

Staying on the meds: Involving young patients in the treatment for their chronic illnesses

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Researchers at The University of Nottingham have examined why large numbers of children and young people sometimes don't take their medication, despite suffering from a range of chronic and potentially life-threatening illnesses.

Many children and young people regularly miss doses of medication for a longstanding illness, with adherence rates as low as just 25% among some groups. This can lead to increased rates of [asthma attacks](#) and epileptic fits.

The study, which looked at young patients with four [chronic conditions](#)—[asthma](#), [congenital heart disease](#) (CHD), diabetes and epilepsies—revealed that [tiredness](#), a change of routine and lack of

parental involvement were three main reasons why children didn't always take their medicines.

The Talking About Medicines (TABS): Involving Children and Young People with [Chronic Illness](#) in Managing their Medicines study was led by Professor Rachel Elliott in the University's School of Pharmacy and funded by the National Institute for [Health Research Health Services](#) and Delivery Research (NIHR HS&DR) Programme.

Surprisingly low adherence

Professor Elliott said: "Children with long-term, chronic illnesses often have surprisingly low adherence to medicines that parents or practitioners may, or may not be aware of. Children often have to assume a lot of responsibility for their own health at quite a young age but their voice is not really heard in the consultation, so we don't get to the bottom of their non-adherence.

"This study aimed at revealing the reasons behind that non-adherence to medication and to develop strategies for encouraging young people to continue with their treatment."

From published evidence, more than 40 interviews with parents and children and focus groups with practitioners, the team found that adherence was affected by a number of factors. In addition to tiredness and routine changes, they found doses taken outside the home; a lack of family routine; single parent families; poor parental supervision; a perceived lack of concern from practitioners; and difficulties negotiating the health system all had an impact on whether children took medication regularly.

Parents wanted to maintain control due to a lack of confidence that their child could self-manage their own medication, while children relied on

their parents and rituals in the home to remind them to take their medicine, take on board the information given by health professionals in consultations and to liaise with school.

Empowering children

In turn, practitioners admitted they were aware that they often 'talk over' children and young people during consultations and that insufficient time was spent talking about medicines.

The team of researchers worked closely with pharmacists and GPs to develop an intervention involving children, parents and practitioners that aimed to empower children to talk openly and be active partners in decisions about medicine-taking for their illnesses.

The feasibility of the TABS intervention was then tested in 40 child-parent groups, with their practitioners (doctors, nurses and pharmacists).

It showed that, in those that used it, there was a significant improvement in children's psycho-social wellbeing over time, and that they rated themselves as being more in control of their own health.

In total, more than half—ten out of 14—practitioners found the intervention useful although it revealed that encouraging practitioners to address adherence in children and [young people](#) is a challenge due to their workload.

Professor Elliott added: "Our observations showed that consultations with practitioners were often targeted at the parent rather than the child, who is expected to play a responsible role in adhering to their own medication.

"A bigger study is needed to test the effects on medicines adherence and

patient outcomes and further work is needed to integrate [adherence](#) into children's care pathways."

Provided by University of Nottingham

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