



Bristol Study Centre

NEWSLETTER

www.dutystudy.org.uk

Issue 16: the-back-to-school issue

October 2011

How are we doing?

Primary care clinicians working with the Bristol study centre have now recruited **1,748** patients, with a **91%** urine sample return rate.

Overall, the study has now recruited **3,858** patients (with **88%** urine samples), so we are **64%** of the way there!

CUT AND PASTE

The cut-and-paste facility on the database has been improved. There are now two short versions of the download which you can find on the far right hand side of the 'Participant's CRF sections' screen. Click on the button with the small or large 'S' and follow the simple instructions in order to paste DUTY data into your practice system.



MYSTERY PRIZE

Last month's mystery prize was won by Jane Stewart, Option 1 Nurse in the Exeter area. A gift is on its way to be shared with colleagues—or not! Everyone who recruits a child in the previous month is automatically entered for this draw.

Quantum leap into autumn!

A month after the return to school, DUTY looks to quantum physics to illustrate the issue of clinical uncertainty that may arise for you in the course of your collaboration with DUTY, and to mathematical logic to emphasise why we so need complete data for each DUTY child. More interestingly, we have an interview with Professor Margaret Fletcher, a champion of effective parent and child engagement for DUTY. (Next month: an update on protocol amendment 8.)

Introducing Dr Margaret Fletcher, Professor of Clinical Nursing at the University of the West of England with University Hospitals Bristol NHS Foundation Trust, and Co-Director of the South West Medicines for Children Research Network.

Q. What role do you play in the DUTY study? I am one of the original grant applicants for the funds for DUTY and as a member of the project management group help make sure we are doing the study in the best way possible for parents, children and clinic staff and to be able to answer the questions about treating urinary tract infection in young children.

Q. What do you think are the main challenges for DUTY? Good quality and complete data/information including keeping the urines coming in and of as good a quality as possible. This is important not just for the study but also as it influences how the child is managed clinically.

Q. What is your top tip for successful recruitment? Being welcoming, facilitative and cheerful and being one step ahead of the parents and child in terms of demonstrating awareness of both what else they are likely to be dealing with and what the child is likely to do next!

Q. What is your favourite book, and why? Too many favourites to choose just one. The Year's Midnight (Alex Benzie) is a beautiful read, very evocative of the Aberdeenshire countryside and people I knew when I worked there and a good story to boot.



ON INCOMPLETENESS

One cannot reach a certain time of life without learning that "there is no consistent set of truths that is capable of proving all truths about the interrelationships of things". This is the first incompleteness theorem of Kurt Gödel (1931, left), which for our purposes means that *the human condition is to be in the dark!*

In DUTY, however, we aim to shed light into the deepest recesses of UTI diagnosis through ignoring all that and aspiring to complete data. Our database is showing that only 58% of the clinical observation examinations (last part of section 3 - the pink bit - of the CRF) are complete. Bristol centre recruiters are doing rather better than average with 70% clinical obs complete, and we would like to call on your help to address this black hole in the dataset. Please try to collect all of the clinical obs in section 3 - they are crucial and valuable data.

We would also like to stress the importance of collecting the responses to the occasionally tricky questions about parental education level and family finances (both only 63% complete) and ideally the NHS number (only 51% complete). We will monitor this and update you in the coming months.



Answers to last months "true or false"

(1) The largest bacterium in the world is bigger than the smallest insect **TRUE: *Eupulviscium fishelsoni***, dwelling in the digestive tracts of surgeonfish, can grow up to 0.7mm, while several species of beetle of the Tribe Nanosellini are only 0.3–0.4mm long. (2) The bacterial version of sex (conjugation) occurs only between the same bacterial species **FALSE: the exchange of bacterial genetic material can occur between different species — they'll do it with just anything.** (3) Turkeys and Komodo dragons can reproduce naturally without having sex (or conjugating) **TRUE; there are more things in heaven and earth...** (4) There is no universal microbiologically agreed definition of a UTI **TRUE: this is regrettable. Could DUTY help to change it?** (5) The name *Escherichia* comes from the Greek word meaning "with tails" **FALSE. It is named after Escherich who first isolated and characterised the bacterium in 1885.**

The Uncertainty Principle



In quantum mechanics, the Heisenberg uncertainty principle states that the better you know the position of an elementary particle, the less you know the momentum, and vice versa. It's basic 'O' level physics. In other words, *you can't have your cake and eat it* (and no, I didn't pass the exam). But what concerns us here is urine samples, not elementary particles, and the issue of clinical uncertainty that confronts some practitioners participating in the DUTY study.

Say you recruit a patient with non-specific symptoms (e.g. a fever), obtain a urine sample which you would not have requested had the child not been in the DUTY study, and three days later are confronted with a lab report stating that the culture result was indeterminate, and

suggesting "repeat sample to confirm". But the child is not one in whom you thought a UTI was even a possibility. The diagnosis was LRTI, certain. What do you do now? You might request a repeat sample, and receive a second report just like the first.

You speak to the DUTY Research Nurse: she advises you to "use your clinical judgement". You call the NHS lab: they repeat exactly what is stated in the lab report and advise you to use your clinical judgement. So there is now an additional decision to be made, balancing a potential "harm" occasioned by the study (e.g. unnecessary treatment or scans) against the potential patient benefits (reduced risk of renal scarring), and this uncalled-for dilemma is plonked in your lap. You would be excused for feeling peeved.

Research can be like opening Pandora's box. DUTY's ultimate aim is to help to clinicians to target urine sample requests at children at high risk of UTI, but in the course of the research designed to achieve this aim, the effect may be in certain instances to increase it. As a result of DUTY, more urine samples are being processed by NHS laboratories than in normal practice, and it is inevitable that unexpected positives and other abnormal results will turn up, an unsought addition to your caseload.

The DUTY researchers are aware of this potential increase in uncertainty and the additional tax this may place, on occasions, on your clinical judgement. To counter-balance this, it is worth bearing in mind that diagnosis and treatment for several DUTY children has been enhanced by the NHS and/or SACU research laboratory results (including one child in whom Type 1 diabetes was diagnosed as a result of the DUTY urine dipstick test - a diagnosis which might otherwise have been a longer time coming).

In the long run, we want to develop an algorithm that will reduce uncertainty for clinicians regarding the children in whom it is worth going to the effort of obtaining a urine sample. But in the meantime, we acknowledge that some "things have got to get worse, before they get better" and depend on your forbearance and ongoing collaboration. DUTY is supported by expert paediatric nephrologists who are available to discuss issues of diagnostic or treatment uncertainty with any clinician involved in the study. If you have queries about the management of any of your patients within DUTY, please contact Dr Jan Dudley, Consultant Paediatric Nephrologist, Bristol Royal Hospital for Children, by e-mail: jan.dudley@nhs.net OR jan.dudley@uhbristol.nhs.uk.

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