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BRITISH BROADCASTING CORPORATION

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THE EXPERT PATIENT

Programme 2.

RADIO 4

THURSDAY 11/08/05 2000-2030

PRESENTER:

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NOT CHECKED AS BROADCAST

MACNAIR

A wet Monday morning in June - and the participants of the first Hammersmith and Fulham Expert Patient Programme are gathering in the community hall for their last meeting.

ACTUALITY

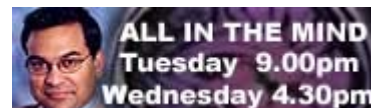
... healthcare ...

The Expert Patient Programme, or EPP, is a course for people who have a chronic health condition. The aim is to help them learn how to take charge of their condition and develop skills which will enable them to manage it more effectively. This week we look at what the health professionals think of a new

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breed of assertive patients.

#### ACTUALITY

Then we're going to take you through working with your healthcare professional ...

#### LOBLEY

The expert patients are mythological creatures that every GP knows they exist somewhere but no one's actually seen one. Parts of the scheme in theory - it would be a fine idea. Let's, for example, take a newly diagnosed diabetic who we'll call Godber, who's introduced to a chap who was diagnosed diabetic several years ago, who we'll call Fletcher. And the idea is that Fletcher passes on to Godber the tricks of the trade so that he can play an active part in the management of his own long term condition.

The Achilles heel in the system would seem to be that the training courses are generic, rather than specific. You'd expect a training course for diabetics to teach them about the condition from which they suffer, but it doesn't - the syllabus is full of fluffy topics, like communication skills.

#### ACTUALITY

#### ARCHIE

... you are not using the words that I understand. To talk about a DVT means nothing to me, yet it's everyday knowledge to you, please just explain under a Patient's Charter what I'm entitled to know what that means. He looked quite shocked, in fact he looked affronted, he said - D V T is deep vein thrombosis. So I said - Why didn't some good soul tell me that rather than me imagine I've got some incurable disease?

#### JEWELL

I have little direct experience of the Expert Patient Programme but I was at a meeting a couple of years ago where it was described and it sounded to me something that could really make a big difference to the lives of people.

#### ASWANI

Where patients have been on the Expert Patient Programme in terms of confidence of their condition and the fact that the patient is more able to ask questions and indirectly take more control of their condition we feel is the first step to their condition improving because that has to be the ultimate goal - that the patient feels confident to manage the conditions themselves.

#### MACNAIR

One objective of the EPP is to teach people how to get the best out of the health system. So there is a strong focus on developing communication skills. Few people would argue that this wasn't a worthwhile aim. People who are able to express their problems are more likely to get the help they need.

But, in private at least, some doctors may worry that this means more demanding patients who will take up more of their time.

Joanne Shaw is Director of the Medicines Partnership, a centrally funded group whose remit is to help people use their medicines more effectively.

#### SHAW

When doctors think of expert patients they think of what they might describe as heart sink patients - people who come in with great sheaves of print outs from the internet, with great long lists of questions they want to ask, people who think they know more than the doctor about the condition, people who are demanding, people who are unreasonable, people who are illogical and difficult to deal with. But that is not what the Expert Patient Programme's about. And I think in reality that reflects a tiny, tiny proportion of real people.

MACNAIR

She thinks the very name "Expert Patient" puts doctors off.

SHAW

Expert patient is a difficult term and it certainly is one that's caused some barriers within the NHS and with doctors. Our view is that the term "involved patient" is possibly a better one. And the thing about the word involved is it doesn't imply a competition between the patient and the doctor about who knows more and it's clear that that's about a partnership, it's about people working together to be involved and engaged in improving care. So that's a term that we like.

MACNAIR

Maybe patient partners or the informed patient hits the note better. But whatever the name David Jewell, Bristol GP and editor of the British Journal of General Practice, thinks that anything that helps patients communicate with their health team is a good thing, especially if it helps them to get the information they need out of their doctors.

JEWELL

People have to know what the questions are that they need to ask when they go and see specialists. The specialist will often have the answers but they can't anticipate what the questions are for each individual person. For instance, somebody with a new diagnosis of diabetes - I know a huge amount about diabetes and it's a terrible mistake to start assuming the patients want to know everything I'm able to tell them, it simply isn't true. So I have to find out from them what it is they want to know in order to get the information as they need it and as they want it. One of the echoes for me was that it said something about the experience I've had with my own mother. She'd had very nasty hip arthritis for years and when she was quite young she had first one and then the other hip replaced and both operations were fantastically successful. But after 25 years or more one had started wobbling around and giving her a lot of pain. And so we went to see a surgeon and it took me a long time to work out what information she needed to help her make a sensible decision.

MUSIC

JEWELL

Although she was I think in her late 70s at the time she still used to do a turn on stage with a friend of hers, where they used to sing and do a little dance. And so when I went with her to see him later on and we talked about doing this operation he talked very specifically about the chances of doing the hip so that she could go back to doing the act on stage. And I - because I was much younger and thought that my mother should have given it up by now - said oh don't worry about that. And then he said - No, no, if that's what your mother wants to do, it's my job to help her do it.

## MUSIC

And as far as I'm concerned this was a lesson in being clear about why you're doing things and making sure you really listen to what those patients need before you decide to give them any advice.

## ACTUALITY - SURGERY

Phone ringing.

Good afternoon [indistinct words] ...

## MACNAIR

GP Ken Aswani, a spokesperson for the Royal College of GPs, has been running the EPP course in his Leytonstone practice, in an area of London that has a diverse population and many healthcare challenges.

## ACTUALITY - SURGERY

Have you got your mum's NHS number there?

## ASWANI

We are running the Expert Patient Programme in this area. I think it's been a successful programme. For example, in diabetes when I'm talking to somebody who's been through the programme and is very informed about their condition they're clearly aware of how they can manage their medication, they're very compliant with their medication and they're very confident and comfortable with their condition. Often people that are leading a normal life and they don't see it as something that's disabling them and they can carry on and enjoy life just as much as anyone else. The other aspect is that we have got the confidence that if there was a problem the patient will know exactly when to consult us.

## MACNAIR

At the Fulham group there is no doubt that some of the participants, six weeks down the line, are looking a bit sprucer and healthier. And what about David Jewell? He said earlier that he didn't have any direct experience of the EPP. So does that mean that despite the fact he thinks it's a good idea he hasn't actually encouraged any of his patients to sign up to the course yet ?

## JEWELL

That's a very fair point. Clearly what I should be doing is thinking of all the patients that might benefit and trying to encourage them to use the - to get involved in the system and I'm not entirely sure why I haven't been doing this already. Except that, of course, it's like any innovation, I don't have any gut sense of who will benefit and it's like anything else - you have to think about it to do it. But you've got me on a very nasty point - I don't like that at all, I feel very uncomfortable. I think, speaking for general practitioners, we tend to be a rather conservative lot, so that the conservatism of doctors in terms of innovations is simply that we like to wait and see until there's very convincing evidence that they're going to do more good than harm. The Expert Patient Programme may well have suffered a little bit because of that.

## MACNAIR

A preliminary survey from the National Primary Care Research and Development Centre at the Universities of Manchester and York, has found that there is relatively low recognition of the initiative within the broader health and

social care community, and that GPs and health professionals have been slow to engage with the programme.

The EPP is derived from a programme devised by Stanford University in California, so perhaps one problem lies in translating an American programme to the UK.

However, the survey also found that health professionals in the UK appeared non-receptive to the idea of a user-lead initiative. But the UK has a strong tradition of self help organised for people with specific conditions by lay-run support groups, albeit with some contribution from professionals. So doesn't the EPP simply fit into this established pattern?

Mike Bury, Emeritus Professor of Sociology at the University of London, has been asked by NICE (the National Institute for Health and Clinical Excellence) to review the evidence for lay-led, self management programmes. Does he think the EPP is formalising what has already been happening in the UK ?

BURY

In one sense it is and one sense it isn't. In the sense that it is it's an imported programme from California - the Kate Lorig Chronic Disease Self-Management Programme - which is a generic programme. Up to now we've been talking about the way in which people manage particular conditions and what's characteristic of the Expert Patient Programme is that it's offered to anyone who identifies themselves as living with a long term condition. So we are looking, in Britain, at quite a radical attempt here to build a programme from the top down, rather than from the bottom up, that is a national programme centrally directed initially through its pilot phase run by the National Health Service.

MACNAIR

In other words, there's an urgent need to carry out some research into EPP as it is in Britain, in order to provide solid evidence about what the benefits of this course, which costs up to £300 per person, really are.

Harry Cayton is National Director for Patients and the Public at the Department of Health.

CAYTON

We're doing two different kinds of research. We have self-reports, both fore and after people have been on the course. And we're also doing a proper large scale controlled trial, comparing some people who are not on the course with those who are. And that's being done for us by universities of York and Manchester and will report at the beginning of 2006.

What the pilot programme showed us that people go to the GP less frequently. That when they go they use the consultation more effectively. That they don't go to A&E - Accident and Emergency - as frequently because they're managing the situation better. That they don't need to use other NHS services as much. But particularly more than half feel more confident, they feel that their symptoms were less severe, six months after completing the course. And a third of people taking the course felt they were better prepared when they did use the health service to get the best out of it.

BURY

What we tend to hear are the voices of those who have been on the programme and who have enjoyed being on the

programme. What we don't hear of course are the people who either didn't want to come, didn't stay and feel patronised or feel that it's unsuccessful.

MACNAIR

The results for the controlled study of EPP in the UK aren't yet available, but Mike Bury is worried about some of the difficulties in interpreting the results of studies of this kind, and is particularly concerned by some of the long term results from Kate Lorig's group in the USA.

BURY

There unfortunately the results are very disappointing in my view. These effects don't seem to be sustained. In one sense it wouldn't be surprising because of course chronic illness is surrounded by many, many factors, so it's not surprising over time, even though people may feel an initial feeling of being more in control, that these other factors will tend to reassert themselves as the months and years wear on. In fact there's very little discussion about what should be the appropriate outcome time to be measured - should we be measuring at four months, six months, one year, two years? For example does two years living with diabetes mean the same as two years living with multiple sclerosis?

MACNAIR

Given all these complications may be we need to be clearer about what we're trying to achieve. Would getting people into groups depending on the disease they have be a better way to go? GP Martin Lobley.

LOBLEY

Well you'd imagine that it would be. But according to a paper in the American Journal of Cardiology recently it probably isn't. They studied a cohort of diabetic patients who have high levels of so-called diabetes related knowledge. The problem is that the nerds among the diabetics did no better in terms of blood glucose levels, cholesterol levels or any other cardiovascular risk factor you care to mention than the numbskulls. And the bottom line is they had just as many heart attacks and just as many strokes.

MACNAIR

Researching this sort of intervention has always been treacherous. It's difficult to try to make precise claims for something that just inherently feels good or right, and the nature of the project easily falls foul of that gold standard, the double blind trial.

BURY

Obviously there are very positive aspects to raising chronic illness in this way and developing new approaches. The point comes when claims are made that this is an effective way of dealing with the public health challenge of chronic illness. To say that for some people some of the time programmes like this work is fine but if you're then going to make stronger claims that this is really a key way of meeting this challenge - that's a claim of a different order. At the same time it also costs money of course to run these programmes, even if they're voluntarily based or volunteer based and that has to come into the picture.

MACNAIR

What does the voluntary sector think of the EPP? There are a huge number of different groups but most people we spoke to, like Jean Dearing Bailey of the National Rheumatoid

Arthritis Society, welcome the initiative.

DEARING BAILEY

Yes this is excellent, this is obviously a wonderful idea and how to be a little bit more assertive if you feel that one of the health professionals with whom you're dealing is not taking you seriously or not listening to what you're saying fully. So the concept of teaching those sorts of skills or acquiring those sorts of skills is an excellent one I think.

MACNAIR

As Jean sees it, the EPP offers a different approach which adds to the range that people can choose from, and which complements her role working specifically with rheumatoid arthritis patients by helping them develop the negotiating skills they may need to fight for the best treatment, as her example illustrates.

DEARING BAILEY

Now this lady had been diagnosed with rheumatoid arthritis three or four years ago and had only seen a consultant once. And subsequently it was left to her GP to treat her. She was miserably in pain, with some of the newer drugs the GP doesn't prescribe them, there are types of drugs that are only prescribed by the consultant. Consequently she's in an absolute stymied position - she can't see a consultant who could prescribe the drugs that she needs and she's feeling dreadfully isolated. I feel that we've become friends really through what we've been through together and we're still working on it, I have to say. Work with contacting local health boards - there's been quite a lot of telephone calls, e-mails, letters etc., flying backwards and forwards.

MACNAIR

Until evidence for the EPP is published, no-one can be sure of the strengths or failings of the project and even then I suspect there'll be a lot of argument.

ACTUALITY

Ian hello, Trisha Macnair. Hi.

Nice to see you.

MACNAIR

Meanwhile another pilot project which has just been launched hopes to open up the EPP to many more people, especially those who can't get to a weekly meeting. I went to Inverness to meet Ian MacNeil, project manager for EPP online.

MACNEIL

What really got me interested in the online courses was seeing its potential for addressing some of the difficulties for putting on courses in the community, particularly in areas like the Highlands here where you've got remote rural dispersed communities, where you can't get the minimum numbers to make a course viable.

MACNAIR

Some people are isolated by disability - is that a target too?

MACNEIL

Very much. Any - anyone really that is unable to access a community course for whatever reason.

MACNAIR

Ironically for a pilot programme being managed in Scotland, only people in England can take part at the moment. People have to fill in an online form to apply.

MACNEIL

... informed consent and people have got full choice of what to do.

MACNAIR

So it's fairly carefully controlled and monitored?

MACNEIL

Absolutely.

MACNAIR

Well perhaps we could take a look at some of the content of the course. Imagine I had signed up and registered and was now taking part in it.

MACNEIL

Okay, let's log you in. Once you'd enrolled in the course you would always come back to this page and so you would just add in what your screen name was and your password, which would be given to you at the time of enrolment. Log in.

MACNAIR

So here it introduces the facilitators. Katie who has irritable bowel syndrome, Ian - that's yourself with arthritis.

MACNEIL

And then it introduces you to your other course members. And you can find out about them just by clicking on the name.

MACNAIR

Now here we are on the course overview with a list of topics which are very familiar from the community course. For example, making an action plan, problem solving, difficult emotions. Perhaps we can look more closely at one of these and think about visualisation techniques - can we see that on the screen?

MACNEIL

Yep.

VISUALISATION TECHNIQUE

Now close your eyes and imagine that you're holding in your hands a bright yellow juicy lemon. Bringing the lemon up to your face and taking a deep breath, the citrus aroma fills your imagination. Now take that lemon, bring it to your mouth, open your mouth and take a big bite out of the lemon - you can taste the bitter rind, the sour tart juice squirts and fills into your mouth, dribbling down your chin. Really suck on that lemon. Now open your eyes and click continue.

MACNAIR

Just explain what that little task was all about.

MACNEIL

It's an introduction to all the participants to realise that using visualisation techniques you can manage your pain using those rather than always looking to, if you like, a pharmaceutical solution to it. That's not to say that people should ignore the pain, that's one of the things that came very clearly through the community course and the online

courses - you don't ignore your pain. It's looking at different ways of managing it again in partnership with what advice you get from your health professional.

MACNAIR

As part of that partnership we need to take some responsibility for our health and this is a major theme of EPP. Everyone so far has talked about how the programme gives people more control and it makes me wonder how far that responsibility and the notion of the expert patient can be taken.

We're already being encouraged to make our own choices in the NHS, about which hospital or consultant we are referred to, and once there we are often expected to take responsibility for certain treatment decisions. Now a new idea has been put forward, that patients should take control of their own health budget.

According to Julian Le Grand, Professor of Social Policy at the London School of Economics there is already a precedent for this.

LE GRAND

Well we experimented with what are called direct payments in social care, that is to say in social services where instead of giving say a disabled person a set of services or a carer who's provided by the local authority or whatever, we've given them the budget so that they can employ their own carer or their own disability aids or whatever. Now these have been terribly popular, the disabled people love them, and say that at last they've got some control over their lives. But one of their frustrations is that they cannot spend any of this money on services provided by the health service, like physiotherapy or whatever. So some people have suggested the idea of maybe extending the social care idea, this direct payments idea, a little bit into the healthcare arena and seeing if it works. There are problems.

MACNAIR

Is there a risk that budgets would run out - the patient would be told sorry you've had your money for this year?

LE GRAND

I think there is a risk of that. The ideas of thinking about and maybe shifting the boundary of these direct payments from social care into a sort of healthcare remit is a very preliminary idea and nobody has yet - I mean neither government nor anybody else - has really worked out all the implications of it. I think that is a question that would have to be answered - what happens if the budget runs out? - or - What happens if you don't spend all the budget? - that's another question too, I mean do you get to keep the money?

LOCK

My name is James Locke. Personally I wouldn't like it simply because the amount of work that's actually involved, you have to really understand everything around buying drugs and VAT and I think it's a whole minefield quite frankly. No I don't think we're ready yet.

MACNAIR

Perhaps instead of making ill people take more and more control, we should be establishing a responsibility for health, and developing health management skills, from an early age, maybe even covering many of the EPP topics within the school curriculum.

LOCK

You know with health everybody has the right to life in health but with health also comes certain responsibilities and people need to understand what those responsibilities are. That comes through education and hopefully when people are sort of educated they're informed and can make healthier choices.

LILIAN

I like working with people anyway, I've had personal experience of that and I have got all the teaching qualifications. I'd like to become a [indistinct word] tutor.

MACNAIR

In Fulham the EPP is drawing to a close. It has enthused participant Lilian so much that she wants to talk to Nicola Kingston, Expert Patient Coordinator, about becoming a tutor. Recruiting new tutors from those who have done the course is essential if the programme is to roll out as planned and be delivered to much larger numbers of people.

CAYTON

Well it's important to know that the trainers are all volunteers and that of course is one of the powers of the thing because they are, as it were, demonstrating to people who take part just how good the course can be and how it can help people to change their lives.

LILIAN

And it's good if you get to the end of the course and you think to yourself - yeah I feel really empowered and I want to share my experience with other people who probably have the same problems that I started off with - feeling very isolated about how they feel. So yeah I want to give back what I'm getting.

MACNAIR

The tutors go through an intensive training and are monitored by assessors during each course they give. But whether there are enough people who are as conscientious and proficient as Liz and James remains to be seen.

I asked James whether he minds working so hard for no money.

LOCKE

It is voluntary action, no one's forcing you to sort of be involved in the programme and as I say I got involved because of the passion.

MACNAIR

I'm going to be very cynical here but I just worry that the government is there getting all its glory, they rely on other people's willingness to help and I think there's a little bit of a cheek there somehow.

LOCKE

Ah well no I disagree with you actually because this is what voluntary action's all about, it's where people are touched by a cause and give their time freely and their reward is the change they see in individuals.

MACNAIR

A characteristically enthusiastic response from James. But at the end of the course, which 11 out of the 13 initial participants completed, what do people think:

STELLA

I'm so grateful for the privilege given to me and my daughter, with so many ways to improve our condition with exercises and we have seen the difference. So I'm so grateful ...

MIKE

In my case worrying about balance and agility - the most important things for me with a spinal injury. They discovered other things but they don't fear me now. I think when I look at how far we've come and you get this sort of - well not superman approach - but I can take these things on. So it sort of refreshes you, you're like a little baby again, enthusiastic, you know, silly isn't it, but there you are.

VIBERT

I think what this course has done for me it makes you look at things much more systematically than I would have done before and give you more courage to confront things you couldn't confront.

ACTUALITY

LOCKE

Now just watch yourself as you successfully complete the steps you need to fulfil your future plans. Now take three more deep breaths and when you're ready open your eyes. Thank you very much everyone.

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