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Foreword

‘I’m delighted to present the annual report of the Royal College of Physicians’ (RCP’s) Patient and Carer Network (PCN) for 2018/19. It documents the huge amount of high-quality work undertaken by our PCN members, in partnership with members of the RCP and with others, all of it directed ultimately to improving the care of patients and the experience of healthcare staff.

Most of this impressive body of work was undertaken before I came into post as chair of the network. It is an honour to have the opportunity to contribute as we look towards next year. Warm thanks and many congratulations to everyone who has taken part in the work showcased here, with special thanks to members of the liaison group, and to our patient involvement officer and patient involvement adviser, without whom this work would not have happened.’

Sally Brearley
Chair of the Patient and Carer Network
As a geriatrician I would like to think that I have always tried to practise person-centred care. I frequently ask my patients “What matters to you?” “What is important?”

However, prior to taking on this role I was less familiar with patient involvement at the team and system level. Seeing the range of work the PCN is involved in, whether at workshops, in the Future Hospital Programme, in RCP publications, in the current quality improvement work on outpatients, in feedback from committees and countless other examples, has taught me how important this involvement and partnership is. Patients and carers have a unique perspective which the health professional never gets to see in the same way. In particular they get to experience the whole “journey” when we just witness one part of it.

I continually strive to take this learning back to the acute and community trusts that I work for. They have some excellent areas of co-production, but other areas where patient involvement is minimal. When it is minimal it is usually because no one has thought about involving patients or carers rather than lack of enthusiasm. There is also some lack of knowledge on how to involve patients. I suspect the county I work in is no different to many others in the country: we need to spread the word.

I look forward to continue working with the PCN over the next year, and hope that we will get closer to the ultimate aim of patient and carer involvement becoming standard practice across the NHS.’

Dr Helen Gentles,
Patient involvement officer

‘As patient involvement officer my main roles are to support the PCN and act as a link with the RCP. This is my second year in post and it continues to be a huge privilege to work with the PCN and see the immense range of activities that PCN members have contributed to.
'The PCN are a vital part of the RCP family and this report shows what an important contribution they make in all aspects of our work. Thank you to everyone in the PCN for their time, energy and enthusiasm – we are indebted to you.

The next few years will be a period of further evolution for the RCP and the PCN will remain an integral part of that as we create our new strategy, develop our work in Liverpool and look to shape the future of health and healthcare. The future is bright and patient-centred.'

Professor Andrew Goddard, president,  
Royal College of Physicians
1 Patient and Carer Network strategic aims

‘What binds us are our experiences of being, or caring for, patients in the NHS and beyond. Our experiences of working life are as varied as our experiences of healthcare, which makes us a rich resource for supporting the development of Royal College of Physicians (RCP) strategy and co-delivering programmes.’
– PCN liaison group

This report documents a range of activities undertaken by the Patient and Carer Network (PCN) from April 2018 to June 2019 that have supported their strategic aims as set out in their work plan.

The PCN aims to:

1. support the RCP to listen to what patients need from their doctors and the health service, with a particular focus on promoting and supporting person-centred care

2. continue to support the 11 principles of patient care that underpin the Future Hospital Commission’s report, contributing to ensuring that health and care services are delivered in an integrated way and informing the development of RCP quality improvement work

3. promote patient safety and high-quality care by influencing the way healthcare is delivered and designed

4. support the development of a sustainable NHS and ensure that patients and carers have access to the information they need.

In order to support the PCN’s strategic aims and ensure that patient and carer involvement at the RCP remains meaningful, targeted and continues to have a positive impact on patient care, the Patient Involvement Unit (PIU) and PCN have been working on embedding the values and principles below with colleagues and teams across the RCP.
Patient and carer involvement should be:

**Meaningful:** Patients and carers having real impact to improve health and health care for all.

**Collaborative:** Building understanding that working with patients and carers leads to better outcomes.

**Accessible:** Communicating information clearly, openly and in accessible formats for all.

**Responsive:** Patients, carers and colleagues sharing success and good practice across the RCP and beyond.

**RCP values**

As part of the PCN’s workshop in May 2018 we completed a session on ‘values’. This was to ensure that the PCN were part of the process to determine what the RCP’s core values would be in 2019 and beyond; this formed part of an RCP-wide values project.

Members of the PCN were asked the following questions:

> What are you most proud of in being part of the RCP / PCN?
> What makes you remain loyal to the RCP/PCN, even in tough times?

In 2019 the RCP values were officially launched: [www.rcplondon.ac.uk/about-rcp/vision-and-mission](http://www.rcplondon.ac.uk/about-rcp/vision-and-mission)

We are committed to taking care, learning and being collaborative. These values drive the way we behave, how we interact with each other, and how we work together to achieve our vision and improve patient care.

The PCN will continue to work with the RCP and share the responsibility of embedding these values in its work. The RCP values come within the membership principles of the PCN’s terms of reference.

**Key words and themes that emerged from the exercise:**

- making a difference
- genuine
- respect
- impact
- commitment
- change
- open
- voice for patients
- support
- profession
- feeling valued
- challenge
- caring people
- feeling valued
- commitment
- change
- open
- voice for patients
- support
- profession
- making a difference
2 PCN membership and structure

‘Among us we have educators, quality improvement experts, engineers, designers, policymakers and business people from all over the UK. Some of us have specific condition-related experiences; others bring a breadth of knowledge of the health and care sector. We strive to be a diverse membership that encourages involvement and participation from a broad range of individuals and communities.’

– PCN liaison group

In 2018/19 the PCN continued as an 80+ strong group of volunteer patients, carers and members of the public from across England and Wales.

The structure of the PCN remained the same (made up of community and forum members). This was supported by the RCP’s PIU, and steered in its work by the liaison group including the chair (Sally Brearley) and three PCN members (Alice Joy, Richard Triffitt and Lynne Quinney), with the RCP patient involvement officer (Dr Helen Gentles) and RCP patient involvement adviser (Laura Burling) in support, all of whom have helped plan, steer and review the work of the PCN throughout the period this report covers.

Representatives from the wider PCN network have been involved in different committees, projects, workshops and involvement opportunities across the RCP. The PIU has continued to communicate regularly with members via quarterly workshops, email and social media.
New members
In 2018 and early 2019, the PIU welcomed 19 members to the PCN community and recruited a new chair, taking the total to 20 new members. The PCN continued with its rolling recruitment policy throughout 2018/19, which allowed the PCN to grow at a manageable rate during a period of change while continuing to contribute meaningfully to the work of the RCP.

PCN volunteer hours
Similar to 2017, members of the PCN contributed around 2,000 hours of voluntary time to the RCP in 2018/19. This figure is partly calculated using estimates for volunteer contributions, particularly where more detailed data were not available. They also include estimates for the time contributed while travelling to and from RCP activities, in order to fairly acknowledge the time contributions that volunteers have made.

PCN structure
In 2019 the PCN liaison group in consultation with network members developed a new terms of reference. It is hoped this will give clarity to the PCN structure, address diversity (through tenure and targeted recruitment), support the PCN strategic aims and help deliver the work plan.

The PCN liaison group and PIU have worked hard on developing the new terms of reference alongside other essential documents that will help the PCN to work fairly, consistently and effectively over the next 12 months. Links to these documents and more are on the PCN pages on the RCP website: www.rcplondon.ac.uk/about-us/get-involved/patient-and-carer-network-pcn

The PCN structure will remain as follows throughout 2019 to May 2020 when the PCN terms of reference will be reviewed, and includes:

- a liaison group made up of the chair and three PCN members, with the RCP patient involvement officer and RCP patient involvement adviser in support, who will plan, steer and review the work of the PCN
- a forum of approximately 30 members who will provide in-depth support for the RCP by committing to attend workshops, and participate in projects, focus groups and committees as well as represent the RCP more widely
- a community of approximately 50 members (to be reviewed annually) who feed in views and experiences to the RCP’s work by reviewing and commenting on documents, attending committees and ad hoc focus groups, and responding to surveys/consultations.
The PCN has continued to be a key partner in supporting and influencing the work of RCP specialty committees, boards and working groups. Sally Brearley, chair of the PCN, sits on the RCP Council as the PCN representative. This remains an important part of PCN work to support RCP-wide projects as well as pick up on key external partnership working opportunities.

In 2018/2019 the PIU recruited a number of PCN members to committee and board positions. Below are a few of these:

- National Guideline Centre Programme Board
- Ethics Committee
- Physician Associate Schools Council
- Joint Specialty Committee for Palliative Medicine
- Chief Registrar Steering Group
- *Future Healthcare Journal* Editorial Board
- Joint Specialty Committee for Nuclear Medicine.
Committee guidance and recommendations work

In 2018 the PIU and PCN began a piece of work to evaluate patient involvement on RCP committees. The evaluation resulted in the PIU and PCN being able to produce some clear guidance and recommendations that encourage the ongoing development of patient involvement at the RCP, while also supporting lay representatives who volunteer their time on committees and projects.

The recommendations support committees in considering the best approach to involving patients, carers and lay representatives, and some best practice guidance to follow once they are involved. The areas covered in the recommendations include:

> general principles
> planning
> recruitment
> supporting and valuing
> monitoring and evaluating.

Alice Joy, PCN liaison group member, talked through the following headline findings from the evaluation at the PCN workshop in May 2019:

> difficult to measure lay and patient involvement as all committees are different
> PCN members felt valued and added value to committees (taken time to get there)
> PCN members felt they needed training and a better understanding of what was expected of them
> overall, lay involvement is of real value but may need to ensure committees think about patient involvement more broadly (engage in focus groups/ invite committees to talk at workshops).

These documents are available to view on the PCN webpage of the RCP website: [www.rcplondon.ac.uk/about-us/get-involved/patient-and-carer-network-pcn](http://www.rcplondon.ac.uk/about-us/get-involved/patient-and-carer-network-pcn)

In 2019/20 the PIU and PCN liaison group members will work with PCN members to find mechanisms that support two-way communication and feedback on committee and project work. An aim is to ensure there is a shared understanding of PCN involvement across the RCP, and that there are opportunities for peer support within the PCN.
Overview of the PCN’s activity and impact

This section illustrates the contributions that PCN volunteers have made to each of the four strategic aims. It is not an exhaustive list of activities undertaken by the PCN to meet each objective, but is designed to illustrate the range of activities that PCN members were involved in throughout 2018/19. Where possible, information has also been included on tangible outcomes from those activities, demonstrating the impact of PCN involvement on the RCP’s work.

Strategic aim: Support the RCP to listen to what patients need from their doctors and the health service, with a particular focus on promoting and supporting person-centred care.

Top tips: Person-centred care

Person-centred care means understanding what is important for the individual as a person, not just a patient with a condition. This understanding facilitates discussions and shared decisions about personalised care planning and management.

In autumn 2017, the RCP facilitated a conversation between doctors and PCN members about person-centred care in the acute setting. As a result of this work in 2018, the RCP and PCN produced a ‘top tips’ document (Top tips: person-centred care) and a short video on good practice in person-centred care.

www.rcplondon.ac.uk/projects/outputs/top-tips-person-centred-care

National Voices (a national coalition helping to strengthen the voices of patients and citizens) promoted the document in their November 2018 newsletter, which reached a wide audience of patients, carers and the public, as well as stakeholders in healthcare.

The PCN will continue to raise the profile of this co-produced document and support its dissemination through their ongoing work and commitment to person-centred care.
Advancing medical professionalism

Doctor as patient partner – ‘The level of deference given by patients to their doctors is changing and the need for a more balanced relationship growing.’ – PCN representative

Documented in the PCN’s 2017 impact report was the involvement of PCN members in helping to shape and deliver the RCP project on medical professionalism, via roundtables and workshops across the country.

In December 2018 the RCP released the report: Advancing medical professionalism

www.rcplondon.ac.uk/projects/outputs/advancing-medical-professionalism

As a result of further PCN involvement in a roundtable (held in December 2018) to support the launch of the report, the January 2019 PCN workshop explored ‘next steps’ the RCP should take to promote the report and its content, and how the PCN can be involved in moving it forward.

Ongoing training for physicians in this area came through strongly in PCN feedback. As a result we will be exploring how the PCN can be involved in supporting and delivering training through the RCP’s professional development opportunities: this will form part of the PCN’s 2019/20 work plan.

Patient involvement officer Dr Helen Gentles shares her thoughts on these projects, and the importance of this work continuing and involving patients and carers from the beginning…

‘Two highlights for me over the last year have been seeing Advancing medical professionalism and Top tips: person-centred care being completed, both of which involved PCN members right from the beginning. Both these projects produced detailed and thoughtful publications which have been well-received and I am sure will make a difference to patient care. Importantly, neither of these projects finished with the publication. Further work is ongoing to ensure that each has meaningful impact. These projects clearly demonstrated to me the power of patient and physician partnership when working together. It is also imperative that patients and carers are involved at the beginning of a project, not once it has started.’

RCP annual conference 2018 and 2019

The PCN contributed to the RCP annual conferences in 2018 and 2019.

‘Innovation in Medicine 2018’ saw the PCN participating in a number of sessions, helping to raise the profile of the PCN and public and patient involvement more generally to the RCP’s membership. Highlights included: the opening plenary session delivered by a PCN member on the importance of listening to the needs of patients; PCN involvement in a panel session on how physicians can remain relevant amid technological change; and the need to improve sustainability and participation in a session on professionalism. The conference itself was co-chaired by Elisabeth Davies (former PCN chair).

At ‘Medicine 2019’ the PCN used the RCP hub at the annual conference to chat to delegates and promote the work of the PCN.

PCN members have delivered powerful messages at the RCP annual conference:

‘Engagement of patients and carers should happen at two levels: the micro and macro levels of healthcare provision. The one-to-one interactions between clinician and patient or carer, and also, importantly, at system or organisational level.’ Lynne Quinney (PCN member) – Improving health through patient engagement.

‘We need your help to feel secure, safe and confident – not just in you the physician but in the team around you and indeed the whole system that will be caring for us. At this difficult time we require empathy, compassion, integrity and respect from you. Involve us in the decision making and really listen to our concerns.’ Iona Price (PCN member) – Professionalism and the patient.
Physician associates

PCN members continue to support the development of the physician associate (PA) role through membership on the board of the RCP’s Faculty of Physician Associates (FPA) (www.fparcp.co.uk) and more recently by exploring links with the Physician Associate Schools Council, the body representing physician associate schools across the UK.

‘I have found the board very welcoming, the topics interesting, and participation greatly helped by discussing ideas with another colleague on the board and others in the working group. It has been great to work with such supportive colleagues. PCN members continue to publicise the role of PAs in the many other projects they are involved in and have found the PA Board very welcoming and receptive’ – Cuthbert Regan, PCN member

In 2018 the government announced it would push forward with legislation to regulate PAs, news which was welcomed by many. PCN members alongside colleagues from the FPA were an integral part of the process in supporting the need to regulate the role of the PA. PCN members will continue to work with colleagues and stakeholders to support and influence discussions as the legislation progresses.

‘Regulation provides the opportunity to embed PAs into the NHS workforce across primary and secondary care. As one of the only growing healthcare professions, PAs have the opportunity to help shape healthcare moving forward to ensure that the NHS meets the needs of patients and delivers high-quality patient care.’

– Jeannie Watkins, former president of the FPA

PCN work with the FPA will continue alongside their new president Kate Straughton and officers who take up their positions in August 2019. Interesting PCN involvement opportunities to come include the PA conference in October 2019, and involvement in PA leadership training where the PCN will be delivering a short workshop session on public and patient involvement.

Strategic aim: Continue to support the 11 principles of patient care that underpin the Future Hospital Commission’s report, contributing to ensuring health and care services are delivered in an integrated way and informing the development of RCP quality improvement work.

Quality improvement and patient safety

The PCN’s move to the RCP’s Care Quality Improvement Department in March 2019 will continue to support meaningful patient involvement and partnership working across the RCP.

The PCN and patient involvement have been central in the development of the RCP’s quality improvement and patient safety (QIPS) offering. The PCN has worked closely with RCP colleagues to establish links with QIPS projects and will continue to strengthen these in our 2019/20 work plan: www.rcplondon.ac.uk/projects/rcp-quality-improvement-rcpqi www.rcplondon.ac.uk/projects/patient-safety

The PCN is represented on the National Early Warning Score 2 (NEWS2) Independent Advisory Group; a group working to promote the effective and consistent implementation of this vital tool for identifying patients at risk of clinical deterioration, including sepsis.

The work of the group is reported to the RCP Patient Safety Committee, which in turn reports to the Care Quality Improvement Department and RCP Council.

Early in 2019 PCN members were instrumental in informing the design of a public information poster on NEWS2 that will be displayed in hospitals throughout the country. Views on layout of information, its clarity and ease of understanding were collated and used by the design team to create the poster.

www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news-2
Chief registrar scheme

Since the chief registrar (CR) scheme pilot was launched in 2016 the PCN has been a key partner in shaping and influencing the programme through involvement on the steering group. In 2019 we were asked to take part in one of the CR workshops to chat with attendees about public and patient involvement and how it could support their quality improvement (QI) projects. We produced a top tips document to support this session.

Feedback from PCN members (Alice Joy, Graham Foulkes, Lynne Quinney and Julia Ellis) who attended the workshop was as follows:

‘Participants were really keen, as you would expect for a group of people who had signed up to QI leadership in the first place.’

‘The groups were interested in hearing our views on how they could, practically, improve their interaction with patients, both at a personal and at a strategic level.’

‘There was clear agreement among us all that we – doctors, patients and carers – should be working as a cohesive team.’

‘I enjoyed meeting the trainees; their enthusiasm for the projects was clear and they are keen to engage with patients in as much of their work as they can, but are finding it difficult to know where they should start or indeed how to start.’

‘I’m confident that this generation of doctors will be the start of a long journey that will make patient participation integral to all that they do. We need to “be there” to maintain the momentum.’

The PCN will continue to work with RCP colleagues as the new cohort of CRs start the programme in September 2019. The PCN will be exploring ways in which they can continue to support the CR scheme and address issues that were raised by participants during the April workshop by contributing to a development day in July 2019.

Audit and accreditation programmes

The PCN contributed to a range of RCP programmes focused on influencing the design and delivery of healthcare in 2018/19. Members from the PCN and general public were recruited to the Falls and Fragility Fracture Audit Programme (FFFAP) patient panel in August 2018 with the support of the RCP FFFAP team, PIU and Royal Osteoporosis Society. The first meeting of the patient panel went ahead in October 2018.

Patient panel members have felt empowered to share their stories and experiences at workshops and events, and have worked in partnership to produce some patient and carer friendly information guides, such as My hip fracture care: 12 questions to ask. www.rcplondon.ac.uk/projects/outputs/my-hip-fracture-care-12-questions-ask
Iona Price joined the PCN and began working with FFFAP in 2014 – ‘5 years later I am still working with the FFFAP team and at the end of 2018 we appointed a 10-strong patient panel which I helped set up and currently chair. The panel members all have experience of fragility fractures either personally or through family members, and are passionate about making improvements to services for other patients and their loved ones. The panel are a dynamic group, with some great ideas, and they are already making a significant contribution to FFFAP’s work.’

The PIU and PCN will continue to work closely with colleagues to promote and support FFFAP work as it develops in 2019/20.

In 2018/19 the PCN have had continued involvement in RCP accreditation work including Quality in Primary Immunodeficiency Services (QPIDS) and Improving Quality in Allergy Services (IQAS). The lay assessor role in this scheme is to ensure that the patient voice is heard and that their feedback informs the assessment of service standards.

www.qpids.org.uk/
www.iqas.org.uk/

‘It has been a great pleasure to be involved in the RCP’s accreditation work across the country this year – it is an honour and privilege to hear the real experiences of patients and carers, and ensure that their authentic voice and journey are assimilated into the full accreditation process. This is a true team focus that demonstrates the benefits for all when collaboration between clinical and lay is embraced.’ – Sharon Ann North, PCN member

Strategic aim: Support the development of a sustainable NHS and ensure that patients and carers have access to the information they need.

Safe medical staffing

In July 2018 the PCN were involved in supporting the working party on safe medical staffing which produced the following report Guidance on safe medical staffing www.rcplondon.ac.uk/projects/outputs/safe-medical-staffing.

This report represents the start of an ongoing process to help hospitals ensure that they have sufficient medical staff to meet the needs of their patients and deliver safe patient care. The RCP will work with the NHS to refine the method in different hospitals.

PCN member Jean Gaffin documents her thoughts on being involved in this piece of work: ‘This was a particularly challenging piece of work as safe staffing is not an area with much research, so much of the work was undertaken by individual members of the working party based on clinical judgement and experience. It also drew on the work of NICE’s safer staffing work which related to nurses, and where I had also been involved. The report was published when the acute shortage of doctors in the NHS was already apparent and when workforce is currently seen as the major NHS problem, making implementation of these guidelines in full particularly difficult. The report was followed by a roundtable discussion I attended where a wide range of other royal colleges were represented, as were other bodies including the GMC and the BMA, where the report was well received.’

The report forms part of the ongoing commitment the RCP has to working with colleagues across the UK to represent the needs of the NHS workforce to a range of stakeholders including ministers, politicians and NHS bodies. The announcement of the NHS Long Term Plan in January 2019 and its continued development will further inform the conversations around workforce planning to ensure safe medical care for all. The PCN will continue to work with RCP colleagues in 2019/20 on this important area of work.
Healthcare sustainability

In 2018 PCN members contributed to, delivered presentations and took part in roundtables and focus groups to support the RCP’s work on healthcare sustainability. The PCN worked closely with Dr Jenny Isherwood and Dr Toby Hillman on the research and final content of the ‘Outpatients: the future’ report.

‘The time has come to re-evaluate the purpose of outpatient care and align those objectives with modern-day living and expectations. The benefits must be measured in terms of long-term value for patients, the population and the environment, not just short-term financial savings.’

www.rcplondon.ac.uk/projects/outputs/outpatients-future-adding-value-through-sustainability

‘PCN members said patients wanted to be empowered to take more responsibility for their own health and care.’

National Hip Fracture Database

In 2018 PCN members, through their involvement in FFFAP, contributed to the award-nominated ‘Strong bones after 50’ project which was commended for ‘Communicating to patients in a more accessible and dynamic way. Working with patients to discover the best way to provide information’.

The patient group involved in this piece of work supported the production of an animation which was produced to be accessible to people who find it hard to use standard printed material.

www.rcplondon.ac.uk/guidelines-policy/strong-bones-after-50-fracture-liaison-services-explained

‘The 3-minute animation describes what a fragility fracture is, what assessments and interventions a patient can expect to receive and where to get further information.’ HQIP Case Study: PPI in national clinical audit – Submission to the Richard Driscoll Memorial Award 2018

This animation alongside the work of the FFFAP patient panel will continue to support the patient and carer journey, particularly those affected by hip fracture, by co-producing accessible information.
Digital Health, Professional Records Standards Body (PRSB) and health informatics

The PCN had significant involvement throughout 2018/19 in digital health work and related projects through the RCP’s Health Informatics Unit (HIU), and more recently directly with the Professional Records Standards Body (PRSB) and NHS Digital. Examples include:

> Alcohol and tobacco use standard workshop
> PRSB – emergency supply of medication survey
> Recording employment status in a structured format in health and care records – interviews and workshop
> Pharmacy information flows project
> PRSB and NHS England – accessing your health and care information

After 16 years of work at the forefront of clinical informatics, the HIU closed for business on 29 March 2019. The PCN will miss working in partnership with HIU colleagues but are pleased to know that several HIU members have joined the recently-formed independent Faculty of Clinical Informatics. The RCP’s own relationship with this faculty will be led by a new clinical director of digital health, and the PCN looks forward to working together with the director and developing the way patients and carers can be involved.

In February 2019 the government announced plans for NHSX, a department which will bring together the Department of Health and Social Care, NHS England and NHS Improvement to ‘bring the benefits of modern technology to every patient and clinician’. It will also have ‘oversight’ of NHS Digital.

Over the past 9 months the PCN has been active contributing to digital health designs for the NHS.

Three PCN members commented extensively on the GP IT Futures programme’s designs for services to patients – (https://digital.nhs.uk/services/future-gp-it-systems-and-services)

One member joined the board for the project which consulted and approved messages for medicine dosages and timings between NHS care providers and settings.

The PRSB creates and maintains such standards for healthcare (https://theprsb.org/projects/digitalmedicationinformation/)

Through all this work the PCN has gained insight into how best to involve lay people, patients and carers in designing digital solutions, which can be complex with many involved parties. The PCN hopes that their continued involvement will bring the essential patient and carer perspective to the fast-developing digital agenda.
PCN involvement in Wales

PCN representatives in Wales remain involved in, and have contributed to, a number of different consultations and major reports during 2018/19:

- Welsh government policy framework for unscheduled care
- Endoscopy services – Senedd (Senate) inquiry
- Welsh government draft obesity strategy
- Welsh government evaluation of health and care winter pressure 2018–19
- Management of follow up outpatients – Senedd inquiry
- Health Education and Improvement Wales (HEIW) draft health and social care workforce strategy
- Provision of health and social care in the prison estate – Senedd inquiry
- Doing things differently: Supporting junior doctors in Wales – May 2019
- Time for research: Delivering innovative patient care in Wales – July 2019
PCN involvement in research – Caerphilly

PCN member Ceri McDade has been working with colleagues and members in the area of Caerphilly, south Wales, on a project that is researching the possible impact and benefits of ‘de-prescribing for older people in a hospital setting’. The project is in progress with the potential to expand once findings have been analysed. Ceri has worked hard with RCP colleagues to ensure the project is person-centred and that the patient and carer voice/experience remains at the heart of the work.

‘Although the planning and red tape involved with working in a research capacity for the PCN took months longer than anticipated, it was well worth the wait. Engaging with patients, doctors and nurses has been an invaluable exercise, as these relationships are core to everything that the PCN is about. De-prescribing for older people with capacity who are over 65 years old and on more than one medication has been received inquisitively and welcomed by both patients and doctors, despite being a potentially misunderstood subject. It is a privilege to relate to all tiers of clinicians in a hospital setting, gaining understanding on how and why clinicians make decisions, discuss patient care, and the genuine concern shown to patients.

The research involves gaining informed consent, a 16-response questionnaire and records medication by group. Presently Dr Richard Gilpin and I are mid-way through data collection, and we are both intrigued and touched how patients describe their doctors and relate feelings about their medication. Prescription medication is such an integral part of care for older frail patients, with some patients prescribed up to 25 different medications at one time. We have found that it is important to comprehend the relationship patients have with their medication, how they cope with their medication in the community on leaving hospital, the psychological effects of being prescribed multiple medications and if they are proactive in decision-making about their medication. It has been an honour to ask groundbreaking questions, and despite the early stage of the research, we have already noted further questions to address if the project develops into an NHS audit.’

– Ceri McDade, PCN member, Wales.
The PCN in 2019/2020

2018 was a year of change for the PCN and the RCP. The PCN welcomed a new chair and the RCP a new president. Both of these changes have brought with them the opportunity to listen, reflect and learn with a view to re-energise and rethink how the PCN works. The ultimate goal for the PIU and the PCN is ‘meaningful patient and carer involvement that supports and influences improvements in health and healthcare for all’.
PCN areas of focus over the next 12 months will be:

- three PCN workshops that are interactive and have clear outcomes to support improvements in healthcare
- four liaison group meetings to help plan, steer and review the work of the PCN
- recruitment of new PCN members to reach under-represented groups and communities
- working with RCP colleagues to implement PIU and PCN guidance and recommendations for lay representation and patient involvement in RCP committees, boards and projects
- inputting to the new RCP strategy, the starting point of which involved contributing to the RCP executive away day and following up on the president’s message at the January 2019 PCN workshop that he would like ‘patient involvement from the start, and for the strategy to be clear and specific, focusing on what is important from a patient perspective. Patient involvement in the strategy would not just be a “tick box” exercise, but would be embedded in the writing process’
- design and implementation of mechanisms for PCN members involved in work across the RCP to feed back so that the PCN can successfully share consistent messages and good practice in patient and carer involvement
- working with colleagues to ensure patient and carer involvement in the RCP annual conference: Medicine 2020
- working with colleagues in the Communications, Policy and Research directorate to support and influence 2020 policy and campaigns priorities
- continue to respond accordingly to emerging public and patient involvement priorities as PCN capacity allows
- continuing to work with colleagues in the RCP Education department with a view to support, design and co-deliver training for clinicians and healthcare professionals
- strengthening PCN involvement in QI projects, particularly the QI collaboratives and chief registrar scheme.

We would like to thank all PCN members and RCP colleagues who have committed extensive time and contributed significantly to the activities and outcomes in this report. The PIU and PCN look forward to the coming year and continued involvement in RCP-wide projects, working groups, committees and policy work.
Further info
To find out more about the PCN, visit the RCP website or contact the Patient Involvement Unit.
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