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ORIGINAL PAPER

Service and Wider Societal Costs of Very Young Children with Autism in the UK

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Abstract Autism spectrum disorders are associated with a substantial economic burden, but there is little evidence of the costs in the early years; the period in which children are increasingly likely to be diagnosed. We describe the services used by 152 children aged 24–60 months with autism, report family out-of-pocket expenses and productivity losses, and explore the relationship between family characteristics and costs. Children received a wide range of hospital and community services including relatively high levels of contact with speech and language therapists and paediatricians. Total service costs varied greatly (mean £430 per month; range £53–£1,116), with some families receiving little statutory support. Higher costs were associated with increasing age and symptom severity.

Keywords Cost · Very young children · Autism · Service use

PACT Consortium is in "Appendix".

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Introduction

There is growing evidence of the substantial economic burden of autism spectrum disorders (ASD). Knapp et al. (2009) recently estimated that the costs of supporting children with ASD in the UK were £2.7 billion per year, of which 95% was accounted for by services funded by the state and the remaining 5% falling to families. The substantial burden of autism on public services has been shown to be greater than that of other childhood illnesses such as diabetes and asthma (Flanders et al. 2006) and intellectual disabilities (Mandell et al. 2006).

Within this growing evidence base however, there are a number of gaps. In particular, very little is known about the service use and economic burden of ASD amongst very young children. The pre-school age group is of particular interest and importance because it is increasingly likely to be the period in which children are first diagnosed with an ASD (Charman and Baird 2002) and it is the period in which early intervention programmes are encouraged. In the UK, according to the National Service Framework for Children, Young People and Maternity Services (Department of Health 2004), early diagnosis and intervention in ASD is now the expected norm. There are very few estimates of the cost of services used by very young children.

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Knapp et al. (2009) estimated the annual cost of autism in those aged 0–3 as £585 per annum for those living with families and with intellectual disabilities, £16,185 for children in foster care with intellectual disabilities and £1,243 for those living with families without intellectual disabilities. However, the accuracy of these estimates are limited as they were made by drawing together service use information from previous studies, many of which had very small numbers in the early years age groups.

In this paper we describe, for the first time in detail, services used by a sample of very young children with autism drawn from three centres across England, and examine the range and scope of service use including the relative burden on different service providing sectors, families and the wider economy. We also seek to compare and contrast actual levels of service use with UK national recommendations for the care of young children with autism. We then report total service costs and explore the relationship between child and family characteristics and costs. Data on the use and costs of services in very young children with autism will provide a more accurate picture of the extent of the cost burden of autism in the early years and how this burden falls across different agencies. Together with information on the factors that may help identify children and families who will incur high costs, the results could help to plan services and identify areas where resources should be focused.

Methods

Participants

The sample was drawn from 152 young children with autism who were recruited to participate in a randomised controlled trial of a speech and language therapist delivered communication intervention, though the data presented here were collected at baseline and therefore refer to the pre-randomisation period. The study received referrals from three centres in South London, Greater Manchester and North East England. Children aged 2 years to 4 years 11 months were included if they fulfilled diagnostic criteria for core autism on two current international gold-standard diagnostic instruments, including the social and communication domains of the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2000), a direct play-based assessment of the child's social and communication skills with a trained assessor, and two out of the three functional domains of the Autism Diagnostic Interview—Revised (ADI-R; Lord et al. 1994). In addition sufficient English had to be spoken at home to allow participation in the communication based intervention. Children with 12 months or less non-verbal age equivalent developmental level, those with a twin with autism, those with epilepsy requiring medication, those with a parent with current severe psychiatric disorder requiring treatment and those with severe hearing or visual impairment (parent or child) were excluded. Full details of recruitment and numbers included and excluded can be found in Green et al. (2010).

Procedures

The study was approved by the Central Manchester Multicentre Research Ethics Committee (05/Q1407/311) and families gave written informed consent. A trained researcher assessed the child and interviewed one or both parents prior to randomisation in order to confirm the diagnosis of autism, to collect brief demographic information and to collect information on service use and clinical measures of outcome.

Data Collection

Service use data were collected using a modified version of the Child and Adolescent Service Use Schedule (CA-SUS), which was developed by the authors in previous studies (Byford et al. 2007) and adapted for the purpose of this study on the basis of expert opinion and pilot testing during the start up phase of the study. The CA-SUS was completed following recruitment by the trained research assistant at each site in interview with the child's parent or parents to collect data on a range of services. First, the use of specialist accommodation such as foster and respite care was investigated. Second, the education and day care facilities used by the children were asked about. In the UK, compulsory primary education begins at the age of five, though in practice children are offered a place and begin primary school in the academic year they become five, thus most start school at the age of four. In addition, 3 and 4 year olds are entitled to 15 h of state funded nursery education a week. Families use a range of day care options including private nurseries, childminders and pre-schools. Education services provided within education facilities were not recorded in order to avoid double-counting the cost of those services included in the overall cost of the education facility, and because parents may not always be aware of all services received by their child, particularly in specialist facilities. Third, the CA-SUS asked about all contacts with health and social care services, in hospitals and in the community, including those services provided by non-statutory organisations. In addition, all prescribed medication was recorded. Finally, the CA-SUS asked parents about time taken off work as a result of their child's autism and any expenditure on specialist equipment or other extraordinary costs, such as home adaptations, conference or training attendance and overseas travel that they considered were a direct result of their child's autism.

Costs

Total costs were calculated by multiplying each resource use item by an appropriate unit cost. All unit costs were for the financial year 2006–2007 and were obtained from a number of sources: the costs of education and day care services were sourced from personal communication with government departments and national surveys (Daycare Trust 2008); NHS reference costs were used for hospital contacts (Department of Health 2008); an annual unit cost publication was used for other community health, social and voluntary care services (Curtis 2007); the costs of medication were taken from the British National Formulary (British Medical Association & Royal Pharmaceutical Society of Great Britain 2007); and the costs of non-prescription items from mainstream retailers (http://www.boots.com and http://www.hollandandbarrett.com, accessed in November 2008). Productivity losses were calculated using the human capital approach. Parents were asked which of a range of 11 categories their salary fell into, the mid-point of each category was used as the wage and total costs were calculated by multiplying this wage by the reported time off work due to their child's autism (Koopmanschap and Rutten 1996).

Analysis

We first describe the pattern of the services used by the children. This pattern is compared to the suggested model of contacts related to diagnosis as set out in the autism exemplar published alongside the UK National Service Framework (Department of Health 2004). The exemplar describes the process of a 3-year-old child receiving a diagnosis of autism and incorporates a detailed list of the health, social care and education services a family is likely to come into contact with. These include health visitors, general practitioners, speech and language therapists, plus multi-agency assessment involving representatives from health, social services and education, and tertiary assessment by professionals such as paediatric neurologist and gastroenterologist, where indicated.

Total costs are presented by service providing sector as mean and standard deviation and the characteristics that are significant predictors of total service costs are explored using regression methods. A list of pre-specified possible predictors was created based on the literature and in collaboration with clinical members of the research team: research centre, sex, age at study entry, ethnicity, parental education, ADOS total algorithm score, number of functional domains of the ADI-R meeting criteria for (2 or 3) and time in months since diagnosis of autism. First, univariate associations between each of the specified predictors and total service costs were explored in a linear regression. For continuous variables whilst analyses were carried out on continuous data, for ease of presentation, the difference in cost is shown in two groups split at the median. Then, multiple regression was used to reduce the variable set to those factors independently associated with service costs. The multiple regression initially included all variables that had significant univariate associations with service costs, discarding from the model all variables that were no longer found to be important. Variables that did not have a univariate association were then added and retained if they added significantly to the model, otherwise discarded. The model derived was checked by re-adding each excluded variable to ensure that no variables would make a significant additional contribution (Byford et al. 2000). A significance level of 0.05 was used.

Standard ordinary least squares regression was used on untransformed costs, despite the skewed distribution of the cost data. This approach was used in preference to logarithmic transformation or non-parametric tests because it allows inferences to be made on the arithmetic mean (Barber and Thompson 1998). The results of the model were subject to two checks; first, they were compared with the results from a non-parametric bootstrap regression in order to assess the robustness of the confidence intervals and p-values to non-normality of the cost distribution. Second, the results from the ordinary least squares regression were compared with the results obtained from a generalised linear model where a non-normal gamma distribution was assumed for costs (Blough et al. 1999).

Results

Participants

The 152 participants were recruited from South London (n = 52), Greater Manchester (n = 52) and North East England (n = 48). The children were on average 44.8 months of age when recruited (SD = 7.9; range = 24–60 months) and were overwhelmingly male (91%). In terms of ethnicity, 57% were white, 9% were mixed race and 34% were non-white. The measure of parental education indicated that 74% of the children had at least one parent with post-16 qualifications. Mean scores (SD) on the ADOS (Module 1 n = 117; Module 2 n = 35) were: communication domain 6.3 (1.3), social domain 10.5 (2.0), and repetitive domain 3.7 (1.4). Mean scores (SD) on the ADI-R were: social domain 18.0 (4.1), nonverbal communication domain 10.8 (2.6), verbal communication domain (n = 47) 15.7 (3.5), and repetitive domain 5.4 (2.1). These scores are all above cut-off for autism and indicate the level of severity of autism symptoms. The mean non-verbal age-equivalent level of the sample using the Mullen Scales of Early Learning (1995) was 26.1 (9.8) months and the average time since diagnosis was 5.9 (5.8) months.

Service Use

Service use for the 6 months prior to interview is detailed in Table 1. All of the children in the study lived at home, no use was made of foster care, and only one child spent one night in a Local Authority residential care placement. Ten percent of the children in the sample spent at least one night in hospital during this period. This was usually following an ear, nose and throat operation such as the removal of grommets, or following an accident and emergency attendance. Fifty-six percent of children had at least one outpatient appointment, most commonly with a paediatrician (25% of the sample). A wide range of other outpatient specialities were accessed (38% of the sample), including ear, nose and throat, audiology, gastroenterology, neurology, psychiatry and psychology.

In the community, speech and language therapy was the most widely used service, with 80% having on average 8 contacts over the 6 months prior to interview. Community paediatricians were also accessed by a relatively large proportion of the group (60%), with general practitioners being accessed by 57% and health visitors by 48%. Twenty-one percent of children had at least one prescription for medication, most commonly an antibiotic or antihistamine, and 45% were taking some form of complementary medication or vitamins, most commonly Omega 3 fish oils and multivitamins. Most of the children received some form of education/childcare provision, with mainstream and specialist nursery places being the most commonly used. Other more disability-specific services were also represented, for example, 25% of children had an average of 11 contacts with a portage worker, paid for most commonly by Local Education Authorities (54%) or the NHS (40%).

Costs

Service and wider societal costs for the 6 months prior to randomisation are reported in Table 2. Mean total service costs were £2,581, equivalent to £430 per month and over £5,000 per year. Almost half the costs (45%) were for education and childcare, 41% were for community health and social services and 12% for hospital services. As suggested by the service use data, total costs varied substantially between the children in the study (range £317 to £6,698 over 6 months).

Parents reported a wide range of out-of-pocket expenses, including adaptations and security for the home and garden, replacement and repair of damage to house and contents, specialist equipment such as pushchairs and toys, attendance at seminars and training courses, travel to receive health services and assessments abroad, and smaller items such as nappies, bedding, education materials, additional clothing and specialist diets. On average, families spent an additional £227 as a result of their child's illness over the 6 months prior to interview (range 0 to £3,350). Fifty-one per cent of families reported taking some time off work due to their child's illness over the 6 months (mean 22 h off work per family, range 0–350), associated with productivity losses of £275 per family (range £0 to £8,005). Total costs, including all services, family costs and productivity losses were estimated to be just over £3,000 over 6 months (range £556 to £9,611), equivalent to £500 per month.

Regression Analysis

The results of the univariate regression analysis are shown in Table 3. There was no significant inter-centre difference in total service cost and no significant difference in service cost according to the sex of the child, ethnicity, parental education or the number of months since the diagnosis of autism. Older age was significantly associated with higher service costs. In terms of severity of characteristics associated with autism, higher ADOS score was not a significant predictor of total service cost, but children who fulfilled all three of the functional domains of the ADI-R were significantly more costly than those who fulfilled only two of the three criteria.

In the multivariate regression, no other variables became significant. The coefficients in Table 4 show that for every monthly increase in age, service costs over 6 months increase by £44, or £7 per month. Fulfilling all three of the functional domains on the ADI-R cost an additional £752 over 6 months or £125 per month, compared with children who met only two of the three criteria. Results from bootstrap regression analyses and those based on generalised linear models were not substantially different from the OLS regression results reported in the tables and the full results of these are available from the first author on request.

Discussion

In this sample of young children with autism recruited from three sites across the UK, we found that the children and their families accessed a wide range of hospital and community services. The total cost of these services over 6 months was on average £2,581 per child, though this average disguises substantial variation. The inclusion of out-of-pocket family expenses and productivity losses increases this total to just over £3,000. Applying the same prevalence rate of 1% used by Knapp et al. (2009) to age-specific population statistics for the UK (Office for National Statistics 2009), we estimate the total burden on services of very young children with autism aged between 2 and 4 years 11 months to be approximately £109 million

Table 1 Use of services over the 6 months prior to randomisation (n = 152)

	Total sample		Children with at least one contact		
	Mean	SD	% of sample	Mean	SD
Accommodation					
Residential care (weeks)	0.0	0.1	1	1.0	0.0
Hospital based health services					
Inpatient (nights)	0.2	0.8	10	2.1	1.4
Outpatient paediatrics (appointments)	0.5	1.0	25	1.9	1.1
Outpatient other (appointments)	0.7	1.2	38	2.0	1.2
Accident and emergency (attendances)	0.2	0.6	15	1.5	0.9
Community health, social and voluntary services					
General practitioner (contacts)	1.5	1.9	57	2.5	1.9
Practice nurse (contacts	0.2	0.7	17	1.4	1.0
Health visitor (contacts)	1.3	2.5	48	2.7	3.1
Community paediatrician (contacts)	0.9	0.9	60	1.5	0.7
Social worker (contacts)	0.3	1.0	18	1.8	1.8
Clinical psychologist (contacts)	0.2	1.0	9	2.6	2.5
Speech and language therapist (contacts)	6.2	11.4	80	7.8	12.3
Educational psychologist (contacts)	0.3	0.7	21	1.5	0.9
Special educational needs co-ordinator (contacts)	0.3	1.3	10	3.1	3.0
Portage worker (contacts)	2.7	9.0	25	10.9	15.6
Play worker (contacts)	0.3	2.4	3	12.5	9.6
Art therapist (contacts)	0.0	0.4	1	5.0	0.0
Occupational therapists (contacts)	0.4	2.5	11	3.4	6.9
Physiotherapist (contacts)	0.0	0.2	4	1.2	0.4
Dietician (contacts)	0.1	0.5	5	1.9	1.1
Homeopathy (contacts)	0.0	0.3	1	2.0	1.4
Massage (contacts)	0.1	0.8	1	6.5	4.9
Osteopath (contacts)	0.2	2.0	1	25.0	0.0
Other community services (contacts)	2.0	5.7	33	5.9	8.8
Voluntary sector (contacts)	1.1	2.8	30	3.9	4.0
Voluntary sector (phone calls)	2.2	5.8	42	5.3	8.1
Medication					
Prescribed medication			21		
Complementary medication			45		
Education and childcare					
Mainstream nursery (weeks)	14.0	12.6	64	22.7	7.7
Specialist nursery (weeks)	3.6	8.2	18	20.1	6.8
Mainstream playgroup (weeks)	3.3	10.2	15	21.9	17.0
Specialist playgroup (weeks)	3.9	9.7	20	19.9	12.8
Mainstream school (weeks)	1.9	6.9	11	15.9	13.8
Specialist school (weeks)	0.9	4.1	6	14.6	9.4
Childminder (weeks)	0.7	4.0	3	25.0	2.0

per annum and the wider societal costs to be approximately £130 million per annum.

The study aimed to recruit children in the early years before their fifth birthday and discussion with families took place as soon after diagnosis as they and referrers felt appropriate (mean time since diagnosis 5.9 months). Given this and the age of the study sample (mean 45 months at baseline), for some of the children in the study, a diagnosis of autism was made during the 6 month period preceding baseline and over which service use data were collected. The National Service Framework exemplar (Department of Health 2004) emphasises the importance of contact with a

Table 2 Total costs per child for the 6 months prior to interview (n = 152)

	Mean £	SD	% of total service cost	% of total cost
Accommodation	16	200	0.62	0.52
Hospital based health services	301	441	11.66	9.76
Community health and social services	1,066	893	41.30	34.58
Medication	16	80	0.62	0.52
Voluntary sector services	30	82	1.16	0.97
Education and childcare	1,152	824	44.63	37.37
Total service costs	2,581	1,247	100.00	83.72
Out-of-pocket expenses	227	481		7.36
Productivity losses	275	601		8.92
Total costs	3,083	1,670		100.00

multidisciplinary team to confirm diagnosis, thus we would expect to see a pattern of multi-disciplinary involvement in the data presented.

The high rates of contact with speech and language therapists (80%), could suggest that speech delay may be one of the earliest indicators of a developmental problem in very young children, particularly since guidelines such as the National Autism Plan for Children (Le Couteur 2003) recommend assessment and treatment by an appropriately trained speech and language therapist. This finding emphasises the need for speech and language therapists to be well trained in the early signs of autism and to recognise their role in assisting parents to find appropriate support for further multiagency assessment. Contact with paediatricians was also relatively high (78% including contact in hospital and in the community). The involvement of educational psychologists and special educational needs co-ordinators appears low. However, reported contacts are those which took place outside of the early years education environment so these figures are an underestimate. In addition many of the children in the sample were yet to begin compulsory schooling so would not have come into contact with those professions allied to education who are responsible for assessing children's special educational needs. Local Authority social services had limited involvement, whilst in contrast the involvement of the voluntary sector was relatively high, suggesting an important pattern of service use to consider nationally. Non-statutory organisations most commonly accessed included the National Autistic Society and Contact a Family for parents of disabled children. Services provided by these organisations varied considerably, but the provision of advice and support was most common and contact was most often by telephone.

Table 3 Univariate associations with total cost

Variable	Number	Mean cost (£)	*p* value
Study centre			
South London	52	2,666	0.532
Greater Manchester	52	2,650	
North East England	48	2,413	
Sex			
Female	14	2,791	0.509
Male	138	2,560	
Age			
<45 months	75	2,323	0.001
≥45 months	77	2,832	
Ethnicity			
White	87	2,694	0.419
Mixed	14	2,353	
Non-white	51	2,450	
Parental education			
No post-16 education	40	2,360	0.192
Post-16 education	112	2,660	
Months since diagnosis of autism			
<4	72	2,451	0.077
≥4	80	2,698	
ADOS total score			
<17	74	2,558	0.436
≥17	78	2,603	
ADI-R domains			
Meets cut-off on two functional domains	19	2,023	0.037
Meets cut-off on three functional domains	133	2,661	

Table 4 Multivariate regression for total cost

Variable	Coefficient[a] (95% CI[b])	*p* value
Age (months)	44 (21–68)	0.000
Three functional ADI domains (versus two)	752 (175–1,330)	0.011

Adjusted $R^2 = 0.099$

[a] The coefficient denotes the increase in cost per unit increase in the variable measure

[b] The 95% confidence interval is from the OLS regression

The regression analysis identified only two factors that were significant predictors of service cost. First, service costs were significantly associated with increasing age. As the children in the sample get older they are likely to change the nature of their daycare to more resource and time intensive activities, for example from playgroup to nursery to school and there is an increasing cost gradient to

these placements. Second, children who met criteria on all three of the functional domains on the ADI-R cost an additional £752 over 6 months compared with children who met only two of the three criteria. This finding suggests that higher rates of service use and thus costs are associated with more severe or pervasively impaired cases. There may be a number of reasons for this; perhaps children with higher scores are more likely to be receiving specialist education with enhanced intensity and more contacts and a wider range of contact with health care services. Whilst these results suggest that use of services and cost are thus sensitive to individual children's needs, as specified in the National Service Framework (Department of Health 2004), the high levels of variation suggest that many children in this study are receiving only very limited service input, which raises concerns about the equity with which services are accessed. It is not possible in the current sample to determine whether lower levels of service use are a result of supply or demand decisions and further research is needed.

The regression analysis was also able to highlight the characteristics that did not significantly impact on service use and cost. For example, there is frequent concern that less well educated parents or those from minority ethnic backgrounds may access fewer specialist services (Liptak et al. 2008; Thomas et al. 2007); we found no evidence of this pattern in our data despite variability in the socio-economic circumstances of the participant families. We also found no significant geographical differences in service cost by study centre, a significant positive finding in the context of the national remit of the National Service Framework. There was no significant difference in cost by gender, although the number of girls in the sample was relatively small. Total cost of services was not associated with autism severity as measured by the ADOS, although there was a significant association with the pervasiveness of symptomatology as measured in the ADI-R. This finding may reflect rating differences between parent self-report (ADI-R) and direct observation (ADOS). When reporting severity in the ADI-R, parents will integrate symptoms and functional impairment across a range of contexts and a high score on three domains rather than two will reflect pervasiveness of difficulty. This may make the ADI-R a more sensitive marker of overall difficulty in relation to cost, and/or reflect the level of parental concern and thus the level of their service-seeking behaviour. There was also no significant association between service cost and the number of months since the child had received their first diagnosis of autism, which suggests that the relationship between diagnosis and service use is complex and that there is currently no simple pathway from diagnosis to service provision, as the National Service Framework recommends. Costs appear to be better explained by the age of the child and their consequent access to special or mainstream education provision, a key cost driver in this group.

The range of total costs in this sample suggests that there are some children with very low levels of service use and some children with very high levels of use. Many families had only limited contact with health services and received little or no child care provision, perhaps suggesting that the daily burden of care fell on the families, whilst others had a wide range of intense and frequent contacts with services. It is not possible to conclude here whether the low or high costs are sufficient, only that there is a range. Indeed only around 10% of the cost variation (adjusted $R^2 = 0.099$) could be explained by the predictor variables identified in the analysis suggesting that there is an absence of association between participant characteristics, needs and costs. This would suggest that there may be an element of randomness in the allocation of resources in this group of young children and that providers should consider better targeting of resources based on need. Alternatively, this finding may suggest that we have failed to measure important characteristics that better explain variation. For example, low levels of service use may be associated with adequate support being provided by parents and carers, which we have not been able to measure here.

One limitation of the data presented is the lack of individual-level data on the services provided to the children within education facilities. An accurate assessment of the level of contact this sample had with educational professionals is therefore not available, although the impact on costs is minimised for professionals paid for directly by the education facilities and thus included in the cost of a placement. The analysis presented also excludes informal care costs—the cost to the family of the additional time spent caring for a child with autism. It is therefore likely that the costs reported are an underestimate of the total economic burden of autism in very young children. A second limitation is the short duration post diagnosis. This study lacks a longer-term perspective on the economic burden of autism which is likely to become clearer as the degree and impact of the child's difficulties become more apparent. Another limitation is that the data reflect UK services and provision. The relevance of these findings to other settings will depend on the similarities and differences in health provision between different health systems.

We report here service use and cost data from the largest sample of pre-school children with autism described to date. Children and their families were recruited from three centres from across the UK; the multiple sites and the range of demographics means the data may be representative of service provision and service use across the UK. We found that children with autism use a range of services across healthcare and education and that the financial burden to services is around £5,000 per child per year. This estimate

is higher than previous estimates of the cost of services for very young children but because it is the first to be based on a specific sample, it is likely to be more accurate. Our results suggest some positive conclusions about the current implementation of National Service Framework recommendations, particularly in relation to access to paediatricians and speech and language therapists, although they also highlight that, even in this group with high health needs, access to resources in individual cases is patchy. Further research in this area should focus on the cost-effectiveness of interventions for very young children with autism in order to ensure that these substantial resources are being allocated in a way that maximises the benefits to be gained for this group of children at a crucial stage in their development.

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Appendix: PACT Consortium

University of Manchester—Katy Bourne, Laura Blazey, Clare Holt, Dharmi Kapadia, Wendy MacDonald, Andrew Pickles, Lydia White.

Stockport PCT—Tori Houghton, Carol Taylor.

Newcastle University—Anna Cutress, Sue Leach, Ann Le Couteur, Helen McConachie.

North Tyneside PCT—Sam Barron, Ruth Colmer, Sarah Randles.

Southwark PCT—Karen Beggs, Julia Collino.

King's College London—Pat Howlin.

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