ENRICH
Enabling Research In Care Homes

NHS
National Institute for Health Research

Successfully working with Care Homes

Executive summary

The Probiotics for Antibiotic Associated Diarrhoea (PAAD) study has successfully conducted and completed stage 1 of its research within a care home. The research team is keen to pass on their experiences and lessons learned along the way to others wishing to conduct research within this setting.

As care homes are all run very differently, challenges for the team varied from care home to care home. Despite the unique nature of each home, the team identified three common factors that helped them in the research:

- Setting expectations at the beginning of the study;
- Trying to ensure care home staff are enthusiastic and engaged;
- Providing incentives for staff that bolster confidence and professional development.

Background and Context

The PAAD study (including Clostridium difficile) in care homes focused on older people; especially those who are frail and have many health problems who are particularly prone to diarrhoea after taking antibiotics. The aim of the study was to provide incidence data on antibiotic associated diarrhoea (AAD) in care homes and also to evaluate care homes as a setting for the conduct of complex studies. The study has two stages, stage 1 involving 270 residents in nine care homes who were asked to consent to a 12 month prospective observational study to collect information on the frequency and type of antibiotics prescribing, and the frequency, seriousness and cause of any antibiotic associated diarrhoea. This stage required care home staff to record details of the type and dose of antibiotics prescribed, to collect stools samples and daily stool chart records from the time the antibiotic was prescribed and eight weeks after treatment completion. In addition to the study a training package was piloted with care home staff, qualitative interviews conducted with residents who were able to consent, focus groups with family members and care home staff and GPs to discuss issues around obtaining advanced consent and assent from residents.

To reduce the burden of the research on care homes the study took advice from a care home expert to ensure that the data collection required was already part of their care plan routines. The study has recruited on time and to target, with 100% recruitment at end of June 2011. Now that stage 1 is complete, the study will move to intervention stage 2 which will involve a larger number of residents - 380 in total (190 residents in each arm of the placebo controlled study).

Challenges

Some of the challenges the research team encountered included:

- Initially care homes felt overwhelmed by the tasks required of them, as not all staff understood the protocol. The start up phase took from 4 -6 weeks and further support in the form of research officers or registered nurses were put in place to support homes during this critical time.
- Although a care home expert provided advice on the design of the study (feasibility of the study and its practical working) ensuring it fitted into the care home daily schedule, from the outset care home managers still felt that it still added extra work to staff's already busy workloads and care workers felt the study had burdened them with yet more documentation.
- The shift patterns of care home staff meant that not all handover information was communicated well – this affected the quality of the data collected so additional training sessions for shift staff were arranged..
- There was little space for equipment or any secure storage area for study documents in the care homes.

The Approach

The PAAD study team worked closely with care home staff to support and undertake the study. None of the ten sites had any experience of participating in research and therefore required additional support with setting up the study and its practical aspects. The research team carefully looked at the following:

Choice of care homes

Initially the team collated a list of all care homes within the region, split into care homes with nursing, residential and dual registered homes. These lists were then randomised and care homes were first approached by phone. A letter was sent out to confirm the meeting and briefly outline the study. The time of year for approaching the care homes was critical, as there appears to be an increased rate of AAD during winter months, and care homes are significantly affected by winter pressures, risking the number of care homes agreeing to take part. PAAD had about a one in two success rate of care homes agreeing to take part in the study (18 care homes were initially approached and 9 agreed to take part).

The trial lead initially met with each care home manager to outline what the study involved and what was required from them and their staff and what benefit they were likely to receive from being involved at an organisational and resident level. At subsequent meetings they discussed the best approach for conducting the study, involving staff, and logistics within the care home. Within each care home three study leads were identified by the care home manager to be the point of contact for other staff and act as leads for the study.

Approach and consent was managed by the care home managers with support from research officers or research nurses. The time taken for each home varied but with additional support all care home residents and or their relatives had been approached for consent or assent within 6 weeks of initiation. The actual process of consenting a resident or getting consultee assents took approximately 1 hour.

Staff Engagement

Many care homes had no previous exposure to research and little understanding of what was research. A fair amount of time at the beginning was spent engaging with the care home staff and building up their understanding, as well as setting up the processes, documentation and training for all staff. The training sessions included a short (2 hour) presentation outlining the study to all senior staff associated with the PAAD study. Once the study started it was clear that the trained staff delegated PAAD related tasks to junior care home staff. For this reason short training sessions (1 hour) were designed and concentrated on each staff's role and responsibility for the shift (day, night, and weekend). Half day workshops were also offered to care home staff to meet the study team and chief investigators to discuss site issues, successes for the site, as well as focusing on topics such as how to improve recruitment or resolve quality of data. Additional training on Nutrition Risk assessment was provided if the home was not already using the Malnutrition Universal Screening Tool (MUST).

The study was perceived by the care homes to be fairly labour intensive for care home staff as it required them to collect information, fill in forms

and collect stool samples. As time moved on, the study removed the administrative burden from care home staff as they were unable to complete the paperwork owing to their busy workloads. At this point the study team took on this activity and increased the frequency of visits to the sites to monitor data collection and build a closer relationship to help with certain tasks. Additionally they set up packs of case record forms to collate the data for each service user, ready for staff to pick up and use straight away.

Communication

Posters were provided for care home notice boards for relatives and residents to let them know about the study as well as newsletters to site staff to discuss any problems the homes were coming up against.

Incentives

The study financially rewarded each care home, as well as providing individual incentives to staff involved in the study. The team felt that it was important to reciprocate and incentivise staff for their hard work and reimburse any out of pocket funds. This was done through training certificates, promotion of good work in newsletters, thank you/ congratulation letters once the first resident was recruited and a system of gift vouchers to staff who were monitoring antibiotics & sampling stools. Since conducting the study each care home has continued to apply what the study introduced and is recognised as good practice. The PAAD study team enjoyed working with each care home and found it very rewarding to see care homes integrating evidence based practice including assessing each resident's nutritional status and implementing the Bristol Stool Chart into routine care.

"We are seeing an affect on what happens to residents on an on going basis which impacts on the quality of care staff provide."
Donna Duncan RD, Senior Project Manager

Lessons Learned

Over 12 months the study team has found that care homes are very different to other environments in which general clinical research is carried out and that some of the issues raised are due to researchers' lack of understanding this new research environment rather than any naivety of care homes. The study team has learned better ways of undertaking research in care homes and would pass on the following tips for future research conducted in these unique environments:

- At the design stage of the study, consult an 'expert' with experience of working in a care home..
- Allow plenty of time to initially approach care homes, set up the sites, recruit residents and undertake the study. Bolster the confidence of care home staff.
- Ensure equipment and processes are easy for staff to complete and ready; so as to not add to their workload.
- Identify study research leads among those working all shift patterns (weekdays, nights, and weekends).
- Provide training to care home staff several times; 2-3 weeks before start of the study, before recruitment and then once the study begins and continuously after that point with specific staff groups to identify what is required of them.

Embed your own staff in the care home to collect information from residents and carry out any sampling.

ENRICH
Enabling Research In Care Homes

For more info contact PAAD study leads:
Dr Arun Acharjya (Trial Manager)
& Donna Duncan (Senior Project Manager)
e: AcharjyaA@cardiff.ac.uk; donna.duncan@wales.nhs.uk
t: +44 (029) 20 687607