Despite the more prominent focus on children’s rights today, reflected in and stimulated by the *International Journal of Children’s Rights*, relatively little attention has been given to children’s rights in the health care area. There are now two monographs,1 one of which is reviewed in this Special Issue,2 and there is increasing discussion in books on children’s rights.3 The questions that can, and have, been raised are many. They include

- who decides whether a sick child should be treated (doctors, parents, the child, courts)?4
- when is a child competent to decide upon treatment (at a certain age or when capable of making the decision)?5
- if a child can agree to treatment, can s/he also refuse treatment (a blood transfusion, an abortion, a heart transplant)?6
- should grossly premature babies be saved?7
- should severely disabled new-born babies be kept alive or allowed to die?8
- can anorexic adolescents be force-fed?9
- can children donate organs to siblings?10
- should parents be allowed to use pre-implantation genetic diagnosis in order to have a child to save an existing sick child?11
- should parents be allowed to sanction non-therapeutic surgical procedures?12
- is the genetic screening of children legitimate?13
- can healthcare and education be separated (for example in the case of the autistic child)?14

Many of these issues, and several others, are discussed in this collection.

The essays by Franklin and Sloper and by Alderson and her colleagues focus on participation rights. The U.N. Convention on the Rights of the Child is pivotal to this (Van Bueren, 1995; Kufeldt, 1993, Prout, 2000, Smith, 2002, Sinclair, 2004). The case for children’s participation has now been made. But, as Franklin and Sloper point out, children are given ‘little voice’ in medical consultations and are rarely consulted as partners in the evaluation and planning of health services.15 They use a model developed by Alderson and Montgomery (1996) which indicates four levels at which children can
participate: being informed, expressing a view, influencing a decision; being
the main decider. It is doubtful whether information needs are met. Equally
doubtful is whether adequate mechanisms exist to allow children and young
people to express their views. There are obvious barriers which obstruct par-
ticipation, one of which is the way we view children. And children are not all
alike. Leaving aside obvious differences of age, there are ethnicity and gender
differences and, of course, disabled children raise a different set of issues
(Cavet and Sloper, 2004). Franklin and Sloper discuss these questions within
the context of England. Are things better elsewhere?

The article by Alderson, Hawthorne and Killen expands our thinking about
participation rights into new terrain, that of premature babies. Alderson (2000)
had already explored young children’s and babies’ rights, quoting Trevarthen
(1999).

It is clear from the beginning that children have a driving motivation to become
part of a meaningful world. They want roles. They want to have tasks, they want
to share interests, they want to have possessions, they like being able to share
things with other people, they like to be able to share purposes and functions.
(see also Mayall, 1993)

In the article in this collection the rights of premature babies are explored using
the U.N. Convention framework. They offer a valuable corrective to the new
orthodoxy, represented by Harris (1985) and Singer (1995), that babies are non-
persons. Alderson and her colleagues note that although the right to life is often
discussed as if it is something ‘adults allow or support’ and ‘babies receive’,
‘many premature babies put much energy and concentration into surviving as
if, consciously or not, they value their life’. The article offers insights also into
participation rights. The authors stress the ways that even premature babies can
exercise their Article 12 rights. And

Countless observed and reported examples in the four NICU showed that many
adults were convinced that they were not mechanically caring for the unconscious
organisms that some philosophers allege babies to be. Instead, they were inter-
acting within human relationships influenced by the babies’ views.

There has been much heart searching in the past on the issue of research with
children. The Ramsey-McCormick debate was especially significant (Ramsey,
1976, 1977; McCormick, 1976). Ramsey argued that children should never
participate as research subjects in ‘non-therapeutic research’. Participation, he
argued, required informed consent which children could not give. Nor did he
believe that parents as fiduciaries could authorise their child’s participation
without being in breach of their duties. McCormick thought that parental con-
sent was ‘morally valid insofar as it is a reasonable presumption of the child’s
wishes’ (1974, p. 11). To McCormick there are certain identifiable values that
we ought to support because they are definitive of our flourishing and well-