Talking about medicines (TABS): a multi-method study to understand reasons for medicines non-adherence in children and young people with chronic illness, and to improve their contribution to managing their medicines

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Author contributions

- Rachel A Elliott has made substantial contributions to the conception and design of the study, was co-responsible for the overall administration and direction of the project, the analysis and interpretation of data and has given the final approval of this report.
- Deborah Watmough was responsible for the day-to-day management of the trial from 2009 to 2011. She was involved in the design and the piloting of the case studies. She has had a major role in data analysis and formatting the report.
- Nicola Gray has made substantial contributions to the conception and design of the study, literature review, led on the qualitative analysis (with CG), contributed to interpretation of other data, was central to intervention design, and contributed to drafting the report.
- Cris Glazebrook has made substantial contributions to the conception and design of the study, literature review, led the analysis and interpretation of the qualitative data (with NG) and quantitative data (with DW and SC), and contributed to drafting the report.
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Executive Summary

Background

Medicines-based self-management of longstanding illness can be suboptimal in children and young people (CYP), with medicines adherence ranging from 25 to 82%.

Aim

To develop a paediatric medicines management package involving children, parents and health care providers that will empower children to talk openly and be active partners in decisions about medicine-taking for long-term conditions.

Key objectives:

1. To use critical evidence synthesis and consensus-building methods to examine the child-parent-provider triad at individual and organisational levels to:
    a. examine expectations, experiences and concerns about medicines;
    b. explore transferring responsibility control for older adolescents, and how to facilitate honest disclosure of medicines-taking behaviours;
    c. clarify perceptions of roles, empowerment, rights and responsibilities associated with long-term medicines use;
    d. understand children's and parents' interaction with the health system in community, primary and secondary care from initial contact to medicines supply, and over time;
    e. identify effective interventions to improve medicines use in CYP

2. To devise a child-centred paediatric medicines management package that works across ages, social characteristics, conditions, complexity of needs and service delivery settings, informed by individual and organisational perspectives;

3. To explore operation of the package, the complexity and nature of resulting consultations, to determine feasibility and generalisability;

4. To assess methods of objective evaluation of behaviour change, clinical outcome and resource use.

This study used a range of methods, and a range of overlapping literature to address the study objectives. Objectives 1a-1e were achieved through a review of the published evidence and focus groups and interviews with CYP, parents and practitioners. Each source of evidence provided some input to each objective. By triangulating the sources of evidence, we were able to address each objective.

An Expert Advisory Panel was convened and a number of individuals and organisations were identified through a snowballing process, as key stakeholders to participate in the study from the outset. The interpretation of data was validated with the stakeholders, and the Expert Advisory Panel. Involvement of stakeholders throughout this project has enabled us to ensure that the research is relevant and accessible

Objective 1e was not in the original proposal. Our overall hypothesis was that, once real reasons for non-adherence had been disclosed and discussed within the CYP-parent-practitioner triad, we would be able to provide recommended evidence-based interventions, linked to that reason for non-adherence, from published evidence, to support the practitioner. However, the published reviews of interventions to improve adherence available did not provide us with sufficient guidance to inform the development of an evidence-based intervention. Therefore, we needed to carry out our own review of interventions.

Determinants of medicines-taking and improving adherence in children and young people

We carried out a review of the published evidence and focus groups and interviews with CYP, parents and practitioners.

Our literature review summarised current knowledge about determinants of medicines-taking in CYP. Of 197 studies, most were American, fewer than 10 percent were British, over half were in asthma, most used quantitative methods and examined parent report of factors. To identify factors relevant to the UK, increase input from CYP and obtain information on diseases beyond asthma, forty-three face-to-face interviews were conducted with 26 parents and 18 CYP with asthma, CHD, diabetes or epilepsies in the East Midlands. (In one of the interviews both parents were present, providing a total of 44 interviewees, but 43 interviews.)Three focus groups were conducted with 19 practitioners.

Similar determinants of non-adherence were identified from these sources. Where both parents' and CYP's views or behaviour were examined, these were likely to differ. Person-related determinants reducing adherence were reduced illness severity, increased illness duration, forgetting, reduced self-efficacy in adolescents, increased age. This was supported by the CYP in our interviews. Tiredness and a change of routine were the most common

reasons for forgetting. Perceived necessity for a medicine was a key driver for adherence. High concern and/or low perceived necessity were associated with lower scores of parent-rated adherence. There is conflicting evidence of an association of knowledge and information use with adherence. This did not emerge as a significant factor in the interviews with parents and CYP.

Regimen-related determinants reducing adherence were poor palatability or acceptability, anticipation of adverse effects, but not the experience of adverse effects, and increased complexity. Once daily regimens improved adherence over more frequent dosing, or doses taken outside the home. Some variables related to social and family context have associations with reduced adherence: lack of family routine, poor family functioning and single parent families. Socio-economic status, racial/ethnic or cultural background and school environment did not have a consistent effect.

Relationship-related determinants reducing adherence were poor parent supervision, highly levels of conflict within family relationships, perceived lack of concern from practitioners, and difficulties negotiating the health system. These findings were strengthened by our stakeholder work. The strongest theme emerging from the study with parents was the need to maintain control of their CYP's medicines-taking, and a lack of confidence that their CYP could self-manage. Support was variable within the family setting and support from practitioners was mixed. The study CYP relied on their parents and rituals within the home to remind them to take medication, share the informational load in consultations and to liaise with schools. The study practitioners were aware that they talked over the CYP, and insufficient time was spent during consultations talking about medicines. They felt that adverse effects and problems with access at school were key barriers to adherence, (this was not reported by CYP or parents) and suspected that CYP stopped taking medicines without telling anyone.

There were key gaps and limitations in the evidence around facilitators and barriers to medicines-taking in CYP. Studies varied in quality, design, age range, measurement of adherence, knowledge or sociodemographic characteristics and there was uneven distribution of the numbers of studies examining each theme. There were few UK studies, and studies in asthma dominate. This was compounded by the general lack of use of validated measures of adherence and the use of parent report of factors rather than CYP report. Consequently, it is not often known what is important to CYP. Few studies examined the association between multiple factors and adherence behaviour. Very few of the studies, other than the 44 studies that specifically examined age, controlled for effect of age.

Our review of interventions assessed evidence about interventions to improve adherence in CYP. Of 48 studies, most were in asthma (29) and diabetes (7). Nine studies showed significant improvements in adherence and outcome. Features of effective interventions were those based on reasons for non-adherence, those taken to the patient, involving the family, convenient for CYP and parent, sensitive to age and development,

sustained over time and co-ordinated with care delivery. There was no optimal approach to improving medicines-taking in CYP. Poor quality study design commonly precluded assessment of effectiveness.

From our interviews and focus groups, adherence seems best when parents and CYP work together to optimise medicines use, and homes with consistent routines are most conducive to good medicines taking routines. The use of evening doses should be minimised. Positively, schools seemed to provide good support generally, although access issues need to be improved in some places.

TABS intervention development

We combined the results of the consensus-building methods and interviews with the critical evidence synthesis of reasons for non-adherence to obtain an overall picture of reasons for non-adherence. We then synthesised this evidence with the findings from the systematic review of interventions to inform our intervention design.

We proposed that the TABS intervention should engender open discussion between parents, CYP and practitioners to identify, and remove, key modifiable barriers to adherence. A pre-consultation tool was proposed, to act as a prompt to facilitate discussion of medicines-taking between parent and CYP prior to the consultation. The purpose of this was to create "proactive patients" through building and supporting the partnership between the parent and CYP, to help both to engage with practitioners. In addition, the intervention proposed to support practitioners by providing a briefing on actual reasons for non-adherence in CYP derived from our work, and to facilitate a more patient-centred consultation, with the aid of a prompt. The "prepared practitioner" should understand determinants of non-adherence and be able to enhance the parents' and CYP's input into the discussion about medicines.

TABS intervention feasibility study

The TABS intervention consisted of a pre-consultation tool for the parents and CYP to complete and use as a basis for discussion around medicines with the practitioner. The practitioner had received a briefing session around barriers to medicines-taking in CYP and how to engage CYP in consultations. During the initial consultation an action plan was to be developed to form the basis of follow-up consultations. The intervention was tested in primary care, community and hospital-based secondary care, and community pharmacy, with 40 parent-CYP dyads in the East Midlands, in CYP with asthma (14), CHD (4), diabetes (11) and epilepsies (11), aged from 5 to 17, most taking one to two medicines regularly. The sample contained dyads from minority ethnic groups and low socioeconomic groups, although these were under-represented.

Assessing the use and usefulness of the preconsultation tool and practitioner prompt required combining researcher observations and parent/CYP/practitioner report.

Of the 40 parents and CYP, 31 parents and 20 CYP completed the pre-consultation form before coming to the appointment and 9 parents and 5 CYP filled it out at the clinic/practice. All parent-CYP dyads took the pre-consultation tool into the consultation and 8/40 handed it to the practitioner.

The CYP used, or found the pre-consultation tool useful in 17/40 consultations. The parent found the pre-consultation tool useful in 21/40 consultations. The practitioner found the pre-consultation tool or practitioner prompt useful in 14/40 consultations. The number of consultations where the pre-consultation tool was used either by the parent or the CYP was 26/40. In 12/40 consultations, CYP and parent used the tool. All members of the triad used the tool in 8/40 consultations.

The number of consultations where the pre-consultation tool or the practitioner prompt was used by any member of the triad was 29/40. Failure to use the tool was associated with stressful consultations, parents or practitioners feeling they did not need the tool, or forgetting to use the tool. Many of the practitioners did not attend the training session, only attended for part of it, or did not engage with the topic. It was not possible to assess either baseline knowledge or learning from the session. Of the 14 practitioners who had used the pre-consultation tool or prompt, ten had found it "useful".

The quality of the interaction between parent, CYP and practitioner was assessed through the use of the Paediatric Consultation Assessment Tool (PCAT). The mean scores of different aspects of the consultation were high, but with variability in the scores of individual practitioners. Parents and CYP aspects were either scored very similarly within an individual consultation, or the CYP aspect scored the poorer, suggesting that consultations were often targeted at the parent.

The group reported high levels of self-reported medicines adherence as rated by CYP (mean 85%) and parents (mean 89%). Self-efficacy was high with a strong sense of personal control of medicines-taking. Child health (CHQ-PF28) scores showed that the sample had poor physical and psycho-social wellbeing.

In a post-hoc exploratory analysis, fourteen parent-CYP dyads were observed by the researchers to have used the pre-consultation tool actively during the consultation. At two month follow-up, there were no significant changes in clinical outcomes for those who did or did not use the pre-consultation tool. In the group that used it, there was a significant improvement in psycho-social well-being over time (Wilcoxon test, $Z=-2.76$, $p=0.006$) and CYP rated themselves as being more in control of their own health at follow-up compared to baseline ($Z=-2.233$, $p=0.026$). There were improvements in adherence but these failed to reach significance. There were no significant differences in outcomes in those who had not used the tool. We must not over-interpret these findings. The parents and

CYP who chose to use the pre-consultation tool may well have been highly motivated and destined to succeed, with or without the tool.

The ability of the intervention to address previously encountered problems affecting adherence and promote behaviour change was examined within each case study by collecting data at both baseline and at two follow-up points (1 week and 2 months after the consultation). An evaluative framework assessing clinical outcomes and resource consumption was also developed. Generally, we were able to collect the data we needed. In terms of evaluation, all the measures used performed well and appeared to be discriminatory. We were able to collect data for a range of resource use parameters including length of initial and subsequent consultations, NHS contact (primary and secondary care) and medicines consumption, although there were some discrepancies between CYP, parent and practitioner report.

We had no control over the selection of patients, by the clinical sites, due to R&D restrictions, although we did ask for patients with poor adherence. This significantly reduced the potential utility of the intervention. Some clinical sites sent out invitation packs to people who did not fit the inclusion criteria. We had no control over this process, due to R&D restrictions. This contributed to the increased length of time taken to recruit, the reduced relevance to the intervention, and the ultimate reduction in numbers recruited to the study. We requested that clinical sites selected patients that they suspected were not adhering to medicines but we had no control over this. We feel the high rate of reported adherence was caused by a number of factors. Lack of appropriate selection of patients by clinical sites participating in the study resulted in the selection of dyads who are already more interested in their medicines and may be more adherent. There was also likely to be social desirability bias leading to unwillingness to admit to non-adherence by patients, parents and practitioners. From our experience, it takes skill to present non-adherence as a "norm" in medicines use behaviour, such that CYP and parents feel they can disclose real behaviour. We have reviewed the literature on adherence and the adherence levels reported here are much higher. However, the sample was not unrepresentative in terms of emotional and physical wellbeing.

Conclusions: implications for healthcare, recommendations for research

CYP with long-term illnesses face challenges presented by the illness, the medicines and the family, social, cultural and healthcare context within which they function. This occurs against a background of developmental changes, and within the complex dynamics of a constantly evolving relationship with parents/caregivers. Both the literature review and the qualitative data from parents and CYP pointed to the importance of parental support in facilitating CYP's adherence. Practitioners need to take account of this complex situation when dealing with the parent-CYP dyad. Flexibility to identify modifiable and non-modifiable reasons for non-adherence, to increase efforts to empower the CYP to voice their agenda, to promote

honest disclosure of medicines-taking behaviour, together with sensitivity to the level of parental involvement wanted within a specific family, are essential. Service users in this context are both parents/caregivers and CYP. The relative rights and responsibilities of parent and CYP with regards to medicines-taking is relatively under-researched, and not explored within a practice context. CYP and their parents need to be supported to discuss medicines more openly with one another, and be supported in presenting their issues to their practitioner.

The advantage of this approach is that the different sources informed the objectives differently. For example, the use of published evidence in combination with focus group and interview data provided a much richer view of reasons for non-adherence in children and young people, and an increased relevance for the local context, given that most evidence was not based in the UK. The disadvantages of this approach are the large amount of data available, the extent to which evidence from different sources can be synthesised and the subjective nature of interpreting data of this type. The resultant interpretation was reliant upon the perspectives, experience and expertise of the research team.

Examination of the published evidence combined with primary data to determine barriers and facilitators for medicines-taking in Phase 1 provided an essential basis for intervention design, approaches for practitioner briefings, and content for intervention paperwork.

We planned an innovative, evidence-based approach to managing medicines in CYP with chronic illness, by investigating the role of the triad of parent, CYP and practitioner. This meant that we had to observe and evaluate the TABS-based intervention, which introduced a level of complexity to the research process, and artificiality to the intervention process. However, this was a successful approach and we would repeat this method in future work.

Implementing the primary research in two phases was intended to allow the interviews and focus groups to inform intervention design, before testing it in Phase 2. This was partially successful. Unfortunately, we were delayed significantly by two sets of transitional NHS R&D process changes, such that our researchers were taken away from field work in order to complete the approval processes. This has critically reduced the time spent working with clinical sites to ensure appropriate recruitment of patients, appropriate briefing of practitioners, and removed our ability to schedule a follow-up consultation. Furthermore, we had no control over which patients were recruited to the study. This has substantially reduced the ability to demonstrate the utility of this intervention

Despite this, our study suggests that the parent/CYP pre-consultation tool was quite successful and acceptable when used, whereas the practitioner briefing and prompts were not always so successful. We have proposed an intervention that, with further development, may improve CYP's involvement in discussions and decisions about medicines-taking, and this could lead to improved medicines-taking and associated health benefits. The strength of this study was that we were able to investigate the

applicability of the TABS tool in a range of clinical settings, being used by different practitioners, disease areas, disease severity and age groups.

Any future version of the TABS intervention needs to better address the challenges of practitioner engagement and education, but from our experience in this study, ways need to be found to enable practitioners to better support medicines use in this age group. We encountered initial enthusiasm by practitioners, and acceptance that medicines use was suboptimal. This was succeeded by lack of engagement in the practice situation. This may illustrate the complexities in introducing a new tool into practice that needs new ways of working, and is trying to change the power dynamic between CYP, parents and practitioners. The lack of engagement by practitioners in this study appeared to result in parents becoming resigned to not being listened to. However, where the tool was used during the consultation, there was evidence of behaviour change, which is encouraging for any future work.

From this early work, we would recommend that a future version of this intervention has the following characteristics:

- Ensures all members of triad understand the purpose of the tool,
- Encourages parents and CYP to complete tool beforehand,
- Makes sure practitioner has engaged with, and had a briefing about the intervention,
- Ensures that the CYP or parent hands the pre-consultation tool to the practitioner at the beginning of the consultation,
- Does not exclude the parents of older CYP from discussions,
- Does not exclude younger CYP from discussions.
- Targeted CYP starting a new medicine for a chronic condition, or where poor adherence is suspected by practitioners (or parents).

Priorities for future research:

1. Better understanding of CYP-parent-practitioner interactions and their influence on adherence;

2. Better appreciation of the needs of CYP as they age and develop, keeping a regular dialogue with age-appropriate updates on medicines;

3. Methods for effective practitioner engagement and education;

4. Simpler design and CYP-centred delivery of the TABS pre-consultation tool, and integration in care pathways, such as incorporating the CYP responses and any resultant action plan into the GP PMR, and targeting CYP earlier in the disease;

5. Future NICE guidance should include advice relating to CYP;

6. Research governance procedures should be examined such that study design of ethically appropriate studies is not compromised unnecessarily, with associated waste of public sector research resources.