Medicines for Children: reliable information for parents and carers

Steve Tomlin BPharm, FRPharmS, Andy Fox MSc, MRPharmS, Helen Sammons DM, MRCPCH, Linda Partridge PgD, Jyotsna Vohra PhD, and Kirsten Olson BA

The vision of Medicines for Children is that any parent, wherever they are, has information that they need and can trust on their child’s medicines. While this is aspirational, the programme has made great progress with its information resource, evidenced by a recent impact review.

Medicines for Children provides practical, reliable and accessible information for parents and carers about giving medicines to children. This information has been available online since 2009 on www.medicinesforchildren.org.uk. An updated version of the website launched in December 2011: it includes a searchable database of more than 150 leaflets, written to a reading age of no more than 12 years, and videos showing how to administer different types of medicines to children.

The resource is a collaboration of the Royal College of Paediatrics and Child Health (RCPCH), Neonatal & Paediatric Pharmacists Group (NPPG) and WellChild.

Aims
The National Service Framework for Children, Young People and Maternity Services outlined standards in 2004 to address inequalities in paediatric health services over a 10-year period. Standard 10 about medicines states: ‘In all settings, professionals enable parents, young people and, where appropriate, children to be active partners in the decisions about the medicines prescribed for them’. ¹

This report notes the proportion of medicines prescribed to children that are off-label or unlicensed: in general practice this was at least 1 in 10 medicines. About 65 per cent of children are prescribed at least one medicine.² Many studies describe poor medicines adherence in the paediatric population, and it is clear there is a need for high-quality information to support families.

Since its beginning Medicines for Children has involved parents. They identified a need for practical advice about how to deal with side-effects, how to administer medicines for which child-friendly formulations do not exist, and what to do when doses are forgotten or the child is sick. This information, however, is generally missing from drug manufacturers’ leaflets: Medicines for Children fills this gap.

A recent paper³ discusses an approach to evaluating written patient information. It highlights the importance of assessing not only readability but overall comprehensibility and communicative effectiveness as well – the latter measured by the patients’ long-term responses to the information. The multi-stage process used to produce Medicines for Children materials – accredited by the Information Standard – aims to ensure the content is both accessible and effective. This is achieved through a combination of doctors, pharmacists, a professional medical editor and a parents’ panel who write and review the content. The programme also responds to feedback on published leaflets and updates them as needed.

Review
Medicines for Children undertook a review of how the key audiences – parents, carers and healthcare professionals – use the resource. From April to July 2012 the website received approximately 50 000 visits; the majority were within the UK, though the site is attracting interest from across the globe. Of the 137 medicines covered by the leaflets, half of the top 10 searched were antibiotics. This indicates that parents are keen to look for information on acute medicines prescribed for their children.

Among the top 15 topic searches was rectal administration of medicine. This may suggest that parents search online for help when they are more reluctant to ask a healthcare professional face to face.

A consultation with parents conducted for this review revealed that, overall, they liked the look and feel of the website, found it easy to navigate and, importantly, felt that the website contained information that they could trust. One parent noted: ‘I would feel safe using the information. I often need information but never quite know what I can trust. In my opinion the involvement of WellChild,
RCPCH and NPPG rubber-stamps it as a quality resource.’

Feedback solicited from healthcare professionals demonstrated that they signpost families to the resource in a range of ways. These included: adding a website link to locally produced materials, community nurses carrying hard copies of relevant leaflets, inserting a card about the resource in discharge and outpatient materials, and making printed and laminated copies available to photocopy or read in a waiting area.

Thus the initial review demonstrated the increasing reach of Medicines for Children. The programme intends to conduct a new review to further assess the resource’s effectiveness, including the impact on patient outcome.

Conclusion
Crucially, Medicines for Children is freely accessible. Parents are not just the audience of the information – they are key to its production. Written information will not on its own solve all adherence issues, but this website is another string in the bow of reliable resources for healthcare professionals to enhance the care of children.

References

Declaration of interests
None to declare.

Steve Tomlin is consultant paediatric pharmacist, Evelina Children’s Hospital, Andy Fox is principal pharmacist, Southampton General Hospital, and chair of the RCPCH/NPPG Joint Standing Committee on Medicines, Dr Sammons is consultant paediatrician, Derbyshire Children’s Hospital, and associate professor of child health, University of Nottingham, Linda Partridge is director of programmes, WellChild, Jyotsna Vohra is science and research co-ordinator, RCPCH, and Kirsten Olson is research administrator, RCPCH