

# **Review of UK Health Research Consultation Response UK Respiratory Research**

## **Introduction**

As the following document illustrates, investment in respiratory research in the UK has been disproportionately low in comparison with the massive burden of lung disease. In response to this, charitable funders of lung research, professional respiratory bodies, the MRC, the Wellcome Trust, Department of Health, and the UK's respiratory research community came together in 2005 to discuss new ways forward in tackling lung disease.

Building on the successful workshops held in October 2005 at the Royal College of Physicians, and in February 2006 at Asthma UK, priorities for UK lung research were developed and the UK Respiratory Research Strategy Committee was formed. The Committee's remit includes pushing forward a unified research agenda which aims to increase the understanding of lung disease, develop novel treatments, preventions and cures for lung disease, and increase the availability of care for people living with lung disease.

The Committee met for the first time on 14th July 2006. Under the Chairmanship of Professor Stephen Holgate, representatives from professional, charitable and educational respiratory organisations discussed how best to take the research agenda forward. Building on the work carried out by a prioritisation exercise undertaken during the workshop process, the resulting respiratory research prioritisation document is due to be submitted for publication in Thorax and is attached to this document as an appendix.

Although the following document centres on lung disease, it is important to note that the problems faced in respiratory research are an excellent exemplar of the problems faced by the wider UK medical research community throughout all disciplines and disease areas.

## **The Burden of lung disease**

- Respiratory disease kills 1 in 5 people
  - 117,000 deaths in 2004
  - 33,000 deaths from lung cancer (breast 12,000, colo-rectal 16,000)
  - 27,000 deaths from COPD
  
- Steepest socioeconomic mortality gradient of any disease area - unskilled manual:professional
  - Tuberculosis 8.9

- Cancer 4.6
  - COPD 14.2
  - Asthma 4.5
- The only countries in Europe with a worse mortality rate from respiratory disease than the UK are Ireland, Malta, Kyrgyzstan, Tajikistan, Kazakhstan, Uzbekistan and the Republic of Moldova.
  - Respiratory disease is the commonest reason for GP consultation
    - 2002/3 25 million working days lost
  - 5 year survival from lung cancer less than 8% (only pancreas is worse - 7000 cases per year)
  - Asthma is the commonest chronic illness in children and pregnant women
  - 10,000 new cases of interstitial lung disease a year - 4000 IPF with median survival of 3 years

### Tackling Lung Disease

- Among all of the health specific categories identified by the UKCRC, lung disease has the greatest difference between disease burden and research.
- Of the research that is being conducted, the majority (>70% is focused on aetiology with the minority on disease prevention and management. There is a real gap in translational research.
- The lung is a difficult and complex organ to gain access to which accounts for the majority of research in the last century being focused on physiology. The last decade has seen a real decline in the integrated biological subjects that include physiology, pharmacology, toxicology and pathology which has disadvantaged progress in lung disease.
- There has been a gradual and relentless decay in the human capital to undertake research across the full spectrum of the disease with a parallel loss of skills.
- To address some of these difficulties the professional bodies representing a lung interest, these lung-based charities and the MRC have identified 7 major disease themes where research might be best focused for maximum benefit: Infection, airways disease, tissue injury

and repair, lung cancer, early life events, new and better phenotyping and delivery of care.

- Involvement of industry and fields outside the biological sciences (eg engineering physics, chemistry, mathematics and the research streams that support these is essential to capitalise on developments on technology.
- Drawing these different interests together creates a new environment for translational research and experimental medicine which could deliver considerable early benefits in the prevention and treatment of lung disease.

### Challenges in respiratory research

- The gap that has developed between basic and clinical research impacts on the evidence available to bodies like the COPD NSF when making practice decisions.
- The NICE guidance for COPD identified many areas where better evidence is needed or greater understanding is necessary. There is no mechanism by which these priorities can be developed as research questions.
- Capacity for this type of work exists but is under threat from cost/work related pressures in NHS Trusts. Previous capacity building exercises have been useful but need to be backed up by a reasonable prospect of obtaining funds to actually do some clinical research.
- Calls for research activity in general areas of importance are usually more effective than very specific research requests and generate good quality applications. This can be a motor for trans-disciplinary research.
- NHS R&D has developed tools to assess research quality which is valuable. There is a need for high quality publicly funded clinical research which is published in peer reviewed journals rather than remaining as an internal report.
- New mechanisms for addressing questions of interest to industry and the NHS should be developed. This will enhance the independence of treatment recommendations from perceived industrial bias. Finally we should emphasise that respiratory disease is a useful case study for these issues and that our integrated approach in addressing disease-related research issues may be a model for others to consider.

## Paediatric Respiratory Disease

Research in children over the decades has been problematic because of issues relating to ethics, consent and the 'vulnerability' of children. As scientific knowledge has increased, however, it has become apparent that the majority of serious, chronic and fatal diseases in adults have their origins in childhood. As medical science has advanced, diseases previously considered only relevant to paediatrics (e.g. cystic fibrosis) are now having a major impact in adults whereas diseases previously considered solely in the adult domain are clearly associated with factors originating in early life (e.g. COPD).

- 30% of children presenting to their general practitioner have a respiratory problem as their main symptom.
- 25% of hospital admissions in children are caused by a respiratory disease or condition.
- 1 in 7 children in the UK have a doctor-diagnosis of asthma.
- 60% of asthma in adults has its origin in childhood.

The size and burden of paediatric respiratory disease is enormous and is greater than any other paediatric speciality. Despite this there are only approximately 80 consultant respiratory paediatricians in the UK, the vast majority of whom also care for general paediatric patients. Only a quarter of the consultants have full training and expertise in paediatric research and the infrastructure to support this is minimal.

This is an exciting time when new developments are occurring, basic scientific knowledge is improving and recognition of the way forward is gaining acceptance. The areas of paediatric respiratory research interest are:-

1. Early life events - now recognised as vital to the understanding and progression of chronic diseases in adults.
2. New non-invasive methodologies aiding understanding of disease progression.
3. Viral infections in infancy and their effect on the developing lung.
4. Cystic fibrosis - national screening is about to commence with the opportunities of evaluating different clinical programmes to modify disease progression.
5. Genetics and the regulation of lung and airway development.
6. The development of medications specifically related to respiratory diseases in children.
7. Environmental issues e.g. tobacco smoke, which is now a recognised paediatric problem.

In the past research has concentrated on understanding diseases in the adult population. We need to focus our attention on the young population to prevent the accruing symptoms in later life.

