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'Did not attends' in children 0–10: A scoping review**

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Abstract:

Background

Patients who do not attend ('DNA') health appointments have been identified as a service problem incurring significant costs to the NHS. In order to explore the causes, effects and costs of child DNAs, we carried out a scoping study to map the literature and identify gaps in the research.

Methods

Given the breadth of issues underpinning DNAs, a scoping study, including research studies, audits, policy documents and conference abstracts, was the most useful way to map the field. To foster public and patient participation, we sought advice from parents participating in the National Children's Bureau's Family Research Advisory Group.

Results

From a pool of 1997 items, we found few UK studies with non-attendance of 0-10 year olds as a *primary* focus, though many more *incidentally* reported DNA rates. Overall, four topics predominated: the conceptualization of DNAs; the correlates of non-attendance; initiatives to reduce non-attendance; and the relationship between non-attendance and safeguarding. The Family Research Advisory Group identified broadly similar issues, but with a stronger emphasis on communication and practical matters.

Conclusions

While there may be circumstances where failing to attend appointments makes little or no difference to a child (or even benefits them) it is likely that there are children whose health or well-being are compromised as a result of failing to attend appointments. Both 'over' and 'under'- attendance can be a source of anxiety to health professionals. Areas where further work is needed include robust evaluation of the effectiveness, cost effectiveness and maintenance of measures to reduce DNAs and a better understanding of the relationship of safeguarding to non-attendance.

[268 words]

Key messages

- There is only a slender UK research literature with DNAs among children as a primary focus;
- Both over and under attendance by children can be a source of anxiety for health professionals and have been identified as incurring significant costs to the NHS;
- Whilst unnecessary appointments are a cost to the NHS, and to parents, carers and children in terms of activities foregone, missed appointments may impact on a child's well-being and raise safeguarding concerns;
- Advice on the management of the safeguarding implications of missed appointments is inconsistent;
- Whilst a number of creative ad hoc solutions have been put in place in various trusts to reduce DNA rates, there is a lack of high quality evaluation of the implementation, effectiveness, acceptability and cost effectiveness of these measures.

Introduction

The reasons why adults fail to attend health care appointments have been well-rehearsed (Neal *et al.* 2001; Neal *et al.* 2005), with the NHS Institute for Improvement and Innovation (2008) listing as possible causes of non-attendance factors such as: patients forgetting; patients no longer needing the appointment or, conversely, being too unwell to attend; administrative errors; communication failures; socio-demographic factors; the costs of travel; and difficulties in cancelling/changing appointments.

Whilst the bulk of this literature refers to adults, a substantial proportion of DNAs - 'Did not attends' - are for children, with DNA rates particularly high in Child and Adolescent Mental Health Services (CAMHS) (Rawlinson & Williams 2000).

Administrative error and system-related problems are likely to be relevant for both child *and* adult non-attendance. However, some reasons for non-attendance may be unique to children and their carers.

This paper scopes the literature on DNAs at NHS child health appointments in the UK with a focus on younger children (0-10 years) who are dependent on an adult carer for access to services. We also draw on comments made by a family research advisory group on the question of 'do not attends'.

Methods

A scoping review including research studies, audits, policy documents and conference abstracts was judged to be more helpful than a narrow systematic review in mapping the field. A scoping study is useful in exploring the extent and nature of evidence, in ascertaining the value of undertaking a full systematic review,

summarising and disseminating findings and identifying research gaps (Arksey & O'Malley 2005).

The review inclusion criteria are shown in Table 1.

[Table 1 about here]

A six-stage search strategy was developed. This involved searches of: electronic databases; Google, Google Scholar and PubMed; journals, conference proceedings, reference lists; and organisational websites such as Trust Boards discussing DNAs. A request for information about unpublished research was made via the JISC Mail service. Search terms used to interrogate resources included: 'attendance', 'child', 'missed appointment' and 'did not attend'. Items identified at the search stage were stored in a Refworks database. Titles and abstracts were screened for inclusion by one of the research team. Where items met inclusion criteria, the full text of the document was retrieved.

In addition, we discussed our work with the Family Research Advisory Group at the National Children's Bureau (NCB). Seven mothers and fathers participated, of whom four were the parent of a child with disabilities or a long term medical condition with extensive experience of NHS services. With the permission of participants, our discussion was audio-recorded and transcribed. The observations from this group are reported alongside the review findings.

Ethical approval

Ethical approval for the scoping review was provided by the Research Ethics Committee, School of Health and Social Care, Teesside University. For our

consultation with parents, the NCB (who organise and host the group) adheres to the Social Research Ethics Guidelines http://the-sra.org.uk/sra_resources/research-ethics/ethics-guidelines. The purpose of our single discussion was to seek comment and advice on our work rather than undertake research. Participants agreed to the discussion being recorded, transcribed and reported. **Results**

The scoping review and the Family Research Advisory Group

After removal of duplicates, 1997 items were identified via EBSCO, ASSIA, PILOTS Database, Science Direct, PubMed and Google Scholar. The searches generated a large number of articles which were excluded (see Table 1) as they failed to meet our inclusion criteria, in particular the age range of interest, UK based research and a primary focus, rather than a passing mention of Do Not Attends. Requests to researchers via seven JISCMail list groups generated four responses, all of which had also been identified through our searches.

In considering this literature - which encompassed research papers, commentaries and 'think pieces', as well as policy and audit documents on non-attendance at child health appointments - we identified little research data, which is surprising given the scale of the problem of non-attendance. In particular, we found few UK-based studies with a *primary* focus on its prevalence, causal factors and consequences, though there was a larger number of audits and many more studies which *incidentally* referred to DNA, including in areas such as immunisation (e.g. Samad et al. 2006). A notable absence was material on 'No Access Visits' (NAVs), a particular issue for health visitors (Crofts *et al.* 2000). Administrative error as a factor in non-attendance for children also appears to be under-researched.

Overall, the literature we scoped fell into four broad areas:

1. the conceptualisation/definition of DNAs and allied terms;
2. the correlates of non-attendance (particularly in CAMHS);
3. initiatives to reduce non-attendance;
4. Non-attendance and child safeguarding.

The Family Research Advisory Group described experiences - as parents accompanying children - of diverse health services. The group identified reasons for non-attendance; some presented as hypothetical, some directly experienced. The possible factors the group considered might influence non-attendance fell into the following areas:

- **Logistical/practical:**
 - Services outside the family's locality;
 - Geographical mobility of patients (especially in London);
 - Difficulties securing a parking space – a particular problem with disabled children and other children in the vehicle;
 - General transport difficulties in accessing hospitals.
- **Financial:**
 - Financial problems meaning that travel was seen as unaffordable;
 - The costs of calling to cancel appointments
- **System-related/technical:**
 - Booking systems that require access to a computer/computer literacy;
 - Inflexibility requiring patients who are running late to rebook

- **Quality of interaction between parent and health professional:**
 - Rude/bullying professionals;
 - Children and young people ignored during the consultation.

The scoping review:

Defining and re-defining the problem

The term 'DNA' is considered by some commentators to be inappropriate for non-attendance by children and young people (Roe 2010). Powell and Appleton (2012:183) suggest: 'a reconceptualisation of DNA to 'Was Not Brought' (WNB) to encourage health professionals to take a proactive and child-centred stance in ensuring the well-being and safety of children and young people who miss appointments'. Their argument is that, since children and young people are brought to appointments by a parent or guardian, missed appointments may raise welfare and safeguarding concerns. However, Munro (2012: 193) observes that, irrespective of whether a parent makes a cancellation or simply does not attend, the consequence is the same: 'in both cases, the child is not seen by a health professional despite someone having deemed this in his or her interests.'

Advocates of the use of WNB maintain that using this term, rather than 'DNA', suggests a discourse beyond the immediate concern about potential risks to the child to a broader understanding of the family-in-context. It encourages providers to consider why parents and guardians do not keep appointments for their children, and how services can better engage with family caregivers to improve attendance for the health and well-being of the child.

Among parents in the NCB Families' Research Advisory Group, there was awareness of the use of the acronym 'DNA', though the term was considered limiting for quite different reasons to those described above:

...where ... I haven't been able to park and I've rung the department...and said, look I am here, we are attending but I can't park.... And there's no leeway there... And they're, well sorry if you can't get here within the next 30 minutes ... and yeah .. I think and that will go down as a DNA. However that person may want to have attended, but it would still go down on record as a DNA.. [mother].

Correlates on non-attendance

Such UK research as there is describing the correlates of DNAs at child health appointments identifies multiple factors associated with non-attendance. These can be summarised as encompassing socio-demographic and socio-cultural factors, as well as practical or logistical factors (e.g. transport, caring for other children), referral waiting times and recording and administrative error. In relation to the latter, the Audit Commission (2003), in its examination of waiting list data, noted that many trusts had 'incorrect or confused policies for how to record DNAs and cancellations.' Healthcare organisations themselves have observed that poor data quality may be partly responsible for high DNA rates (Whittington Hospital 2010) and that addressing all of the factors affecting non-attendance needs sustained effort (Whittington Hospital 2011).

Of the other studies, most focus on non-attendance in CAMHS. Minty and Anderson (2004), for example, examined 211 referrals to a child psychiatry department and report a 22% failed first appointment rate. Reasons given include the lack of availability of transport, anxieties about attending and long waiting times. Social deprivation, single parenthood, carer responsibilities and system-related factors such as the quality of the referral letter were described as factors related to non-attendance. In terms of interventions, family contact prior to the appointment was described as helpful. Calam and colleagues (2002:215) suggest that maternal expressed emotion, stress and depression may be related to child non-attendance for therapy for behavioural problems. In addition, waiting times for referral to CAMHS (Rawlinson & Williams 2000; Foreman & Hanna 2000) have been suggested as important with Rawlinson and Williams reporting long waiting times resulting in non-attendance (followed by longer waiting lists). Unaccompanied minors (UAMs) who arrive in the UK without a legal guardian and who are able to access services independently, attend fewer sessions and miss more CAMHS appointments than those accompanied to the UK by a primary caregiver (Michelson & Sclare 2009). Bradby and colleagues (2007) suggest that stigma may play a role in disengagement from mental health services.

A study undertaken on non-attendance at CAMHS in the south west of England (Barnardo's 2011), whilst acknowledging system-level and logistical/practical barriers to attendance (appointment times clashing with school drop-off/pick-up times transport costs, distance to services), also highlights the role of parental anxiety. Parents were worried about being 'blamed' for children's illness and reported feeling judged by practitioners and, in some cases, anxious about losing custody of their children.

Whilst a number of authors have described reasons for non-attendance at CAMHS, there is less research on child non-attendance for other services. Cameron and colleagues (2010) explored factors affecting non-attendance at Birmingham Children's Hospital and found non-attenders to be older than attenders and have a higher deprivation score. A relationship between ethnic background and attendance was also observed, with Chinese and Indian groups less likely to miss the appointment than other ethnic groups. The waiting time to appointment also affected rates of attendance with the average waiting time for a first appointment two weeks longer for non-attenders. Cameron *et al.* (2012) also conducted interviews on DNAs at general paediatric outpatient clinics, interviewing parents, stakeholders (e.g. managers) and NHS staff (including GPs and consultant paediatricians). Parents discussed factors such as not receiving the appointment letter, while staff/stakeholders were more inclined to relate non-attendance to family characteristics, sometimes reporting non-attending families as 'dysfunctional'. In their analysis of 67 missed appointments at community paediatric clinics, Stathopulu, Ajetunmobi and Selling (2003) reported non-attendance as associated with the age of the child (under five); developmental delay and a child living in a deprived area.

Children with disabilities may experience multiple uncoordinated appointments (Every Disabled Child Matters 2011). Some of the parents in the NCB advisory group felt that poor communication between parent and professional or parent and clinic clerk (as in the parking example above) was significant. One described an incident which she felt demonstrated a lack of keen observation on the part of a health professional:

...one of my children has only got one hand. And I remember going to see... [health professional] and [s/he] was quite rude...[s/h]e hardly looked at my little one and then proceeded to ask me the question, 'Is this child left or right-handed?'...At the end of that meeting when [s/he] said...'if you come back to me in three months..', I walked out that meeting and said to my husband 'there's not a cat in hell's chance I'm going back'. If [s/he] cannot at that moment in time even look to make [a] basic observation... [mother].

However, many of the problems that the parents of disabled children face are similar to those experienced by parents of non-disabled children. Limited financial means and transport problems were flagged up in both the literature and the group:

...supposing you'd moved to [place] and your appointment was in [place], you may not have the money for the fare because it's so expensive to use public transport. And if there's three of you...you and a couple of kids...you've got to take with you, you won't go because you haven't got the money [mother].

Initiatives to reduce non attendance

Interventions to promote attendance in this population are similar to those aimed at adults since it is the parent rather than the child who is the recipient (if not the focus) of the intervention. Most published studies of this kind do not focus *solely* on under 10s. They largely involve the use of reminders of some kind (text messages, letter

reminders), changes in the booking system itself (opt-in systems, or patients noting the time of appointment themselves) or other service-level changes.

Those studies aimed at child populations include Clemente and colleagues' (2006) findings from the evaluation of a system designed to manage referrals to London-based CAMHS services and reduce DNA rates. The authors found that the new system was associated with a significantly shorter average waiting time for the first appointment (nine weeks) and a lower DNA rate. Whitworth and Ball (2004) describe how staffing changes (a new primary mental health team) was associated with a positive impact on referrals and attendance rates. Other interventions aimed at reducing DNA in paediatric settings include the use of a sticker with the next appointment date and time given to parents. In one study (N=65), the DNA rate was 9.23% for patients given stickers, while the control DNA rate was 18.4% (McMillan & Jayatunga 2012). Kapoor (2012) reports findings from an audit of DNAs in community paediatrics, suggesting that DNAs are predictable and that targeting high risk groups according to previous DNA, deprivation, and 'carer factors' resulted in a reduction in DNA rates. Hawker (2007) reviewed 'opt in' systems (responding to the appointment letter) for mental health out-patient clinics which included CAMHS; in eight of the nine studies, a reduction in non-attendance was reported. Sachdev and colleagues (2011) evaluated the effect of text and phone call reminders to carers and young people for attendance at a paediatric diabetes clinic. No statistically significant differences in attendance were reported.

Two recent Cochrane reviews (Car *et al.* 2012; Atherton *et al.* 2012) on interventions to improve attendance at healthcare appointments across *all* patient age ranges examined the effectiveness of mobile phone messaging and email reminders. In the

first (Car *et al.* 2012), four RCTs involving 3547 participants were included. Three studies assessed by the authors as moderate quality showed that mobile text message reminders can improve attendance at appointments compared with no reminders (risk ratio (RR) 1.10 (95% confidence interval (CI) 1.03 to 1.17)). One (low quality) study demonstrated that text message reminders *and* postal reminders, compared with just postal reminders, improved attendance (RR 1.10 (95% CI 1.02 to 1.19)). Two moderate quality studies showed that text message reminders and phone call reminders had broadly the same impact on attendance (RR 0.99 (95% CI 0.95 to 1.03)). The other review (Atherton *et al.* 2012) attempted to examine the effectiveness of email reminders but studies for inclusion could not be identified. The review authors suggest that, given the opportunities that email presents, there is a need for 'rigorous studies addressing the review question'.

Some members of the Family Research Advisory Group were aware of initiatives to reduce DNAs. Most thought that reminders might be useful, while emphasising the competing demands on their time.

My schedule is so busy and I just forget things at the drop of a hat [mother].

I think people need reminders, people might completely forget [father].

Non-attendance and child safeguarding

Missed child health appointments have been identified as possible indicators of child safeguarding concerns. In a retrospective audit of paediatric outpatient appointments in London, it was reported that of the 685 missed appointments, one third of child

non-attenders were known to Children's Social Care (Watson & Forshaw 2002). A review of 126 child deaths in 2006 conducted by the Confidential Enquiry into Maternal and Child Health (CEMACH) reported that while death related to failure to follow up 0-18 year olds who had missed appointments is rare, opportunities to help children had been missed (Pearson 2008). The Enquiry recommended that 'Health Services, including primary care and Child and Adolescent Mental Health Services...should proactively follow up children who do not attend appointments' (Pearson, 2008: 6).

There is, however, variation in approaches to missed appointments. Action for Children's Child Neglect in 2011 review (Burgess *et al.* 2012) reports that children missing appointments may simply be relegated to the end of the waiting list. The Quality Network for Community CAMHS Service Standards stipulates that a CAMHS service must have procedures such as risk assessment in place when an appointment is missed (Barrett *et al.* 2011). However, some CAMHS teams close cases after missed appointments, assuming disengagement (Auditor General for Wales 2009).

Each NHS Trust is required by the Care Quality Commission (Care Quality Commission 2009) to develop safeguarding policies in relation to non-attendance, although there is some variability as to how vulnerability and safeguarding are regarded. Although *repeated* non-attendance for follow-up health appointments is seen as an alert for possible child neglect (NICE 2009), in some cases, NHS Trust safeguarding procedures may be triggered sooner, usually where there are pre-existing safeguarding concerns. For example, in their policy document on managing missed appointments, NHS Bolton states that 'A missed appointment may indicate

the family and child require support to promote health and prevent harm' (NHS Bolton 2010: 5), with even one missed appointment suggested as potentially significant.

In some areas, actions to alert GPs about child safeguarding issues have been implemented using new information technologies. Gurney and colleagues (2012) report an evaluation of a NHS Devon audit of hospital DNAs among 0-18 year olds using a new hospital IT system for alerting GPs to DNAs. This was tested with one GP practice over a four-week period so that the GP could identify 'vulnerable families'. Of the 354 referrals to hospital outpatient appointments, 25 (7%) children were reported as not having attended. However, of these, 13 (52%) had in fact attended, six had not received an appointment, two parents had cancelled the appointment in good time, and four families had moved practice. Inaccurate information about attendance was the result of non-completion of outpatient clinic outcome slips by staff.

The assumption of child vulnerability or risk, and the consequent need to enact safeguarding procedures where appointments have been missed, has been challenged. Confining her discussion to health visiting, Robinson (2004) discusses the tension between supporting mothers and safeguarding babies and children. Her perspective echoes earlier work on families' ambivalence about health visitors where Dingwall and Robinson (1990) found that a significant number of their sample of Scottish parents in their sample did not trust health visitors and developed strategies to limit interaction with them.

The National Service Framework (NSF) for Children, Young People and Maternity Services (Department of Health 2004:97) gave failure to attend child healthcare

appointments as a potential indicator of vulnerability, whilst allowing that 'It can equally be an indicator that a service is difficult for families to access or considered inappropriate, and requires reviewing.' Echoing this observation, Mathura and Webb (2010) argue that child healthcare is less easily accessed and less effectively used by some minority groups.

Safeguarding in the context of DNAs was not mentioned by the Family Research Advisory Group although one participant reported the consequences of her poor relationship with a health visitor:

...it was...a health visitor who was really rude and bullying and I thought, I don't need to talk to you so I didn't answer the door. You know...she didn't have people skills [mother].

Discussion

A child not accessing an appointment may arise because a parent makes a rational decision about a child's health needs, it may be the result of administrative error, or it may be an indicator of vulnerability either in terms of appropriate healthcare or broader safeguarding issues. In making decisions about their children's health and medical appointments, parents can be between a rock and a hard place. They may over or under-consult, they may not use the services when they should, or use them in the wrong kind of way (Stacey 1986). Whilst limiting our work to the UK literature may reduce its generalizability, many of the issues described here are likely to be relevant to other jurisdictions.

Whilst there may be circumstances in which not attending is beneficial to health (if, for instance an appointment is unnecessary and the child would be missing half a

day of school to attend), and rather more circumstances when failing to attend makes little or no difference to outcomes, there will be children whose health and/or well-being is compromised as a result of failing to attend appointments. We found little evidence of substantial costs to the NHS from DNAs, given the management mechanisms to take these into account in booking services. As a clinician colleague pointed out, without DNAs, many clinics would be unmanageable (Viner, personal communication).

Linking missed appointments or no access visits to safeguarding can have problematic consequences. Canvin and colleagues (2007), for instance, in their study of the experiences of service use among parents who had experienced a child protection investigation, found that many parents refused to engage with services out of fear of the consequences of seeking help. Recent proposals to create a database for children brought to A&E (Guardian 2012) underline the need to better understand the extent to which safeguarding concerns drive or subvert the help-seeking behaviour of parents. Given this, relationship- building with children's charities working with the most disadvantaged children and families may be fruitful in designing services which are responsive to children and families (Barnardo's 2011). Whilst we identified no items focused on children's own views of attendance and non-attendance, a Barnardo's colleague on our advisory group for this study observed that: 'We frequently come across young people and children who report how scared they are of health appointments and parents who try and take their children to their appointments and the child is too distressed' (Roberts E, personal communication).

The evidence base, as it stands, suggests a number of areas that might be a focus for future research activity:

1. Work on understanding the impact, if any, of redefining 'DNA' to 'WNB'. Trusts have been under pressure to reduce waiting lists, which may act as a considerable disincentive to chasing or offering new appointments to those who do not attend. Does re-categorising the event act as a driver to consider potentially vulnerable children and the family as a whole, or does 'WNB' imply an unhelpful judgement on parents?
2. Analysis of the role that administrative errors (especially data inputting) play in the construction of DNAs. What proportion of DNAs is attributable to error? Does this vary across service settings? Pope's (1991) study on the management of waiting lists provides insights into the ways in which waiting lists are created and managed may provide a useful framework for such an analysis;
3. Qualitative studies with families, administrators, nursing and medical staff to better understand their perspectives on non-attendance, and their views on appropriate interventions;
4. Explorations of the tension between the provision of care and the safeguarding of children. This might usefully be undertaken with professionals with a safeguarding role such as health visitors.
5. Research focused on the development, sustainability and, in particular, the rigorous assessment of the effectiveness and cost effectiveness of interventions to address child non-attendance, which might include well-designed controlled trials.

Greenhalgh (2012) has recently provocatively suggested that 'less research is needed'. We would argue that this is an area where more high quality research, tied to development, could make a difference to both service providers and children.

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