

CHILDHOOD VACCINATION: PUBLIC ENGAGEMENT WITH SCIENCE AND DELIVERY

RESEARCH REPORT

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1. Background

Across the globe, childhood vaccination is widely regarded to epitomise the effective (and cost-effective) application of science and technology to current public health problems. It is central to future hopes in tackling diseases both of poverty and of excess. The production and delivery of new vaccines, combinations and applications has become a major focus of research and funding within a highly globalised field. Multi-national pharmaceutical companies, NGOs, research institutes, foundations and global health organisations now interact with wealthy and poor governments in initiatives and new forms of partnership which are extending vaccines to every person on the planet, and moulding health services in the process.

Recent, high-profile controversies nevertheless point to public anxieties around the application of vaccine technologies. In the UK, parental concerns over possible adverse effects of the measles, mumps and rubella vaccine (MMR) since the early 1990s have built into a movement interplaying with scientific and media debate, and MMR uptake levels have, in some localities, fallen by 30%. In Northern Nigeria in 2003-4, parents and their communities refused the Oral Polio Vaccine, associating it variously with HIV transmission, infertility and international and national genocidal politics. The global polio eradication programme stalled, and polio reappeared throughout West Africa.

Whether in Europe or Africa, such controversies - at the broadest level - can be understood as emerging where the rapidly advancing, globalised health technology and technocracy involved with vaccines and their delivery encounters the deeply intimate personal, cultural and social worlds of parenting and childcare. It is perhaps inevitable that childhood vaccination has become a key issue around which debates over public engagement and trust in science and technology proliferate. As these debates have unfolded in social science literature, public health discourse and popular commentary, recurring themes and contrasts have emerged which link vaccine-specific anxieties to broader dimensions of society, and science-society relations.

First, a strong contrast is drawn between 'North' and 'South': the idea being that a concern with vaccine side effects is a luxury of those in the north no longer familiar with the childhood diseases ravaging the south, where the more important clamour is for vaccine access (Obaro and Palmer 2003, Streefland 2001). This evokes a broader contrast between late-industrialised 'risk society' (Beck 1992) and a still-to-modernise 'underdeveloped society'. Second, and relatedly, a contrast is drawn between the anxious middle classes, as against a more compliant poor (e.g. Pareek and Pattinson 2000). A third contrast turns on irrationality vs. rationality, associating vaccine anxieties in the south with incomplete (rising) scientific rationality in settings where 'traditional' beliefs still predominate and in the north, with a 'rise of irrationality' in society, as evidenced for instance in the increasing popularity of alternative medicine (e.g. Fitzpatrick 2004).

Other debates turn on the role of knowledge and information. Fourth, then, low vaccine uptake is linked to public ignorance, or deficit in scientific understanding, of the value of vaccination or evidence of vaccine safety (e.g. Elliman and Bedford 2001), and to misinformation and rumour spread by irresponsible media and pressure groups (Andre 2003, Hargreaves et al 2002, UNICEF 2003). Fifth, and relatedly, reason (driving evidence-based decisions or governance) is contrasted with emotion (as driving some parents' personal choices). Finally, vaccine anxieties in the north are being cast as part of a generalised breakdown of trust in public institutions (Fitzpatrick 2004, Hobson-West 2003), evidence of growing critical public engagement with scientific expertise (Irwin and Wynne 1996). In contrast, southern analytical traditions stressing the non- or incomplete integration of expert science with 'indigenous knowledge' and beliefs tend to attribute vaccine anxieties to collective resistance based on religion or traditional beliefs (Streefland 1999).

These contrasts and stereotypes - which often pass for 'explanation' of vaccine refusal - can be seen, in part, as rooted in scientific and public health frustrations with non-compliant publics, and research framed by these. They are also rooted in long-established differences between the analytical traditions that reflect on science-society relations in European and African settings, respectively. Our research set out to consider these terms of debate from a different perspective, rooted in ethnographic and anthropological understanding of how parents are thinking and deciding about vaccination, amidst diverse personal experiences, cultural knowledges and perspectives, social relations, and experiences of national and international institutions. It explored how parents in localities in Britain and West Africa are engaging not just with routine vaccination, but with issues involving vaccine science and scientific controversy.

2. Objectives

The overall objective of the research was *to develop comparative insights into science-society relations in European and African settings which have conventionally been theorised very differently, through the case of childhood vaccination research and regimes*. This objective has been addressed in a preliminary way through drawing key comparative themes and insights from the country-specific analyses, as reported in section 4.3. This comparative work, which is necessarily at a broad level given the stark differences of context between Britain and West Africa, will continue in post-award analysis in engagement with wider literatures and be presented in full in the proposed book output from the research.

To do so, it focused on the intersection of routine vaccination with the MMR controversy in the UK and with MRC-orchestrated vaccine research in The Gambia, aiming in each context to:

- *Identify how public concerns with vaccination research/ regimes are socially differentiated and shaped by diverse conceptual frameworks and knowledges around infection, disease and immunity, and experiences of the state and of science in other domains*. This was addressed and met fully through ethnographic and survey research with parents in Brighton, UK and The Gambia, reported in sections 4.1 and 4.2 respectively;
- *Specify how different people consider trade-offs between social and individual benefits and risks, the differentiated notions of 'community' and 'communities of trust' implied, and how this influences socio-political organisation around vaccination*. Again, this was successfully met through ethnographic and survey research with parents in Brighton, UK and The Gambia, reported in sections 4.1

and 4.2 respectively, as well as through a focused case study of the parental movement around MMR.

- *Identify how vaccine scientists and public health professionals conceive of public knowledge and attitudes towards vaccination programmes, and how 'frontline' staff mediate professional and public views.* This was addressed and met successfully through interviews with scientists, public health professionals, and fieldworkers nationally and locally, reported for the UK in section 4.1 and for The Gambia in section 4.2. International public health and scientific discourses (summarised in Background above, and to be documented more fully in forthcoming book) were gauged through participation in several conferences and networks, e-mail discussion and literature study.

Further, the research aimed *to support the development of new approaches to public involvement in research into vaccine technologies targeted at children, their delivery and promotion.* This objective was addressed through (a) working collaboratively with local and national governmental and research organisations (detailed in Activities and Achievements Questionnaire 2B), with whom intensive discussions were held throughout the research; (b) feedback workshops to a wider set of users in each country, and (c) proactive seeking-out of new citizen-participatory approaches and 'experiments' in each country context. In both settings, these interactions have led successfully to some minor shifts of approach and communication strategy by established institutions, as indicated in section 7. However, as embracing new participatory approaches involves challenges to powerful public health and bioethical discourses, encouraging these is a long-term challenge which will necessarily extend beyond the project's timeframe. In this context, innovative experiments that we might interact with have proved rare. An exception in the UK context is the New Economics Foundation's 'DEMOCS' gaming approach which has developed an MMR pack, and where we made advisory inputs based on our research.

3. Methods

Our research approach was characterised by its meta-level comparative framework, its collaborative context, and its combination of qualitative and quantitative methods. The Gambia and southern England were chosen not with any claim to be fully representative of African and British conditions, but as places where pressing controversies around public engagement with vaccine science are ongoing, allowing the generation of context-specific insights which could then be drawn together in broader comparative discussion.

The Gambia has been the locus of British Medical Research Council (MRC)-orchestrated medical research and vaccine trials for the past fifty years, with research stations throughout the country engaging a large proportion of the population as actual or potential 'study subjects', alongside the administration of routine vaccination through the country's relatively strong primary health care infrastructure. The research focused on rural Upper River Division (URD), the site of the joint MRC-Gambia Government Pneumococcal Vaccine Trial, and on urban Western Division, where some parents had engaged with the MRC Sukuta Birth Cohort study researching infant immunity and responses to infection. These two sites also enabled a comparison of rural and urban settings, an important distinction in rapidly-urbanising West Africa. The research was developed in collaboration with local and national staff of MRC and the Gambian Government Expanded Programme on Immunisation, through preliminary discussions, a methodology meeting and preliminary feedback

workshops. Approvals were obtained from the MRC Scientific Co-ordinating Committee and the joint Gambian Government-MRC Ethics Committee.

In the UK, the research focused on the city of Brighton and Hove, chosen for its locality to the researchers and its particularly sharp decline in MMR coverage. Collaborative partnerships were developed with the Brighton and Hove Primary Care Trust and a Stakeholder Advisory panel comprised of key national policy-making, health professional and parents' organisations (see Activities and Achievements Questionnaire section 2B) who participated in preliminary discussions, a methodology meeting and preliminary feedback workshop. The study was approved by the East Sussex, Brighton and Hove Local Research Ethics Committee and appropriate research permissions given by South Downs NHS Trust and Brighton and Hove City PCT.

In each country, a first phase of in-depth qualitative research was conducted using ethnographic methods. In The Gambia, this took place during March - November 2003, with ML and JF spending 3 months and Gambian Research Officer Mary Small completing the work. Ethnography focused on the peri-urban settlement of Sukuta, rapidly-growing from an old Mandinka settlement, and on the rural Mandinka village of Tambahansang in Upper River Division (URD). In the UK, ethnographic research took place during February - October 2003, conducted primarily by Research Officer Mike Poltorak but with major inputs also from ML, and focused on the catchment areas of two collaborating GP practices: Whitehawk, a stereotypically 'deprived' area, and Fiveways/Preston Park, a stereotypically 'middle class' area - thus illustrating contrasts which have been significant in popular debate over MMR. Ethnographic methods included participant observation in social settings where parents take infants (Gambian compounds, clinics and markets; 5 Brighton carer and toddler groups), recorded focus group discussions (9 in The Gambia, 4 in Brighton), observation of clinic interactions and interviews with frontline health professionals (12 nurses and 18 MRC fieldworkers in The Gambia, 8 GPs, 3 practice nurses and 6 Health Visitors in Brighton), and narrative interviews with mothers identified through participant observation (100 in The Gambia, 23 in Brighton). Initial interviews in both settings suggested the value of an open-ended biographical format to allow mothers to speak openly about the processes and issues surrounding their decision-making, so narratives took the form of 'child health and immunisation biographies'. These were tape recorded and fully transcribed in Brighton, and noted by hand and later fully typed up in the Gambia where recording is socially sensitive, and analysed by drawing out key narrative themes. All have been stored confidentially.

In the second, quantitative phase, a survey questionnaire was developed for each country to explore the significance of the key narrative themes amongst wider populations, and in relation to social variables (see Annexes 1 and 3). Survey design and methods were adapted to the particular issues and logistical possibilities in each country context.

In the UK, the sampling frame consisted of all children aged 15-24 months listed on the Child Health Dataset held by South Downs Community NHS Trust as resident in the catchment of Brighton and Hove City PCT, on the date of record extraction in early March 2004. Children were categorised into those who had and had not had an MMR immunisation recorded, and of the 1800 children eligible, a sample of 1000 MMR uptakers and non-uptakers in a ratio of 1:1 was randomly drawn, using the statistical programme STATA 8. All the 135 registered children who had had no vaccination events recorded were also identified. A postal questionnaire addressed to the mother or guardian of each child was sent in March 2004. This contained a questionnaire for the mother, and also one to be passed where possible to the father of the child. A follow-up letter with a second

questionnaire was sent after 3-4 weeks to non-responders. The questionnaire explored rank of child within the family, sources of information on parenting and immunisations; early health of the child (including its birth); views on the risks associated with measles and the MMR; interactions with health care professionals and others in relation to MMR; the process of decision making, including attitudes to public bodies and governments as sources of advice and influence. In addition, a range of specific statements made by Brighton parents as part of the ethnographic phase were offered for agreement or disagreement. Completed questionnaires were linked with children's data as recorded on the child health database, from which additional information was derived relating to: gestational age, birth rank, prematurity, age of mother at child's birth, and immunisations given within the NHS. Apart from mailing lists, all person-identifiable data was handled only on secure NHS servers with appropriate permissions. 452 of 1135 mothers' questionnaires were returned, representing an overall response rate of 39.8% (Annex 2 table 1), as well as 257 Fathers' questionnaires. Data were entered by the firm Abacus, and analysed using STATA software, especially to explore differences between mothers who complied (reported choosing to have MMR on time) and who did not comply (choosing to delay MMR, not to vaccinate with MMR, to obtain single jabs, or who remained undecided). Analysis of Fathers' data and paired Mother-Father responses to draw out gender differences and negotiations is yet to be carried out.

In The Gambia, we drew half of the respondents from three rural districts of URD (Fulladu, Wuli West and Sandu) which were covered by the MRC Pneumococcal Vaccine trial and had received MRC-related support to immunisation infrastructure, and half from the two more urbanised districts of Western Division (WD) (Kombo St. Mary and Kombo North) which have been the foci of rapid immigration. All children aged 12-24 months resident in these Divisions at the time of survey (October - December for WD, January - March 2004 for URD) were eligible. We used a two-stage stratified sampling process to select 800 respondents in URD and 800 in WD. Enumeration areas used for the 1993 Census were identified within the chosen districts, separately within URD and WD. 35 enumeration areas in each Division were then randomly selected using a random number list. The sampling method within enumeration areas was based on a random walk method well established in immunisation coverage surveys. A team of five fieldworkers employed through MRC and supervised by Mary Small aimed to interview the mothers of a target number of children identified by random walk. The questionnaire explored mother's immunisation understandings and practices as part of broader notions of protecting child health, the process and timing of immunisation decisions, and perspectives on engagement with MRC studies. Fieldworkers also copied data from the child's health record card when available. The response rate was near 100% (only 3 mothers refused to be interviewed). The completed paper questionnaires were returned to a central MRC office where coded survey data were double entered into a database by clerical staff, and free-text data entered once. Quantitative data were stratified into responses from the urban west and the rural east, and analysed using STATA software. Free text was coded by ML and JF where appropriate.

4. Results

The research has generated an enormous wealth of ethnographic and quantitative data and analysis has generated findings which speak to a range of debates concerning vaccination, medical research ethics and science-society relations. These are being written up in full in outputs targeted to a range of audiences (see section 6). Statistical tables are included in Annexes 2 and 4. This section gives only a brief summary of some of the most significant findings, first for Brighton, then for The Gambia, and then comparatively.

4.1 Findings - Brighton

In the UK, research and policy discussions focussing on parents' engagement with MMR has been dominated by analysis of the proximate influences on their choices, and in particular scientific and media information. This has led health policy to focus on information and education campaigns. Most health professionals also reiterate the policy stereotype that MMR-anxiety is primarily a middle-class phenomenon. Nevertheless as our interviews also revealed, local health professionals frequently face two dilemmas: between their felt institutional obligations to deliver information that MMR is safe and their own uncertainties, and between advice to vaccinate for the social good of herd immunity and encouragement to personal choice - leading to a wide variety of interactions in practice.

The Brighton ethnography questions such reasoning in showing how wider personal and social issues shape parents' immunisation actions. It indicates anxiety about MMR amongst mothers from a wide variety of social backgrounds; what some mothers from 'deprived' Whitehawk lack is rather the confidence to go against professional expectations. The narratives by mothers reveal rationalities rooted in a particular child's health, behaviour and genetic history, not in generic ideas of risk. This contrast is encapsulated in the statement 'MMR may be safe but not for my child'. Vaccination outcomes depend not on a singular deliberative calculus which information might influence, but on unfolding personal and social circumstances into which information plays. Personal histories, birth experiences and related feelings of control, particular engagements with health services, and friendships and conversations with others are all relevant here. Whilst many see vaccination as a personal decision which must respond to the particularities of a child's immune system, 'MMR talk', in which these concepts are discussed and which articulates parenting values and ideas of responsibility, has become a social phenomenon in itself now integral to wider socialising. Within this, there is high social acceptance of those who decide differently, and high tolerance of personal choice in negotiating scientific uncertainties and pro- and anti-MMR advice. People assume personal responsibility and blame (for the consequences of both vaccination and non-vaccination).

The survey results (to data analysed only for mothers) confirm that class is relatively unimportant. Neither graduate status, nor newspaper readership (as proxies for class) were significantly associated with the decision whether to have MMR at the recommended time (Annex 2 table 5). The 13.3% of mothers who reported that they had chosen "single jabs" (i.e. separate measles, mumps and rubella antigens, available only privately or overseas) were more likely to be graduates, however ($P=0.043$), (Annex 2 table 6).

The survey confirmed ways in which personalised ideas of immunity and vulnerability shape thinking about MMR (Annex 2 table 14). Most mothers agreed that each child's immune system was different (although significantly more non-compliant mothers - 79% - strongly agreed with this, compared with 61% of those who complied). What is different, however, is how mothers evaluate how MMR plays into this, with 86% of mothers who did not comply strongly agreeing that 'the MMR is too much in one go' compared with only 21% of those who complied. Equally, more than half of the non-compliers agreed that there is a chance of serious side effects from MMR if there is a weakness in that child, compared to only 18% of those who complied. 46% of mothers who did not comply strongly agreed that it was better to get immunity naturally, compared with only 5% of those who complied. Interactions with 'alternative' therapists were also significant: 21.1% of noncompliant mothers had consulted a homeopath, by contrast with 9.4% of compliers ($P=0.001$). Those who did

not comply are significantly more likely to have had their thinking influenced by family health history. In explaining more about this, seven mentioned a family history of asperger's syndrome; two mentioned autism in the family; three mentioned experiences of autism onset following MMR in the family; thirteen referred to relatives reacting badly to vaccines; ten referred to a family history of eczema, asthma or arthritis; five referred to a family history of irritable bowels, and several gave examples referring to neurological problems, auto-immune problems or ME. Of the 15% of mothers who rejected the Vitamin K injection at birth, almost 80% went on not to comply with the MMR regime. Overall, the survey found the strong significance of a cluster of variables linking ideas about immune system susceptibility and family health history, early thinking about MMR, and personal responsibility, associated with MMR non-compliance (Annex 2 table 19).

The survey confirmed mothers' strong sense of personal responsibility for vaccination decisions and their consequences amongst both those who did and did not comply with the MMR regime, although unsurprisingly those who complied expressed their personal responsibility more in worry about measles than about possible MMR side-effects (Annex 2 table 15). Importantly, few mothers (11-12%) agreed that they considered possible benefits to other children in their calculus about MMR. It does not appear to be the case, therefore, that the social good from 'herd immunity' is important in mother's choices. Rather than take this to indicate 'contemporary selfishness', this - taken with the high sense of personal responsibility evident in mother's responses - suggests that the MMR issue has become so important that personal parenting concerns are paramount, leaving less space for wider social considerations. Nevertheless a much higher proportion (70% of those who complied, and 33% of those who did not) felt that it was right for health professionals to push the social message.

Wider issues of trust in government and science are nevertheless significant to mothers' MMR thinking and practice (Annex 2 table 16). 74% of those who did not comply, but even 31% of those who did, strongly agreed that 'you can't trust the government over science'. Even higher proportions of mothers strongly expressed suspicion of the influence of pharmaceutical companies over the MMR issue (52% of those who complied, and 81% of those who did not). The survey extended this consideration of how mothers relate to public issues involving science by exploring attitudes and practices around BSE and genetically-modified foods. A significantly higher proportion of those who did not comply with MMR claimed to have stopped eating beef because of BSE (41%, compared with 35% of those who did comply) - and this proportion might have been higher still but for the fact that 37% of non-compliers were vegetarian already (compared with only 17% of those who did comply). 86% of those who did not comply with MMR, and 56% of those who did, claimed that they checked food labels to see if they contain GMOs - again, a statistically significant difference. These findings suggest that while many mothers across the vaccination spectrum may be taking a precautionary approach around these other issues of scientific uncertainty, there is a cluster of those who do not comply with MMR whose views of food and vaccination issues may be similar, and mutually-reinforcing. Further statistical analysis will probe this.

While our UK study focuses on a single locality which has particularly low rates of MMR uptake, and in offering an "alternative" lifestyle may not be representative of the UK as a whole, there is no reason to think that the social factors causing low uptake in Brighton are different in kind from those operating elsewhere, even if their distribution is different. A response rate of 39.8%, though lower than desirable, is slightly higher than average for postal surveys of the public. The potential biases of self-selecting postal respondents have been assessed and controlled for. Overall, then, these findings can be taken to suggest the importance of public discourses about individual

responsibility and lay perspectives on immunity for shaping parental anxiety about the MMR regime in the UK. They suggest the contemporary significance in the UK context of what has been identified by anthropologists as an 'age of immunity' (Martin 1994, Napier 2003). The findings suggest that health professionals and immunisation policy-makers will need to develop forms of discourse and dialogue that acknowledge these perspectives if they are to engage effectively with parents. That parental perspectives correspond with certain strands in the high-profile scientific and activist debate over MMR also carries with implications for how the controversy is playing out.

4.2 Findings - The Gambia

As in the UK, our ethnographic work in The Gambia revealed a range of contrasts between the perspectives of health institutions and of parents. Findings concerning conceptualisations and experiences of child health and routine vaccination are important for understanding parents' engagement with vaccine trials, and hence are initially outlined here.

Concerning routine vaccination, our interviews with immunisation policy-makers and community nurses revealed a powerful discourse associating vaccination acceptance with the acquisition of modern scientific and biomedical knowledge, and a prioritising of modern health care. Professionals see the (relatively few) 'defaulters' in this high-uptake setting as neglectful, either through ignorance or by prioritising travel or trade over health.

The Gambian ethnography found, in contrast, that parents view immunisation as one of a set of complementary practices for promoting infant strength and health, including the use of a variety of Islamic talismen, herbal medicines, daily care practices and adherence to moral codes. Individual infants are seen to have unique pathways through the diverse physical, social and spiritual hazards that can afflict them. Core ideas concerning strength and wellbeing centre on an economy of blood and body fluids, which vaccinations can influence positively. These conceptualisations underpin a widespread desire for vaccinations. In this context, occasions of 'default' or lateness usually arise through contingent events that could affect anyone, such as family misfortune, temporary work overload or practical difficulties in getting to the clinic. There, default is sometimes compounded as conflicts with clinic staff and worries about multiple vaccines 'stacking up' deter future attendance. The ethnography also revealed how vaccination uptake is not just a matter of individual dispositions, but shaped by social processes. Thus Infant Welfare Clinic days are enjoyable social occasions for some women, encouraging attendance, while others feel excluded or worried by them due to their social circumstances, the health of their child and the judgement of others about these. Women also negotiate clinic attendance with husbands and older female relatives in ways shaped by age and household circumstances.

The parts of the survey dealing with routine immunisation confirmed and extended many of the ethnographic findings. For instance, for 47% in the urban west and 59% in the rural east, immunisations were seen to play a general role in giving a child 'strength' or 'power'. When asked about their expectations of protection by immunization in relation to disease, 29% of mothers in the urban west, and 48% in the rural east, reported no "correct" diseases, while many of those reporting "correct" disease also mentioned others (e.g. malaria and diarrhoea), suggesting a generalised conceptual link between immunisation and common childhood illness (Annex 2 table 8). Mothers with higher western educational status named more diseases (Annex 4 table 9), regardless of whether they are correct; suggesting that education is associated with a more disease specific perspective but also with an increase in knowledge that from a biomedical point of view is

inaccurate. Findings confirmed that traditional practices are used in the interpretation and encountering of immunization practices, and are not an alternative to or opposite of such encounters. For example at interview, 57% of children in the urban west and 51 % in the rural east were wearing an Islamic talisman; this did not vary significantly according to education (Annex 4 table 12).

Very few social factors are significantly associated with default in the rural east (not ethnicity, not number of children, not age, not occupation and not wealth). In contrast, a cluster of poverty related factors emerge as significantly associated with general defaulting in the urban west (poor compound, rented compound, no mobile phone, non-Mandinka - indicating higher likelihood of being a recent immigrant) (Annex 4 table 3). Survey findings suggest that the routinized and social role of the Infant Welfare Clinic is important in supporting uptake in the rural areas, but that this is lacking in the more socially-fragmented urban context where negative experiences of interaction with other women and with clinic staff are also more common for poorer, less socially-integrated mothers. Our detailed analysis of the relationships between defaulting on different immunisations suggests, *inter alia*, that default on the first (BCG) vaccination is more likely to signal a repeated default pattern for urban mothers than it is for rural ones (Annex 4 table 7).

Turning to engagement with MRC studies, our interviews revealed discourses amongst trial administrators and fieldworkers that echo public health discourses around routine vaccination. Thus MRC workers assume people to perceive MRC studies as a distinct, scientific activity, and those who accept to participate are assumed to have understood study aims and procedures and to have given their 'informed consent' according to bioethical protocol. Acceptance (or not) is assumed to reflect people's relative trust in MRC and appreciation of science and modernity - with 'refusers' understood as people of particular social or ethnic categories; ignorant; irrational, over-traditional, or susceptible to ill-founded rumour.

In contrast, our ethnographic work on people's engagement with the Pneumococcal Vaccine Trial (PVT) revealed that people treat medical studies less as a separate scientific entity and more as part of normal health practices. In this context registering with MRC had become a further complementary way to secure infant health, along with visits to government infant welfare clinics, herbal and Islamic healers. Parents had very little understanding of the nature and aims of this particular trial, and attached little significance to the informed consent process; rather, their reflections about participation were framed within broader perceptions and historical experiences of MRC as an institution. Acceptance (or not) reflected a calculus of benefits vs. danger, which were negotiated through social processes, gender and power relations in various ways, to produce a diversity of outcomes. Benefits and dangers are conceptualised in relation to prevailing ideas about an economy of blood. Thus engaging with MRC is seen to involve balancing its 'good treatment', involving strength-giving, blood-enhancing vaccines and medicines which people perceive as coming free to study subjects, with its 'stealing' of blood. In many cases, people interpret blood sampling and laboratory practices as evidence of MRC's wish to accumulate blood, presumably for sale in Europe where it is felt that 'strong' African blood is desired. This blood is not paid for, unlike commercialised blood in Gambian hospitals, enhancing the sense of an unjust economy.

The part of the survey addressing relationships with MRC confirms many of these findings. The rural East survey population were all potential PVT study subjects. 464 had been invited to participate, and of these 15.3% refused. Refusal was not significantly associated with any social, ethnic or educational variables (Annex 4 table 10). Of those who were invited, 45% had no idea

what the study was about; 30% said it was for improved child health; 18% said that it concerned free checking and treatment for their children, and only 6% mentioned pneumonia or the term 'pneumococcal vaccine trial' (Annex 4 table 15). Trial participants and refusers alike named both positive and negative aspects of engaging with MRC, hinging, as in the ethnography, on good/free treatment vs. blood-taking (Annex 4 table 13).

This research shows that trial communication processes and debates around informed consent need to move beyond just the moment of decision, and consider the wider social context, including the prevailing discourses through which people frame their engagements with scientific institutions. Taken along with the findings concerning routine vaccination, the Gambian data show that the categories of vaccination 'complier' and 'defaulter' and trial 'acceptor' and 'refuser' obscure the range of experiences, concerns and dilemmas faced by parents as they seek to raise their infants and keep them healthy.

4.3 Comparative perspectives

In both British and Gambian settings, then, the research has shown how parents think about and discuss vaccination issues as part of wider reasoning concerning child wellbeing, which interplays with intense parental observation and evaluation of a child's *particular* health history, strength and vulnerability. Public engagement with (globalised) vaccine technologies is strongly mediated through this, rather than being more straightforwardly a matter of generalised risk perceptions or political imagination of, and trust in/distrust of, state, scientific, corporate and global institutions.

Similarities across the Gambian and British settings in these respects, and in the integration of vaccine engagements with a variety of biomedical and non-biomedical forms of knowledge and practice, undermine dichotomies which cast Southern societies as becoming biomedicalised, post-traditional, and rational/modern, and Northern societies as becoming de-medicalised, post-modern and more irrational.

In both settings, debates and controversies about vaccine science appear to be playing into current conceptualisations of health and social relations - an 'age of personalised immunity' in Britain, and what we would dub an 'age of blood' in West Africa - in ways which feed, and may lay the ground for further, controversy. The research suggests that science-policy approaches, even those seeking participation, deliberation and dialogue, need to appreciate such dynamics or they can badly misfire.

5. Activities

Phase I: Preparation (October 2002 - February 2003)

Literature research

Consultations with users

Creation of collaborative arrangements and UK Stakeholder Advisory Panel

Creation of project web pages

Phase II: Ethnography (February - November 2003)

Ethnographic research in Brighton and urban and rural Gambia

Recruitment and capacity-building of British and Gambian research Officers
Preparation and publication of two ethnographic working papers
2 feedback workshops/survey methodology meetings (held in Brighton and at MRC, The Gambia)
Feedback/training meeting for Health Visitors in Brighton
Presentation to GP learning group, Brighton and Hove City PCT

Phase III: Survey (November 2003 - August 2004)

Design and conduct of postal survey in Brighton
Recruitment and training of MRC fieldworker team
Design and conduct of interviewer-administered survey in The Gambia
Second presentation to GP learning group, Brighton and Hove City PCT
Presentation to Brighton and Sussex Medical School Research Day
Research and writing of paper on mobilisation around MMR, with co-funding from IDS-based DFID-funded Development Research Centre on Citizenship
Survey data entry and analysis

Phase IV: Dissemination (September 2004 - March 2005)

Survey feedback discussions with British Stakeholder Advisory Panel
2 survey feedback workshops in The Gambia, one to government staff, one to MRC staff
Preparation of written outputs
Interaction with New Economics Foundation in development of MMR-focused 'DEMOCS'
Participation in new international network on Vaccine Innovation systems (to continue)
Interaction with IDS initiative on 'Future Health Systems' (to continue)

6. Outputs

Dataset on Childhood Vaccination in The Gambia (offered to Data Archive)

Dataset on MMR in Brighton and Hove (offered to Data Archive)

Poltorak, M., M. Leach, J. Fairhead and J. Cassell, in press 2005, "'MMR talk" and vaccination choices: an ethnographic study in Brighton', *Social Science and Medicine*.

Fairhead, J., M. Leach and M. Small, 2004, 'Childhood Vaccination and Society in The Gambia: Public engagement with science and delivery'. *IDS Working Paper* 218. Brighton: Institute of Development Studies.

Poltorak, M., M. Leach and J. Fairhead, 2004, 'MMR 'choices' in Brighton: Understanding public engagement with vaccination science and delivery. *IDS Working Paper*. Brighton: Institute of Development Studies.

Fairhead, J. and M. Leach, forthcoming, 'Engaging with science? An ethnography of a West African vaccine trial', *Journal of Biosocial Science*, special issue on Anthropology and Public Health

Leach, M., forthcoming, 'MMR mobilisation: Citizens and science in a British vaccine controversy', *IDS Working Paper*.

Fairhead, J. and M. Leach, in prep, 'Fluid anxieties: technoscience and the economy of blood in The Gambia', paper presented to Anthropology seminars at LSE and Brunel University, under revision for journal submission

J A Cassell, M A Poltorak, M Leach, J R Fairhead, C H Mercer and A Iversen, submitted, 'Putting MMR non-compliance in context – a quantitative survey of mothers based on ethnography', *Vaccine*.

J.A. Cassell, J. Fairhead, M. Leach, M. Small and C.H. Mercer, in prep, 'Vaccine uptake in rural and urban areas of The Gambia - a quantitative survey of mothers based on ethnography (provisional title), for submission to *Health Policy and Planning*

Fairhead, J. and M. Leach, in prep, *Vaccine Anxieties*. Book manuscript in preparation for Science in Society series, Earthscan.

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7. Impacts

In Brighton, the research findings MMR have fed into discussions amongst GPs and Health Visitors concerning the ways they communicate with parents. In particular, the PCT Immunisation co-ordinator has incorporated key findings (e.g. re. early thinking about MMR, and the relevance of birth experiences and homeopathy) into the talks she gives to Health Visitors.

In the UK nationally, our findings have helped shape the development of an MMR pack for the citizen-deliberation card game DEMOCS, designed by the New Economics Foundation with funding from the Wellcome Trust. This will be piloted and used during 2005 with the aim of clarifying public opinion on MMR policy choices, and feeding the results to the Department of Health and key vaccine policy-makers.

In The Gambia, the research findings, communicated to government and MRC staff through feedback workshops and briefings, are feeding into ongoing deliberation about improving uptake of immunisation services, and improving the communication processes used in trials.

Inevitably, bringing about change in established discourses and practices in medical research and health institutions is a slow process, especially where these discourses are strongly entrenched and polarised, as with vaccination. We hope that further examples of application and impact will emerge as the study findings continue to be published and disseminated, and to feed through media communication into wider public debate.

8. Future Research Priorities

Immediate future priorities, drawing on research data from this project, include (a) analysis of gender-differentiated and paired mother-father perspectives on MMR vaccination, in relation to existing literature on gender and public engagement with science, and (b) further comparative analysis of British and African issues in public engagement with science, in relation to current discussions of science, citizens and globalisation.

The project suggests a number of further lines of research, which we hope to take forward in interaction with other colleagues, partners and funding sources over the next few years. These include:

- Investigation of the experiences, imaginations and politics of science involved with contemporary 'anti-vaccination rumours' in diverse contexts globally;
- Investigation of how publics perceive and might participate in the global policy processes around vaccine development, including new public-private partnerships;
- Comparative study of the citizen-science and governance issues involved with new health technologies such as vaccination, and new technologies in other fields (agriculture, environment);
- Further investigation of the rapidly-changing, plural health systems which this study has shown to be relevant in both British and African settings, examining user perspectives, interactions, and issues of trust and regulation, towards achieving better health outcomes, especially for the poor.

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