Transcript of Radio Ombudsman #12: Rachel Power, CEO of the Patients Association, on putting patients at the heart of NHS care

Rachel Power, CEO of the Patients Association, talks to Rob Behrens about the importance of listening to patients, and making sure their voices are heard and acted upon. Rob and Rachel also explore how our organisations can work together to improve complaint handling.

Rob Behrens: Welcome to Radio Ombudsman. It's Rob Behrens here with background music from the rising young composer, David Ridley. Thank you very much for that.

My guest today is Rachel Power, Chief Executive of the Patients Association, with over 20 years' experience of working in health and social care. She joined the Patients Association, as its chief executive, in June 2017 and has overseen a significant period of change. We're delighted to have you here, thank you very much for being with us.

We like to start each episode by hearing a bit about our guests and where they come from. Anyone who has met you knows where you come from, but tell the listeners where you come from.

Rachel Power: Thanks Rob. I come from Ireland, which is why I think people know where I come from. I come from the west coast of Ireland, from Galway.

Rob Behrens: Tell us a bit about your early life.

Rachel Power: I have two sisters and a brother, and I lived in Galway with my mum and dad. It was a very different upbringing because it

was a very small town at the time. It's now quite a big city. My upbringing was surrounded by huge love and a family who was looking out for me all the time.

Rob Behrens: Okay. Did that instil values, obviously it did, in you that you've tried to continue with, to live up to?

Rachel Power: Yes, I hope so. I think the values of compassion and integrity were two that I was very much brought up with. I hope they're two that I have instilled in my two beautiful children. One of community and understanding how we can all help each other, and one of just caring quite a lot for each other and thinking about how we can support each other.

Rob Behrens: When you were growing up, when did you decide what it was you wanted to do?

Rachel Power: I'm not sure I still have decided. (Laughter), I think, when I was younger, I wanted to be a nurse. Then I realised that was actually a really difficult job and that it probably involved dealing with people. I loved hanging around with my grandmother and her friends. I decided I couldn't really do that because that involved quite a lot of medical stuff.

Then I probably just fell into the voluntary sector. My first role in the voluntary sector was working with the National Autistic Society. I was always involved in different areas of volunteering. I was the chair of governors at my local school for a number of years. I think that's probably where I started

my journey in the voluntary sector, in organisations that are there to support people.

Rob Behrens: Yes, but you did that for quite a long time.

Rachel Power: Yes, yes.

Rob Behrens: Where did you move on to?

Rachel Power: My role, from there… My last role in the voluntary sector, before I joined the Patients Association, was working in a children's hospice in east London called Richard House. I think there, as well, the bit that I brought to the Patients Association was very much about, "It is not about the condition or the disease that a patient may have, but it's about the whole person".

What we need to do as a society, and within the NHS and social care, in looking after that whole person. Values became a huge part of the work we did in understanding that, if you were to look after a child you have to look after the family and the community around that family in order to let people live the best possible life that they can do.

Rob Behrens: Yes. Then you joined the Patients Association just over two years ago, and you've overseen a period of significant change. Can you tell us something about the motives behind that?

Rachel Power: When I joined the Patients Association, I could see the great work that the organisation had done for a number of years. Anyone looking at our financial accounts at the time could see that we were in a pretty large deficit and that we had a lot of work to do.

We secured a team. There had been quite a high turnover of staff for a while, so we're pretty much a brand new team since the beginning of 2017. With a large turnover of trustees, mainly because a number of the trustees had been there for a number of years and it was time for the change. So, pretty much a brand new trustee board as well.

We started to do a lot of work on the evidence, how we gathered evidence, and the ways in which we analysed the data that was coming through our helpline and analysed the data that was coming through the survey and the patient-focused work that we were doing, to build a much stronger evidence-base.

Rob Behrens: So you now have a new three-year strategy?

Rachel Power: We do.

Rachel Power: Well we're a year and a half into that new strategy.

Rob Behrens: The same as us. Could you just give us the highlights, the headline points, of that strategy?

Rachel Power: Yes. Our strategy is completely about listening to patients and using that information that we've received through our helpline, and through our survey work and our project work, to inform the changes that we think need to happen within the health and social care system, to ensure that patients are truly at the heart of their care and that they're equal partners within that care.

Rob Behrens: Right. The relationship between our two organisations hasn't always been uncomplicated, amicable. When you came, you took a particular stance on that. Would you like to just tell us a bit about it, because the Patients Association historically has been very critical of the Ombudsman Service?

Rachel Power: Yes. I think the criticism was for good reason. We had been receiving abundant evidence of the PHSO letting patients down and making things worse when they needed their help, right or wrong. We issued three reports, 2014, 2015, and 2016. In those reports we called for change, and we succeeded in getting change. PHSO has recognised the scale of its problems and the action needed to correct them. You set out in place a strategy for how to improve its performance across a period of years. We welcomed that and we welcomed the new organisational leadership.

Rob Behrens: Now, we asked for questions from followers on Twitter. One question to you is this: Why did the Patients Association take down the three damning reports into PHSO from their website? These should be the baseline from which we measure improvements.

Rachel Power: They are the baseline from where we measure improvements. We took them down. We launched a new website in 2018, and had to make a decision about what remained on the website, because we wanted something that was more up to date. Our position statement on the PHSO remains on our website.

Our position is that we recognise the extent of change that PHSO has embarked on, and we agree it is extremely necessary. We will judge the results for patients on their merits, and would hope to see substantial benefits from this process in the next year or so.

Rob Behrens: Okay. You haven't stopped being critical of us. As we'll come on to discuss, you've made some critical points about our clinical advice review and taking that forward. We've addressed that.

Rachel Power: We will continue to hold PHSO to account where we feel we need to. We will continue to monitor, through our helpline, the number of calls that are coming in around PHSO. With our helpline, most of the calls that are coming in are around complaints across the whole system, not all about PHSO. We will continue to raise concerns with you, Rob, when we hear things that concern us.

Rob Behrens: That's reassuring. What do you think is the best way of ensuring that patients' voices are heard and acted upon by those in power?

Rachel Power: I think the best way… The solutions are… Solving it will be hard for as long as there are the constant staffing pressures going on within the NHS.

Moving to a no-blame culture is key. It doesn't mean that nobody is held responsible for their actions, but it means that NHS professionals can feel confident that systematic problems will be dealt with at systems levels and they won't be scapegoated.

How we get patients' perspective in there, it's about training. That means it's going to have to be a generational shift, because we need to see patient involvement built into the training curricula from the very early stages.

For the moment, we still don't really have patient-centred care. For the most part, most decisions really made about the patient aren't really made with the patient as an active and informed partner.

We've got the recent stories out there about the number of people being left on prescription drugs, many of them without even properly being informed about their prescriptions.

Again, the financial and workforce pressures are part of the problem. If the system is barely functioning, you can understand people concentrating on system type problems. Placing people in a role of constant crisis will, inevitably, shape their behaviour.

Rob Behrens: I think I agree with you that culture is at the core of what needs to be done. I also agree that individual clinicians, professionals, and managers tend to see situations through the lens of the system, as you put it, rather than through the eyes

of the patient. It's doing something about it that is the big issue.

It's about resources, of course, it's about what sort of training we're talking about. For example, in my organisation, we have devoted a huge amount of resource into skilling everybody about their ability to communicate with complainants, which has been suboptimal in the past, so that they have the confidence to be able to treat people as individuals and not as cases. That's difficult, but it needs to be done.

There is also a defensiveness in the health service, which is more difficult to drive away. To some extent, it can be addressed through what you call the safety culture issues, the safe space. What is it going to take in order to remove the defensiveness of the health service?

Rachel Power: I think leadership is key. I often wonder if the term 'complaint' is helpful. You talk about communicating, and the work that you've been doing at PHSO on communicating. Listening is really, really, important. Acknowledging that we have learning, that there is always learning… If a patient raises a concern or a complaint, the ability to say sorry immediately and then to involve the patient and see that the patient is the expert in their care, and know more about their care in certain instances. So it's about involving them fully, but that needs leadership to allow that to happen.

Of course, treatment of whistle-blowers within the NHS can illustrate that problem that staff are scared that it's going to be harmful for them, personally. How do you change that culture so that when I have a complaint to make, somebody welcomes the fact that I want to give feedback?

Rob Behrens: Yes. Listening and learning and being prepared to have leaders who protect people who speak up is a big issue.

I was visiting a big trust earlier this week. What they said to me… I had a good look around the wards, I talked to patients, I talked to the complaints staff and to nurses. One of the issues for them is that their resource and staffing situation is so acute that that pushes into the background the issue of complaints. Too often, they don't have the time or the skills to be able to listen and react in the way that you're talking about. So it's not just about changing behaviour. It's also about resources as well, isn't it?

Rachel Power: Yes, which I think I said earlier on. The whole financial and workforce pressure is a huge part of this problem. If people are working in what can be constant crisis, to have the time to sit and listen to a patient… I still take it back to culture and leadership because, even in that environment, if we're encouraged to listen and encouraged to seek solutions, in the long term, that can only benefit our practice.

Rob Behrens: One of the ways we're trying to address that issue directly is through the work we're doing on creating a national complaints standards framework. Happily, a whole tranche of regulators and patient groups, including the Patients Association, have committed themselves to working on this as we go to consultation. So we can get better complaints handling on the frontline, so that our organisation becomes less essential because issues should be resolved by then.

Do you think that such a framework has the potential to be useful?

Rachel Power: Yes, I do. I think the role that you see yourself in, as the complaints standards authority, is helpful and useful. I suppose, how does it fit in with other initiatives like NHS England and NHS Improvement's Patient Safety Strategy?

There has been other really good work done in terms of our good practice standards for complaints handling, that was recommended by Sir Robert Francis in the Mid Staffs Report. Also, the My expectations for raising complaints that was done between the PHSO, Healthwatch, and the Local Government Ombudsman. Building on that practice, just what is the intended purpose? When there are so many other good things that have been out there, as long as we don't lose those.

Rob Behrens: Yes, I agree. It's easy to say, but our job is not to reinvent the wheel but to build on good practice.

Rachel Power: And that would be my concern, that we're not reinventing the wheel and that we are developing on the back of those two very good documents.

Rob Behrens: The other issue that you raise is more sensitive, I think. To me, there is ultimately a tension between the need for a safe space and the need for accountability, if they're pushed to extremes. I believe that the current situation, there is plenty of room for everybody to operate. Like HSIB, for example, creating the safe space and us creating the accountability. If

it's pushed too far, then it becomes difficult for people to have confidence that there is real accountability.

Rachel Power: Yes, and there has to be accountability. That's where the Patients Association would sit. Which is why those two previous standards that were there, we feel, are really good as long as they get built on. We look forward to… We will continue to work with you on there, and see where it gets to.

Rob Behrens: Well that's good to hear. Another question from Twitter, can I ask that?

Rachel Power: Yes, please.

Rob Behrens: Someone has written in very frustrated, "Can you ask Rachel why the hospital trust that I had complained to tried to talk me out of it by telling me I was unusual, which is not true, and at a local resolution meeting made commitments that were quickly backtracked on? I have all these on a recording. Don't you think that just saying sorry is not enough?"

Rachel Power: Absolutely, saying sorry isn't enough. Saying sorry is a very important factor in listening to a complaint, but showing the learning and showing what impact the complaint will have on standards of service is crucially important for any patient.

Rob Behrens: Yes. Okay, I agree with that. What I find is that hospitals are not very good at saying sorry. Regulators are even worse at saying sorry. If you're going to say it, you need to mean it because people are not naïve. One more question…

Rachel Power: Sorry can feel like such a naïve statement. I think I spoke earlier on about values of empathy and understanding. When you're receiving an apology, it has to feel meaningful and impactful and show that there is a difference. I think there is a lot of work done with learning from deaths. I know I've seen some letters, over my time, where it just doesn't feel genuine. I think that's really unfair on a patient who has raised concerns.

Rob Behrens: The final question from Twitter is this: "Can you ask Rachel what the Patients Association plan to do when hospitals don't follow good practice in terms of clinical advice about, for example, pain relief options and other issues?"

Rachel Power: I think I'd want to understand more about that question but that's what my helpline is there to do. Our helpline [0800 345 7115] is there to give advice and support, and signpost where they can. I would suggest, to that question, that they should really get in touch with my helpline to get more information about next steps, if they feel that the hospital haven't been following the clinical guidelines.

Rob Behrens: One of the commitments that I made, in the strategic plan of PHSO, was to do a review of clinical advice. We commissioned

Sir Liam Donaldson to undertake a very important, independent, review of how we use it. I think it's fair to say you were quite critical of some aspects of how we went about the review. Would you like to say something about that?

Rachel Power: Yes. It was a very short timeframe. We advised that, given the short timescale for consultation, other than just written responses, it would've been good for the PHSO to give more opportunity for face-to-face engagement. You did one, I think it was one, quite small face-to-face engagement. We advised that there should be an open invitation to such events. The one event you did have, it seemed to have filled up really, really, quickly. Some of the feedback that we were given… That ended up with disquiet, from some harmed patients, about not being able to have a say in that forum. Unfortunately, I think that wasn't helpful.

Rob Behrens: Okay. Can I respond to that? I think the points you make are fair. I don't think it impacted on Liam Donaldson's criticisms of some of our practices, which hopefully will be addressed in the course of the coming year. There is a need to restore trust between complainants and the clinical advice we receive. The way to do that is to become more transparent. The learning that I take from that is that we will make sure, when we consult on the good practice framework, that we make it democratic enough to ensure that patient voices are heard face–to-face and there is plenty of time to do that.

Rachel Power: Well that's really good to hear, because I think that all the way through this interview we have been speaking about the

needs of patients to genuinely feel that they're being listened to. I know some of the feedback we received was, by the time they'd got the invite, the event was full. If we can open it up and make sure that those voices, those voices the PHSO did not serve well over the years, can be heard so the learnings can be taken forward.

Rob Behrens: That's true. That's why we have an annual Open Meeting, that's why we have Radio Ombudsman. It has been a chastening experience, but we have learned from it.

So we move towards the end. You've been around a long time in terms of advocacy and representing patients. I have a whole tranche of young graduates in Manchester who've come to work for us as case handlers in the Ombudsman Service, what advice would you give to them as they embark on their careers?

Rachel Power: Oh, I have quite a lot of advice for them. I think the most important thing is they need to learn, from the history of the PHSO, what went wrong, the fact that patients did not feel they were being listened to. While you were undergoing a major culture change, through the clinical advice, we heard that patients didn't feel that their complaint was understood, that people didn't come back and ask questions.

For new case workers, being very clear with the complainant what the crux of the complaint is so that they're starting at a point where the patient feels that they're being listened to completely. That they live to the values of the organisation and that there is a genuine personal value that they want to

get it right, and they want to get it right for the patient. I think they would be my two.

Also, the whole skill and competency… I know that you've been doing some work around competencies, which you mentioned earlier, around communication and listening. We often talk about them being soft skills. They are the most important skills that any case worker can bring to the job.

Rob Behrens: Yes. We'll have to get you to do a masterclass in Manchester, so you can develop these very important themes. For the moment, Rachel Power, it's been a privilege and a pleasure. Thank you very much indeed.

Rachel Power: No, thank you for inviting me.

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