

NHS North West Research & Development
Paediatric Respiratory and Endocrine Research
Catalyst Workshop

Friday 11th December 2009
Malmaison Hotel, Piccadilly, Manchester

Event sponsored by NHS North West
Research & Development

Author: Gail Green
December 2009

Introduction

Dr Stuart Eglin, Director R&D NHS North West opened the workshop and outlined the purpose. The NHS North West Research & Development (R&D) team aim to facilitate NHS organisations and Universities working collaboratively to develop and secure high quality, innovative bids for research funding and part of our programme is to run a series of catalyst events/workshops which will raise awareness of research strengths and expertise in the region and identify areas of common interest.

The North West has a complete spread of research networks and we are an area which is well respected nationally and known for good collaborations. An example of this is that the North West was chosen for the national “Exemplar Project” in 2009. Research funding coming into the North West has increased in the last two years from £32 million to £72 million and we really want to continue with the growth of research funding coming into the North West and capitalize on our strengths, by being creative and innovative in the type of bids we submit which result in successful funding.

Amongst the audience which were invited to the event, some will know each other and have worked together on research projects in the past, however some will have never met each other as they will be coming from completely different backgrounds, however all will have a common interest in research for children.

Purpose

- The aim is to create new collaborations and networks to develop new bids for research funding
- To contribute to the development of research questions of importance to parents and children, academics, clinicians, commissioners of services and policy makers

Case Study

To set the scene for the workshop and to give some insight into the discussions which had taken place prior to holding the event, Professor Ros Smyth, Head of School of Reproductive and Developmental Medicine, University of Liverpool/Director of NIHR Medicines for Children Research Network and Professor Peter Clayton, Professor of Child Health & Paediatric Endocrinology, University of Manchester/Network Director Medicines for Children Research Network outlined a recent case study which highlighted some of the issues and problems regarding the case management of a particular patient. The case raised issues around a number of areas:

- case management
- issues surrounding the management of adrenal insufficiency
- the affects steroids have on behaviour
- what is the best way to identify synacthen tests
- difficult to interpret cortisol data

Methodology – Open Space

The event was conducted using a forum known as ‘Open Space’ led by Steve Pashley www.stevepashley.co.uk. The method is designed to enable people with mutual interests to meet and progress ideas in a short period of time. Participants have control over what is discussed and can choose to include themselves in various forums generated on the day. At the conclusion of the various forums, decisions are made about outcomes and further steps to progress them. Participants are expected to contribute further via the networks developed on the day.

A summary of the open space discussions, including the names of participants and those expressing an interest in being contacted at a later date, form the basis of this workshop summary.

The discussions are presented in random order and do not reflect the popularity or other merit of the research themes.

Group 1

Topic: **How can we ensure research features in forthcoming child health strategy**

Convenor: Eustace de Sousa

Participants: Eustace de Sousa, Peter Arkwright, Clare McGuire, David Taylor Robinson, Paul McNamara

Key Aspects of the research proposal

Non identified

Key Barriers and how to overcome/weaken

- Network(s) bringing clinicians/others together to promote best practice, with academic aspects also
- Patient quality measures (link with Patient Recorded Outcome Measures (PROMS) plus minimum data sets/benchmarking
- How do we get independent research/solicit opinions
- How do we assess adherence? Whose responsibility
- How do we better manage patients in primary care instead of acute/specialist use of care pathways measuring its effectiveness e.g. allergy

Next Steps (next 3 months)

Non identified

Group 2

Group 2 combined two topics which were very similar

Topic: **1. Further investigations into abnormal cortisol responses at different ages, severities of asthma and levels of treatment**
2. Identify what “impaired” synacthen may or may not mean for patients

Convenor: 1. Ros Smyth
 2. Dan Hawcutt

Participants: Ros Smyth, Dan Hawcutt, Elaine Kelly, Helen Pidd, Ned Rowlands, Leena Patel, Clare Murray, Paul McNamara, Naomi Wallin

Key Aspects of the research proposal

- Further analyses PASS/EMSC data – is there a relationship between dose and peak cortisol?
- Does asthma cause adrenal insufficiency? (non-steroid treated)
- Is there adult data re adrenal suppression in inhaled steroids? – Yes – ?Dundee
- Can we ascertain if any differences (e.g. school attendance) in group with “not normal” synacthen test?
- Does puberty/certain ages affect sensitivity to adrenocortisol suppression?
- Non steroid asthmatic - reproducibility

Key Barriers and how to overcome/weaken

- Ethics of long synacthen in large populations – difficult partial test (salivary, cortisol)

Next Steps (next 3 months)

- Lit search for LD557 in children

Who

Dan Hawcutt

Ros Smyth, Dan Hawcutt, Leena Patel and Clare Murray interested in pursuing further

Group 3

Topic: **Molecular mechanisms of GC sensitivity and engaging families in such research**

Convenor: Peter Clayton

Participants: Peter Clayton, Munir Pirmohamed, Enitan Carrol

Key Aspects of the research proposal

- Genes influencing PK/PD of GLS – custom v. whole genome
- Monitoring compliance
- Genetics v. other end points – bones
- Measuring steroid in blood after ICS
- Communicating complex concepts to families and implementation

- Reproducibility of synacthen
- Biomarkers of adrenal function

Key Barriers and how to overcome/weaken

- Urinary metabolic biomarkers of adrenal function - child/adult
- Using Manchester cohort for validation for GWAS

Next Steps (next 3 months)

- Initiate further
- Continue discussions
- Translational projects

Who

Peter Clayton, Munir Pirmohamed

Group 4

Topic: **Biomarkers in respiratory disease**

Convenor: Paul McNamara

Participants: Clare Murray; Enitan Carrol; Ros Smyth

Key Aspects of the research proposal

- Overall aim to find a biomarker which could help in the diagnosis of asthma in pre-school children
- Airway epithelium becoming recognised as central to the pathogenesis of asthma
- Research proposal aims to use gene expression/proteomics techniques to look for biomarkers in airway epithelial cells from asthmatic and healthy children. These cells will be obtained using a bronchial brushing technique from children undergoing routine elective surgery
- Compare lower respiratory brushings to those from upper airways

Key Barriers and how to overcome/weaken

- Will candidate proteins be biomarkers of asthma or biomarkers of atopy?
- May be too ambitious trying to look for biomarkers of asthma in pre school child given the number of different phenotypes – better to start with well defined asthma in older children

Next Steps (next 3 months)

- Either submit to Wellcome Trust or submit locally for pump-priming funds
- Need for a keen Specialist Registrar

Group 5

Topic: **An open discussion on the impact of psychological factors and the relation to childhood asthma, plus endocrinological problems**

Convenor: Claire Maguire

Participants: Claire Maguire, Peter Callery, Elaine Kelly, Helen Pidd, Maria Thornton, Sarah Rickard, Ned Rowlands.

Key Aspects of the research proposal

- Increasing psychological input in children with physical illness
 - Protective to other children in family
 - Counselling – diagnosis
 - Parenting skills
 - Anxiety management
- Embed psychological service in medical team – more accessible
- How messages are presented to family – important
- Experiencing parenting – what points trigger admission
 - Debrief what the experience was like?
 - Need to learn from experience and educate parents
 - Adherence to medication/compliance/attitudes
 - Question – what interventions are effective? – cost, reducing patient stays, reducing medication
 - Identifying families that need more support
 - The role of active case management
 - No one looks at the needs siblings of sick child

Key Barriers and how to overcome/weaken

- Need to demonstrate patient benefit
 - Engagement
 - Resources
 - Mental health services aren't acceptable, therefore use third sector partners to engage with hard to reach young people
- Brittle asthma/difficult to control – doesn't come into hospital – what patients/clinicians worry about most:
 - High levels of treatment
 - No school attendance
 - Lots of psychological problems
 - Family problems v hospital admission

Next Steps (next 3 months)

- Focus groups – parents/child to develop research questions/intervention
- exploring/re analysing IAP data
- Run with a few small ideas
- Explore academic/clinical links
- Explore development of fellowship bid

Group 6

Topic: **Scale of the problem**

- Severity
- Potential/risks
- Need for intervention

Convenor: Leena Patel

The topic was not run as a group, but informal/local discussions took place

Next Steps

NHS North West will, at a later date, contact discussion leads to ascertain if any assistance is required in furthering discussions and possible development. The event summary and contact details will be circulated to participants to facilitate discussions to develop the proposals outlined. The event summary will be posted on NHS North West's R&D Team's website www.research.northwest.nhs.uk to promote the paediatric and endocrine research catalyst programme and to encourage people not already involved but with an interest or experience in paediatric and infection research to get involved.

Gail Green
R&D Project Officer
NHS North West

January 2010