Annotations

NHS Direct: here and now

In December 1997, the UK government committed itself to creating “a new 24 hour telephone advice line staffed by nurses.” The first three call centres were operational three months later and 16 pilot sites, covering 60% of England, will have been established by the end of 1999. NHS Direct will be available throughout England by 2001. A fully networked system will then emerge, taking calls from an estimated 20% of the population each year. Wales will have its first call centre operational in April 2000 and Scotland will follow with its first pilot sites the same year.

Currently, 95% of calls are about symptoms but it is not the function of the telephone consultation to reach a diagnosis. The intention is to recommend further care or referral through a system of triage that reflects the nature and potential urgency of the clinical problem. Typically, 45–50% of all calls are about children and the highest level of use is from mothers of young children. Nurses answering the calls are supported by computer software that can guide questioning, help to weigh information for significance, and suggest optimal disposition according to local circumstances, including self care at home. There is integral access to corresponding advice and information databases, and electronic links should enable communication with primary care services, hospital accident and emergency (A&E) departments, the ambulance service, and other agencies. Calls solely for information are expected to increase with time.

NHS Direct is evolving rapidly with detailed development work going on behind the scenes, including efforts to form alliances with general practitioner cooperatives and other services. It is being strongly promoted as an integral part of the “New NHS”. £280 million (US$450 million) has been committed to it and to complementary projects over the next three years, on top of the £40 million (US$64 million) already spent. The justification for all this has been criticised but the political imperative that has given it such momentum, and the resources already committed, suggest that NHS Direct is here to stay.

Front end of the NHS, or thin end of the wedge?

Whereas telephone consultation is intended to be the reassuring face of NHS Direct, from its inception it has had the more fundamental purpose of becoming the “gateway” to all local health services. Gateways of this kind can streamline access but they also tend to have turnstiles, and the management of demand that becomes possible may not just be facilitatory but prescriptive. This is not necessarily inappropriate but inevitably there are the concerns regarding who sets the ground rules, how they are prioritised, and what other agendas are entrained. It will be necessary to develop much tighter integration between services to which the gateway gives access, and the implications for primary care and other parts of the NHS, even if they have been anticipated, have not been made explicit. If this leads to greater coherence between general practice and paediatrics, it will be welcome from a child health perspective. For the time being, however, the demand management function of NHS Direct amounts to directing callers to the most appropriate service or advising home care and giving relevant advice. This is intended to divert minor problems and release professional time for more pressing clinical duties while giving the public the confidence and knowledge to be more selective in their use of health services.

Telephone triage for the problems of children

Telephone consultation heightens uncertainty because the dynamics of normal conversation are changed and visual cues are absent. Most would agree that parents tend to be excellent observers but less good interpreters of their children’s symptoms. It is not clear that the essential subtleties and nuances apparent in face to face consultation will be transmitted over the telephone, or that they will be obviated by training. The literature on the safety and effectiveness of telephone triage for the problems of children, particularly young children, is limited and not particularly reassuring. Recent studies provide some empirical evidence of safety in terms of the absence of major adverse events but fail to relate to current practices in NHS Direct in a number of ways. For example, by using only experienced paediatric nurses for triage, or excluding from triage all children younger than 1 year old. Managing telephone consultations with parents of sick children are more difficult for general practitioners than most comparable situations, and the absence of robust evidence to underpin paediatric triage in NHS Direct as a national service, is of concern. Evidence of the appropriateness of consultations, and the extent to which these reflect best practice, are also lacking. The causes of the inconsistent disposition and advice reported in the initial evaluation of NHS Direct, are difficult to determine because of the diverse operational nature of the pilot sites but ambiguities in protocols and guidelines have the same effect.

Software support

Clinical Decision Support Software (CDSS) is intended to reduce uncertainty and facilitate consistency but there are many unresolved issues. Broadly, systems driven by guidelines tend to exploit the clinical judgment of the nurse advisor and harness intuitive skills. Those using more restrictive procedures, such as binary (yes/no) algorithms, tend to have higher sensitivity but to be less responsive to contextual information that might have a useful bearing on interpretation. Systems of both types are currently deployed in NHS Direct. It is not clear whether hybrid arrangements would be possible or how to determine which approach would work best in a national context.

Origins and authenticity of knowledge

At the core of the CDSS is the knowledge base. This is derived and formulated by the commercial supplier of the software using their own advisors, but a “yellow card” system can feedback users’ suggestions for modifications. It should not be assumed that the paediatric components presently used by NHS Direct reflect either best practice or optimal advice. Independent, systematic analyses should be a prerequisite to national procurement. It would be unacceptable, in the long term, for a national service like NHS Direct not to have control and ownership of the knowledge and advice it was dispensing to the population. This can only be achieved through a national structure in which multidisciplinary evaluation and accreditation take
place. Systems must have specific pathways and modules for dealing with childhood problems, recognising that requirements for adults are entirely different. Internal consistency is important but the advice given by NHS Direct will need to be compatible with that given by general and community paediatric services. There are parallels with the development of pathways of care between primary and secondary services that could be exploited. There has been talk of referring the whole issue of validation to the National Institute for Clinical Excellence. If so, it is important that evaluation begins before final implementation, and that clinicians are not left to pick up the pieces when the Department of Health signs off the pilot phases of the project, and carrot turns to stick.

Nursing resources
Approximately 1000–1500 experienced clinical nurses will be required to staff NHS Direct as a national service, and recruitment has not been difficult so far. Some sites favour whole time appointments, others favour split posts or rotational schemes with primary or secondary care services in an effort to maintain clinical competencies. There may be serious consequences to other parts of the health service, and paediatric services are particularly vulnerable. Although it is not a requirement, a paediatric qualification is welcome. How many paediatric nurses will join NHS Direct is unknown. Changes to the educational system for nurses as a result of Project 2000 have had a significant impact on areas of work where both adult and paediatric patients are seen together. How these will be resolved in NHS Direct is unclear. Most sites require four to six weeks of training (short by commercial standards) in telephone systems, the use of CDSS, and in local practices and procedures but this does not include specific training in paediatric telephone triage or in child health. One solution might be to consider the secondment of relevant staff to obtain a paediatric qualification. Training by consortia allied to a university department of nursing (currently available at two sites) seems likely to develop as the full range of needs becomes clearer. National standards should be formulated. Professional nursing issues are being considered in detail by the Department of Health.

Steering groups to take the helm?
Audit and monitoring is taking place centrally but individual sites are expected to establish multidisciplinary clinical steering groups and appoint a medical director. These groups will have responsibilities for local clinical governance. Paediatricians will want to advocate audit that is linked to health outcomes for babies, infants, and children to show real benefit and exclude disadvantage. Confidentiality and security fall within the remit of clinical governance to some extent but national guidance and monitoring is essential, and wider debate would be reassuring. Areas of uncertainty about legal liability in NHS Direct also need to be resolved, particularly those concerning the use of commercial CDSS, the application of guidelines and protocols, and the extent of the chain that could be followed in the event of litigation.

“What to do when you don’t know what to do”—or is it?
Nobody really knows if NHS Direct will work in clinical terms. Many parents with children they believe to be sick will want to see their doctor immediately. This will not change unless NHS Direct proves to serve parents exceptionally well. It is encouraging that callers generally say that they like the service, but crucially this does not indicate whether their consultation has been appropriate or reflected best practice. Evidence of the modification of pre-call intentions by advice from NHS Direct is unconvincing because those who use the service, almost by definition, are those who do not know what to do, and because what callers think they might have done in the absence of the telephone helpline is usually recorded after the consultation. Much more detailed evaluation is required, and it is possible that this will emerge from the assessment being carried out for the Department of Health by Sheffield University following their interim report.

Will children’s health be improved?
The potential to improve and develop the child health knowledge of the population, and to do so consistently and in a manner that supports parents, is an important goal that should be welcomed. It remains to be seen if NHS Direct can do this effectively. The use of its projected Healthcare guide may consolidate the information given over the telephone but the recent evaluation of Baby check emphasises the complex implications of this type of material. The NHS Direct website, perhaps providing interactive health information, seems an abstraction to those at the sharp end of patient care, but it could turn out to be a route liked by the current generation of adolescents and it might have considerable application in the long term. It would be premature to consider the inclusion of the NHS Direct telephone number in parent or patient held records because this would require endorsement of NHS Direct as a valid source of accredited child health information and advice, which it is not, at least for the present. Paediatricians will also be interested in the possible use of NHS Direct to follow up patients who fail to attend outpatient clinics, and in the capacity to disseminate immediate and coherent information if there is an epidemic, crisis, or health scare. These possibilities are new opportunities to benefit the health of children and families but I wonder whether they justify the investment, given the priorities of underresourced needs that already languish within child health.

Is their a role for paediatricians?
NHS Direct will be judged not just by its capacity to respond sensibly to the everyday problems of children so familiar to general practitioners; it will also need to recognise and respond appropriately to unusual, uncertain, or difficult clinical situations. These include actual or potential child protection issues, and the range of circumstances in which a child might call in person for help or advice. It would be futile if NHS Direct were unable to address other questions or concerns that a parent might wish to raise about their child in the course of a consultation.

Whereas NHS Direct must be seen through the eyes of general practitioners and the nurses who lead it, there is also a need for a child health focus. For paediatricians there is a role in multidisciplinary working both within local clinical steering groups and within the central advisory structure. Helping to validate clinical protocols, information, and advice; involvement in local monitoring and audit; working to develop effective lines of communication with local secondary level child health services; and contributing to training, are all areas in which paediatricians could help in making NHS Direct work well for children.

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2 NHS Executive. NHS Direct—final stage of national rollout. Health Service Circular 1999/02, 5 February 1999
Growth hormone insensitivity: a widening diagnosis

The term growth hormone insensitivity describes a group of disorders, both inherited and acquired, in which there are clinical and endocrine features of insulin-like growth factor 1 (IGF-I) deficiency and resistance to exogenous human growth hormone, associated with growth hormone secretion that would not be considered abnormally low. In childhood, the principal result of growth hormone insensitivity is the failure of postnatal growth, leading, if untreated, to adult short stature. This group of disorders classified as growth hormone insensitivity however is becoming larger and more heterogeneous, as diagnostic methods improve and molecular analysis is applied to a wider range of patients with short stature.

The original description of growth hormone insensitivity was of a genetic dysmorphic syndrome (Laron syndrome) characterized by extreme short stature, spontaneous hypoglycaemia, abnormal craniofacial development, microphallus in boys, and final adult height of 120–130 cm (less than −5 SDS (standard deviation score)). Several series of patients, mostly originating in consanguineous populations of Middle Eastern origin, have since been described. Of biochemical features in this classic form of growth hormone insensitivity consist of raised growth hormone secretion contrasting with low concentrations of serum IGF-I and IGF binding protein 3 (IGFBP-3). The primary defect in Laron syndrome was demonstrated to be at the level of the growth hormone receptor (GHR), with failure of growth hormone binding to hepatocytes, and lack of a mitogenic response to growth hormone in T lymphocytes from affected subjects. The term GHR deficiency has since also been applied to this disorder.

For about 20 years since its original description, Laron syndrome remained a very rare untreatable condition. In the late 1980s two pivotal developments occurred, which were to refocus attention on this disorder and subsequently transform the field of growth hormone insensitivity. First, cloning of the GHR in 1987 led to the identification of the first molecular defects of the GHR gene in Laron syndrome. We now know that most mutations occur in exons coding for the extracellular domain of the GHR, but also that GHR deficiency is genetically heterogeneous with over 30 different mutations described including several in the intracellular domain of the receptor.

The second development was the availability of recombinant IGF-I for human use. Naturally Laron syndrome, with its severe deficiency of IGF-I, became the prototype disorder in which to conduct early therapeutic trials. IGF-I treatment was soon demonstrated to accelerate linear growth, the potential for treatment led to a renewed interest in Laron syndrome resulting in the collection of a large, predominantly European series of 82 patients, fulfilling strict biochemical criteria for growth hormone insensitivity. Because this series was assembled according to biochemical criteria, a new clinical and biochemical heterogeneity in patients with growth hormone insensitivity emerged. Height SDS varied from −2.2 to −10.4 and IGFBP-3 SDS from −1.4 to −14.9, these two variables being positively correlated. A group of patients with normal growth hormone binding protein (GHBP) values was also identified. Extremes of physical appearance were seen with the classic Laron syndrome phenotype at the severe end and children of completely normal appearance at the mild end of the spectrum. Growth hormone insensitivity was no longer a clearly defined clinical entity. The possibility of growth hormone insensitivity occurring in children with short stature who did not have features of Laron syndrome led to the search for biochemical and molecular evidence of growth hormone resistance as a cause of idiopathic short stature (ISS). The demonstration of low GHBP associated with subnormal IGF-I and raised growth hormone secretion resulted in the emergence of so called “partial growth hormone insensitivity”. We suggest that a spectrum of growth hormone sensitivity exists that is negatively correlated with quantitative growth hormone secretion—that is, sensitivity to growth hormone is highest in growth hormone deficiency states whereas if growth hormone sensitivity decreases, growth hormone secretion becomes raised as a compensatory mechanism. Some children might also be short because of failure to increase their growth hormone secretion to match a decrease in sensitivity. The biochemical features of partial growth hormone insensitivity are however not yet defined. We have studied two pairs of siblings from a consanguineous family with severe growth hormone insensitivity and normal appearance who have severely raised growth hormone secretion (Bjarnason, unpublished data, 1999). We have also performed IGF-I generation tests in a series of patients with ISS; however,
it is likely that a modification of the test using a lower dose of human growth hormone and more frequent sampling of IGF-I and IGFBP-3 will increase its specificity for mild degrees of growth hormone insensitivity.

Goddard and colleagues24-26 have reported heterozygous mutations of the GHR gene in some cases of ISS, although this appears to be a rare cause of short stature. Perhaps the most conclusive proof of genetic defects causing ISS is from the families described by Ayling and colleagues26 and Iida et al.,27,28 where a dominant negative effect of heterozygous GHR mutations on GHR function was demonstrated. The field of partial growth hormone insensitivity associated with ISS remains wide open and relatively unexplored. The lack of growth response to human growth hormone in some growth hormone deficient patients is also a relatively common event and remains largely unexplained.29

Finally, it is now recognised that acquired growth hormone insensitivity may occur in a number of clinical situations. Predominant among these are states of acute catabolism, such as in intensive care patients.30 Growth hormone insensitivity in acute illness has been much more widely studied in adults; however, the same biochemical features are present in genetic states (high growth hormone and low IGF-I). Growth hormone insensitivity of varying degrees is also seen in other acquired disorders such as juvenile chronic arthritis,31 Crohn's disease,32 and advanced liver disease.33 When studying these conditions it is worth noting that the changes in growth hormone sensitivity might be tissue specific and not necessarily reflected in markers of growth hormone action such as serum IGF-I.34 For example, in coeliac disease there may be an acquired defect in growth hormone sensitivity.35-36 Successful treatment of the chronic illness may lead to resolution of the growth hormone insensitivity. Studies identifying mechanisms behind growth failure in chronic disease states will increase our understanding of the regulation of normal growth, making diagnostic tests in short stature more precise.

Consequently, growth hormone insensitivity is becoming recognised in a wide range of paediatric disorders. The effective treatment, aimed to promote linear growth, in these disorders is currently being thwarted by lack of supplies of recombinant IGF-I. Although high dose human growth hormone treatment may promote growth in mild growth hormone insensitivity, treatment with IGF-I is clearly effective on a long term basis in severe GHR deficiency.37 However, the absence of a major indication for IGF-I treatment is restricting its commercial production and hence its use in a wider range of growth hormone insensitive states.

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