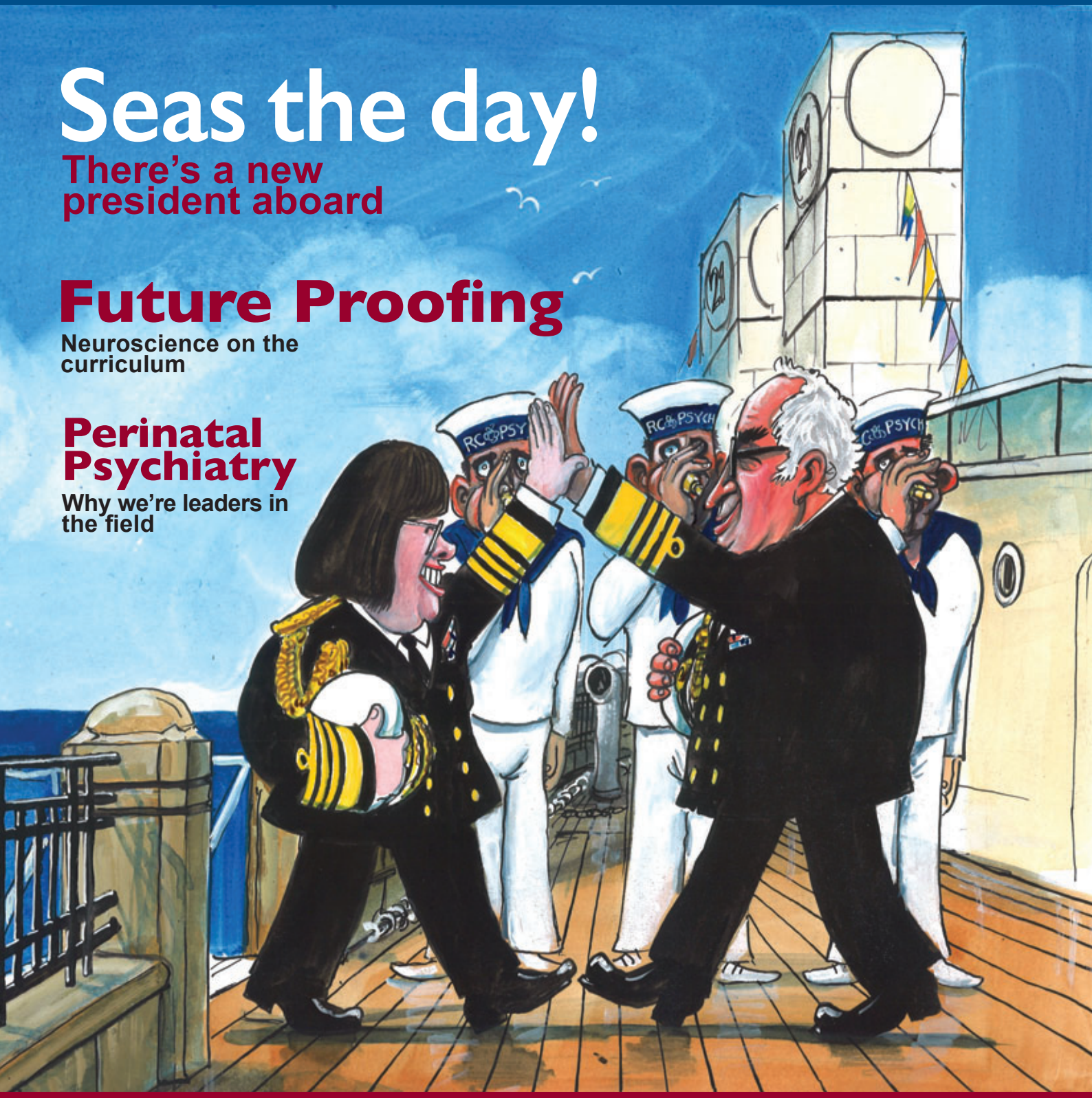
There's a new president aboard

Future Proofing

Neuroscience on the curriculum

Perinatal Psychiatry

Why we're leaders in the field



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CEO's **welcome**

By Chief Executive
Paul Rees

We have launched the magazine in response to feedback from some of our members that they would like more information about what the RCPsych is doing on behalf of psychiatry, and how the College works.
We hope that RCPsych Insight will keep you informed of what we have been doing to secure the best outcomes for people with mental illness, learning difficulties and developmental disorders.
We also hope that it will helpfully highlight how we promote excellent mental health services, help train outstanding psychiatrists, promote quality and research, set standards and act as the voice of psychiatry.
We want it to be a celebration of what is best in psychiatry, and there are features that provide a fascinating window on the working lives of a diverse range of psychiatrists.
As a charity with 18,000 members across the UK, and throughout the world, it is imperative that we explain to you the work that we do, and strive to provide an excellent membership experience.
We do hope that RCPsych Insight will become an indispensable member benefit, and would love to hear your feedback on the first edition.

If you would like to express your views please send an email to magazine@RCPsych.ac.uk

COLLEGE **NEWS** IN BRIEF

New Chair for Scotland

Dr Alastair Cook steps down as Chair of RCPsych in Scotland after four years in the role. He hands over to Dr John Crichton, former Chair of the Faculty of Forensic Psychiatry in Scotland.
During his term in office, Alastair has overseen the College's expansion, initiated the Healthy Start, Healthy Scotland campaign, and commissioned a working group on personality disorders.
In his role as Chair of the Scottish Mental Health Partnership, he contributed to the new mental health strategy which runs up to 2027 and outlines Scotland's focus on prevention and early intervention.
Dr Cook praised his support staff at the College, "I would like to acknowledge the huge support I have had from Karen Addie and the rest of the office team. Without their back-up, the role of the officers would be impossible. I have enjoyed the role of Chair and hope to continue to contribute to the College and support John and his new team of officers in their work."
His successor Dr John Crichton was instrumental in bringing about the national training programme in Forensic Psychiatry which has proved a successful model for other psychiatric subspecialties.
Dr John Crichton said "It is an exciting time for mental health in Scotland with the opportunity of having a dedicated Minister; a ten-year strategy and the prospect of the College in Scotland having policy-making authority."

Choosing Wisely – Old Age Psychiatry at Congress

The global campaign to end waste in medicine; Choosing Wisely will introduce the College's policy on the psychiatric care of older people at this year's International Congress.
The Old Age Faculty has identified a list of wasteful practices in dementia care and the mental health of older people. This will be presented at the annual summit, before a nationwide launch involving other medical royal colleges in the autumn.
Patient choice supported by strong evidence is the fundamental principle of Choosing Wisely which encourages a patient and doctor dialogue on avoiding wasteful or unnecessary medical tests, treatments and procedures.
Choosing Wisely sees evidence-based information as crucial in empowering patients and clinicians alike. It aims to promote healthy and honest conversations between clinicians and patients.
The next phase of Choosing Wisely for the College is for each of the other Faculties to develop their own lists of recommendations.

Record News Coverage for the College

The College achieved a record number of media hits in the first quarter of this year with a total audience reach of 198 million. Our President, Professor Sir Simon Wessely set the standard with an appearance on Panorama, and in a BBC documentary about George III. He followed this up with an interview on Radio 4's The Life Scientific which reached an audience of nearly 3 million. The communications team stepped up its work to seize on media opportunities and pushed out comment pieces by Sri Kalidindi in The Observer, Pamela Taylor in The Times, Agnes Ayton in The Guardian Healthcare Network, Tony Rao in The Guardian, and, most recently Jed Boardman in The i. These have been well received – Sri's piece on the need for supported housing was retweeted 88 times on our Twitter feed.

Marine A

Much of our high-reaching coverage in March and April took the form of comment pieces and broadcast in response to the trial of Alexander Blackman/Marine A, whose murder conviction was reduced to manslaughter because of his poor mental health at the time of shooting dead an injured Taliban insurgent in Afghanistan. Professor Neil Greenberg, RCPsych's lead for veteran and military mental health, gave evidence at the trial, and was interviewed by Channel 4, ITV, Channel 5 and BBC. We were also able to place a lengthy comment piece in the Daily Mail.

Our advice

Prince Harry's confessional interview about dealing with grief for The Telegraph generated more coverage for the College with another comment piece from Simon Wessely. Sadly, more recently, the appalling terrorist attacks in London and Manchester provided us with the opportunity to demonstrate our expertise around appropriately dealing with post-traumatic stress. Bernadka Dubicka's comment about how to talk to children and young people after the atrocities was picked up by over thirty different news outlets including BBC online.

Closer working with the Faculties

Our President-elect Dr Wendy Burn catches up on our latest media success

The College has been working closely with many of the Faculties to see how closer collaboration can generate more media opportunities. The Old Age Faculty has been working very successfully with the media team and, as a result, this has generated a Guardian pull-out on mental health. Amanda Thompsell featured in an article about loneliness calling for organisations dealing with older people to use psychiatrists along with GPs and carers in their support programme.

Hello and **Goodbye**

By Professor
Sir Simon Wessely

The good news is that we have a new RCPsych magazine. The bad news is that means I have to write a column. The not so bad news is that I only have to write it once. So, keep this, it could become a collector's item.
Leading the College these last three years has been an honour. I know everyone says that, but I mean it. And I think we have achieved more than we could have expected. Highlights included playing a leading role in developing and now delivering the Five Year Forward View for Mental Health; ditto for the Crisp Commission and the strong case it makes for transforming acute mental health care; getting agreement that the expansion in medical student numbers will be linked to increasing the numbers opting for psychiatry, as all right thinking medical students should; and much more.
What will I pass on? I am proud that we have kept the promise to improve our image and reach. It means Dr Wendy Burn will inherit a new and vibrant communications structure, that is ensuring that mental health is getting ever greater prominence, and that we are delivering our vision of a calm and authoritative voice for psychiatry.
I'm sad that it's goodnight from me, because we have much to do when it comes to achieving genuine integration of the physical and mental, and to build on the foundations (pun intended) we have made in recruitment.
But I am reassured that I am handing over to the very capable hands of Wendy. I wish her luck, confident that she won't need it. But more than that, if she has half as good a time as I have had, she will not just successful, but also very happy.

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Want to contribute or offer feedback?
Send your suggestions to
magazine@RCPsych.ac.uk

Making sure the voice of psychiatrists is heard **loud and clear**

People used to call mental health the ‘Cinderella service’, when politicians talked about the NHS it seldom even got a mention. In 2005 mental health was mentioned five times. In the Conservative, Labour and Lib Dem manifestos for this election it was mentioned 75 times. It now appears if you want to get elected you need to declare how important mental health is and how your plans are so much better than your opponents.

At the Royal College of Psychiatrists, we like to think that we have played our part in making this happen. We have been engaging with politicians across the political spectrum about the need for parity of esteem between mental and physical health and the important leadership role psychiatrists play. So, while the election caught us by surprise we were in a good position to help the political parties quickly scramble to finalise what to say about mental health in their manifestos.

We spelt out our political priorities in our own pre-election manifesto called ‘Five Steps to Fairness’ These are:

- Implement the Five Year Forward View for Mental Health in full by 2021.
- Ensure fair access to mental health treatment and support.
- Improve the mental health of children and young people.
- Improve the recruitment and retention of the mental health NHS workforce.
- Set a greater ambition for the nation’s future mental health.

We are pleased to see that you can trace a direct line from many of our recommendations to the promises made by the various parties. So, for example the Conservative promise that all trainee doctors get a chance to experience working in mental health and that medical exams better reflect the importance of mental health, could have been taken directly from our manifesto. We were also particularly pleased with the Labour commitment to ring-fence mental health budgets and the Lib Dem promise to introduce mental health waiting time standards to match those in physical health care.

Forward Thinking **in Scotland**

In Scotland, our policy work has focussed on the Mental Health Strategy 2017-2027. Dr Alastair Cook in his role as Chair of the Scottish Mental Health Partnership largely welcomed the strategy, which included actions around early intervention and prevention as well as social factors such as housing, poverty and education. However, despite the 800-additional staff promised in the strategy, RCPsych Scotland and the Scottish Mental Health Partnership expressed concern about whether this would be enough to achieve the ambitions of the strategy.
RCPsych in Scotland has a full calendar for 2017, with events to suit all interests. The biannual Old Age Faculty Conference in May was well-attended as usual. Our General Adult Faculty conference also attracted many delegates due to the thought-provoking programme which included ADHD and gender identity. Earlier in the year, our Liaison Faculty held their conference in the Medicinema at the new Queen Elizabeth University Hospital in Glasgow, donated to their charity for use of the venue.

Keeping an eye on **criminal justice in Wales**

The criminal justice system is one area the College in Wales has been following with keen interest. The local health board in Wrexham, which will be paying for the new super prison’s mental health services, has been in special measures for two years, so this is something the College in Wales will be keeping a close eye on in the coming months. On a positive note, the Welsh government has agreed to sign the new prison up to the College CCQI accreditation scheme.
Elsewhere, the College in Wales had the opportunity in June to contribute to the ‘Options for implementing the Additional Learning Needs and Education Tribunal (Wales) Bill’. The bill, if passed in the Assembly, would establish a new statutory framework to support children and young people with Additional Learning Needs (ALN) from birth, whilst in school, and whilst they are in further education. Statementing will be replaced by Independent Development Plans for everyone with an ALN. It is a progressive piece of legislation, but the question is whether the intentions can be realised, with services currently struggling to meet demand.
Former RCPsych President Sue Bailey has been providing advice to the Welsh government on an ad hoc basis since the programme’s inception in 2015.
The College in Wales has also been asked to give both written and oral evidence on perinatal mental health services. There are no perinatal mental health inpatient services in Wales. The only mother and baby unit in Wales closed in 2013. Again, the need for reform is evident.

Influencing behind **the scenes in NI**

Despite the political impasse in Northern Ireland, RCPsych has been working tirelessly to engage with commissioners and policy-makers in Belfast, offering expert response to various consultations such as the Commissioner for Older People for NI Consultation, and the GMC Consultation on Securing the Licence to Practise.
RCPsych in NI’ s events schedule continues to engage its members, with just one recent example being the organising and facilitating of an event to celebrate the role of women in medicine across the whole of Ireland. The event, held on 16 May, was a great success, attended by the Dean of the College, Dr Kate Lovett, and an array of prominent local psychiatrists. Chair of RCPsych in NI and College Vice President Dr Gerry Lynch was pleased to welcome new members in NI at the same venue later that day.

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A standard bearer **for psychiatry**

As Professor Sir Simon Wessely's presidential tenure comes to an end, he reflects on what's been achieved – and explains why he'll continue to be up with the lark.

"I'd hate to do a job that wasn't stressful. When I took over as President, I started waking up early in the morning because I was anxious about taking on such a massive challenge. But it makes you feel alive, so it's a good thing."

His presidential tenure may be ending, but it's unlikely Professor Sir Simon Wessely will have the luxury of sleeping late.

Alongside resuming his research career, he was made the world's first Regius Chair of Psychiatry at King's College London in May, and next month [July] will be inaugurated as President of the Royal Society of Medicine, the first psychiatrist to be elected to the role.

That he is a standard bearer for psychiatry is without doubt, but he has conflicting feelings about it. "It's good on one hand, but bad if I mess up!" he laughs. It is this willingness to take a stand and 'speak without fear' that has characterised his three years as RCPsych President, and that has helped him achieve traction on one of his presidential priorities – improving the image of psychiatry.

"How psychiatry is portrayed is something that has always been at the forefront of my mind. Previously, we were in a position where non-psychiatrists were speaking on behalf of the profession, and that wasn't right."

To address this the College has invested significant time and resources into stepping up its communications. This is having the desired impact, with recent analysis suggesting a 300 per cent increase in reach due to a surge in both proactive and reactive media work.

While he says the College's open-plan offices in Prescot Street "often feel a bit like the West Wing – it's one of the things I'll miss," the outcome of this frenetic activity is to ensure the College is the calm, authoritative voice in conversations around mental health, which sometimes means not responding to the story of the day.

"We're not here to catch headlines, and so we don't always do the popular thing, for example we don't comment on celebrity stories," Simon explains.

"We're extremely responsive when we need to be, and this means acknowledging positive stuff as well as the negative. We need to show support when government do things we think are right, as well as telling them when we think they are doing things that are less than helpful."

While Simon benefitted from the work of his predecessors in terms of inheriting a better system of governance in the College, he says incoming President Wendy Burn will inherit a much slicker communications - and policy - operation.

The other side of the coin in increasing the College's visibility has been to extend its influence in Parliament, an area where it has had some impressive successes, including the Crisp Commission ('a useful piece of work'), whose findings were accepted in NHS England's Five Year Forward View.

"It's not being implemented as fast as we would like, but it is happening," says Simon. "What I like about it is that we did the grown-up thing. We could have just gone for headlines about people being shipped up and down the country because of a lack of beds, but instead we took a year to look at it properly. We saw it was a wider health economy issue, and that change needed to happen in other parts of the system. This put us in a strong negotiating position because we were able to set realistic targets."

"How psychiatry is portrayed is something that has always been at the forefront of my mind"

His other presidential priority was addressing recruitment difficulties, something that has taken a great deal of his time and energy – not least because he made good on a manifesto commitment to visit every one of the UK's 34 medical schools.

While he is confident in saying that the College has 'stopped the rot' in recruitment, he admits it hasn't yet turned it around.

"A lot more medical students are interested in mental health but this hasn't translated into them wanting to do it as a career. A lot of this is to do with the negative attitudes of some senior clinicians. That's a big barrier. Our 'Ban the Bash' campaign is aimed at tackling this, but we would like students to own it."

The good news, he says, is that government has committed to expanding medical student places by 1,500, and that the College has secured a further commitment that those places will focus on producing psychiatrists, and GPs. "Wendy will have the challenge of making this happen, but the key thing is that we have a mechanism."

What really concerns him, however, is making sure that junior doctors have good experiences on placements.

"That's a challenge for our members. If we fail, we'll have shot ourselves in the foot. One of my biggest worries is that we won't respond to that challenge. But I think we will. I hope we will."

While he says he has made 'varying degrees of progress' on his presidential priorities and has done 'quite a bit of shaping' over the past three years, he is equally forthcoming about the things that didn't happen during his tenure, including tackling the crisis in addiction, which he admits 'disturbs' him.

His other concerns include Brexit ('A disaster. A shadow that will hang over us for a generation and that will uniformly be bad for health and for science'), and the junior doctors' dispute - something which he cites as an ongoing issue that Wendy will face, along with the potential 'tearing up' of the Mental Health Act.

The role of President, he says, was 'immensely enjoyable', and he credits his successes to the support of College officers and colleagues.

"I was lucky to have had good officers and amazing colleagues to help me and make the role so enjoyable. Wendy will benefit from this too, and I have no doubt she'll continue to make sure the College is a trusted, credible and useful organisation for members, the NHS and government."

Follow Simon on Twitter @WesselyS

The **Wendy Way**

Dr Wendy Burn outlines the priorities of her presidential tenure – including maintaining patient contact.

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It wouldn't be unreasonable to expect the College's new President to want to spend some time getting her feet under the table.

Not Wendy Burn, however. Staying still isn't the 'Wendy way.' She intends to hit the ground running, and is already planning a UK tour to meet the membership and find out first-hand about the issues concerning the profession.

"I want to hear what the membership has to say. If I'm asked, I'll go – I'll visit trusts or divisions, anywhere there's a Premier Inn!," she laughs.

President-elect since January, Wendy has spent the last six months 'getting lots of ideas' and is now in the process of firming up her plan of action. While she says this is very much a work in progress, she has identified three main priorities that she will begin work on as soon as she takes up post.

"There's a lot of work to do. Recruitment and retention, morale and making the case for psychiatry are ongoing issues that are very much at the forefront of my mind. Now it's about getting focused and being clear on what the desired outcomes are."

Wendy is clear that her agenda will be - in part - a continuation of former President Simon Wessely's work, particularly around the implementation of the Five Year Forward View. "I worked very closely with Simon while I was Dean, so the handover will be more like Obama handing over to Michelle than to Trump. In fact, the only thing we disagree over is football – despite his best efforts to convert me, I'm simply not interested!"

"I'm a clinician heart and soul. It's essential that I understand what my colleagues on the frontline are experiencing"

While the handover will be smooth, Wendy has plans to make the role very much her own. A full-time, frontline clinician for the past 30 years, and a passionate educationalist, she has seen many changes in the profession and is determined to maintain her clinician's perspective to inform her policies.

To allow her to accommodate her new responsibilities, she will soon retire from her community post as a consultant Old Age Psychiatrist in Yeadon, North West Leeds, but will go back to work two days a week.

"I'm a clinician heart and soul and I need to continue understanding what my colleagues on the frontline are experiencing. I will definitely miss working full-time - hearing patient stories becomes a part of you."

Wendy's main clinical interest is dementia, something that she has had personal experience of, her father having suffered from the condition. "It's hard to believe but when I started out we didn't tell people they had dementia. Now breaking the news that they have it is probably the most difficult part of my job, but it's about getting across how to live with it. There was no drug treatment when I started but it's available now, and it does make a difference - it gives people hope."

Wendy was made a consultant at age 31, when she took up a post in Old Age Psychiatry in Leeds, becoming the first female consultant at the hospital. As the youngest consultant she was automatically made College Tutor, which kickstarted her long-term interest in postgraduate education.

This was also the beginning of her involvement with the RCPsych, which has seen her perform several education-related roles over the years, including being a College examiner and Continuing Professional Development Regional Co-ordinator, culminating in her election as College Dean, a post she held from 2011 to 2016. Her involvement in education continues as Co-Chair of the Gatsby/Wellcome Neuroscience Project, which is aimed at introducing neuroscience into the core curriculum.

"Education has always appealed to me because I really enjoyed the nurturing aspects, bringing people on," explains Wendy, who, alongside her College roles, also set up the Yorkshire School of Psychiatry, becoming its first Head of School.

Now, she says, the education system she first encountered has changed beyond all recognition, and in her opinion, has become too rigid. "The Modernising Medical Careers scheme, I believe, is at the root of the problems with junior doctors. People on the ground have lost their autonomy because the system has become so inflexible.

"For example, once they are offered a training place, people need to take up the offer at the next intake, but we know that some people would like to be able to apply and then defer their place – this isn't unreasonable and we should be able to accommodate them."

That the mother-of-two managed to combine working full-time as a clinician while being involved with the College and in local education, she credits her employers - the Leeds and York Partnership Trust - and her family for their ongoing support. "I've been extremely fortunate, but understandably many people struggle to balance competing priorities. If we want to attract and keep people in the profession we need to offer them as much flexibility as possible."

One of Wendy's immediate priorities will be implementing a refreshed recruitment strategy with a focus on targeting foundation trainees, addressing the stigma surrounding psychiatry and improving their experience on placement.

"I feel that with recruitment, at the moment we're like Alice and the Red Queen, running on the spot to stand still. If we want to move forward we need to bring foundation trainees into psychiatry. We've had mixed feedback on the quality of placements, so I want to go out and talk to lots of trainees and see how we can improve things.

"There's also still so much stigma surrounding the profession. When I decided to enter psychiatry, I was told by the professor I worked for that I could do something better, but I had a really good trainer who inspired me and I never looked back.

"We need to get across the positives. In my own experience, every week something will happen that's never happened before. It's never boring or repetitive. The feeling of treating someone with depression who, when they first came to see you didn't see the point of life, but then becomes happy and functioning, is so rewarding. You can't beat it."

While psychiatry is currently enjoying a high public profile, this isn't enough, she adds. The conversation on mental health needs to be turned to the profession's advantage and translated into action.

"Mental health services are now getting a lot of attention, but no more money or resources, which means people get burnt out. Things on the ground are getting worse and we're facing an increasing workload and decreasing resources as well as a lot more red tape and bureaucracy. I want to try to address these issues, and ensure that we have the resources and time to allow us to provide the care and treatment that our patients need and deserve."

While she sets about tackling the big issues, Wendy is already experiencing some of the benefits being President can afford, securing a coup for her first President's Lecture in September – former psychiatrist Joanna Cannon, bestselling author of 'The Trouble with Goats and Sheep'. "I asked her via Twitter," says Wendy, proudly. "It was the first time I realised the power of being President!"

Follow Wendy on Twitter @wendyburn

Preparing the psychiatrist of the future

The RCPsych's Gatsby/Wellcome Neuroscience Project aims to ensure trainees will be 'neuroscientifically literate.'

In response to the rapid advances in neuroscience that are bringing a new perspective to mental illness and will improve therapy for patients, psychiatric training is changing.

The Gatsby/Wellcome Neuroscience Project is a two-year RCPsych initiative to introduce a modern neuroscience approach into psychiatrists' clinical work. Led by a 15-strong commission of international experts, it involves a full review of the core curriculum and will run until summer 2018.

Dr Mary-Ellen Lynall, an Academic Clinical Fellow at the University of Cambridge and a CT2, was asked to join the commission to give a trainee's perspective.

"There are great advances in treatment in the pipeline and we need to be prepared," explains Mary-Ellen. "In medicine, it's common for knowledge and skills to just trickle down, but we can't do this with neuroscience – it's moving too fast. In future, it will be essential to be neuroscientifically literate."

"While the question we're trying to answer is how to make neuroscience accessible and relevant to psychiatrists, what we're really aiming for is to improve patient care, and to help increase understanding of mental illness"

The Gatsby/Wellcome Project aims to equip trainees for the advances in basic and clinical neuroscience that will be made during their working lives, to ensure future psychiatrists are better prepared to develop and deliver biomedical approaches to the diagnosis and treatment of adult mental health, neurodevelopmental and neurodegenerative disorders.

Once it has completed the process of gathering evidence from stakeholders, the Commission will agree the content of the revised curriculum and MRCPsych examination syllabus, oversee the approval of the new curriculum by the regulator, and direct the development of teaching materials to support the delivery of the neuroscience content of the new curriculum.

While acknowledging there are some concerns about the impact of neuroscience in psychiatry, Mary-Ellen is clear that neuroscientific advances will be an enhancement of the training offer – not an end to psychiatry training as we know it – and will bring a host of wider benefits not only to the profession, but to patients too.

"Neuroscience won't change the social determinants of disease, or how psychiatry operates, but the point is that it will bring a new perspective and new treatments," she says.

"There are potentially many advantages - for example, if we can communicate the biomedical basis of mental illness to patients and carers, this can help to address the stigma that unfortunately still exists around it. So, while the question we're trying to answer is how to make neuroscience accessible and relevant to psychiatrists, what we're really aiming for is to improve patient care, and to help increase understanding of mental illness."

The Gatsby/Wellcome Neuroscience Conference in March was a timely reminder of the need for psychiatry training to adapt. Leaders in the field demonstrated how, in future, there will be more neuroscientific evidence for changes in brain organisation caused by maternal deprivation, childhood abuse and other classical psychoanalytic traumas. They also discussed how neuroscientific evidence could be integrated with psycho-social explanations, bridging the gap between latest research advances and everyday clinical practice, allowing for a more holistic explanation of mental health problems.

"The conference was inspirational. It showed us the cutting edge of neuroscience and the treatments we will be able to offer, for example Deep Brain Stimulation," explains Mary-Ellen. "There was so much positivity, from psychiatrists and psychotherapists to junior doctors and medical students.

"The brain is the organ we as psychiatrists deal with, so it seems obvious that we should have an in-depth understanding of it, and eventually be at the forefront of developing therapies that bring the biomedical and the psycho-social elements together to improve patient care."

Using Deep Brain Stimulation to tackle anorexia nervosa

CASE STUDY

Rebecca Park is Associate Professor at the University of Oxford's Department of Psychiatry, and Consultant in Eating Disorders Psychiatry for Oxford Health NHS Foundation Trust. Her research group, OxBread, are piloting Deep Brain Stimulation (DBS) as a potential novel treatment for severe, enduring anorexia nervosa.

This is the first UK-registered study of the experimental treatment, in collaboration with Professor Tipu Aziz, a pioneering Oxford neurosurgeon. It includes investigation of the ethical issues involved in treating this severe eating disorder.

"I investigate anorexia because more effective forms of treatment are urgently needed: it has the highest mortality of any psychiatric disorder and leads to chronic morbidity, yet the evidence base for treatment is weak," explains Rebecca.

"It is essential to develop novel, more effective treatments based on an understanding of the key processes maintaining the illness."

DBS is a reversible, adjustable, intervention that involves surgically implanting fine wires to target specific brain areas. Using these implanted wires like a 'brain pacemaker', carefully controlled electrical pulses are delivered to the precisely targeted brain area, stimulating it in a controlled manner.

DBS has been used for over 20 years to help severe Parkinson's disease, and more recently has been used to treat movement disorders in adults and children, chronic pain, and some forms of intractable psychiatric disorder such as severe OCD.

Rebecca says: "DBS is a relatively high-risk intervention in those with severe anorexia as it's an invasive brain operation. It is an ethically defensible option for those patients who are very stuck, motivated to recover but who have been struggling with anorexia for many years. At the same time, we can't exploit those who are really desperate because there are no guarantees it will be effective in relieving their symptoms - this is a feasibility study at this point. There will be those I'll see who are too desperate or too underweight to be considered and there are also those who are not ready to consider living without their anorexia, or might find the procedure too anxiety-provoking or overwhelming."

Based on her prior research, Rebecca's group chose to target specific 'reward centres' in the brain, in the nucleus accumbens. There is emergent evidence that applying DBS to these brain areas can help some patients with intractable severe OCD and addictions, which share some features with anorexia. This study aims to explore the acceptability and feasibility of using DBS to treat anorexia, and will also further map the neural mechanisms underpinning reward. It should report back in January 2019.

Self-reviewing for success

Dr Ruth Barr explains how the North Belfast Community Mental Health Team became the first in Northern Ireland – and one of the first in the UK - to achieve ACOMHS accreditation.

Taking part in Accreditation for Community Mental Health Services (ACOMHS) has helped the North Belfast Community Mental Health Team make significant improvements to their working practices, including addressing carer needs, increasing provision of psychological therapies, and an increased focus on team building.

Based in a socio-economically deprived area, with legacies from the troubles such as exposure to trauma, high unemployment and high suicide rates – one of the highest in the UK – the 15-strong team has around 500 people on their caseload at any one time.

The team, part of the Belfast Health & Social Care Trust, applied to take part in the ACOMHS pilot in October 2015.

"We were interested in service improvement, working in collaboration with service users and carers, and were looking for the right framework to support this," explains Consultant Psychiatrist, Ruth Barr.

"We were looking for something that was specifically geared towards community mental health teams with relevant standards for us to work towards, so ACOMHS was a perfect fit."

Part of the College's Centre for Quality Improvement (CCQI), ACOMHS sets standards for community mental health services. It works with teams to assure and improve the quality of community mental health services for patients and their carers through a comprehensive process of both self and peer review, helping them to identify existing good practice, as well as addressing areas for improvement.

The team underwent a three-month period of self-review, where they issued questionnaires to service users and carers, and performed case note reviews. The data was collated by ACOMHS who then sent the team an initial report outlining where they stood against the standards, and suggested areas of focus. This was followed by a visit from the ACOMHS peer review team.

Areas identified as needing attention included providing carers with more information and guidance; increasing patient access to psychological therapies; increasing admin support; and updating key documents such as care plans.

The process was led by an ACOMHS Project Team, including service users and carers, who set about implementing changes, including an education programme for staff to raise awareness of carer needs, and an information pack for carers and service users to help them better understand the service.

They also ensured there was dedicated one-to-one time for carers to meet with keyworkers at initial assessments.

Other improvements included freeing up staff to provide increased access to psychological therapies, and using the ACOMHS review to provide evidence of need for additional admin support resource.

"Nothing that was identified in the report came as a surprise, but being involved in the whole process of review helped us prioritise where to best focus our energies," says Ruth.

"Simple things like becoming more systematic in our recording made us much more efficient."

The team achieved ACOMHS accreditation in November 2016 – the first in Northern Ireland to do so, and one of the first in the UK.

While she says they were 'delighted' to receive accreditation, Ruth is clear that the most satisfying aspect of the process was the impact on patients and carers.

"There was a lot of positivity with service users saying they had been given a voice, and that they felt empowered by staff. That really captured the recovery ethos we are trying to instil in the service, and helped motivate us to keep improving."

However, the self-improvement process is still very much ongoing, and we recognise there is still a lot more that can be achieved, adds Ruth.

"The key thing for us wasn't achieving the accreditation per se, but being part of an ongoing and collaborative learning process of quality improvement. That's where the value is."

Flying the flag for psychiatry

Charlotte Blewett talks about how stigma and peer pressure put her on a roundabout path to becoming a psychiatrist.

A Dual Higher Trainee in General Adult and Old Age Psychiatry, Charlotte Blewett was on the brink of becoming a physician in respiratory medicine when she decided to take a change of course. She is now putting her personal experience to good use in her role as Psychiatric Trainees' Committee (PTC) Vice Chair, where she works on recruitment campaigns including Supported and Valued, and Ban the Bash.

Charlotte, 33, applied to medical school with the intention of working in mental health and took up a foundation post in psychiatry, but it was during a spell on a medical ward that she started to question her choice.

"I was doing lots of practical procedures, and when on call would be part of the crash team and it was all very exciting. I thought that was what being on the frontline of medicine meant. Also, not many of my peers had done psychiatry, and had the perception it was just sitting in ward rounds with tea and biscuits, not proper medicine. I really felt the pressure to be the same as my peers."

This, coupled with seeing mental health patients being stigmatised 'as soon as they stepped through the door' while working in an A&E department, helped Charlotte make up her mind to do core medical training instead of psychiatric training.

"You can win someone over – or lose their interest – at any point"

However, 18 months in, she began to have doubts.

"Halfway through I realised that what I really enjoyed was time with patients, but I couldn't do that until the evenings when 'proper work' was done, so I began staying later and later to get that patient contact. Eventually I realised I'd made a decision based on what I thought I should be doing rather than what I wanted."

With support from her clinical supervisor, Charlotte applied to do psychiatry training at the Yorkshire School of Psychiatry, and was accepted into training by the Head of School, who happened to be President-elect, Wendy Burn. Since then, she hasn't looked back.

"When I said I was applying to train as a psychiatrist my colleagues said 'Why? Psychiatrists don't actually make people better,' which is quite a shocking thing to hear from your peers. I know this isn't true, and looking back I know 100 per cent I made the right decision."

Reflecting on her experience, Charlotte says there are several things the profession needs to think about. Chief among them, she says, is the need to challenge misconceptions and stigmas and be proud to 'fly the flag' for psychiatry.

"I know from attending careers fairs that even while at school young people have misconceptions about what we do. For example, some think we don't have a medical degree. When I explain that being a psychiatrist is about treating a person holistically, and that we look at the patient as a whole, not as body parts or systems, it's a real eye-opener."

She also says there are several touchpoints where interventions could have a big impact in attracting – and retaining – people into the specialty.

"The transitional periods are really important – for me, it was the huge change from F2 to CT that was the turning point. We also need to be aware that across the five years of their degree, medical students have different expectations and needs, so we can't rely on having a 'one size fits all' strategy. You can win someone over – or lose their interest – at any point."

Charlotte practices what she preaches. As well as her PTC role she organises local 'Engage your Mind' seminars for medical students and foundation trainees in South Yorkshire, which feature speakers from various areas of the profession including forensic and sports psychiatry.

"Events like these give people the chance to network and to hear about what we do straight from the horse's mouth," she explains. "Seeing people who love what they do and who are living by their values has been so inspirational for me, and has pushed me to keep progressing. In my view, there's no better way of selling psychiatry."

Follow Engage Your Mind on Twitter @EymPsychiatry

Supported **and valued?**

A trainee-led review of morale and training has identified areas for improvement – and it's the simple things that could make all the difference.

The Junior Doctor Contract dispute in England exposed deep-seated concerns about the working lives of trainees and highlighted an urgent need to review morale and training in the profession.

The College's Psychiatric Trainees' Committee (PTC) took up the challenge, creating and leading the 'Supported and Valued' project, giving the UK's 3,500 psychiatric trainees the chance to share their views.

"The review was completely trainee-led and, as it involved all four nations, we believe it was the biggest trainee engagement project any medical royal college has carried out to date," explains Alex Till, the Supported and Valued Lead and PTC North West rep.

The year-long project saw 40 PTC reps organising 28 engagement events across the 11 regional divisions of the College, and culminated in April with the publication of a review report.

Each event concentrated on three lines of enquiry, asking trainees for their views on what they valued, and what steps needed to be taken to improve their work life and training in the short and long-term.

The review found that trainees most valued team-working, supervision time and support from their seniors. However, it also found that 23 per cent do not receive regular weekly supervision; 20 per cent do not receive weekly protected educational time; and 24 per cent do not receive protected time for psychotherapy.

There were also concerns about local variability in the Annual Review of Competence Progressions (ARCP) process, and lack of appropriate work and rest facilities available 24/7.

To address the findings the report highlighted four 'core recommendations' - including that all trainees must receive their minimum allocation of supervision and teaching per week - and three 'desired commitments', such as clearer ARCP guidance and access to enhanced junior doctor forums.

"Overall, the message we heard was, yes, some things need to be improved, but we have it good. It's a positive report," says 28-year-old Alex. "Where we've raised issues, some are very simple things that if we get right, will make all the difference. For example, the fact that a quarter of trainees don't have access to a hot drink 24/7 is ridiculous, but something that could be easily remedied."

RCPsych Dean, Kate Lovett, agrees. "A lot of it is about people being good employers and educationalists, for example, things like getting rotas out on time are really important," she says.

The College welcomed the review, she says, and is committed to making the report's recommendations and commitments a reality. She describes the College's response as 'multifaceted', with roles for employers and education providers to play.

"Chief Executives and Medical Directors are absolutely key. A couple of days after the report was published, we heard that in Derby, local trainees presented it at their Board meeting, and that their CEO arranged a shadowing programme as a result," she explains.

"Within each trust, directors of medical education are in a good place to influence regular access to psychotherapy. Likewise, Heads of Schools have a role in monitoring supervision, and in tackling local ARCP variation."

As well as being presented to the April meeting of RCPsych Council, the report has been discussed at Heads of Schools and Education and Training Committee meetings.

Although influential stakeholders are key to taking the report's recommendations forward, Kate and Alex are clear that the biggest impact will come from College members using the report as a lever for change at a local level.

"If trainees take the report to their senior leadership team and show that something is an issue, they're in a position to make change happen. The College is fully supportive of the report so they have weight behind them," says Alex.

"This is a report for every single member of the College," adds Kate. "You don't need to be in a formal role to influence and lead change."

www.rcpsych.ac.uk/traininpsychiatry/trainees/ptc/supportedandvalued.aspx

Get involved and engage with RCPsych for success

The College's first Associate Registrar for Membership Engagement explains his role and plans for improving engagement.

Dr Santosh Mudholkar is a man with a plan.

The College's first ever Associate Registrar (Membership Engagement), he will be assisting RCPsych Registrar, Dr Adrian James, to deliver the College's Strategic Plan 2015-2018, with a remit to improve communication and membership engagement.

"The College's central role is to promote, represent and support its members. We need to make sure we're doing that in a non-elitist and inclusive manner," says Santosh.

A full-time Consultant Forensic Psychiatrist at Leicester Partnership NHS Trust, Santosh took up his Associate Registrar role in July 2016. He has spent his first year meeting frontline psychiatrists up and down the country - from trainees and newly-qualified psychiatrists, to established members, retired and international members.

A strong proponent of a multi-pronged approach, he works closely with the RCPsych Communications Team, and Membership and Professional Standards departments, as well as the Psychiatric Support Service.

"Listening to the concerns of members and their ideas about what they would like from the College has been a very constructive process. The concerns and expectations are different for trainees/newly-qualified psychiatrists, established members and retired members," explains Santosh.

Previously a Psychiatric Trainees' Committee (PTC) rep for London region, Santosh says he understands the pressures psychiatrists are facing, and the importance of establishing a strong link with the College as a source of support for members. This came out clearly, he says, in a pilot membership survey carried out at the end of last year.

"Listening to the concerns of members and their ideas about what they would like from the College has been a very instructive process"

"There's been enormous change over the last 20 years in our understanding of mental health problems and how mental health services have evolved to meet the rising expectation and demand for services. Members can at times struggle to keep pace. It's no secret that trying to continue providing a high-quality service under continuing financial pressures affects mental health workforce morale, recruitment and retention.

"The members interviewed in last year's pilot survey said they felt that no one was standing up for the profession and representing them. They also felt the College was too academic and research-focused, and not in touch with the frontline – it shouldn't just be about the science of psychiatry."

Taking those findings as a starting point, the main priority Santosh has identified for the coming year is to develop a comprehensive membership survey. This will help him improve membership engagement with a robust action plan for the next four years.

"The pilot survey was very useful in identifying key themes, but I want to dig deeper, and launch a full-scale membership survey so that all members have a chance to share their views.

One of the big things identified in the previous survey was a lack of two-way communication. So a membership-wide survey is a step in the right direction in beginning to address this."

Santosh will provide regular updates via RCPsych Insight and the monthly RCPsych e-newsletter. In the meantime, he wants to meet as many members as possible at the International Congress of Psychiatry 2017and RCPsych Divisional Meetings.

He says, "Key to my role is listening and meeting as many members as possible from diverse backgrounds and involving them in College activities. There is excellent work going on around the country. The launch of a College magazine is a unique opportunity to start a two-way dialogue with membership, and share positive stories across the College membership."

associateregistrar.membershipengagement@rcpsych.ac.uk

Bringing research **into practice**

Genetic research is on the brink of helping psychiatrists to target treatment more effectively, says Dr Tony O'Neill in Belfast.

Dr Tony O'Neill has worked in research alongside clinical practice for the whole of his 30-year career, and has experienced a lot of change during that time.

"Technology has advanced amazingly during the time I've been working. We're coming to the point that within the next 10 to 11 years, what we're learning will have an impact on clinical practice," he says.

The 56-year-old is a Senior Lecturer at the Centre for Public Health at Queen's University, focusing on the genetic epidemiology of psychosis, and a Consultant Psychiatrist in the Belfast Health and Social Care Trust, where he is part of a resettlement team that is responsible for the community rehabilitation of patients with long-term illness, including schizophrenia.

Between 0.5-1 per cent of the population will develop schizophrenia during their lifetime, generally in their early 20s. A common and a chronic disorder, it's a significant public health problem from both a physical as well as a mental health perspective, not least due to the fact that people with schizophrenia smoke a lot more than the general population, significantly lowering their life expectancy.

"In a similar way to heart disease or diabetes, mental health problems can have a big public health impact. With schizophrenia it's a double whammy – an increase in physical as well as mental symptoms," explains Tony.

"We know that genetics is a big component of schizophrenia and that there are a lot of genes involved. There are numerous presentations and outcomes, but the more we know, the better care we can offer patients. That's why research is so important."

Environmental factors are also a factor in schizophrenia, with evidence to suggest that people in developing countries have better outcomes than those in western countries.

"Previously we were in 'clash of the paradigms' territory where everything was either genetic or environmental. We couldn't agree on the basics," adds Tony. "There's now an acceptance that there is a genetic component to most disorders, and an environmental component too. Research is helping psychiatry to become a more mature speciality."

The next big thing, he predicts, will be the introduction of 'personalised medicine', where clinicians will be able to use genetic markers in combination with imaging to try to pre-select medication that patients should respond to better, with fewer side-effects.

"For example, there are several types of anti-depressants we can prescribe, but there's currently no way to decide in advance which is best. In five to ten years we'll know much more about that. Instead of treating people as being the same, we'll be able to treat them as individuals. Psychiatry will become more efficient and targeted."

Having successfully looked at whole genome sequencing to find common variants for people at risk of developing schizophrenia, Tony and his research team are now looking for rare variants. They are also examining the inflammatory response and how that may be important in the development of psychosis. "We know that stress can cause changes in the inflammatory system, and so we are looking at models of how complement proteins work in the brain," he explains.

Psychiatrists need to be able to interpret new research and change practice, so another project the team is working on, is how best to translate information such as genetic scores into clinical practice.

"There will be complicated decisions for clinicians to make. The challenge for psychiatrists is to have the skills and tools to deliver the best care for patients, using all the information that will become available over the next few years."

A twin-track career

Dr Stephen Potts discusses his role as a psychiatrist - and as a screenwriter.

Following his interests has led Stephen Potts down two very different paths.

A transplant liaison psychiatrist who helps make difficult decisions on the suitability of potential organ donors and recipients, he has a parallel career as a children's author and as a screenwriter, specialising in adapting historical novels for the big screen.

"While they are separate, the common thread is that I follow my interests. Working in transplant liaison is fascinating, and writing is something I've always had an urge to do," says Stephen.

Of the eight screenplays he has written, six have been optioned and one has been produced - Philip Pullman's 'The Butterfly Tattoo', which won Best Adaptation at the New York Independent Film Festival.

Occasionally, though, the worlds of psychiatry and writing coincide. One of Stephen's latest projects is a feature film based on the book "Anatomy of Malice: A psychologist and psychiatrist compete to understand the minds of Nazi war criminals on trial at Nuremberg" by Professor Joel Dimsdale, and he has also written a pilot of a TV drama called 'Shrink Proof', about psychiatrists working in a US hospital.

In addition to the 'Anatomy of Malice' screenplay, he currently has another two writing projects underway. "If one happens, I'll be happy. If two happen, I'll be delighted. If all three happen, I'll be worried!" he says.

Finding time to pursue both his interests has seen the 60-year-old work part-time in psychiatry over the past 20 years, and he currently spends two days a week at Edinburgh Royal Infirmary, where he has been a consultant in Liaison Psychiatry since 1996. In 2014 he took up a new role in the UK's first Transplant Psychiatry post, working with the kidney, liver and pancreas transplant services.

He spends the bulk of his time in the kidney service, mostly dealing with 'related' donors, but increasingly with 'altruistic' donors, where people donate to someone they don't know. This became legal in the UK in 2006, and after a slow uptake, has seen rapid growth over recent years.

"Altruistic donors are impressive people. Typically they are approaching or just after retirement, are in good health, are often health professionals, and have a history of charitable activity. Becoming an organ donor fits how they have lived their lives up to that point," says Stephen.

"Pursuing the things that have interested me has given me two very different, but equally rewarding, careers"

"However, a proportion are drawn to it because of mental health problems – 10 to 15 per cent of applicants are declined on mental health grounds."

Although new guidelines have been introduced to make mental health assessment of potential donors mandatory, whether someone is mentally and medically fit doesn't always mean it is ethically right to allow someone to donate, he adds.

"This is something we're currently struggling with – there are increasing numbers of altruistic donors coming forward, and some of these are in their late teens. While we wouldn't take a kidney from a teenager, there are people who have donated while in their early 20s. Being young isn't a mental disorder, but psychiatrists are often turned to as people who can answer difficult ethical questions. The fact is, we share the wider clinical team's unease – these issues shouldn't be framed as psychiatric issues."

To help address this, Stephen – who led on the development of UK guidance for psychiatric assessment of altruistic donors - is now working on 'a pragmatic approach' to dealing with young altruistic donors, producing resources to help transplant teams make the difficult call on whether to proceed. He hopes that this will be ready by the end of the year.

"Pursuing the things that have interested me has given me two very different, but equally rewarding, careers," says Stephen. "I feel very fortunate to be able to do both."

From **vision** to **reality**

Dr Trudi Seneviratne explains why maternal mental health services are finally getting the investment they deserve.

The Chair of the College's Perinatal Faculty is in a positive frame of mind.
"The future is looking greener and greener and greener. It's an incredibly exciting time to work in perinatal psychiatry. We've worked hard for years to get the investment we need, and finally it's happening," says Dr Trudi Seneviratne.
Her optimism is well-founded. Funding for the expansion of perinatal psychiatric services is a priority in the Five Year Forward View, and the College has been commissioned by NHS England and Health Education England to deliver a project to train 10 consultant psychiatrists in the speciality.
But Trudi admits that achieving this has taken time, and a concerted effort over the years by leading perinatal psychiatrists, including Professor Channi Kumar, who inspired her to take up the specialty after hearing him speak at a conference she attended as a junior doctor.
"He talked about how the foetus was affected by the mother's mental health, and how intervening at an early stage has a profound effect not only on the developing child, but on the whole family. I knew then it was what I wanted to do."
Trudi went on to work for Professor Kumar at the Institute of Psychiatry as a research registrar, and in 2002 became a Consultant Adult and

"I feel very proud of where we have got to in the UK – we are leading the world in perinatal psychiatry"

Perinatal Psychiatrist at South London and Maudsley NHS Foundation Trust.
Throughout her career, the 48-year-old has had an unrelenting focus on making the case for the importance of investment in perinatal services, building on the work of trailblazers including Margaret Oates and John Cox.
In 1992 the College produced a paper about the importance of perinatal psychiatry, and a generation later the vision of those doctors is becoming real," she says.
"I feel very proud of where we have got to in the UK – we are leading the world in perinatal psychiatry."
The long journey leading to this achievement has been paved by evidence about the widespread nature of maternal mental health issues, and the devastation they can cause. One in five women will experience a mental health problem during or post pregnancy, and psychiatric disorder is a leading cause of maternal death.
Although pregnancy can exacerbate pre-existing mental health disorders – for example there's a 50 per cent chance of relapse of bipolar disorder after childbirth – women with no previous psychiatric history can also be severely affected, as shown by recent high-profile and tragic cases such as Alice Gibson-Watt.
Despite the strength of the evidence, it was a report detailing the financial cost that was the turning point, says Trudi.
"The voice of the suffering woman wasn't enough. A Maternal Mental Health Alliance Report carried out by London School of Economics in 2014 showed that the cost of leaving maternal mental illness untreated was £8.1bn. After that, things began to change."
NHS England has now invested £365m in specialist perinatal services as part of the Five Year Forward View. This includes the creation of four new Mother and Baby Units and a rollout of community perinatal services, with 20 areas expanding or developing services.
Addressing the shortage of perinatal psychiatrists is key to the success of the scheme, and so NHS England, in partnership with Health Education England, commissioned the College to deliver the Building Capacity, Psychiatry Leadership in Perinatal Mental Health Services project.
The project has created bursaries to backfill 10 consultant level psychiatrist posts to allow them to train as perinatal psychiatrists, and then establish and lead local Perinatal Mental Health services.
This has seen the College develop the first specialist training programme for perinatal psychiatrists, under the guidance of Dr Liz McDonald, former Perinatal Faculty Chair.
Despite the progress underway, Trudi says there's more to do. But things are looking up, RCPsych in Scotland pushed to improve services which led to a new clinical network for perinatal and infant mental health.

An individual approach

Dr Adarsh Shetty talks about his life as a rehabilitation psychiatrist in Wales – and explains why he gets paid to play football.

The welcome Dr Adarsh Shetty received when he went for interview as a Consultant Rehabilitation Psychiatrist in Merthyr Tydfil seven years ago set the scene for his life in Wales.
"When I arrived, the door was opened by an older nurse who gave me a big hug. Everyone was so warm and welcoming and it had such a community feel, that I knew it was the right place for me," he says. "Beautiful lakes and beaches, vibrant city life, sports and walking trails – Wales is really a fantastic place to work!"
Until recently Clinical Director for Adult Mental Health, Adarsh's role in Cwm Taf University Health Board's Outreach and Recovery Team sees him working at the heart of small, close-knit valley communities, treating, with other rehabilitation consultants, around 150 patients across community and inpatient rehabilitation. "Many of our staff live in the communities they serve and that makes a difference – we are able to build long-term relationships with our patients," he explains.

"Some of our patients don't want medication or to come to the clinic, and that's fine – we find another way"

Chair of RCPsych Wales's Faculty of Rehabilitation and Social Psychiatry, Adarsh is passionate about the role Rehabilitation Psychiatry can play in supporting individuals and communities.
"Rehabilitation Psychiatry is a vibrant specialty – it's forward-looking and builds on hope. It attracts people who want to work with challenging conditions and innovate in the treatment they offer."
Innovation is central to Adarsh's approach, and his team works hard to try to provide treatment specially tailored to individuals.
"Some of our patients don't want medication or to come to the clinic, and that's fine – we find another way. We look at the narrative of the person and try to engage them in a way that's meaningful to them," he says.
In some cases, this even means playing football. "I tell my trainees that aside from being a professional player, it's the only job in the world where you get paid to play soccer!" says the 42-year-old. "It's about engaging patients and not having the power imbalance of the traditional doctor-patient relationship. Simple things like making a patient a cup of tea - treating them like a human being – goes a long way and can remove barriers."
Often practical solutions are the ones that break the cycle of recurrent hospital admissions and can help a patient on the road to recovery, he adds.
"We had a patient who was having ongoing problems with his electric meter, which he found very stressful. To cope he took amphetamines, which made him psychotic, and as a result he had been admitted to hospital multiple times. Those services didn't deal with the meter, as it didn't seem important, but we took that seriously and had it repaired - it was outwardly simple, but it had a big effect on that patient's health."
But there is more to do, says Adarsh, to be able to offer truly individual packages of care. One of these is bringing back patients, who have previously been sent out of area for treatment, by investing in rehabilitation services. Another that remains high on his wish list is better supported housing. "This is often the key to helping someone stay well. The right social interventions at the right time can prevent hospital admission," he explains.
"We need to try to take people on a journey of recovery – this doesn't mean an absence of symptoms, but how a person achieves quality of life living with their challenges. By looking at their specific circumstances, and what is important to them, we can achieve this."

Reducing the risk of SUDEP

Dr Rohit Shankar explains the thinking behind the world's first epilepsy self-monitor app

We need to focus on the individual, not the condition. Our job is to give evidence-based information and help people take control of their health and wellbeing.

It is this philosophy that led Rohit Shankar to develop an award-winning app that is helping to reduce the risk of seizures to prevent Sudden Unexpected Death in Epilepsy (SUDEP).

A Consultant Developmental Neuropsychiatrist and Clinical Director, Adult Intellectual Disability Neuropsychiatry Services for Cornwall Partnership NHS Foundation Trust, Rohit was the medical lead in the team that created EpSMon – the world's first epilepsy self-monitor app.

Advertised as 'epilepsy awareness in your pocket', the evidence-based app was developed by a team from Plymouth University, Cornwall Partnership NHS Foundation Trust and Cornwall Royal Hospital, and the charity SUDEP Action.

It saw off 83 entries from 25 countries to win the Epilepsy Foundation America SUDEP Challenge Award, along with five national awards including the BMJ Neurology and HSJ Patient Safety Awards in 2016.

Of the 600,000 people with epilepsy around 600 die of SUDEP every year in the UK, accounting for up to half of all epilepsy deaths. Its causes remain under investigation but there is a growing body of evidence on risk factors including type and patterns of seizures, and lifestyle and wellbeing issues such as compliance, alcohol and substance abuse, and depression.

The app is aimed at over 18s with epilepsy and has over 3,000 users.

It encourages people to check their condition and overall wellbeing every three months by answering a series of questions which flag up any changes or increasing risks they need to be aware of, encouraging them to seek advice from their doctor.

EpSMon was launched in 2015, and is a digital version of the SUDEP and Seizure Safety Checklist for clinicians, which Rohit and colleagues developed in response to a NICE recommendation that every person newly-diagnosed with epilepsy should be made aware of SUDEP.

"We discovered that only four per cent of those diagnosed with epilepsy had ever discussed SUDEP. Epileptologists told us that as less than one in a thousand would die from it, they didn't want to scare the other 999. So, the challenge was how to go about this in a way that empowered patients," he explains.

They began by building an evidence-base, undertaking a comprehensive literature review where they found 22 separate risk factors associated with SUDEP. The next challenge was considering how best to bring the information together, in a way that would be practical in a clinical setting.

The solution was the SUDEP checklist. Containing 19 risk factors to score against, it takes just 10 minutes to complete and is designed to be used as part of a review of an epilepsy care plan.

Of the 300 patients in Cornwall who the checklist was trialled on, 98 per cent responded positively. "It put to bed the debate about whether the discussion with patients should be held," says Rohit.

With the permission of the local Coroner, the team then applied the checklist to 2004-2012 epilepsy deaths in Cornwall. They found that in SUDEP deaths where seizures had increased before death, 80 per cent hadn't seen a specialist in a year prior to their death, and 60 per cent hadn't visited their GP.

"It brought home that we needed something that explained the risks, and supported patients to manage their condition."

The app was developed to do just that, and along with the checklist, is having a significant impact. From 2004-2011 there were 48 SUDEP deaths, but from 2012-2016 – when the checklist and app were launched - this number fell to just seven.

The team is now looking to develop a children's version of the app, and are continuing to validate the risk factors.

"The Holy Grail would be to score them," says Rohit. "So, for example, to be able to say that the risk of drinking alcohol would multiply SUDEP risk by five for a person with epilepsy."

For the last seven years, the 42-year-old has held a monthly mental health phone in on BBC Radio Cornwall, and he is adamant that public awareness has been a key element contributing to reducing local SUDEP deaths.

"We need to funnel our knowledge to the people it affects – they need to know if they are at risk, and what they can do to protect themselves. If the app has saved just one life, I'll be happy."

www.sudep.org/epilepsy-self-monitor