Patient and Carer Network

Impact Report, 2017

April 2018
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1. **Foreword from the PCN chair**

Being able to share the first ‘Impact Report’ for the Patient and Carer Network (PCN) feels like another significant milestone in the PCN’s constantly evolving journey. Articulating and measuring impact in patient and public involvement is far from straightforward and isn’t always easy, but it is absolutely vital. When we work with the various teams across the RCP we place a great deal of emphasis on outcome. The review of lay involvement on committees is a really good example of this as we work with committees to encourage them to start with the outcome – the quality improvement – and to then question what type of patient and public involvement (PPI) will help to deliver this.

And that’s why we’ve held ourselves to account – it’s essential we go through the same process ourselves and can respond to the question: What impact has the PCN had? This document is the start of an answer to that question.

It’s just the start for a number of reasons. We haven’t tried to capture every activity that our members are involved in. That would be measuring what we can count and would be a very long list but wouldn’t necessarily capture impact. So we’ve focused on mapping those activities with tangible outcomes under each of the objectives we set ourselves for 2017.

It’s also just the start as we refine our own methods of data capture and communication with our volunteer members.

And finally, it’s just the start because we know we will continue to grow and have a greater impact thanks to the motivation and commitment of our volunteers to whom we are indebted.

In the current NHS climate you could fall into the trap of thinking of PPI as a ‘nice to have’ but not necessary. You could think quality is about patient safety and clinical effectiveness but patient experience is less important. You’d be wrong. Patient and public involvement has never been more necessary. Engaging patients more effectively is part of the solution – if services need to be used differently, ask us; if services need to be redesigned, involve us. This document should give you just a flavour of the kinds of answers you might get from us.

**Elisabeth Davies**  
**Chair, Patient and Carer Network**
2. PCN strategic aims

The strategic aims below reflect the PCN’s refined focus moving forward into 2018.

The PCN aims to:

1. support the RCP’s strategic aim 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 health and care services are delivered in an integrated way and informing the development of the Quality Improvement Hub.

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 including by ensuring patients and carers have access to the information they need.
3. PCN membership

Structure of the PCN

The PCN has 73 members, and is made up of three key groups.

The **PCN Liaison Group** brings together the chair of the PCN, the patient involvement officer (a practising physician) and three other PCN volunteers. The Liaison Group plays a central role in the strategy and day-to-day running of the network.

The **PCN Forum** is comprised of members who are regularly engaged in a range of activities across the RCP through workshops, focus groups, projects and committees. Forum members come together three times a year at PCN workshops.

The **PCN Community** is made up of newly recruited volunteers and alumni members. Alumni members have reached the end of their 3-year tenure on the PCN Forum, but remain involved in some activities. Community members may still be involved in committees and in ad hoc projects, or they might engage with the RCP more remotely through surveys or commenting on documents.

![Figure 1: Structure of the PCN](image)

**Liaison Group – 5 members**

**PCN Forum – 28 members**

**PCN Community/Alumni – 40 members**
New members

In November 2017, the PCN welcomed 21 members. Of these new members, 13 were inducted into the Community and eight to the Forum. The PCN adopts a rolling recruitment policy, and hopes to induct another cohort of new members in 2018. Not only will this allow the PCN to grow and maximise its contribution to the work of the RCP, it will also support with the implementation of the PCN’s policy of volunteer tenure. This policy was introduced in 2017 to create a framework for Forum members to transition into the Alumni, forming a part of the wider PCN Community after three years as a volunteer.

Figures 3 and 4 show how the new members fit into the rest of the volunteer network. Figure 5 shows the geographical spread of PCN members.

PCN volunteer hours

Members of the PCN contributed around 2,000 hours of voluntary time to the RCP in 2017. Volunteer hours are collated using a combination of data collected from interviews with Forum members as part of the support and review process and from other methods for logging volunteer involvement. These figures are partly calculated using estimates for volunteer contributions, particularly where more detailed data were not available. They also include estimates for the time contributed whilst travelling to and from RCP activities, in order to fairly acknowledge the time contributions that volunteers have made.

<table>
<thead>
<tr>
<th>Key Indicator</th>
<th>Q1 to 31.03.17</th>
<th>Q2 to 30.06.17</th>
<th>Q3 to 30.09.17</th>
<th>Q4 to 31.12.17</th>
<th>Year total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteer hours</td>
<td>Approx 319</td>
<td>Approx 650</td>
<td>Approx 539</td>
<td>Approx 431</td>
<td>Approx 1,939</td>
</tr>
</tbody>
</table>

*Figure 2: Volunteer hours (2017)*

PCN membership breakdowns

*Figure 3: PCN Forum membership* – longer standing and new members
* These figures do not include the five members of the PCN Liaison Group. This group consists of an additional four lay volunteers and one clinician.

**Figure 4: PCN Forum membership – longer standing and new members**

[Diagram showing PCN Community membership with breakdown: Inducted Nov 2017 (13) and Previously inducted - alumni (27).]

**Figure 5: PCN membership by RCP region***

* The geographical location of two members is unknown; one member is based in Scotland, where the RCP does not have a national office.
4. Overview of the PCN’s 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 through 2017. Where possible, information has also been included on tangible outcomes from those activities, demonstrating the impact of PCN involvement on the RCP’s work.

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

Medical professionalism

PCN members helped to shape and deliver an RCP project on medical professionalism through contributions at roundtables and workshops across the country. This ongoing project aims to evaluate the role of professionalism in modern healthcare and make recommendations for the future, and PCN members were involved to ensure that the conversation remained focused on patients and their needs.

The PCN contributed to the scoping stage of the project, which will help to inform the development and promotion stages and ensure that the needs of patients remain present across work focused on facilitating the delivery of better quality care.

RCP annual conference 2017

The PCN played a central role at the RCP annual conference in 2017. A Forum member gave a plenary session entitled ‘Having a real conversation with patients’, that focused on patient experience and practical ways for doctors and patients to engage on a human level. This was one of the best-attended and most highly rated plenary sessions at the conference, demonstrating the desire among physicians to hear from patients and carers.
The chair of the PCN also chaired the opening and closing plenary sessions of the conference, and joined the RCP clinical vice president and other external speakers for a session on maintaining clinical quality in a system under pressure.

These contributions from the PCN helped to keep the voices of patients and carers at the centre of the conference, and raised the profile of patient and public involvement across the work of the RCP.

**Physician associates**

PCN members support the development of the physician associate (PAs) role through membership on the board of the RCP’s Faculty of Physician Associates (FPA).

In 2017, PCN members participated in a focus group to provide in-depth commentary on strategic documents and curricula shaping the governance and roles of PAs. This included a number of recommendations on issues such as how to effectively explain the roles of PAs to patients and carers. As a result, the patient-centred nature of the role is reflected in training programmes and official documents. PCN members also engaged directly with PAs, running a session at the FPA’s annual conference on how to meaningfully engage patients and carers in their work.
4.2 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 the Quality Improvement Hub.

**Future Hospital Programme**

PCN members provided support at Future Hospital Programme (FHP) development sites throughout 2017. They were primarily involved as ‘buddies’ for local patient representatives and worked with them to facilitate effective engagement with clinicians, and to identify potential solutions to challenges they may have been facing. PCN members were also involved in aspects of the governance and design of the FHP and provided additional support to the quality improvement team through developing new ways of engaging patients such as a Patient Advisory Group.

Patient involvement was a key aspect of quality improvement approach taken by the FHP team and development sites. The PCN helped to ensure that the importance of co-production, patient involvement and patient experience were also woven throughout the FHP final report and evaluation. The importance of putting patients and carers at the centre of healthcare design and delivery was one of the key learning points highlighted within the Delivering the future hospital report.

Similarly, the evaluation of FHP carried out by the University of Liverpool also placed significant emphasis on engagement and co-production. This independent report reinforced patient involvement as a key strength of the FHP and the work of the development sites. The findings of both reports and the FHP’s work are now being taken forward in work to develop a new RCP offer around quality improvement. The PCN, and patient involvement, has central to the development of this work.

**Academy of Medical Royal Colleges**

PCN members contributed to a review carried out by the Academy of Medical Royal Colleges (AoMRC) into its Patient and Liaison Committee, and to various pieces of work carried out by its Quality Improvement Working Group. This has helped the AoMRC to ensure that the interests and perspectives of patients and the public are taken into account across all of its work, particularly that which relates to quality improvement.
4.3 Promote patient safety and high-quality care by influencing the way healthcare is delivered and designed.

Audit programmes

The PCN contributed to a range of RCP programmes focussed on influencing the design and delivery of healthcare in 2017. PCN members supported the work of the Asthma Audit Development Programme, the main aim of which was to conduct a pilot study to inform the establishment of a national asthma audit. This involved contributing a patient perspective at five teleconferences and meetings throughout the project’s development. The final report is due to be published in April 2018.

The PCN also contributed to National Mortality Case Record Review Programme, which aims to develop a standardised methodology for reviewing case results of patients who have died in acute hospitals, through representation on the Advisory Group.

The PCN has contributed to a range of publications and public-facing materials for the Falls and Fragility Fracture Audit Programme (FFFAP), including the annual report for the National Hip Fracture Database (NHFD). These contributions have helped to keep patient experiences and the importance of patient safety at the centre of the work of the NHFD and this is exemplified by the ‘patient perspectives’ section, which features alongside the foreword of the Fracture Liaison Service Database report. PCN involvement in the FFFAP also included attendance at a focus group on NHFD reporting, membership on the Steering Group for the Physiotherapy Hip Fracture rehabilitation sprint audit, and contributions to patient-led sessions at the ‘Leaders in Healthcare’ conference and the RCP’s audit and accreditation away-day.

Internal medicine curriculum

PCN members also participated in a consultation to review the Joint Royal Colleges of Physicians Training Board’s internal medicine curriculum through attending a number of focus group discussions. Contributions from PCN members have helped to ensure that patient safety and quality of care remain a central focus throughout the curriculum, which forms a key component of Core Medical Training for trainee physicians in the UK.
Improving teams in healthcare

The PCN contributed to a project entitled ‘Improving teams in healthcare’, which culminated in the publication of a set of practical resources for healthcare professionals. The four resources provide guidance on specific topics such as team building and effective communication in order to enable clinicians to provide high quality patient care in the NHS. They are some of the most frequently downloaded documents from the RCP website, suggesting that these resources are being used by healthcare professionals across the country and that the efforts of PCN members to ensure that clinicians remain focussed on delivering high quality patient care have been effective.

Figure 4 – RCP resources produced as a part of the ‘Improving teams in healthcare’ project
4.4 Support the development of a sustainable NHS including by ensuring patients and carers have access to the information they need.

**NHS pressures**

PCN members contributed to the RCP’s *Against all odds* report, which collates personal accounts from doctors and patients. Published in February 2017, the report offers a compelling illustration of what it’s like to provide and receive care in an overstretched NHS. The contribution of PCN members offers a stark reminder of the very real impact that NHS pressures have on the quality of care patients receive.

The report formed a key part of the RCP’s *Mission: Health* campaign, which called on government to invest more in NHS and social care and improve working conditions for clinical staff in order to promote high quality patient care.

**Brexit**

The impact of withdrawing from the European Union on health has continued to be a major area of focus for the RCP in 2017. Members of the PCN reviewed the RCP’s series of *Brexit briefings*. Their feedback was used to develop a more accessible and comprehensive series of *Frequently Asked Questions* outlining the impact of Brexit on health, research and patient care.

**Sustainability and climate change**

PCN volunteers participated in a workshop session on sustainability in the NHS, contributing to debates on what can be done to reduce the carbon footprint of the NHS and how best to communicate the impact of climate change on health. This has helped to inform the scoping stages of a project on sustainability and models of care, and further contributions will be made to the project at PCN workshops through 2018.

**Our Future Health**

The RCP’s *Our Future Health* (OFH) programme confronts some of the major challenges facing the health service, doctors and patients in 2018. The PCN has been involved in OFH from the outset, helping to define the scope and shape of the project. At the PCN workshop in September 2017, members discussed a number of issues related to resources and the provision of healthcare, such as debates around length versus quality of life, and the management of limited resources in the face of increasing demand. Patient, carer and public engagement in conversations about these difficult issues is a crucial component of OFH. The PCN are represented in the governance structures of OFH, and PCN members – and a wider group of patients, carers and the public – will be involved in OFH activities throughout 2018.
5. Supporting PCN members

In 2017, the RCP continued to develop a more intensive package of support for PCN members. This included a full ‘support and review’ process involving a one-to-one conversation with each PCN member about current involvement, interests and any support or development needs. This was complemented by an enhanced database for monitoring PCN activity, and the development of better mechanisms for communicating – eg a revamped newsletter and a new PCN Facebook group.

In November 2017, the RCP also ran its first full PCN induction session, which was attended by 16 of the 21 newly-recruited members. As well as finding out more about the RCP and the work of existing PCN members, attendees also discussed the impact that they would like to have and some of the challenges they felt they may face. This feedback will be factored into future PCN development.

Overview of new member feedback – PCN induction, November 2017

What impact do you want to make as a PCN member?

- Give patients and carers a voice, and raise visibility and awareness of issues that they face.
- Empower doctors to adopt patient and public involvement (PPI) in a meaningful way.
- Use RCP500 as a springboard for raising the profile of the PCN and the importance of PPI.
- Persuade health professionals of the importance of viewing each patient as a person, not a set of symptoms.
- Change the language used by health professionals in order to facilitate a dialogue with patients and carers.
- Proactively change culture and behaviour to be more inclusive of patients and carers.
- Improve the patient journey, particularly in relation to safety and dignity.
- Have a positive impact within the broader context of health and healthcare in the UK.
- Challenge the status quo in a productive way to elicit lasting change.
- Work towards the standardisation of information and the sharing of patient data for positive health outcomes and the delivery of holistic care.
- Support the development of remote care mechanisms that meet the needs of patients.
- Join up some of the work already being done to involve patients and carers in the improvement of health and healthcare.

What challenges might you face achieving this?

- Change may take time to implement and impacts of involvement may not be sustainable.
- Attitudes and behaviours may be hard to change, and there may be a culture of tokenism or a resistance to PPI on the part of some healthcare professionals.
• Use of acronyms and technical jargon may mean that there is a communication barrier preventing meaningful engagement.
• A lack of confidence or understanding of technical issues could make some lay members feel that they don’t have the credibility to contribute.
• It may be hard to measure the success of many intended impacts, particularly those that are longer term or involve less tangible outcomes such as cultural change.
• Some of the intended impacts may be idealistic, and slow progress could be disheartening.