

Major report identifies significant gaps and weaknesses

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Children and young people who have chronic health conditions or need operations don't always have access to the high-quality, child-friendly information they need to understand what is happening to them. That is the key finding of a three-year study funded by the National Institute for Health Research Service Delivery and Organisation (NIHR SDO) programme and led by Bangor and Cardiff Universities.

The Children's Health Information Matters report, published in conjunction with the NIHR, highlights the need for [children](#) to be provided with information that is engaging, accessible, accurate and appropriate for their age.

Fiona Smith, Children and Young People's Adviser for the Royal College of Nursing has welcomed the report. "Nurses have a key role in communicating complex information to children and young people" she says. "The importance of this study should not be underestimated as improving access to appropriate information resources and young people's understanding is likely to lead to [improved health](#) outcomes."

The report's authors point out that although there are some strengths in the health information provided for children and their families, there are also significant weaknesses and gaps. They believe their research identifies a clear need to address how children's health information is developed and delivered.

"Our research included an in-depth study of the material currently

available and observations and interviews with more than 150 participants, including children aged from six to 18, parents and healthcare professionals" says joint study lead Professor Jane Noyes, from the Centre for Health-Related Research at Bangor University. "It has given us a clearer understanding of what needs to be done so that the right child receives the right information at the right time."

The study brought together a unique team that included media and journalism specialists, a children's illustrator, health services researchers, children's researchers, anthropologists, doctors, nurses and psychologists. The team were particularly interested in health information that focussed on children's self-care and medicine management and wanted to know the best way to design and deliver health information in partnership with children and their families.

"The wide-ranging expertise of the team enabled us to explore innovative perspectives and consider improvements to the complex issue of children's health information production, delivery and use in the National Health Service" says joint study lead Emerita Professor Anne Williams from the School of Nursing and Midwifery Studies at Cardiff University. "We believe that our findings make a new and important contribution to current understanding of the 'state of the art and science' of children's health information."

Key findings of the research include:

- Despite the growing number of children's health information resources, including books, leaflets, toys, games, DVDs and websites, there are significant gaps in provision.
- There are a large number of information producers - from children to pharmaceutical companies - and wide variations in the quality and accuracy of material currently available.

- There are good examples of NHS children's health information websites, where information is checked for accuracy.
- Children want their health information resources to be more realistic and meaningful and matched with their age, circumstances - including family, home, school or college - and differing health needs.
- They also want health information at key points, such as at diagnosis, starting school, changing school, growing up with the condition, lifestyle issues and the transition to adult care.
- Children often struggle to manage their health conditions and medicines at school because teachers and pupils don't have the information they need to understand their illness.
- Information is often conveyed verbally by [healthcare professionals](#) and children can forget the advice they have been given.
- Many resources are not free or not accessible to the NHS. Nurses and doctors who do have access to high-quality resources would benefit from more support about the best way to use them. Nurses and specialist nurses play a particularly crucial role in children's health information.
- Many family members also want high-quality health information about their child/sibling's condition and care and some, but not all, obtain information for the child.
- Some parents filter the health information they find, which means that their children do not necessarily have the important information they need to look after themselves.

Harriet, 17, was diagnosed with diabetes ten years ago. "It would have been useful to have information that I could relate to as a child as I found it difficult to understand the complicated science behind diabetes" she says. "I think the newsletters are great and should be published more often and more information needs to be provided on issues such as alcohol consumption for young people with diabetes."

Harriet also believes that schools need more information on how to deal with pupils with diabetes. "My primary school teachers often had no idea how to act when I became hypoglycaemic and one even lost my emergency glucose supply, not understanding its importance. When I was first diagnosed some pupils even avoided me in case the 'contagious' disease was passed on. This was common, even up to high school."

Sally is very positive about the support she received from health professionals caring for her son, who has epilepsy. But she adds: "I am concerned that there is a wealth of [health information](#) readily available on the internet, but it might not always be legitimate or regulated appropriately. Children and [young people](#) require information that is accessible to them and to have the opportunity to ask questions and discuss what it means to them."

More information: Children's Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people is available from www.sdo.nihr.ac.uk/projdetails.php?ref=08-1718-145

A lay summary of the report can also be downloaded from: www.bangor.ac.uk/healthcaresci...matters/index.php.en

Provided by Cardiff University

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