

## Programme 30: Successful Research into Chronic Conditions

### ***How a patient group is getting involved in setting health policy for chronic conditions.***

*How can patients with chronic pain get involved with research into managing their condition? Paul Evans talks to SUCCESS (Service Users with Chronic Conditions Encouraging Sensible Solutions) a group of patients, carers and former patients with experience of chronic conditions who work with researchers at Swansea University. The service users get involved with advising research teams working on healthcare policy, ensuring that patients' priorities are reflected in social research and policy and that researchers get the benefits of the service users' expertise.*

**Paul Evans:** Hello, I'm Paul Evans and welcome to ***Airing Pain***. The programme brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain. This edition's made possible by Pain Concern's supporters and friends, and more information on fundraising efforts is available on our Just Giving page at [Painconcern.org.uk](http://Painconcern.org.uk).

**John Flynn:** The initial beginning was scary and there was nobody that you could turn round to, to talk about it.

**Jill Edge:** I meet people who are far worse off than me, I only have one chronic condition. Many of the people in the group have more than one, some of them have several, and they have to manage those as well, and they're prepared to come to meetings, and they're prepared to try and do research to help other people in the future.

**Mostyn Toghill:** You treat a specific condition by finding treatment for the condition, but the associated pain, frustration, anger, disappointment, fear and all the rest of it that's associated with long term illness, they're common regardless what the illness, they're common ground across the board.

**Flynn:** The first doctor you get, he can either break you or make you. He didn't see me as a person, he saw me as a brain and that angered me.

**Evans:** Now the importance of the patient's experience and input into the mapping of health management and policy is something we've dealt with in previous editions of ***Airing Pain***. But in today's programme I want to look at how that same experience of people with chronic conditions can be used to influence research into health and social care. SUCCESS is an acronym for Service Users with Chronic Conditions Encouraging Sensible Solutions. And

they're a group of patients, carers and former patients who all have experience of chronic conditions. So earlier this year I went along to one of their meetings at Swansea University. The first person I spoke to was Angela Evans, she's a Research Officer at the university.

**Angela Evans:** They don't want to be involved in research as the subjects of research, they don't want to give data, they want to shape the way that research is taking place. They want to shape the research agenda, so decide what sort of questions are asked and they want to decide how those questions are asked. And then try and help run the research, with the very long term aim that it makes a difference to the services. They themselves probably won't benefit, they all recognise that but they all want to make some contribution, using their lived experience, make some contribution towards improving the services in the future.

SUCCESS stands for Service Users with Chronic Conditions Enabling Sensible Solutions – good name 'cos it does what it says on the tin, doesn't it?

**Evans:** So how did it come about?

**A Evans:** In 2007 the Welsh Government launched a new policy to improve the management of chronic conditions. They commissioned Swansea University to evaluate that policy – Is it going to work? Has it worked? That's the questions we've been trying to answer for a couple of years. When we started planning that research we made an explicit decision to include service users in that, because we felt it would make the research better. It would help us ask better questions and try and answer them in a more effective way.

So I was given the task, because of my interest, in pulling together a pool of people who could take part in the research. We were researching a whole programme of research, this wasn't an opportunity for two people to come along and sit on one research study, I needed a process that would enable people to be involved in several research studies, a whole programme of research. So I pulled together a pool of people and they chose the process for them being involved, if you give people a say in how things happen, you're more likely to get an effective process. So they set up this organisation, which has become SUCCESS, and they've decided how it runs, they've decided the key principles. And they're key principles like, if we're involved, then we get involved because we think the research will be better.

[Noise of voices at meeting, tea cups clinking.]

**Edge:** [banging] Can we resume? Now it's just gone half past one, right, just before we start. Now Angela, you are recording this aren't you?

[Cuts to interview]

**Evans:** You mentioned the chronic conditions management policy?

**A Evans:** Yeah.

**Evans:** What was that?

**A Evans:** It's a very innovative policy. It's the Welsh Government's response to the problem that exists in health services across Europe – increasing numbers of people who have chronic conditions and need more and more support from health services, and how do you do that and maintain equitable and effective health services? So the Welsh Government's response was this chronic conditions policy. And it's trying to set up services which help people manage their chronic condition to stop it deteriorating and help people stop getting a chronic condition if they're at risk of it.

One of the unusual things about it is that it's a policy for all chronic conditions, not just the main ones which people experience. And that's because they believe that there are common experiences that you have if you have a chronic condition. And the main focus of the policy is to move services out of secondary care and into the primary care sector, or the community care... Really to stop people needing to go into hospital. What happens a lot at the moment is that people have a chronic condition, it's not managed very well, the condition flares up, they end up in hospital, they're stabilised, they're left to go home, they're sent home again, the condition flares up, back into hospital. It's a revolving door syndrome and the policy is trying to improve services in the community, so that you don't end up deteriorating quickly and then needing to use secondary care services.

[Cuts to meeting]

**A Evans:** The first page is actually SUCESS meetings, the second page of the regular research opportunities, so that's the Swansea University research team, the prism meetings...

**Female voice:** Prism meetings? Excuse me, I thought you said prison meetings. [Laughter].

[Cuts to interview]

**Evans:** Ok, we'll come back to that misunderstanding later. Now David Rae works in the college of Human and Health Science at Swansea University. His background is in Social Research and Policy.

**David Rae:** There's quite a long history now of clinical research, medical research, which has tried to engage patients, and sometimes it's the other way, where patients have

demanding that the clinicians, or the research programmes, are carried out in areas which perhaps have been neglected or services aren't provided, or drugs aren't provided because there isn't sufficient research. So people are saying: how can we help make sure that there is research. And that's quite a long tradition now. And there's a requirement now that anybody who gets funding to carry out medical research, or social care research, should involve patients in the process of designing the research, designing the research instruments, the method of data collection and sometimes in the dissemination of the results.

When a researcher now applies for funding to do research, if it's from the Medical Research Council or the National Institute for Health and Social Care, then they would have to answer a question about how they had involved service users or patients.

**Evans:** Now we're not talking about guinea pigs here are we?

**Rae:** No, they're involved in it as people with expertise of having had the condition. They're not there as 'We want to try out these drugs', you know, a randomised control trial or something. They're there in terms of identifying what research needs to be done, taking part in the process of designing the research, taking part perhaps in applying for the funding to carry out the research. Putting researchers in contact with patients like themselves who have the conditions that the researcher wants, or the funding wants. So they're a participant in that sense, you know, they're involved in the whole research process, they're not the object of the research process.

**Evans:** Because, for example, in many conditions a researcher might want to do something about a particular condition [**Rae:** yeah] and the patients may come back to him and say: well actually, you need to be looking at such and such.

**Rae:** And it can also be about the way a service is delivered; it's not just about the clinical aspects of treatment. Often it's about whether services are well connected to each other, whether they talk to each other. Whether doctors talk to community based doctors, or social workers, it's about those communications and the fact that a person with a chronic condition has to negotiate their way through a range of different services, financial services as well as health and social care services.

**A Evans:** Prism stands for Predictive Risk Stratification Management, it's a tool that is going into GPs, will go to GP practices, every single patient on the GP's practice list is given a score, and that score is carefully calculated. It pulls together 37 different pieces of information about every single patient and it tells you the risk of being an emergency admission into hospital in the next twelve months. And the idea is to help all the health

professions in the practice to target their care to stop you going into hospital, as an emergency admission. And we're evaluating how it actually works in practice: what difference does it make to GPs behaviour? How are patients actually feeling about the different care? Are we getting better care? Is it changing their experience of going into hospital? It's a fairly big, long term study which is going on at the moment in Swansea.

**Toghill:** I'm Mostyn Toghill and I've been a member of the SUCCESS team since its inception in 2008, been diabetic for fifty plus years, type 1 diabetic, multiplicity of other complications associated with type 1 diabetes.

Although we don't actually directly influence policy, that's not part of our remit, we feel we're having some influence in the way things are being framed. And we're helping the researchers to put a proper framework for the projects that they're doing. I think a lot of what we do is to just point out the obvious, because sometimes you can be too close to a problem and 'cause you're so close you can't see it.

The big thing that we did, we actually, before the change of the last election, where there was every HB, every local health board had to publish its chronic condition management policies, and we as a group evaluated those policies within a framework that we were given. But one thing that we did say with that, I mean that as a group I think that we generally feel that what there is, is too much localisation of services, not enough uniformity across the country. And that's one thing that I would certainly be wanting to fight for and I think the group would support me on that.

[Cuts to meeting]

**Edge:** What we're talking about is whether there are any particular research items that you think we should, I mean how do we research podiatry, podiatry is just one of the things. If there are a lot of elderly people who have foot problems living in an area and they haven't got enough podiatrists. [**Participant 1:** Yes.] That's simple, they need to prove... there's no research there is there? Really, it's just a case of, you know, the health board, or whoever it is, just needs to [**Participant 2:** That's right...] engage more podiatrists. Come to Pembrokeshire, it's a lovely place to live...[voices talking over each other]

**Participant 3:** Jill, that wasn't the point. The point was that podiatrists, whereas they used to be called 'chiropractors' and did everything, now will not cut toenails. I hate to keep raising the subject of toenails... [background laughter]

**Edge:** I understand.

**Participant 3:** And it's a major problem and there's a...

**Toghill:** My podiatrist cuts my toenails, I'm going on Thursday. [Background laughter and talk]

**Edge:** I can understand that there is a problem, I don't understand where we... [**Participant 2:** Where we're going?] ...yes. I mean...

**Participant 4:** No, I don't think it concerns us.

**Edge:** As a group perhaps we could lobby the local health board, to engage more podiatrists.

[Cuts to interview]

**Toghill:** That perfectly illustrated a point where, the point was made by one member of the group, that podiatrists no longer cut toenails. Well I have a podiatry appointment on Thursday when I get back and the main object of that will be to cut my toenails. So instantly there's a difference. I mean, I come from North West Wales, part of the Betsi Cadwaladr Health Trust, and being a diabetic it obviously... I mean feet are a major issue with diabetics. So, yes, they do my nails and they look after my feet generally for me, but then I can do that on a regular basis, every six weeks or so, every six to eight weeks I go to a podiatry appointment. One of my colleagues on the group, who lives down in South Wales Valleys, has real trouble getting to see a podiatrist and that member is also a diabetic so [sighing] there's no consistency of services. It's very much a postcode... where you live determines what you get.

Now to a certain extent that will happen with things like COPD, chronic obstructive pulmonary disease, as a results of things like pneumoconiosis and that sort of thing, with the mining and the heavy industry, but we get, you know we get silicosis up in North Wales from the quarrying industry. So there's a similarity there. But, okay, you probably wouldn't get that in Aberystwyth, but there'll still be people there with COPD.

**Evans:** But that is a national policy isn't it? I mean why have a head injuries unit in Swansea and in Cardiff, when you could have a massive one serving the whole of Wales, where you'd double the expertise.

**Toghill:** Well the argument in that particular case is that South and Mid Wales are served at Cardiff by the South Wales Neurological Service and North Wales is served by Liverpool... Manchester and Merseyside. So they don't seem to, they don't perceive a need for it up there. But if those two decide to close their doors to North Wales patients, that would leave

the North Wales patients, often ill and in great pain, having to travel by ambulance on very poor roads, probably six or seven hour journey because you can't really put your foot down with somebody with head injuries.

But the biggest problem you've got obviously with everything these days is cost. We can't have an acute hospital in every town. You can't have an acute unit in every town. So you have to sort of do the best you can with what you got. And just by sheer volume of population, the bulk of services are going to be in South Wales, in the old coalfield areas basically, 'cause that's where two thirds of the population of Wales lives.

The difficulties that people face are all, although the causes may be different, the difficulties that people come up with, with a chronic condition are quite common right a... they're quite common. I came through this initially by the expert patients programme, many moons ago, which effectively made you realise just how much common ground there was between people with different conditions. That is where I think we should be focusing. You treat the specific condition by finding treatment for the condition, but the associated pain, frustration, anger, disappointment, fear and all the rest of it that's associated with long term illness, they're common regardless what the illness, they're common ground across the board.

I mean obviously treatment for an insulin treatment isn't going to help somebody with arthritis, likewise treatment for arthritis isn't going to help someone who needs insulin. But they both suffer with poor circulation, both suffer with painful joints and they both suffer with a list of common symptoms shall we say.

**Evans:** So what can you as a group do about this?

**Toghill:** Well as a group most research projects which involve lay members, shall we say, service users, involve two, three or four people on reviewing or advising or whatever, and they will take possibly a bigger sample for clinical testing. We're currently up to 17 members. We're the only group which has a total involvement in the research project as a group. And our particular focus is chronic conditions. Now there are other groups out there which focus on particular illnesses; we try and take an overview and look at it all. We look at the service delivery for chronic conditions full stop, that is our brief.

**A Evans:** What SUCCESS brings is added value, because when a member of the SUCCESS group goes to take part in research, gives us the patient perspective into a research study, they're bringing their perspective and the perspective of all those patients behind them, who are members of SUCCESS, who have that common experience of living with chronic conditions. And what SUCCESS is doing is trying to contribute that expertise – 'cause it is a

real expertise – contribute that into developing and undertaking research. So that *hopefully* the research that you undertake is more relevant to patients and more appropriate to patients and there's some evidence to say it may be the message will be taken on board more readily than if the research doesn't involve patients.

**Evans:** What struck me today is that they are their own bosses, it maybe under the auspices of Swansea University, [**A Evans:** Yep.] but it is their group not your group and I got a grilling for what I wanted to do today.

**A Evans:** [laughing] Yes they're highly, they're very, very motivated people, very motivated, very strong sense of their own identity, strong sense of what they have got to contribute. They all recognise that their experience of managing their chronic condition is very relevant and while things may be obvious to them, they realise that they're not obvious to people who don't have that personal experience, but they are very useful and very relevant if you are going to undertake research. Yes they're a very motivated, dynamic and *skilled* group of people.

I suppose their motivation and that sense of identity is partly because I gave it to them, when the group was set up I always said very clearly from the beginning 'you decide how we operate', because I thought then, I believed then, and I still do, that if they take charge and they have that ownership, they're going to be more motivated and be more effective.

[Cuts to meeting]

**Participant 5:** Are these patients selected randomly?

**A Evans:** That's exactly what I was going to...

**Participant 6:** Exactly the conversation we had, they're not selected randomly, [**Participant 5:** I'll just be quiet then] they were selected...

**Edge:** 'Purposively', is the term...

**Participant 6:** Purposely, [background talking] not randomly. [laughter]

**Edge:** You decide the types of people you want to interview and then you pick for those criteria...[**Participant 6:** yes]... So we want to interview people who are quite severely ill, rather than not very ill, who are likely to have gone into hospital rather than not.

[Cuts to interview]

**Flynn:** My name is John Flynn, I'd been healthy until about 25, 27 years ago. I had an accident, had a punch but I hit my head on the floor, but I can't remember how long after that initial concussion, I was walking from my house to my father's house and was coming up the street, the only thing I can remember was like this lens in front of me, closing down and the screen going off like a television. Next minute I'm back in my own house, with the key in the front door and the light just opens up and I'm looking at my arm like this and not recognising what's happening and I was confused for about five to ten minutes. Didn't know what day it was, nothing. I was panicking, so I went to the doctor and they diagnosed epilepsy. Because I had meningitis when I was a child, that was the initial scarring of the temporal lobe, this concussion of hitting the floor that's what...

**Evans:** What kicked it off.

**Flynn:** ...kicked it off. The initial beginning was scary and there was nobody that you could turn round to talk about it. The first doctor you get, he can either break you or make you.

**Evans:** Just explain that to me, how could a doctor break you?

**Flynn:** My first neurologist I came across, okay, he didn't see me as a person, he saw me as a brain and that angered me. The specialist nurse was more like a mother, I could talk to her, I could be open with her. Like, everybody I've spoken to, they send you home and you learn things off internet, hearsay, luckily the wife was working in a community-like thing and there was this self-help group for epilepsy. I went to it, and I went on to forums, and I thought that was the fantastic... best thing that ever happened.

And the expert patients programme, you saw the perspective of everybody's condition, you couldn't believe how depression came in, into every condition. And by talking it out you felt more at ease. And the best thing I've ever done was come to a counsellor and to be honest [laughing] after doing about two or three sessions the only thing that person was doing, like you are doing now: listening to me. Why didn't you tape yourself, listen to it and solve it? 'cause you had a shock, but you had so much strength inside you, and don't look at it that it's you that's talking, look at as a person on the other side and feel it in a different way.

Because of my memory, it's like this morning, going to my hotel I had a card, swipe card, to put into the door, and I've been carrying the wallet with 221 on it. I've been doing it for a day, okay I felt stupid, the first thing I did was got my phone, put it into the notes, 221 on the notes, so that I could see it on the front of the phone when it came up. I don't have to look at the phone now, 'cause I can see the picture.

**Evans:** So you're translating numbers into pictures?

**Flynn:** Pictures. And that's what happened with the memory class, exactly, in Liverpool. With me, say I want to go shopping tomorrow morning, put the bag in the front door so when I come down, 'oh yeah'.

**Evans:** In the old days it used to be tie a knot in your handkerchief.

**Flynn:** That's it.

**Evans:** Of course you'd have to remember what the knot was there for, but that's so obvious.

**Flynn:** Yes.

**Evans:** If you're going to do something tomorrow that you remember now, make sure you see it first thing in the morning.

**Flynn:** But it's like, in epilepsy, the side of the brain that's not been damaged, been scarred, is the recall, to me. I can't store, I can't bring it back. But they were telling you, say it, read it and look at it. So there's three sides of the brain that can store it, so if one is damaged, there's two bits again that can help you more. And by writing it, is another thing again.

[Cuts to meeting]

**Edge:** Can we, I think we do need to move on. Maybe those of us who want to contribute at the end of the meeting...

[Cuts to interview]

**Edge:** I'm Jill Edge, with a condition, a chronic condition known as ankylosing spondylitis, which is a rheumatic condition of the spine.

**Evans:** You've been chairing this meeting of SUCESS today, was this a typical meeting?

**Edge:** This wasn't a typical meeting actually, because for the last, say three and a half years, we've been meeting regularly as a group of people who all know each other, but today we had some new members. So in that sense it was out of the ordinary and we had to make a presentation about ourselves to the new members. So, again it refreshed our memories about what we're doing and what we're about.

**Evans:** Okay, tell me what you're about.

**Edge:** Well, we're a group of people, all with chronic conditions, all varying chronic conditions, who've come together originally to help with Swansea University's health and

social care research, into the chronic conditions management policies of all the local health boards in Wales. That's what brought us together, we did some research, we worked with Angela Evans, who was the researcher and when we completed that, we'd formed such a relationship that we decided that we would stick together, depending on whether we got funding, to actually present ourselves as a group of people with chronic conditions offering our services to researchers for any further research.

**Evans:** And what sort of research do you get involved with?

**Edge:** Oh, it's been quite varied. Obviously it's... some of our group are involved in going to meetings organised by the Welsh Government. Those are research management meetings, so they look into all sorts of different kinds of research projects. We've looked at pieces of equipment, some of us have tested pieces of equipment that can be used in people's homes to make them remain independent. These are people with chronic conditions who can remain independent longer. We've looked at data and interviews given by people with chronic conditions and tried to find themes to help researchers.

The amount of research we've done is quite varied actually and it's usually very interesting.

**Evans:** What's the most interesting thing you've been involved with?

**Edge:** I think it's actually reading through some of the interviews. They're so revealing, they vary so much. Some people are very upbeat about their condition and are going to not let it get them down and get through it whatever. Then there are people who, it was very interesting, you know, they'd been prescribed drugs and decided on their own that they couldn't tell their doctor that they weren't going to take them and then had to go and confess it. Yeah, very, very interesting reading about other people's experiences of having chronic conditions actually.

**Evans:** How do you relate that to your own chronic condition?

**Edge:** Well, in my case, I've had my chronic condition for a long time. I think my condition started when I was about eleven and [laughs] I suppose in a way I've sort of grown with it. So I have a fairly, kind of healthy respect for my condition, but I'm like one of the upbeat people. I don't think it stops me really doing anything that I want to do and, you know, obviously I do believe that you have to, you know, look after yourself. I think it's important to keep your mind active and do as much as you can even if you have physical problems. So, yeah, I definitely put myself in the upbeat category.

**Evans:** Firstly that means that you're managing your condition well, the fact that people are downbeat about it, the reports you read, does that tell you something about how they're managed?

**Edge:** Yes, obviously, it is much better if you can be positive about things. If you see the glass half empty, then it could be so easy to become depressed, so along with whatever chronic condition, if that isn't depression, you could get depressed as well. People tell me, you know, 'Oh you're great, you do this, you do that, you live with what you've got and you get on with it', and meetings like this, I meet people who are far worse off than me, I only have one chronic condition. Many of the people in the group have more than one, some of them have several, and they have to manage those as well, and they're prepared to come to meetings, and they're prepared to try and do research to help other people in the future.

**Evans:** That was Jill Edge, who chaired the meeting of SUCCESS that I attended and thanks to all of them for letting me do so. Now coming to the end of this edition of *Airing Pain*, I just want to remind you of our usual words of caution, that whilst we believe the information and opinions on *Airing Pain* are accurate and sound, and they're based on the best judgement available, you should always consult *your* health professional on any matter relating to your health and well being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Before John Flynn and Angela Evans bring this programme to a close, don't forget that you can download or obtain copies of all the previous editions of *Airing Pain* from Pain Concern's website and that's at [painconcern.org.uk](http://painconcern.org.uk). And from there you can also get the contact details to put a question to our panel of experts, or just make a comment about the programme via our blog, messageboard, email, facebook, twitter or even pen and paper.

**A Evans:** I want to encourage researchers to include service users and not to see it as something which is threatening, not to see it as something which they have to do just to tick a box, not to see it as something which is a waste of time, but to come at it with an open mind and really experience the benefits of including service users in their research.

**Evans:** Now to me, I would think it's daft not to use them.

**A Evans:** It's not always an easy process. It can take longer because you're including more people in what you do; service users don't always work at the same pace that you do; if they're not well, they can't, if they're not used to that working environment. You will have different perspectives and you may disagree about things as well as agree, so it's not always easy, but the benefits are considerable.

**Flynn:** I would like to help others on the ground, to give the feedback for them to go to the government to help out. Never mind where people come from, you still come across the pitfalls, they shouldn't be there, but I come across people coming to the information desk in hospitals and I've had a shock how many people open up about epilepsy and nobody comes to the groups. I wish they'd give children from infancy [information] about chronic conditions, they wouldn't be afraid of it and that would cut costs, by recognising the condition in the first place. So that's where you want to start, from the roots, not now, we're too old, you want a fresh man's eye, a child.

**A Evans:** I'm most proud of hearing researchers and members of health boards say how impressed they are when they are at a meeting at which a SUCCESS member is at and how helpful the contributions that SUCCESS members have given has been to the research, how helpful it is to hear the patient perspective and to see a patient in the room and to have their focus put onto a patient so they don't forget them. I think that's what I'm most proud about.

## Contributors

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