

# A qualitative study, using focused interviews, of the information needs of families whose children's names are on a cerebral palsy register

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## Abstract

**Background** We were concerned that information held on a register of children with cerebral palsy was not being made available to contributing families, and that the existence and purpose of the register was not sufficiently understood.

**Methods** Focused interviews with 13 families selected by purposive sampling.

**Results** Many parents would like more information about the data on registers which include their child. They would also like to be more involved in the design of the register and its reports, but there are practical difficulties in making time available for such activity. Although parents were surprised that they had not already been given more information about the existence and purpose of the register, none were resentful that their child's name was on the register once they were reassured about confidentiality and database security. Parents also had general concerns unrelated to the register which were about their need to be treated as equals by professionals, to have more information about equipment and to have earlier and clearer diagnoses.

**Conclusions** Registers of children with uncommon conditions have well-established roles in epidemiology, planning and research. By fully involving parents in ways suggested by this study, registers can also empower parents. The study should also provide reassurance to those who hold such registers without explicit consent that the requirement to now obtain consent should not create resentment or jeopardize completeness.

## Keywords

cerebral palsy, focused interview, information sharing, qualitative

## Introduction

We were concerned that information held on a local register of children with cerebral palsy was not being made available to contributing families,

and that the existence and purpose of the register was not sufficiently understood. We also needed to improve the information we gave to parents about the register so that their consent was fully informed as required by law (Health and Social Care Act

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2001); and we needed to increase consumer involvement in the use of the data for research as required by the Standing Group on Consumers in NHS Research, a subgroup of the NHS Central Research and Development Committee.

Registers of children with uncommon conditions have well-established roles in epidemiology, planning and research (Newton & Garner 2002). The North of England Collaborative Cerebral Palsy Survey (NECCPS) is a register of children with cerebral palsy born in the north of England since 1991 (Colver *et al.* 2000). It collaborates with four other UK registers and 14 other registers in a European collaboration (SCPE 2002). In NECCPS, data are collected prospectively on demography, risk factors, severity of impairments and impact of disability on individual and family life – the latter through completion by parents of a Lifestyle Assessment Questionnaire (Mackie *et al.* 1998) when their child is 4–5 years old. These data are an important quantitative guide to service provision needs and the socio-economic impact of childhood neurodisability.

The principal aim of this study was to seek families' views about what information they would like about the NECCPS and how they would like this information to be conveyed. However, while interviewing these families, it became clear that they also wished to discuss their own information needs regarding cerebral palsy as distinct from information about the register. Given the strength of their feelings, we thought it appropriate to report and discuss these findings as well.

## Methods

The convenors of NECCPS (who are consultant paediatricians working in the districts of the north of England) were invited to select families for the study from those registered within their districts. Purposive sampling (Rubin & Rubin 1995) was employed to provide a range of participants with respect to age of child, severity, socio-economic status, pattern of disability and area of residence. Parents were then invited by letter to attend a focus group at a central venue.

Despite the availability of reimbursement of travel and childcare expenses, no focus groups

were run as a result of the poor uptake rate of those invited, and faltering attendance among agreeing participants. Therefore, a focused interview method was adopted (Booth & Booth 1994; Holstein & Gubrium 1995). The researchers invited those in the sample to participate in a tape-recorded conversation at a venue of their choice – all chose their family home. The interview, which lasted about 1 h, was semi-structured and followed a topic guide, which is given in the Appendix. Audio transcriptions and contemporaneous field notes were then analysed to ascertain themes and priorities (Glaser & Strauss 1968).

## Results

Thirteen families participated in the interviews (50% of those invited) and their characteristics are shown in Table 1.

A number of themes emerged from the interviews, which are described below and illustrated with verbatim quotations.

### Parents' views on their need for information about NECCPS register

- 1 All participants approved of NECCPS holding data about their children.

'To be honest I haven't seen it. I've never ever seen this (NECCPS data collection form) form.'

'I think its fine. I would expect such data to be collected.'

'It doesn't bother me at all that this information is being kept.'

'Data of this nature might be able to help predict the likelihood of your child having brain damage mightn't it? It seems absolutely obvious to me that data of this nature should be collected and I would think it would be very valuable. I would applaud it.'

'I'd be interested in accessing this data and it would be nice to know for example, whether keeping severely premature babies alive is increasing the incidence of cerebral palsy. I think that information would be interesting. Its fine if it's going to help.'

**Table 1.** Characteristics of the 13 interviewed families

Number of families	13
Residence	Northumberland, Newcastle, North Tyneside, Durham, North Tees, South Tees
Ages of interviewees (years)	22–60 (median 38)
Those interviewed	Five couples Seven mothers alone One father alone
Married	All (Two were adoptive mothers)
Other children	All
At least one parent with employment outside the home	11 families
Ages of children with cerebral palsy (CP) (years)	2–16 (median 8)
Types of CP	Five unilateral spastic CP Two bilateral spastic CP with lower limbs involved Four bilateral spastic CP with four limbs involved Two athetoid CP

## 2 Parents would like more information about NECCPS.

‘Information on prognosis would be helpful.’

‘We don’t know about prognosis. We’re in the dark so any information at all would be appreciated.’

‘Information on other children with the same severity.’

‘The most I would like to know about cerebral palsy is more about the particular type of cerebral palsy rather than just cerebral palsy because I would like to know about our (daughter’s) type of cerebral palsy than just cerebral palsy itself . . . what I find lacking is not enough information about her particular type of hemiplegia.’

‘Information on behaviour you know we have had some really difficult times in the past . . . not knowing that it is common (with this type of hemiplegia) to get epilepsy and the absences.’

## 3 Parents had views on the annual report being directed to parents.

‘Excellent idea. It would be an excellent voice for parents and carers.’

‘The ultimate aim should be to provide information which will help my daughter and other people like her who have cerebral palsy.’

‘You could go too much the other way in

terms of information giving so there has to be a balance.’

‘It is worthwhile. Getting all that information together is always worthwhile isn’t it, especially to see what the needs would be in your area and how people are doing and how they are coping.’

Anonymity and confidentiality were a concern for one parent:

‘It wouldn’t give names though would it?’ (Participant reassured by interviewer.)

### • Format and length

‘A newsletter definitely but not just solid blocks of text.’

‘A CD-ROM for the PC – all the family could access that. Not a video, its not interactive enough is it, just sitting watching?’

‘The length isn’t really important – it doesn’t matter so long as everything is presented in an interesting way and is relevant.’

### • Frequency

‘Annual would be fine.’ (This was a majority view although others were expressed.)

### • Who to distribute to?

‘Definitely to health centres. The sort of thing you might pick up and read in the doctors waiting room, to families and to a wider audience.’

'My family know that she's got cerebral palsy but they don't know what it is and I think they're scared to ask us. Often I think they just don't want to know. Sending it to them would educate them and that would help them and us.'

'To doctors and health centres – they have information and newsletters on everything else so why not on cerebral palsy?'

'Its not the carers of people with cerebral palsy that need information or education about the impact of the condition on family life or need to have their awareness raised, it's other people who do – the general public... just to be more flaming helpful when your struggling with a severely disabled child in a wheelchair.'

- Style: clarity of information was paramount. Parents stressed that information should be easy to read, non-threatening, and free of medical and technical jargon. Most did not want too much detail, rather a general overview.

'Easily digestible and light-hearted. Headlines that get you interested.'

'Something a bit light-hearted really, not too many facts and figures.'

'Not full of medical or technical jargon. We already get enough of information that we don't understand. The doctor baffles us with jargon and we always have to ask the physio afterwards.'

'We feel intimidated by the doctor and all the medical terms. We always have to ask for explanations and we feel stupid because we don't understand. Something in the information on our terms would be very helpful especially about diagnosis and prognosis.'

- Parents contributing to report

'We've got our hands full with x (daughter with CP) and two others under the age of five but we're still willing to help and contribute. I think it's an excellent idea.'

'They mightn't want to contribute but I think they would still read it. They would still want the information.'

Others said they appreciated and supported the initiative, would be interested in receiving information in the form of a newsletter but wouldn't want to contribute (citing mainly reasons of time and lack of confidence).

### Parents' views on their need for general information

- 1 Parents wanted better information sharing with professionals.

- Information sharing: parents thought that information sharing by professionals with each other and with families was inadequate. There was a clear need to be able to access any kind of information as equals to health professionals. This concerned both the quantity and quality of information.

'Professionals need to improve information sharing and be more equal.'

'On the whole I've been treat by most doctors as an equal but the neurologists in particular consistently kept information from us, lulled us into a false sense of security. I don't see why I couldn't have been told and had equal access to information about my child. They said it was due to a fear that I might not bond if I heard anything bad.'

'My GP allowed me to sit down and read through my daughter's notes and see what the neurologist had written... I was very angry and distressed because all the time we were being fed only partial information and being lulled into a false sense of security.'

'When we take x (daughter) to see her consultant, there are usually other doctors and health professionals in the room and he (consultant) always talks to them, he never ever talks to us. We always have to ask the physiotherapist to explain to us what was said afterwards.'

All parents interviewed had a need for more information than they are currently being given:

'I feel there is still a notion of power and privilege with regard to information and

doctors still keep privileged information. My GP does but he's not the child's parent. It does make me very angry. I'm as qualified in my field as doctors are in theirs and they should share information with me as an equal.'

'Being kept abreast of what they (doctors) know and what the current thinking on the condition is would be good, rather than them have their own little secret research societies and groups.'

An understanding of the complexities of sharing information was highlighted:

'The fact that I can articulate myself is unusual and I know from the other parents that I come into regular contact with, that they often don't have the same ability to articulate themselves but they do have exactly the same concerns and the same rights to information as I do.'

## 2 Parents wanted better information about special equipment.

Parents experienced difficulty in accessing appropriate commercially aids, fittings and equipment even when there were no financial barriers to obtaining the items.

Difficulty in knowing about and obtaining appropriate aids, fittings, and equipment. This was especially for the older child. It was a practical problem, not a financial barrier.

'Practical information would be useful – you know, on specialist equipment. We need lots of equipment as our son grows and we didn't know where to get it. It can be very expensive. We only found out by default that some good equipment is available second hand.'

'We never get told about equipment we only found out about it by chance. The doctors don't tell us. The NHS doesn't tell us. It would be excellent.'

'Definitely information on equipment. She is getting older now and has started riding a bike with stabilisers and she wants to try without the stabilisers. It is knowing about equipment . . . we don't know much about equipment and types of equipment that we

can get and what is available to us and that sort of thing.'

## 3 Parents wanted clearer information sooner after getting a diagnosis.

Diagnosis of cerebral palsy was not specifically on the interview schedule. One of the opening questions by the researcher was 'Can you tell me something about your son/daughter's cerebral palsy?' Issues relating to diagnosis and communication and information problems at the time of diagnosis were raised spontaneously by each participant and appeared to be of crucial importance to them. It was discussed as a communication failure on the part of the health professionals. Breaking bad news was an issue and even though children had been diagnosed years ago, many parents remained angry and bitter about the way in which this had been done.

'We only found out by chance (that daughter had CP) when she was a year old. We overheard doctors talking about her.'

## 4 Parents wanted information on the emotional effects of cerebral palsy on unaffected siblings.

## Discussion

The main findings of this study relate to the views parents have about the register and how they would like to have better information about it. Parents were very interested in a register, even though it was not likely to directly help their child. Many parents also wanted further information about a number of aspects of cerebral palsy. This research has informed the frequency, content and distribution of this year's annual report (a copy of the annual report for parents is available on request from the corresponding author), which, for the first time, has been directed to families and has been sent to all families with a registered child. Feedback from this report, together with links made with families during the research will refine future reports. Recent work (Mitchell & Sloper 2002), using focus groups of families with disabled children to explore formats in which parents would like to receive information, found in-depth booklets to be a favoured format. We found similar needs for

the written format, together with a plea for clarity and brevity. This echoes recent work regarding optimum length of explanation by professionals (Goore *et al.* 2001), which cautions that too much information can be as problematic as too little.

Although parents were surprised that they had not already been given more information about the existence and purpose of the register, none were resentful that their child's name was on the register once they were reassured about confidentiality and database security. Thematic analysis of the interviews suggests parents would support even wider dissemination of information from the register rather than any restriction. This is a most encouraging finding and should provide a degree of reassurance to those who hold databases on children with relatively rare conditions without explicit consent that the requirement to now obtain consent should not create resentment or jeopardize completeness.

Our secondary findings concern the ideas which parents brought to the interviews in addition to those in the researcher-determined topic guide with its implicit assumptions about what parents might want to know. Particular areas raised in this way were unresolved issues surrounding diagnosis, effects on siblings of affected children, and access to aids and equipment. Many parents also said they wanted to know more about the cause of cerebral palsy in their child. Our sample size was small but our findings are supported by other studies of the information needs of parents of children with disability (Hollingsworth 1992; Gough *et al.* 1993; Collier 2001). Parents also emphasized the lasting impression made on them by the manner and sensitivity displayed by professionals when imparting the initial diagnosis. Experiences of this event in cerebral palsy and other chronic disabling conditions predict to some extent perceived empowerment and locus of control (Taanila *et al.* 1998), subsequent parental mental health (Baird *et al.* 2000), and future information needs (Starke & Moller 2002). More work is required to understand the changing information needs of parents as their children grow older, as the data here are conflicting (Taanila *et al.* 1998; Collier 2001), and we could not draw conclusions because of small sample size.

The difficulties parents had in attending meetings might have been misinterpreted as parental apathy. When we changed our methodology to suit the lifestyles of the parents, it became clear that parents were very interested and had strong views. Focused interviews may be a good technique for assessing the information needs of families for other chronic, disabling conditions (Pain 1999), not least because of their easier accessibility (researcher comes to participant), and the more flexible, open and consumer-led discussion which one-to-one interviewing permits.

Registers of children with uncommon conditions have well-established roles in epidemiology, planning and research. By fully involving parents in ways suggested by this study, registers can also empower parents. The study should also provide reassurance to those who hold such registers without explicit consent that the requirement to now obtain consent should not create resentment or jeopardize completeness.

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## Appendix

### Topic guide for focused interviews on the information needs of families with children registered with the NECCPS

- 1 General introduction and confidentiality statement
- 2 Aims and objectives
  - Aims: to discover what information families would like about the NECCPS, thus developing a sense of ownership of the data by those from whom it is generated
  - Objectives: to gather opinions and share views as to what information families would like to get out of the survey, and how best it can be conveyed to them
- 3 Style
  - Newsletter
  - Magazine
  - 'annual report' type
  - length
  - layout
  - ?other media, e.g. audiovisual/IT (future)
- 4 Content
  - Numbers enrolled
  - Process of data-handling
  - Severity and spectrum of problems
  - Associated conditions such as epilepsy
  - Geographic and demographic findings
  - Format for presenting statistics
  - Changes in prevalence, aetiology, etc.
  - Summaries of scientific meetings and reports
  - Parental input in the future
- 5 Frequency
  - Annual or less frequently
- 6 Distribution
  - All families on the register
  - Requesting families only
  - Outlets for a broader readership
- 7 Summary of discussion
- 8 Thanks

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