

accommodate and implement small changes with the aim of evolving and improving on current treatment.⁹ In an area characterised by the often conflicting dictates of evidence, economics, equity, and empowerment, the focus needs to be changed from academic research based paradigms to pragmatic health management approaches which reflect the context in which interventions are delivered.

This approach requires investigative frameworks where the practical realities of patient management are not seen as confounding variables in an otherwise perfect study design. The need is to align the three key elements of research, commissioning of care, and service delivery around the day to day health and social problems of patients. The formation of primary care groups in England (and some of their equivalents elsewhere in the United Kingdom) provides such an opportunity.

Primary care groups are developing as the major force in the planning of English health services and could provide the ideal vehicle for commissioning, producing, and using research that is relevant and acceptable to users. Within a collective and accountable framework of governance, primary care professionals and patients could make mature decisions about the sort of evidence they require, which could then be commissioned or undertaken locally. This would be bottom up research relevant to the context rather than top down, well intentioned, research that may not change anything. For example, quality improvement projects and integrated care projects will be soon under way in primary care groups as part of the new health improvement programmes. Where several primary care groups are linked to a single secondary care provider this would provide an opportunity to undertake comparative studies to evaluate the effectiveness of these interventions.

National structures would need to be developed to support and facilitate this new approach, in which commissioner, producer, and user are all one—an approach that would reflect a shift towards a wider methodological base and an acceptance of the social construction of so many events. Increasingly, patients would be partners in every part of the research process, emphasising a move towards user led and controlled research.¹⁰

The closer that decision makers are to the production of purchasing appraisals, the greater is the likelihood that they will be influenced by their findings.¹¹ The evolving primary care groups would

provide an ideal focus for health service research, offering a more realistic perspective for the NHS research agenda than remote regional funding centres. Research practices and networks are in a unique position to align their research perspectives to service provision and the commissioning of care and could work closely with their primary care group boards and clinical governance leads to strengthen a service based research culture. This integration could be promoted through the research practice accreditation scheme currently being developed by the Royal College of General Practitioners.

Funtowicz has described how, in some complex systems where one viewpoint predominates, there can be a vulnerability to sudden collapse or oscillation at lower levels as the system “shakes itself to bits.”¹² It could be time for the providers of primary care to start rattling the academic cage and seize this unique opportunity.

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Children with HIV: the challenge for general practice

General practitioners do have an important role

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Managing HIV in general practice can be complex and becomes even more difficult when it is children who are infected with HIV. A study by Boulton et al, reported in this issue, of a small group of families attending a single paediatric HIV service in London, questions the role of the general practitioner in the care of children with HIV infection (p 232).¹ The

study emphasises the importance of specialist care teams for children with HIV and details concerns expressed by the parents of such children about the appropriate level of local general practitioner involvement. Yet as vertical transmission accounts for most new diagnoses of paediatric HIV, most of these children have infected mothers, and sometimes infected fathers and

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maybe siblings, infected or uninfected, who have their own health problems and needs.

Many general practitioners providing care for adults and children with HIV would therefore strongly disagree with any suggestion that families affected by HIV would all be better served by tertiary care teams in major centres. Indeed, this is an impracticable model of care for many of the world's children with HIV. In many areas of the world the only practical solution to improved care for children with HIV is to strengthen primary care based programmes. The contribution of many general practitioners remains undocumented and unnoticed in HIV care, and wider research is warranted.²

Several different models exist for the care of children with HIV in developed and developing nations. One model of shared care often used is where HIV management is principally carried out by a specialist paediatrician in a multidisciplinary team, while an informed general practitioner manages "all the other childhood problems." This includes psychosocial support of the family and other carers and, perhaps later, the maturing child. This emphasises the need for models of care with two way communication between the specialist team and general practitioners.³⁻⁵

Boulton et al emphasise parental concerns about confidentiality in the general practice, the perceived level of competence of their general practitioner in HIV management, and the parents' concern about their own ability to distinguish whether a problem might be HIV related and therefore requiring prompt consultation with their paediatric specialist team.¹ These concerns do not, however, negate the need for the family still to have a strong and supported relationship with their general practitioner.

Although urban general practitioners may often not be the principal providers of medical care for HIV, they will still see the child for many other problems. In rural and remote areas general practitioners may be the only informed medical advisers available to treat children with HIV, especially in the evenings and at weekends. As HIV often affects disadvantaged families, sometimes from ethnic minority groups, there is a challenge to provide culturally appropriate, language specific services close to home.³⁻⁶ Family members with a child with HIV often welcome the involvement of a general practitioner who expresses concern and offers psychological support.⁷

The child with HIV may be the first member of the family to be diagnosed with HIV, and a supportive general practitioner can greatly help the family as other members are being tested. Many of these families are single parent families, with the mother also being infected with HIV and requiring support. The medical and psychosocial needs of any uninfected siblings in these families must also not be forgotten as they may show significant depression and behaviour problems.⁸ HIV infection is often only one of the many problems facing these families. Other difficulties include the stress of poverty, unemployment, lack of support, and self imposed isolation due to fear of disclosure of their HIV status and the risk of subsequent discrimination.

If general practitioners are going to have an active role in managing children with HIV, they must be aware of the symptoms and signs of possible acute presenting problems, their investigation and management, and when to refer. Children with HIV may present with

symptoms of many familiar acute respiratory and dermatological problems which are competently managed in general practice. Yet general practitioners must be aware of critical symptoms and signs that indicate the possible development of more serious disease and the need for prompt consultation with paediatric specialists and appropriate referral. Similarly, the specialist team must keep general practitioners informed about the results of the child's monitoring tests of viral load and immunological, biochemical, and haematological function; any significant medical problems; and current medications.

The general practitioner certainly has a role in assuring that attention is paid to the general health needs of children with HIV—which sometimes risk being overlooked in specialist clinics. Children with HIV still need attention paid to issues such as their growth and development, nutritional status, oral hygiene, immunisations, and advice on the management of behaviour and psychological problems.⁷ As the child approaches adolescence the general practitioner may take on a preventive role, providing advice about sexual and intravenous transmission. General practitioners may also have a role in supporting older children who often question or react negatively to frequent clinic visits, invasive procedures, and complicated medication regimens.⁹

Networks of specialised multidisciplinary teams working closely with general practitioners have been shown to enable general practitioners to deliver optimal care to adults with HIV infection.¹⁰ The medical care of children with HIV also requires a comprehensive, coordinated approach to the child and their family members and other carers. The family's general practitioner has an important role in this process. This role needs greater identification and supportive education, especially in areas where the incidence and prevalence of this disease are increasing.

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