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The DIPEX project: collecting personal experiences of illness and health care

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How DIPEX came about

The Database of Personal Experiences of Health and Illness (DIPEX) launched its website in July 2001 (<http://www.dipex.org>). This chapter describes how and why it came about, what it covers, and the many issues the project has raised about the methodology of collecting patients' narratives. Andrew Herxheimer (a clinical pharmacologist) and Ann McPherson (a GP in Oxford) had the original idea of setting up a database of people's accounts of their experience of hospital treatments. The database was intended to complement the Cochrane Library (which reports on the best evidence from medical treatment trials) and help people facing treatment decisions to decide what to do. The idea for the database resulted from Ann and Andrew's own "illness experiences" – Ann was treated for breast cancer in 1995 and Andrew had a knee replacement in 1996. Ann had written a personal view in the *BMJ*, and Andrew, a poem about his new knee (Box 6.1). These experiences sharpened their awareness of the value of hearing from others what it has been like to be ill and be treated.

Box 6.1 Poem written two weeks after a total knee replacement

Renewal

After 70 years the knee was tired, weak, rebellious, though still a friend and part of me.

They replaced grating bone with plastic and steel, fixed to the old bones, bound by faithful muscle and skin, new parts of me on probation.

I bend them to my will to make them a full member of the team: a happy and confident knee, setting off only a few alarms.

Ends need means, said the foot to the hand.

Read our lips said the hips, gritting their teeth.

(Andrew Herxheimer, 1996)

In 1996 Andrew asked the Consumers' Association, with which he had worked for many years, for a small grant of £1000 to help develop the idea of a Database of Patients Experiences (DIPEX). Local research ethics committee approval was obtained for distributing a self-completion questionnaire. GPs and

hospital consultants were asked to give this to people who were undergoing hospital treatments. Rachel Miller (a health researcher) joined the group to help with the survey and Barbara Sackett (temporarily in Oxford from Canada) provided administrative support. A poster introducing the DIPEX idea and with results from the survey was presented at the Cochrane Colloquium in Amsterdam in October 1997. In many ways the questionnaire responses were disappointing. Doctors forgot to ask patients to complete them. People who did fill them in wrote little about their experience and feelings about illness – tending to treat the questionnaires as patient satisfaction surveys (“the food was horrible and the nurses were lovely”). The group therefore decided that different methods were needed and asked Sue Ziebland (a medical sociologist working in Oxford) for advice about undertaking interviews with patients. Sue recommended using qualitative research methods to conduct systematic and rigorous studies of each condition or disease included in DIPEX. This would require using purposive (or maximum variation) sampling methods to ensure that the broadest possible range of experiences was included. Rachel had used similar methods before and we started to plan DIPEX as a set of good, publishable research studies that would also make a website resource for patients. We all read Arthur Kleinman’s *The Illness Narratives*.² Andrew and Sue went on a Wellcome History of Medicine oral history course in the summer of 1998 which further influenced us to use a very unstructured “oral history” approach to collect people’s narratives. We also learned from the methods of consent and copyright that oral historians use to deposit interviews at the British Sound Archive at the British Library. These formed the basis of our later multicentre research ethics committee approval. At this stage DIPEX meetings were very informal and conducted around Ann’s kitchen table. Andrew and Rachel were both based in London and drove over for meetings every 4–6 weeks. Sasha Shepperd (a health researcher then based at Imperial College, London) joined the group to advise on the health information side of the site. Sasha had recently developed a tool entitled DISCERN for evaluating the content of consumer health information and we were keen to ensure that information included in DIPEX met these standards. During this time Ann and Andrew (in particular) went to many meetings to promote the DIPEX idea to try to get funding. Almost every time we met to discuss the project we (or others) thought of another potential use for the resource: for carers as well as patients; to improve scientists’ understanding of the public as well as public understanding of science; to help balance the relationship between patients and health professionals; in teaching medical students; illustrating medical text books; contributing to shared decision making; for health issues (for example, screening and smoking cessation) as well as illnesses; as a resource for patients’ representatives on committees and many more.

DIPEX: what it is and what it does

DIPEX is now a registered charity with a research group based in the University of Oxford Department of Primary Health Care. Its primary aim is to describe the widest practicable range of peoples’ individual experiences of health and disease, and to provide a rich information resource for people affected by diseases and for those who look after them. The steering group, responsible for strategic planning and policy, comprises the co-founders (AH and Ann McPherson, also medical director), the research director (SZ), a medical consultant (Rachel Miller), a senior member of the research team (Alison Chapple), the

administrator of the DIPEX charity and a patient/user representative (to be appointed). The research team of nine are all senior qualitative researchers with backgrounds in medical sociology, anthropology, history or policy research, and each is responsible for collecting the data and analysing one module. Each researcher is supported by another DIPEX qualitative researcher and one of our medical team, as well as by members of their project advisory panel. Many of the researchers have said how much they enjoy being part of a project that has a product of such tangible benefit to the patient group they have become involved with in the study. (This benefit is sometimes contrasted with some of the more nebulous outputs of academic research.)

Box 6.2 A story from the DIPEX breast cancer database

Okay last August one Sunday evening I was reaching over on my desk to get a pen and felt a dreadful pain inside my right breast. Prior to that I had had some itching, my nipple was itching very, very intensely and er I didn't think about it, itchy nipple to me didn't mean anything suspicious. But when I felt the pain and the lump er I immediately was struck with fear and foreboding and didn't know what to do. My family were away visiting the in-laws and I had a dreadful night, but I had an appointment at the doctor's for the next day for something else, something totally unrelated. When I saw the doctor that day, the next day after finding the lump er, when we'd finished about the prior consultation I mentioned that I'd found a lump in my breast and I was terribly afraid. He sent me in to see the nurse, the practice nurse, and er she basically dismissed it as being hormonal, my age, "80% of breast lumps are nothing, don't worry, go home, keep a diary." I went home feeling still very anxious and very worried and er kept a diary. That was on the Monday, on the Thursday I hadn't slept for 2 nights, I felt dreadful and er so I phoned the nurse again and told her. And she said "We need an appointment with me and the doctor so can you come in on Tuesday?" That was 8 days after the original appointment, which I agreed to. I went to the surgery that day and sat in the nurse's room for 22 minutes, half naked, feeling absolutely ghastly. She came into the room and said that the doctor was too busy to see me. That was like somebody stabbing a knife in me. Er she took my blood telling me that this was all hormonal and I had nothing to worry about, go home. I went home, I went outside of the practice and broke my heart in the car. It still hurts to talk about this bit of my treatment because I felt as if I wasn't worthy of even seeing a doctor at that point. To be told that the doctor is too busy to see you when you have an appointment, when you're very worried and you've got a breast that won't even fit in your biggest bra was dreadful. Anyway I went home and my sister who was a mammographer of all things was away on holiday. She came back on the Saturday and I confided in her. It was at this point that my life was turned around. She made me promise her that I would go to the doctors and demand an examination. That I did on the Tuesday. I had the appointment for the results of my blood test and I walked into the doctors, put my diary on the table and said "I demand an examination." The doctor said he had examined me and I told him he had not and he said "Okay let's examine you now, I'll go and get the nurse." Prior to this the nurse had told me she wasn't qualified to examine breasts, but that appointment she did examine my breast with the doctor there. Again I felt as if I wasn't worthy of the doctor's attention, that the doctor was shunning me again but at least he did the right thing and he sent me straight to hospital.

The first two DIPEX collections ("modules") dealt with hypertension and prostate cancer. At the time of writing, six more modules have been added, on cancer of the breast, bowel, testis and cervix, epilepsy, and children with congenital heart disease. Work on 12 further modules is progressing (see Table 6.1). We have a list of 100 conditions that we would like to cover in the next five years, but which we will actually

do depends on funding. There are some issues (for example, experiences of medically unexplained symptoms) that, though important, are not associated with a particular voluntary group or area of Department of Health funding, whereas the cancer modules have attracted funding from several sources (see Table 6.1).

Table 6.1 Dipex programme (January 2004)

Module name	Completion expected	Funded by
Lung cancer	November 2003	Department of Health, UK, Macmillan
Heart failure	Feb 2004	2004 British Heart Foundation, UK
Rheumatoid arthritis	March 2004	Arthritis and Rheumatism Council, UK
End of life	March 2004	Gadsby Foundation?
Sexual health of young people	Spring 2004	Department of Health, UK
Chronic pain	June 2004	Private patients?, Trust
Breast screening	June 2004	National Screening Committee, UK
People with dementia and their carers	Summer 2004	Alzheimer's Society, UK (part)
Depression	August 2004	Department of Health, UK
Antenatal screening	October 2004	National Screening Committee, UK
Ovarian cancer	Spring 2005	Cancer Research, UK
Melanoma	2005	Department of Health, UK, Macmillan

Several other UK research groups see the website as a means of public dissemination and added value for their own research on health and illness and therefore collect interviews that are compatible and copyrighted for DIPEX. We are keen to encourage such collaborations. We also promote the use of DIPEX resources in teaching clinical communication and qualitative research methods as well as for secondary analysis by researchers. DIPEX enquiries use the qualitative method of in-depth interviews. Participants are encouraged to talk without interruption about all aspects of their experiences that have mattered to them. This type of “illness narrative” provides raw data and has long been used in social science analyses. In the 25th Anniversary edition of the journal *Sociology of Health and Illness* (2003), Julia Lawton³ reviews how indepth interviews have been widely used by medical sociologists, often to “champion patients’ perspectives, by putting them centre stage” (p 25). However, sociologists do not simply record peoples’ views and perspectives and present them without comment. Research informed by medical sociology

typically examines the contexts in which illness and health behaviours take place, and seeks to understand how society, self, and physical bodies, shape experience of illness. Important explanatory notions which have arisen from this sociological approach include the careful analyses that led to Charmaz's perspective of "loss of self",⁴ Bury's concept of 'biographical disruption',⁵ and Williams's notion of "narrative reconstruction".⁶ These concepts have helped to build understanding of experience of illness, and have inspired research into many different conditions. The rich qualitative data behind every DIPEX module have convinced us that building a website is not enough to alert a diverse audience to the significance of our findings. Papers, announcements, and chapters reporting our findings could help all who communicate and deal with patients, as well as some research communities, and time for writing these is built into the DIPEX programme. We want DIPEX research to contribute to qualitative social science as well as to clinical practice. We therefore aim to publish our results in journals with differing readerships, covering self-help groups, GPs, nurses, various clinical specialists, researchers, medical sociologists, and managers.

Examples of findings from DIPEX narratives

The DIPEX researchers have undertaken analysed, collated, and indexed over 750 narrative interviews so far. We list below some examples of findings that we believe have widespread implications for the management of patients and the design and delivery of health services.

Getting the right information

Many people still do not know how to find information they need when facing a diagnosis or dilemma. This applies to those with common diseases, such as breast and prostate cancer, which are frequently written and talked about and for which information resources and self-help groups are well established. Health professionals are not good at guiding people at an early stage of their disease to sources relating to personal needs and preferences. In our evaluation, based on focus groups with breast and prostate cancer patients, participants reported that information provided by health professionals had been "patchy, inconsistent, contradictory, and haphazard". As one man with prostate cancer reported: "*The information is there but it's not generally and freely put to you unless you go and drag it out of the system.*"⁷ Most participants regarded health professionals as a reliable source of general medical information, but several pointed out that it could be difficult to get unbiased information about treatments from consultants, who often appeared, perhaps not unreasonably, to favour the particular treatment they advocate and offer. People we interviewed distinguished between medical advice, which they said they would not accept from the unqualified, and the practical and experiential information and support they could receive from other patients. They valued DIPEX because it offers access to the experiences of others without the emotional demand involved in personal interaction. Some people are happy to join a support group, but others hesitate to expose themselves to perceived additional emotional demands. Private access to personal information through Internet resources can help those who are shy, uncertain, or simply unconvinced that they could benefit from a support group.

Follow-up – quality and frequency

Specialist cancer services in the UK are under considerable pressure, sharpening attention on the need for appropriate and cost effective follow-up after hospital treatment. When there is little evidence to support specialist follow-up, an individual patient's preference is particularly important. We have explored the follow-up needs and preferences expressed in DIPEX bowel cancer interviews, and have also surveyed follow-up practices in UK hospitals within colorectal cancer collaborative services.⁸ We discovered a wide variation in follow-up patterns, involving different tests, time periods, and personnel, yet very few (3/35 (< 10%)) policies that we were referred to stated that patients should be given a choice about the type and pattern of follow up. Analysis of DIPEX interviews indicates that not all patients welcome specialist follow-up. Some had little faith in tests offered by specialists, were made anxious by hospital visits, or thought bowel cancer patients should be given better information about symptoms and should be encouraged to report any problems to their GP or specialist nurse. Patients' needs were rarely judged resource-intensive: generally, those interviewed wanted a responsive and interested GP, guidance about where to find information and support from the voluntary sector, and clear consistent advice about diet.

Understanding the meaning of “screening”

Interviews with men with prostate cancer revealed that many had had the Prostate-Specific Antigen (PSA) test, often as part of routine private health screening, without being fully informed of the implications of the test results. The UK National Screening Committee does not recommend a national screening programme because there is insufficient evidence, as yet, about the effects of screening, or treatment, on longer term morbidity and mortality. However, we found that men with prostate cancer felt strongly that healthy men should be screened with the PSA test, even if they knew that the test lacks accuracy and that earlier diagnosis has not been shown conclusively to lead to more effective treatment. They believed that early diagnosis *would* reduce mortality, improve quality of life *and* save the NHS money. They argued that testing should be available because (a) symptoms can be ambiguous, (b) screening is seen as responsible health behaviour and would encourage men to look after their health, and (c) there is equivalent screening for women's cancers.⁹ These perspectives explain why prostate cancer support groups campaign to establish a PSA screening programme.¹⁰ Our sampling methods require that we include the broadest range of views, but the research team had to make considerable efforts to find men to interview who were not in favour of PSA screening. Our study also included interviews with men who much regretted having been PSA tested, because the test result came to dominate their thoughts and, in some cases, led to invasive treatment with unpleasant complications. Once a raised PSA has been found, and has therefore to be followed by regular repeat measurements, the man and his family often worry and feel that “something must be done”. Such pressure can be hard to resist, but we hope that the careful balance of views expressed in the DIPEX prostate cancer module, may help men to make a more informed decision about whether to have a PSA test, or not.

[Un]informed treatment choices

People's accounts of what treatments they were offered revealed that some potentially appropriate choices were frequently not mentioned. Sometimes such choices were considered only when the patient had obtained independent information (often from the Internet). For new treatments this is understandable, but a man with prostate cancer expressed a frustration that other men also felt, when he complained that it was hard to get an unbiased assessment of the pros and cons of treatments, because surgeons tend to favour surgery and radiotherapists tend to recommend radiotherapy:

The problem with the options was that it was very, very much compartmentalised. When I went to see the surgeon I think his idea was that radical prostatectomy is the thing. And that's what I've heard from everybody else, because all urologists are basically surgeons and they say to a hammer everything looks like a nail, and I think that's very much the way it is. And so you know, if I went to him he could only give me information about surgery. I was put onto somebody who was involved in radiotherapy and he gave me a lot of information about external beam radiation. (Testimony of a 51-year-old man who chose to have brachytherapy in 2000)

An example from the cervical cancer study is a woman who was offered hysterectomy, but learned through her husband – who was a doctor – about a new operation, trachelectomy, which would leave her uterus intact and so not preclude future pregnancy. The patient consulted the surgeon who happened to be introducing this procedure in another hospital, and she was happy to become the first patient in the UK to undergo the procedure. In two striking scenarios, it seemed quite common for patients not to be offered a well-established treatment option. The first was where “watchful waiting” (also known as “active monitoring”) for men with prostate cancer was judged appropriate as an alternative to surgery or radiotherapy, each of which has potentially serious drawbacks.¹¹ The second example concerned the management of testicular cancer. Testicular prostheses have been available since the 1970s, and men should be informed, in advance, about the possibility of inserting a prosthesis at the time of orchidectomy. However, a number of men reported that they were not told that prostheses were available, and some of those who were told were given no time to decide what to do.

What people say about their medicines

In ordinary practice doctors focus on specific questions, for example, whether the patient is taking the medicine, whether particular effects have occurred. DIPEX interviews differ from such conversations in that the participants have no clinical relationship with the social scientists who interviewed them, they were interviewed at home and may have felt less inhibited, when talking about their perceptions about a medicine and how they use it, than if interviewed in a health care setting. People's beliefs, understandings, and routines often become clear only when they feel free to talk about the medicines and anything else that is important to them, *without interruption and for as long as they want*. Box 6.3 summarises perceived benefits and concerns about hypertension medication, and the following quotes from the hypertension study illustrate some of these key issues.

Box 6.3 Perceptions of taking anti-hypertension medication

Benefits

Feeling protected against stroke

Migraines stopped

Perceived symptoms reduced

Concerns

Side effects, now and in the future

Dislike of taking any drugs

Questioning the necessity of taking any drugs

Not being able to forget about the hypertension

A 61-year-old doctor interviewed for the hypertension module explained why he did not want to take beta blockers, although the impotence that he feared is not, statistically, a notable problem with the medicine:

I never wanted to take beta blockers because they were the main thing that seemed to cause impotence. Those were the ones where impotence was high profile. And therefore I thought I would cut out that worry ... I think I am quite suggestible and once you'd read that the beta blockers might make you impotent ... I said "Oh to hell with that. I'd rather try something that was less up-front about it."

A professional woman aged 60 described how she disliked taking beta blockers and how her perspective on the effects of the medicine differed from that of the trainee doctor she saw:

I saw a young GP, in fact I don't think he had yet passed his exams, who said "High blood pressure, no problem, we will put you on beta blockers." And immediately did this and took my blood pressure a week or so later and it was down to 120 over 80. He said, "That's fine we have solved the problem." And I said, "I feel awful, I feel much worse than when I wasn't taking anything and I don't think beta blockers suit me and can we try something else?" and he said "No, these work. What's your problem?" And I got absolutely enraged with him because he was not listening to what I was saying which was that the quality of my life was wrecked by these things. I felt physically exhausted, I could barely climb the stairs. It was quite a low dose, about 20 mg. I could barely climb the stairs without my legs aching so much I wanted to collapse and I felt depressed ... That's what depression is like ... I remember it very vividly. And this was directly related to that medication.

It is also quite possible to feel that medication protects against a condition, whilst voicing considerable concerns about side effects. However, some participants questioned whether they really needed to take the prescribed drugs, and suspected that they might have "white coat hypertension", which only manifests itself in a hospital clinic. Participants with home blood pressure monitors were able to reassure

themselves that they really did have hypertension, which removed the concern about taking tablets unnecessarily. For this woman in her 50s, dislike of taking medication was serious enough to make her consider not taking any drugs:

And I am seriously thinking of not taking the tablets. I do feel ... I wake up in the morning and I actually feel quite good and then I take the pill and I seem to lose energy. I really ... I don't know if I am imagining it but I seem to not have that life force that I had before I took the pill and I don't know whether that's because I secretly don't like drugs – do you see what I mean? And obviously I'm not stupid and if I knew my risk was incredibly high I would just say "Well I'd rather be here than not be here, rather be here feeling a bit rough than not be here" and I would take them.

What emerges is more complicated and more interesting than “compliance” or “concordance” viewed mechanistically. For example, many people with hypertension, for various reasons, chose not to take their tablets at least part of the time. Some – among them a doctor – “forgot” to take the medication, because they did not want to be reminded there was something wrong. Others felt that the side effects of the medication were greater than could be justified by the risk that they would run if they did not take the medication. One man reasoned that since so many people with hypertension are not being treated, if he left off his tablets, he believed he would be no different from them.

How people seek information about their health, and why

DIPEX interviews contain many accounts of how, and why, people have sought information. Many of our participants had used the Internet – either directly or via a friend or relation – to try to find out about their condition. Their experiences are interesting because little empirical research has so far examined the possible effects of health information on the Internet,¹³ though there has been much speculation. We have analysed the various ways in which people with cancer talk about using the Internet, and have identified not only a far broader range of purposes than has previously been noted, but have also looked at accessing health information means for patients. People use the Internet to check the significance of symptoms, to find out about diagnostic tests, to check that they are being offered the best treatments, to learn how others may have told their children about their illness, to give and gain support, and to share information and campaign. They also describe considerable caution in interpreting the information they find on the Internet – checking it against several different sources and being very skeptical about information that is found on only one site. We conclude that this facility enables people to display – to family, friends, and health professionals as well as the researcher – their expertise; thereby they maintain their sense of “social fitness” which can be threatened by serious illness.¹⁴ This positive aspect of Internet use has escaped other commentators, who have often been more concerned with the dangers of inaccurate and misleading Internet information, or perceived threat to professional identities in medicine.^{15,16}

Uncomfortable topics

Doctors recognise some aspects of diseases as important, but frequently find them too uncomfortable to discuss, among them, incontinence, stigmatisation, sex, and how to tell children when a parent is seriously ill. People who have had cancer describe how sexual difficulties were ducked, and how they struggled to maintain their previous persona. For example, although bowel cancer is often described as an “embarrassing” illness, our interviews suggest that the word is quite inadequate for the utter humiliation and loss of adult identity that many patients experience when they lose bowel control.¹⁷ Professionals who do not understand this are in danger of sounding glib and out of touch when they give advice. Stories of how people had (or had not) told their children about their disease help others to decide what to do themselves. We would have found it hard to imagine how a mother could tell her four-year-old son that she had bowel cancer.

A major theme in the prostate cancer stories is that *“hormone drugs attack a man in every department where he feels he is a man”* – impotence, labile mood, lack of energy, inability to work. Patients may not be warned about these possible effects, and by the time they have had the treatment it is too late.¹⁸ This contrasts with the experience of men with testicular cancer, who seldom reported feeling less masculine after treatment. Most could resume normal life, including sexual activity. An unexpected discovery, which may help in consultations, concerned the way they used jokes. Many who had lost a testicle initiated jokes to manage feelings, to hide embarrassment, to reduce tension, to share a sense of solidarity with others, and to encourage others to examine themselves. These men also described their reaction to jokes made by others, which was usually positive; jokes helped to dispel tension and reassure them that they were being treated as normal by their family and friends. Exceptions were men born with only one testicle who then developed cancer, those who had lost both testicles, and a man who could not ejaculate. These men were sometimes upset about jokes made by others, or by the idea of jokes being made, fearing humiliation, stigma, and prejudice.¹⁹ Although the ability to “take a joke” is an important part of young male identity in the UK, these findings demonstrate the need for clinicians to be careful about using humour until they are confident of the patient’s perspective.

Attitudes to the National Health Service

Positive accounts of experiences within the UK NHS were reassuring at a time when weaknesses in the delivery of health care were receiving widespread media coverage. For example, the parents of children with congenital heart disease expressed enthusiastic admiration for health services, and the way their predicament was handled, and seemed untarnished by the reports on events in Bristol and at Alder Hey Hospital in Liverpool. This was a welcome contrast to the stream of criticisms of the NHS at this time (2002–3), suggesting that it was dysfunctional and ready to collapse. In some cases, an abnormality had been detected during pregnancy, in others it had not been correctly predicted. Whatever the story, parents praised the sympathetic attention and explanation they had received; and when surgery had been needed, they were particularly appreciative of the support from the cardiac liaison nurse, who could be reached at any time. Parents said that they were never made to feel their request for advice was unnecessary, and that the response received was always prompt and appropriate. Intensive therapy units

were also universally admired: mentions included the anticipatory visit which was always offered to the patients interviewed, the constant individual care (one nurse per patient), and the impressively advanced technology used. Open-heart surgery was being performed in tertiary hospitals, often quite far from the family's home, with the resulting potential for expense and domestic disruption. Thoughtfully, funds had been provided for journeys (in one instance visits to outpatients entailed a plane journey), and in some places accommodation was provided for parents and other children if required, with beepers so that relatives could quickly be called to their baby's bedside. DIPEX participants with lung cancer were asked if their experiences had had any effect on their views of the NHS – a question phrased carefully and neutrally to prompt positive as well as negative responses. Either implicitly (by using phrases such as “I couldn't find any fault”) or explicitly in their accounts, patients contrasted their own (usually good) experiences of care with their (usually poor) expectations of the NHS. Low expectations included: that it would take a long time to see the specialist, or that they would have to wait for treatment; and that doctors and nurses would be too busy to give explanations.

Methodological and theoretical issues

The DIPEX initiative has raised a number of methodological and theoretical issues around the collection, analysis, and publication of patients' stories. From the start, we were concerned that a long and detailed interview might upset some patients. Reliving unresolved problems and experiences can be painful; public exposure of private reflections might cause some harm. These possibilities cannot be entirely prevented, but the risk is lessened by employing only experienced qualitative researchers skilled in handling sensitive issues, and by the interview method. At the start of each DIPEX interview the participant is asked to tell the story from the point when she or he first suspected that there was something wrong. The researcher provides an audience for this story, avoiding interruption, until the account has arrived in the present, the day of the interview. Some participants are able to relate a coherent and lengthy story covering the many issues we would ideally like to hear, while others are evidently less confident in talking about what has happened to them. We describe this section of the interview as the oral history or “narrative” part, because the floor is very much handed over to the participant to tell their story in whatever way they want. The researcher may then ask for clarification or expansion of some of the issues raised, before using a set of additional semistructured questions and prompts to explore topics that we are always interested in (for example, ideas about causes, medications, and side effects, where information has been sought, views on the NHS and medical communication) as well as further issues particular to the condition concerned, identified from the review of the literature and earlier interviews. Unlike many research studies that set out with a single, closely defined research question, this type of qualitative study aims to understand the different perspectives, priorities, and interpretations of the research participants.²⁰ Interviews have lasted between 1 and 6 hours and have sometimes involved more than one visit. They are a very rich form of data for many different types of analysis. In a narrative interview the participant controls its structure, length, and content, and intrusive questions are avoided. To guard against publication of material that might cause embarrassment on the website we are careful about our consent and copyright procedures. After detailed explanation about the

nature of this research and the publication intention of the researchers, participants sign a consent form before the interview but they are not asked to sign a copyright form (which gives permission for the interview to be used in broadcasting, teaching, and research) until later. Participants receive a copy of the transcript and are free to withdraw the interview, limit the selections to anonymous written or audio clips, or to identify sections to be withheld. To date about 10% of participants have chosen to remove part of their interview, very few have withdrawn the full interview. Researchers are now categorising the removed sections (for example, personal detail about self or family; pejorative comment about health professional) to elucidate further what types of information people withdraw. In contrast to most quantitative studies, such as surveys that are designed to answer a limited number of precise, pre-defined questions, the relatively unstructured nature of narrative interviews means that interviews for DIPEX projects can be used for many different qualitative analyses. An individual narrative interview can be the focus of an analysis (using, for example, sociolinguistic methods), or interviews can be looked at in their condition-specific collections of 30–50 interviews, or a particular theme can be analysed across several collections. Each of the DIPEX collections is selected as a maximum variation sample (chosen to include people whose experiences are likely to differ because of condition-specific factors as well as the usual age, gender, ethnicity and treatment choice), which is not intended to be numerically representative of the population from which it is drawn. Analyses based on the assumption of a statistically representative sample would therefore be misleading, even though relatively large numbers could be achieved by combining different collections. Patients telling their story have a sense of altruism and solidarity with others, analogous to giving blood. We have been struck by how they feel more part of the wider community in sharing their story; some may even gain greater self-understanding and self-esteem. Many participants have become enthusiastic about DIPEX and feel a bond with it. We also feel a bond with those who do, and want to maintain some contact with them. We have held launch parties for several of the modules when interview participants are invited and many attend. Participants who had contributed to recent modules, and their guests, came to an event held at the House of Lords in March 2003. Many very much enjoyed meeting other DIPEX participants – some had never before talked to other people with their condition.

Conclusion

We believe that the DIPEX collections bring qualitative health research findings to medical audiences and the public, and in the process, *bridge* the different views, interests, and perspectives of these distinct audiences. There is considerable interest in promoting public understanding of science – we believe that a parallel enterprise should be to further science’s understanding of the public. To this end we have encouraged the use of DIPEX interviews in undergraduate and postgraduate education of doctors and other health workers. Patients’ experiences are an important touchstone for the modern NHS, yet there is little agreement about how to incorporate and make use of them. Many committees now routinely have a patients’ representative, but there are concerns that they are rarely “truly” representative of their identity group (a criticism that, it is only fair to point out, is rarely levelled at the sole GP, epidemiologist, pharmacologist or sociologist on the committee). The DIPEX collections are freely available to all and are

a straightforward and powerful way for patients' representatives to enhance their understanding of the experiences of other patients – including those who would never be willing or able to take part in a committee. As more modules are published many different health service committees will be able to draw on DIPEX data to identify the patients' perspectives. The selection of national, maximum variation samples in all DIPEX collections is important for this purpose and should enhance the ability of patients' representatives to contribute to their committees. We are also keen to persuade clinical scientists and their funders to include a patient-centred qualitative component in research.²¹ We have made a start by proposing a link between individual Cochrane reviews and the corresponding DIPEX module.²² For example, the review of chemotherapy for advanced colon cancer would be linked to the summary of what patients who had undergone such treatment had to say about it in DIPEX interviews. To date, DIPEX collections have only included participants who are living in the UK – although people of minority ethnic groups have been included in all our studies. There is, however, considerable potential for international collaborations and we are keen to encourage groups to start collecting compatible narrative interviews of patients in their countries, using the local languages. That should eventually make it possible to compare illness experiences in different cultures and health systems. The first step in this direction has been to publish accounts of the project in other major languages – articles have now appeared in German, Italian, Japanese, and Spanish; Chinese is next.

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