

SECTION TWO

WORKING WITH PEOPLE WITH LONG-TERM CONDITIONS

Introduction

Tom Heller

This section contains five chapters that consider various aspects of working with people with long-term conditions from very different viewpoints. Because the authors approach the subject area from different directions the totality of the section covers many of the most important aspects of this topic.

The first chapter in this section, 'How to Make Health and Social Care Research Radical and Really, Really Useful', looks at the way that people with long-term conditions can and should be involved in research that deals with the issues that are central to their lives. The chapter is presented in the form of a heart-felt debate between the two authors: Rachel Purtell, who is a long-term user of health and social care services, and Andy Gibson, an experienced researcher and academic. The debate is conducted in a warm, friendly and self-disclosing manner, but uncovers many of the complexities and practical difficulties that researchers continue to experience in their attempts to include people who use health and social care

services in research in a meaningful way. Rachel, in her turn, is clear that much research that purports to include people with long-term conditions who use health and social care services can turn out to be tokenistic, patronizing and full of practical hurdles to be overcome. Andy remains optimistic that some of the problems of involving people who use health and social care services in research can be overcome by a mixture of allocating a realistic amount of resources, clear policy directives and flexibility by all parties. The message remains though that 'really really' including people with long-term conditions in the research that will affect their lives is a special skill that requires new ways of working – but that without this effort the research will always be of limited usefulness.

The following chapter by Tom Heller, 'Naught for Your Comfort: Quality of Primary Care for People with Long-term Conditions', takes a case history approach that looks at a 60-year old person who suddenly develops a long-term condition. 'Eric' has a stroke that immediately propels him into being a person with needs. The transition puts a strain on Eric, his self-image and his family relationships. Health and social care services are found to be lacking, in particular the lack of co-ordination between services causes additional problems ensuring that Eric and others like him fall between the gaps. Deficiencies in service provision for people with long-term conditions have been exposed by research and official surveys, but despite well meaning official policy statements, the actual experience for people like Eric remains patchy and unpredictable. New ways of working in health and social services seem to focus on 'efficiency', often seemingly at the expense of continuity and even humanity. The reward system within primary care that provides payment for the teams of health care professionals looking after people with long-term conditions such as stroke seems to reward clinical and formulaic care at the expense (literally) of more person-centred types of caring. The introduction of 'payment by results' for primary care teams has led to instances of 'gaming' and manipulation of those results in order to maximize payment – but with no evidence of improvement in the quality of care experienced by people who use the services or their carers.

Chapter 8, 'Diabetes and Pregnancy: Service-users' Perspectives on Services and on Research', by Cathy E. Lloyd and Sarah Earle, is based on qualitative research that looked in detail at a group of women who were both pregnant and had diabetes. These two conditions separately pose searching questions for health and social care services as well as for all professional practitioners in those services – but the combination of conditions adds additional complexity and a series of new challenges. Both conditions are potentially risky in terms of possible complications and

recent policy directives seem focused on the prevention of tangible clinical problems – but at the expense of attention to the perceived needs and psychosocial requirements of women living with the reality of both conditions. The particular concern of people from different ethnic backgrounds emerges clearly from these stories. Many women felt that their need for support and reassurance had not been met while the staff attended to, and became almost fixated by, clinical issues such as blood sugar measurement and control. Indeed access to ‘normal’ types of care, for example by community midwives, was not routinely available because women with diabetes and pregnancy were deemed to need specialist services that may not include more general supportive types of pregnancy care. Research into these conditions has traditionally been *performed on* the women with these two conditions. But this chapter describes the way that women with the experience of diabetes during pregnancy are keen to help to mould further research, the outcome of which will be valuable for the future design of services.

Chapter 9, ‘Coeliac Disease: Psychosocial Factors in Adults and Children’, explores the available literature from both sides of the Atlantic that has looked in great detail into the experience of living with coeliac disease. In this chapter Ruth Howard and her co-authors document the struggle that adults and children with this long-term condition have to lead a normal life, with reference to a large number of published qualitative and quantitative research studies. Because the disease may not have any external manifestations it is often diagnosed only after a long delay during which time people with the condition may be feeling poorly, often in non-specific ways. Even after diagnosis the need to stick to a strict diet without gluten sets them apart from other members of their family and their social groups. A picture emerges of the life of restriction and ‘otherness’ that children and adults with coeliac disease go through and the possible problems that this can create. Feeling different and possibly excluded while growing up may result in a range of emotional symptoms and a generally lower quality of life than their peers. The parents and carers of young people with coeliac disease often describe a feeling of burden that comes with the additional work involved in arranging a gluten-free diet at all times. For adults with coeliac disease the condition can lead to anger, sadness and pervading tiredness. Always being aware of the need for ‘special’ dietary arrangements and the curbing of spontaneity creates difficulties in the social arena. However a message of hope emerges; when people, young or older, become stabilized and receive suitable support services the condition can be successfully controlled and any psychosocial manifestations minimized or overcome.

The final chapter in this section of the book by Mary Larkin, 'Working with Vulnerable People: Experiences of Disability', espouses the social model of disability and considers the way that services and practitioners could and should work within this model. Mary Larkin argues that a lot of adjustment to policies and services is needed because of the dominance of the medical model and the potentially damaging effect that this has on the lives of people living with impairment. The social model of disability throws light on the myriad ways that contemporary society creates disability and inequality by discrimination, social oppression and inaccessibility of the built environment. Although recent legislation and official policy pronouncements move the agenda in a progressive direction many services have failed to live up to the standards that have been set by the best services – to the detriment of many people who are not able bodied. The chapter does provide an indication of some of the positive ways that progressive policy can be translated into improvement in the lives of people who previously were passive recipients of services. Personal budgets, direct payments and the entire personalization agenda is discussed and a case study describes the way that more positive outcomes can be achieved. Individual health and social care workers are exhorted to take note of the new policy imperatives and use them imaginatively to improve the lives of people who are currently disadvantaged because of their impairments.

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How to Make Health and Social Care Research Radical and Really, Really Useful

Rachel Purtell and Andy Gibson

Overview

- How can people with long-term conditions and other users of health and social services really be involved in relevant research?
- In what practical, ethical and principled ways can people make a meaningful contribution to, and have real influence on, research activities that may affect their lives?
- Redistribution of power will be required if people who use services are to become the main driver in the research process and not simply research subjects

Christmas time 2000, the millennium was dawning, but I was celebrating quite a different milestone. On the 18 December 2000 I, yes me – who had been advised to work as a volunteer for the Samaritans by a careers officer at my ‘special school’, whose educational achievements were somewhat dismal for a whole host of reasons, not least because of the barriers that disabled people face in education and the system’s difficulty in coping with people like me – graduated at the University of Leeds with a Master of Arts in Disability Studies. It had possibly been the hardest two years of my life. True, the Snowdon Awards had funded my place on the course, but I had also worked full time while studying the distance learning course.

On the same day I graduated I was handed a job advert by my Professor, Colin Barnes, the man who had also put his money where his mouth is and accepted me on the course in the first place (for which I will be eternally grateful). The advert was for a Research Fellow at the University of Exeter, to co-ordinate the Folk.us Programme. Folk.us was, and is, an organization funded by the National Institute for Health Research (NIHR), which aims to bring the world of researchers and service users closer together.

A month later I was working out how to get myself moved to Exeter and thinking how utterly bizarre life can be! I was about to start work in a University, me of all people, with my solid working class roots, having had in excess of 80 bone fractures as well as being dyslexic and hearing impaired. Me, who when asked what support I needed, said, 'Well I really won't know until I get there!'

Folk.us, what a job, what a way to make a living! I even get to interview people for jobs, people like my friend here, Andy Gibson.

Andy: I first met Rachel in March 2009. She was on the interview panel for my current job as a Research Fellow in Patient and Public Involvement (I'll explain what that means a bit later on). To be honest I didn't think I was going to get the job, but I did, and a little over three months later I, and my family, were heading from the Midlands to a new life in Devon. Funny where you end up – I left school at 16 with a handful of GCSEs. My first job was as a fitter with what was then known as the National Coal Board. It was bad timing. I started work in 1982, just two years before the miner's strike began. Anyway we lost the strike and in 1989 I was made redundant. I'd been doing some 'O' and 'A' levels in the evening at the local FE college and so I decided to apply for a place at university and managed to get in. So began a journey that brought me to the Peninsula Medical School via a route that included a few years as a social worker and doing a PhD with the Open University. Anyway here I was feeling a bit pleased with myself – and a bit nervous about all the things I said I could do at the interview and which I would now be expected to prove that I could! I'd drifted into the area of service user involvement in research while in a previous job at Warwick University. I'd enjoyed this part of the work and I'd learnt that I'd got some of the necessary skills – such as being able to talk to different audiences and all kinds of people. Perhaps my peculiar career route made it easier for me to have one foot in academia and another

in the ‘real world’, whatever that means. Perhaps this would be a good point to explain what service user involvement, or patient and public involvement (PPI), is. Here we run into our first problem. Although lots of people use these words (in fact it’s become very fashionable), it’s not altogether clear that we are all talking about the same thing. This can lead to some odd experiences particularly when you realize, part way through a meeting, that you and some of the others in the room share very little in the way of a common understanding of PPI, beyond knowing what the initials stand for.

Rachel: Welcome to my world Andy! See, the thing is that PPI isn’t a term we tend to use in Folk.us, we have always stuck with ‘Service Users’ as defined by Viv Lindow and Jenny Morris (1995: 1): ‘People who need some kind of support in order to live in the community, (or take part in the community)’. At Folk.us we also use the phrase ‘Service users, patients and carers to inform and guide research at all stages’ (Folk.us, 2008–9). The debate about language and about how we describe people is a very long and complex one that we could spend this entire chapter on – and still be no nearer any kind of answer. For someone like me, I feel the issue is somewhat clearer on a personal level yet more complicated when relating to the external world. In my own world it is simply a question of my identity at any given time in any given situation. I am someone who is defined as a ‘service user’, ‘patient’, ‘disabled person’, ‘someone who has a long-term condition’ and ‘Research Fellow’. All of these terms can be appropriate. I’m very clear about what I mean when I use the term ‘Disabled Person’. I mean the term to be attached to a very clear Social Model of Disability approach (Oliver, 1983). That is I am someone who has a physical impairment, but is disabled by societal structures (from attitudes to physical barriers). This disabling effect is experienced by many disabled people. When I talk about service users, then the definition of Lindow and Morris fits very well, but I’m also referred to as a ‘patient’, well I’m a pretty heavy user of health care services, and ‘patient’ is how we are described. However no one really fits exclusively into these categories, just like most peoples’ lives.

Andy: Rachel, I think you raise a very important point here. Some of these terms such as ‘service user’, have been promoted by people who have direct experience of living with an impairment and experience disability and who have campaigned for things like better services. Other terms like ‘Patient and Public Involvement’, have been thought up by organizations such as the NHS. There is

an important difference here between 'top down' and 'bottom up' approaches. I think in terms of involvement in research there are examples of both approaches. There are research projects where the initial ideas have come from service users, and others where the ideas come from clinicians or academics. I think both are needed, but something very important is missed if we don't ensure that there are mechanisms which allow service users to influence the research agenda. This can be via suggesting what questions should be researched, or by ensuring that service users have a say in which research projects it is important to fund.

Rachel: Or by supporting service users, patients or carers to become co-researchers in their own right, Andy. I also think there is a different 'stake' in all of these things. I do think that there are different issues in involvement for people who need health and social services to support their daily lives, as opposed to those who use health services very occasionally. That's not to say that occasional service users, or patients, don't have important things to say, but they are different. At Folk.us we tend to focus on regular service users, patients and the carers, who have a slightly different interest in all this, but are deeply affected by what happens in services.

I always find it somewhat amusing when some dear eminent researcher in academia, expects Folk.us to have a bunch of 'patients' in a warehouse out back. They roll off the list of characteristics they are wanting in the 'patients we want to involve in our research'. At the end when I say, '*so, you wouldn't want someone like me then?*' they turn a strange colour and bluster about a little. Then as I gently take apart their notion of patients that fit in to their box, we move on to the idea that perhaps they need to think what sort of experience it might be important for a patient to bring to their project. Perhaps more importantly what sort of support their project will offer the patient to enable them to be involved. But equally it can work in reverse. On more than one occasion I've been contacted by an academic who has asked, 'Can I add your name as the service user or as the patient representative, to our bid?' I reply, 'What is the bid about?', 'Chest function while running up a mountain'. Me, 'Mmm... and how exactly would I be representative, of who and of what, as clearly I'm not about to run up a mountain?' Yes that is a little extreme, though not as extreme as you might imagine. The whole issue of who fits into what box in involvement is very live. It frustrates me intensely. For years there has been work involving people who use services and research that has been service user led, but sometimes it feels like hardly anyone employed professionally to

do 'PPI' has read it! If we were really doing involvement well and properly we would start entirely from the other end. The people we most need as part of the involvement movement are the ones here using the service. At Folk.us we do probably get closer to the idea that people who really do use the services tell us what they want to do. Even when Andy and I speak I sometimes think, 'that's me you're talking about not "a" group, "a" patient or "a" service user – but people like me', though I suspect I might be equally putting the non-service user, non-disabled people, non-long-term patient world into a group – am I Andy?

Andy: I don't think you are. However, one of the first questions to ask is why are people being involved in the first place? Is this based on an ethical commitment that people have a right to be involved, because it might improve the quality of the research or is it about creating some form of democratic accountability? All these things lead to different ways of approaching involvement but the assumptions underlying them are frequently not spelt out. Even when we talk about occasional users of services I think there are important differences in the experience of health and illness and of services. For example, there is research which suggests that doctors share more information with patients they perceive to be better educated (i.e. more like themselves), than they do with other patients (Tuckett et al., 1985). This straight away creates a basic inequality in the treatment that even occasional users of health and social care receive. I hope this is changing. People are less likely to accept what doctors or other professionals say at face value, and they have access to alternative sources of information via things like the internet, albeit of variable quality. This, plus other factors such as advances in medical science that impact on all our lives, means that the pressure for user involvement is likely to increase – although different governments will undoubtedly put their own political spin on it.

However in order to take service user involvement in research seriously it would be necessary to start at the beginning and ask why academics predominately decide what research questions get asked? It should be just as common for service users to be asking the research questions and prioritizing research projects for funding as it is for academics to be involved in these processes. This is something that we both feel strongly about and have worked on to develop. If this happened research would probably be much better at addressing the health needs of service users and would probably save the NHS a bit of cash by spending less money on inappropriate research or badly delivered services.

Another important issue in the world of research is that we slip into using language like ‘health impact’, ‘disease burdens’, ‘epidemiology of this or that condition’, etc. Sometimes it’s useful to think in these terms, but all too frequently these words can distance academics and health professionals from the realities of people’s lives. This distance, which is sometimes defended on the grounds of objectivity, can frequently result in research which doesn’t address the needs and concerns of service users and carers, or which results in new services and treatments that aren’t very accessible or easy to use – particularly by those who need them most. I’m all for the highest possible standards in research, but I also think that one of the many important contributions that user involvement can make to health and social care research is ensuring that the needs of people who are supposed to benefit from all of this are at the very centre of the research process. There is more recognition of this now. Many research funding bodies make user involvement a prerequisite for funding, such as the Research for Patient Benefit programme (see NIHR, 2010 website) but I think some academics still treat it in a superficial, patronizing or over-simplistic way, don’t you Rachel?

Rachel: Mmmm, well yes! I think mostly they just start in the wrong place all together. Partly I think there is an overwhelming and wrong headed need to control the process on behalf of academia and services. *‘Tell people how they will be involved’*; I say *‘No, no, no’*. Tell people the parameters you or your project is working in, what resources you have to support the work including their involvement, what timescale you have. But do not limit their role before you even begin, that is simply opposite to the point of having them there at all. Projects and initiatives have limits, but the wealth of people’s experience does not.

I and others like me, occupy this strange world; I’m a Research Fellow, disabled person and service user. In many ways I think our presence in this world is a challenge. Andy shall I talk about the amount of ‘PPI’ events funded in one way or another by the Department of Health that are physically inaccessible to anyone with mobility or hearing impairments, etc? They are designed for non-service users or non-patients, people who seem to be doing ‘involvement’ for a living, but who are not themselves people who use services. It appears they only apply the value or need for access if they know it’s ‘for a group of patients’ not that it’s part of a good value base to work from, or will you?

Andy: Since you ask I will! Sometimes researchers are concerned that going through the motions of ‘doing user involvement’ can take

up a lot of time and money, while adding little to their research. Alternatively they see it only in terms of the benefit it can give to them or their work. This can lead to people ‘doing involvement’ in a superficial, half-hearted or mechanical way. Unfortunately these examples of bad research practice happen all too frequently. Of course if the process of involvement is done badly it isn’t surprising that the benefits are unclear. It would be like carrying out a piece of research badly and then saying, when the results are inevitably inconclusive, ‘See, I told you this research was a waste of time.’ This kind of experience can be very damaging for both academics and service users and have the precise opposite effect to what is intended. As Brett et al. (2010) point out, the negative effect on service users can be that they feel overburdened, not listened to, frustrated and marginalized. The key issue here is that user involvement is seen as something that is done to people rather than with them. When I see this happening I sometimes feel it would have been better if they hadn’t attempted any involvement at all. At least that way they wouldn’t have done any damage!

So what should involving people in health and social care research be about? I think it is about giving the people who are meant to benefit from this research a say in shaping all aspects of the research agenda. It requires service users to be involved on the same basis as academics and health care professionals. This includes not just participating in research that has been initiated by academics, but also in shifting the power balance so that users and carers are encouraged to initiate research in which professionals are invited to offer their skill and expertise. The interactions and relationships between researchers and service users should be based on mutual benefit rather than researchers extracting useful knowledge and experience for their own benefit. This is partly based on an ethical principle that service users have a right to influence research priorities. More pragmatically it should ensure that the research deals explicitly with service users’ needs and perceptions of the issues – which will increase the probability of effective use of the research in practice. Of course this means ensuring that user involvement becomes as equally integral to health and social care research as good methodology is. Bringing this about in practice would require a fundamental change in how systems operate and a fundamental shift in power.

Rachel: One advantage to being someone like me in this area of work is that often, though not always, I can explain the need for systems to change, not from a distance, but from direct experience. Folk.us

tends to work from the idea that what is essential is to create the right conditions which allow involvement to take place. I think the crucial thing to understand in involvement is that if you get the process right, which means all the boring stuff, then you can pretty much let the outcomes take care of themselves. People think the dull stuff, like sorting payment for people, which generally means hours arguing with your finance department, getting car parking right, finding a format for the written material, is about how you get to involvement. It's not! It is a fundamental part of DOING involvement because if you do that stuff it means that you are valuing what people contribute enough to have had that argument with the finance department. I guess this is second nature to me – the idea of creating the right conditions. Certainly this seems time and time again to be what works. Then all you really need to do is give people the space, the subject matter, or the freedom to come up with their own subjects for research. Currently there is too much emphasis on fitting people into a box and setting too many restrictions. However that is not surprising as the fundamental concept of involvement is to hand over control of the issues. I guess the other thing that is difficult is that involvement isn't meant to be comfortable. Although it does need to be safe for the people involved it is also meant to challenge the status quo. Too often involvement is approached as the need to get service users or patients or carers trained so they will all behave in the same way – again this misses the point.

It also gets forgotten that involvement isn't simply about 'letting the issues be raised' it's about finding the solutions together too. The 'so what' is something we need to ask of much research and again we need people deeply involved with working out those answers too.

There is a huge emphasis on measuring the amount of involvement that has taken place in funded research. This makes sense in terms of public expenditure – the public accountability argument – and no one wants to be wasting public funding especially in 2010. However, it is something that service users involved in research need to be cautious about. In the same way that people tend to be fitted into the 'involvement box', there is a danger of trying to fit involvement into a box that can be measured in separate parts. If the research appears to lead to successful outcomes the danger is to say 'that works so if we just repeat it, it will work again'. Good involvement is never like that because it is an organic growing and changing thing, so you can't repeat it; you can attempt to create

similar conditions each time, but it will never be the same – nor should it be.

One of the reasons that there are problems with putting effective involvement into health and social care research is that it requires systems that adapt and change; that is the point, involvement is supposed to challenge and change things – including how whole systems run. This is also reflected in the reality of the lives of individuals living with long-term conditions who are involved in research. An example is that, as a member of University staff, I am subject to the HM Revenue and Custom rules on staff expenses. That's fine, except that for dinner (while away on University business) the allowance is £13.50, which is pretty low. Add to that the need to find somewhere at the end of a long working day that has good wheelchair access, that is near to where I'm staying in somewhere like London and you get to see how all these difficulties start to stack up. We will, with the support of my University, write to HM Revenue and Customs to ask if I might be allowed a higher allowance. This is where whole system approaches become important. During my time at Folk.us, both on a personal level and working on behalf of Folk.us, I have always tried to explain what we need from the systems that have been established to support our work. Involvement is never just about the project or piece of work that you are currently focused on, but always requires a whole system approach. We have to be willing to take on a whole range of issues or involvement will only ever be tokenistic. This dull, boring stuff is actually about the day-to-day lives and barriers lots of us face. It is a challenge in itself. It bothers me greatly that the 'bread and butter' of making involvement work will simply be overlooked. Furthermore, if we really believe that what we are doing has merit we should simply see involvement as one of the ingredients in successful health and social care research. We've emphasized in this chapter the importance of embedding PPI in the entire research process so it seems illogical to me to come up with measurement ideas that explicitly separate involvement from the whole project and examine it as a separate entity. I don't think it makes any sense Andy.

Andy: I agree and I think in evaluating user involvement a burden of proof should not be placed on service users that isn't placed on other members of a research team. At the same time I think service users do want to know that they have made a difference to the research. It is important to improve practice in user involvement, but in a way that moves beyond simple 'How to' toolkits to take account of precisely the type of complexity we have been discussing. Joanna Brett

and her colleagues (Brett et al., 2010) in a recent literature review on the impact of user involvement emphasize the importance of separating context and process. They define context as whether the right conditions are in place for involvement and process as the specific factors around the way in which involvement is carried out. They suggest that these factors could be described as the ‘architecture’ of involvement and suggest that if they are not appropriately established the chances of beneficial impact seem to diminish. Any evaluation of the impact of involvement on research needs to take these factors into account. Anyway, perhaps the interaction between aims, processes, context and outcomes is a whole new debate or material for another chapter!

Summary

In this chapter we have attempted to cover some of the issues that arise when trying to ensure that the involvement of people with long-term conditions becomes an integral part of health and social research that may affect their lives. We have jointly authored this chapter in an attempt to clarify the issues for ourselves and for people reading the chapter. In summary we might say that if involvement is worth doing then it is worth doing properly or not at all. Getting all the facets of user involvement in research right involves getting stuck into detail as well as sticking to important underlying principles. Dealing with the ‘boring stuff’ is important not because someone says you should do it, but because it has a real and profound effect on the lives of people with a long-term condition. We have also tried to show that simple boxes don’t work. Rachel went from being a badly educated disabled woman, to Research Fellow, to Folk.us director, and is now generally thought to be very good at what she does.

We have also tried to outline some of the current debates about involvement, the need for evidence about its effectiveness versus the risks of turning involvement into something that fits neatly in a box, which we feel is counter to good involvement.

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Further reading

- AMRC and TwoCan Associates (2010) *User Involvement in Research: A Route Map* [Online]. Available at: <http://www.twocanassociates.co.uk/routemap/>. This is an interactive route map for health research charities and other organizations that commission research who wish to involve service users in their work.
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