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By email to ournhs@dh.gsi.gov.uk

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Dear Lord Darzi

IMPRESS response to Lord Darzi's Our NHS Our Future Interim Report October 2007 and letter to stakeholders of 19 November 2007

1. Introduction

IMPRESS[1], a joint venture between the British Thoracic Society (BTS) and the General Practice Airways Group **(**GPIAG), appreciates the opportunity to comment on the interim report. We strongly support your vision of a World Class NHS and wholeheartedly endorse the need for clinicians to take the lead in promoting and developing evidence-based patient-centred services. We set up IMPRESS to improve access and equitable provision of integrated care for patients with respiratory conditions, and we are drawing on both our work experience and evidence when offering these ideas and comments for your review. They are particularly focused on those areas commonly dealt with by both primary and secondary care such as asthma, chronic obstructive pulmonary disease (COPD) and allergic rhinitis; however many apply beyond these categories to other respiratory problems, or long term conditions.

2. Background

IMPRESS represents both primary and secondary care clinicians (doctors and nurses), with an interest in respiratory disease, working together. It also has project management support from an experienced NHS manager and commissioner, and lay representation. Our core belief is that the integration of services along care pathways that bridge primary and secondary care is necessary for high quality care, and that current policies can endanger this integration. We also believe that patients need to be offered generalist and specialist care, as appropriate, and that policies must acknowledge the value of both; care provided at the right time in the right place by the right person.

3. Why respiratory disease should not be overlooked

Respiratory disease accounts for 1 in 5 deaths in the UK (more than ischaemic heart disease); it accounts for about one quarter of all GP consultations and 2.8 million bed days per year.[i] [ii] Furthermore in 2002-03 there were nearly 25 million sickness absence days related to respiratory disease.[iii] However when long term conditions are discussed by managers and commissioners the perspective taken is often that of healthcare utilisation. Therefore the only respiratory element that receives significant managerial attention is COPD, because of exacerbations and potentially avoidable admissions. The DH Strategy Unit showed figures comparing future trends in utilisation by patients with various long term conditions and showed a relatively slow increase in COPD compared to diabetes and obesity-related conditions particularly if smoking quit rates increases. However, this overlooks the fact that because the time lag before expression of clinical disease, the burden of COPD will continue to increase for many years to come.[iv] [v] The only other area which has received attention given the other policy driver of 18 weeks is sleep services. This creates a skewed and unrealistic approach to respiratory disease.

[1] Improving and Integrating Respiratory Services in the NHS. A joint British Thoracic Society (BTS) and General Practice Airways Group (GPIAG) initiative providing the clinical leadership required to drive high quality patient-centred care across the traditional boundaries of secondary and primary care to integrate and improve the services for people with respiratory disease http://www.brit-thoracic.org.uk/IMPRESS Also at NHS networks http://www.networks.nhs.uk/networks/page/942

We welcome the forthcoming National Service Framework (NSF) for COPD, and we hope that its publication will be presaged sufficiently to commissioners so that resources can be identified and its implementation begin as soon as the report is published. We also hope that commissioners are encouraged to consider all respiratory conditions not just COPD.

4. The eight areas of care

Respiratory disease has an impact on all the eight areas of care highlighted in your interim report. We would hope that the following aspects would be covered.

Maternity and newborn care: Poorly controlled asthma is associated with poor maternal and foetal outcomes in pregnancy and there is evidence of undertreatment of asthma in pregnancy.[vi] Smoking causes failure of lung growth and development predisposing infants to respiratory disorders in early life. Clinicians with a respiratory interest can be powerful advocates for stopping smoking initiatives and work with commissioners to develop and champion appropriate strategies for tobacco dependency.

Staying healthy: We support reframing smoking as tobacco dependency; a disease/problem in its own right, with a number of effective interventions. We believe this may encourage smokers and clinicians to take the problem more seriously. This is a key priority. The COPD NSF is likely to set targets and standards for both lung health checks and pulmonary rehabilitation and exercise. Through the NSF consultation process we will make our views on standards known, but we want to highlight here that there is a need to support real-life research about effectiveness (e.g. in promoting screening for COPD) before inappropriate investments are made.

Children's health: Asthma and rhinitis (often co-existent) represent the most common long-term illness among children in the UK,[i] and despite advances in their care over the last decades, there remain many children who are not optimally managed, compromising schooling and examination performance.[vii]. Such suffering is largely unnecessary because there are effective interventions available. About 25[viii] children die each year due to asthma, with deaths in children and young adults peaking in the summer months when allergen levels are high.[ix] In 2005 in England there were 12060 admissions of children aged 0-4 for asthma, and 11553 for children aged 5-14.[x] We urge commissioners responsible for long term conditions to focus on asthma, not only because it is responsible for a hospital admission by a child every 19 minutes[viii] but also because of the burden on quality of life it imposes if suboptimally managed, both on the child and the whole family. There is a need for commissioners to evaluate tools which measure asthma control, which is pertinent to patients' needs rather than rely solely on Quality and Outcomes Framework (QOF) points to be a driver for change. For example, under eights are excluded from the patient population to be reviewed because of their relative inability to perform lung function tests; yet they still have symptoms that require management. The Royal College of Physicians together with the GPIAG and the BTS have just produced a scoping document for a National Asthma Audit including markers of quality care, for the Health Commission.

Planned care: Proactive care of people with asthma by primary care teams has led the way for the delivery of care closer to home. Research on diagnosis in primary care, action plans, telephone consultations and the use of mobile phone technology are years ahead of other long term conditions management. These developments for the delivery of personalised, effective and efficient interventions, which are evidence-based, have been paradoxically excluded from the QOF process which does not allow the use of such innovation. Lessons may be learned from these studies to improve uptake and implementation.

Asthma care also reveals how problems can arise in primary care when services are left without investment in monitoring, and continuing professional development. We have concerns that the current variation in performance in asthma care will be even greater for COPD unless this investment is made.

We strongly advocate an evidence-based approach to planned care, and to refrain from investing in the roll-out of untested schemes, particularly in COPD where the evidence for what makes the difference remains unclear.[xi] Current evidence[xi] suggests that for beneficial outcomes in COPD, a combination of one of more of these interventions is necessary: 1. an extensive self management programme with an individualised action plan (pulmonary rehabilitation) 2. advanced access to care (knowledgeable healthcare providers), which means some people may need admission to gain access to the right teams of specialists; 3. guideline-based therapy and 4. a clinical registry (or database).

In addition, there are groups of patients for whom planned care is a particular challenge due to their mental health problems, alcohol dependence and/or deep-seated patterns of health service use. Depression and anxiety levels are recognised to be very high in COPD. We strongly encourage commissioners to invest in psychological support for them.

We would also like to highlight three IMPRESS initiatives to improve planned care.

1. We have developed referral criteria for advising GPs when to refer patients with a range of respiratory diseases to specialist care accepted for publication by Thorax in November 2007 that we will make available on our website.

2. We acknowledge that clinicians' communication skills need to be developed in a systematic way through education, feedback

and monitoring if the experience of patients is to improve. We have submitted a final bid to the Section 64 team to develop an educational package using interviews with patients with COPD and carers about their experience of consultations, particularly about diagnosis and end of life care. We hope this will begin to address the experiences illustrated in a study in the West Country[xii] where patients describe *their perception* of what the doctor was telling them at the time of diagnosis with quotes such as "nothing could be done", "finished", "self inflicted".
3. We are preparing a proposal for a national audit of COPD care pathways across primary and secondary care, using qualitative methods to explore the experience of an admission from the patient's perspective. We would welcome help and support to set this up.

Acute care: there has been some important learning from the changes in the assessment and supply of oxygen that we could usefully share with you – they range from innovative new ways of providing care closer to home, to huge frustrations with the contracting process.

Mental health: People with severe COPD are two and a half times more likely to have depression than age matched controls.[xiii] In addition, older people with long term conditions such as COPD who require hospital care may have confusion and other mental health problems. The clinical community needs appropriate investment in training, education, appraisal and feedback on mental health assessment and care. There may also be a role for more talking therapist input.

Long term conditions: we have covered the issues here under the previous paragraphs but it is of note that many older patients have numerous co-morbidities. The current focus on disease specific pathways, whilst providing vertical integration of services, risks overlooking the important need for strengthened generalist services able to provide holistic care. Equally, we must also ensure that the patients who need specialist hospital services, including non-invasive ventilation and intensive care have timely access to specialist care..

End-of-life care: the arguments are now well rehearsed about the inequity between end of life provision for people with malignant and non-malignant disease. In some areas patients with COPD still do not have access to specialist palliative care services and hospice care and this should be addressed urgently. There are also challenges in discussing and providing timely end of life care for patients with chronic respiratory disease. This is an area of active research in the respiratory community. In our view, there are models of excellence offered by some acute hospitals and primary care services that take account of new legislation, the Mental Capacity Act, and best practice such as the GOLD framework and Liverpool care pathway. Lasting Powers of Attorney (LPAs) are an excellent development which could be used to empower patients much more; as could increased used of advance decisions. However, these are not available reliably, throughout the country, in either community or hospital settings. There needs to be more attention paid by commissioners to ensure that patients and clinicians have the knowledge, skills and beliefs to achieve optimum end of life care. IMPRESS is willing to work with others to offer guidance on this.

5. A fair NHS

Access to GPs and out of hours care

Our view is that the most important issue of fairness is about everyone having the same opportunities to receive high quality care from general practice within the current GMS contract hours of Monday-Friday 0800-1830. If, during these hours there are continued improvements in the systematic care and review of patients with long term conditions, particularly the many with co-morbidities, this will reduce the need for out of hours care. It is difficult to maintain a comprehensive level of service outside of normal working hours because of lack of personnel and the increased staff costs. There may be some public demand to extend hours in some places, but we strongly advocate local solutions based on local representative surveys, rather than a top-down one size fits all approach. Extensions of availability without a concomitant increase in resources for reception staff as well as clinical staff may lead to reduced daytime availability and a compromise of quality and continuity of care. We do not see how that helps to deliver continuity of care, which surveys by patient organisations and our own conversations with patients conclude that people with long term conditions want. Indeed, if there is to be an extension in care, then it should be linked to local plans to reduce health inequalities.

We also recognise that some commissioners are awarding contracts to non-NHS providers. In these cases we would expect the same degree of transparency about costing and performance and the same degree of monitoring. And, please, let us learn from the expensive mismatch between demand and capacity of the Independent Sector Treatment Centres (ISTCs), which were commissioned without due regard for need or local knowledge or proper discussion about accountability and clinical responsibility.

Life expectancy and mortality rates

We accept some responsibility for poor clinical coding in the past, and now recognise its importance for both financial planning and clinical care. In addition, the funding for skilled coders has not been made available leading to sub-optimal coding. This has created an unfortunate analytical legacy – it appears secondary care is responsible for a large number of pneumonia deaths, whereas, actually, these patients may have had complex problems accounting for lengthy stays in hospital, but ultimately their cause of death was coded as pneumonia. This is why clinicians should always be involved in discussions about data, information

and measurement.

Access to pulmonary rehabilitation and hospital at home
We expect and would support strong guidance from the NSF COPD team about offering all patients who would benefit, a programme of pulmonary rehabilitation and also care at home delivered by professionals trained in the care of people with COPD. IMPRESS has supported the development of standards for pulmonary rehabilitation (attached).

The recent very helpful report Invisible Lives[xiv] by the British Lung Foundation highlights the huge variation between PCTs in the prevalence of COPD and in levels of case-finding. We strongly encourage SHAs to monitor the performance of the "hot spot" PCTs to improve case-finding. This requires us as clinicians to work with PCTs to share responsibility for improving public awareness of the condition. By contrast, the evidence for screening is insufficient to recommend this as an effective health strategy.

6. A personalised NHS

Voluntary sector
IMPRESS strongly supports the involvement of patient organisations such as British Lung Foundation and Asthma UK that can champion the user perspective and experience in policy development nationally, and increasingly in local delivery. IMPRESS and the two clinical societies BTS and GPIAG work closely with both.

Choice
A personalised service requires elements of choice for the patient in terms of location and timing of care and choice of aids, devices and drugs, but what should never be a matter of choice is access to adequate numbers of a skilled workforce. In terms of service provision repeated surveys demonstrate that what patients value above all is continuity of care.

Quality framework
We support this framework.

We hope that the NSF for COPD will champion improvements in care, and will be accompanied by a performance management framework that achieves implementation in 100% of PCTs.

We hope that widespread use of our referral guidance will assist in improving standards.

7. An effective NHS

We believe we are providing increasingly effective care. Following the introduction of the QOF two years ago there has been an almost 15% increase in prevalence of diagnosed COPD, (1.27% in 2003 to 1.45% in 2005); numbers with recorded spirometry rose from 18% to 62% and use of combination inhalers used by people with severe COPD rose from 25% to 44% over the period.[xv] Whilst we have already mentioned the lack of evidence about the most effective care models, particularly for COPD patients, there is good evidence for intermediate care at home for people with respiratory disease (known as Hospital At Home in the literature[xvi]) and pulmonary rehabilitation (although work needs to be done on refining the best models of providing it). In the absence of evidence, we appreciate that commissioners will apply improvement methodologies, test new models of care and use databases of improvement pilots. However, because respiratory care has received less policy attention, there is a shortage of such published examples for respiratory care. For example, respiratory GPwSIs were not part of the original GPwSI schemes, Action On schemes did not involve respiratory care and there is currently no NSF or National Clinical Director to champion respiratory care. IMPRESS offers to collate respiratory good practice to share with commissioners and clinicians. Furthermore, we feel there are opportunities to spread the ideas of good practice that clinicians share with each other via their clinical meetings (such as the GPIAG annual meeting, and the biannual BTS meetings) but which are not necessarily published in places to which commissioners have access. IMPRESS is examining ways in which commissioners can have rapid access to such information.

If there is a need to pilot new models of care, then please let us carefully design the evaluation, and wait for the evaluation results before national roll-out. We have heard the suggestion of routine lung health checks as part of the forthcoming NHS for which there is currently no evidence of public health benefit.

Importantly, in terms of effectiveness, If we wanted to focus on outcomes, then we should have Payment by Outcomes not Payment by Results, The current tariff does not take account of complex or innovative interventions that use clinical time and expertise to achieve commissioners' goals of preventing admission or providing follow-up alternatives to outpatients. We are willing to contribute to discussions about how to make the system better.

Similarly, in primary care, the QOF should move to rewarding improved outcomes, rather than process standards. We would be keen to contribute to discussions about how this may be achieved.

Finally, let us be fair in our appraisal of what works. There are some excellent examples of positive change in the USA such as the Saving 100,000 Lives movement[xvii], but equally there are some terrible health inequalities and huge transaction costs.[xviii] We should look closer to home and to and other publicly-funded systems for examples too.

8. A safe NHS

One issue of safety that we hope will be addressed at European level through its pharmacovigilance review, is the use of off-licence medications for children with asthma.

9. **A locally accountable NHS**

Workforce planning, education and training

In terms of staffing, IMPRESS does not believe there is one ideal model but a number of models that can provide the very best integrated care that patients with respiratory disease require. To a large extent, the model will depend on both the local expertise available and geography with a mix of "in-reach" and "out-reach" services For example, there will be nurse specialists in hospital and community settings, there may be GPwSIs and consultant physicians with a special interest in community medicine. As long as they have sufficient training and experience for the level at which they need to operate, and are accredited, patients will be well served.

However, we would like reassurance that the projected £1.8bn savings recently reported as savings from recent financial restraints are not the result of cutting back by trusts on R&D, education and training and maintenance of our building stock. This will create problems downstream in delivering a quality service.

We have produced a document on competences (to follow). It highlights concerns about services, whether NHS- or independent sector-managed, that do not have sufficient competent staff. In addition, in this letter we would like to highlight a few issues that apply within and beyond respiratory care.

We feel that every service needs highly skilled respiratory leaders, with in-depth knowledge of their specialism. We have concerns that there is likely to be a loss of respiratory leaders as retirement takes the most skilled ones away. The level of training of incomers is not sufficient.

Our observation during IMPRESS working party discussions, is that expectations of secondary care clinicians about the potential of primary care to accept the shift in care are relatively low. This may be in part because the nature of the referral system means that many secondary care physicians will not observe the care of which the best primary care is capable, as they see the patients whom the primary care physician cannot manage. We therefore advocate more local opportunities for primary and secondary care clinicians to meet and to network for a common understanding of what is possible. Evidence from NHS Networks[xix] suggests that networking is most successful if there is some financial investment in coordination and boundary-spanning. We may also need to consider ways to help doctors in training, not on the vocational training scheme, to gain more community experience. We also enclose our paper on community consultants.

Leadership

We support the need for clinically-led improvements; this is the raison d'etre of IMPRESS. We would encourage managers and policy-makers to align policies and messages to support clinicians to work with patients to achieve improvements. We support the policy of clinicians making resource allocation decisions such as practice-based commissioning but have concerns, highlighted in the recent Audit Commission report on practice-based commissioning, that the level of information they have to work with is inadequate and that their training and development needs further investment. Crucially, there are conflicts of interest enshrined in practice-based commissioning that need to be more transparent if the trust and goodwill from primary and secondary care necessary to develop services is to be maintained. The Audit Commission's findings that most practice-based commissioners intend to provide more themselves rather than commission differently needs careful attention. We are aware that a handful of PCTs, including Westminster PCT, have written a contestability framework and we applaud such moves and recommend that this is picked up nationally, with some urgency.

We understand that the current perception amongst policymakers is that many secondary and primary care clinicians are "difficult". In our experience, most clinicians are passionate about care and there are many good examples of significant service improvements over the last 5-10 years created jointly by clinicians and managers. However many clinicians, particularly doctors, currently feel disenfranchised. One contributing factor is the language of commissioning and management which is foreign to most clinicians. As an example, look at our Jargon Buster, which runs to 20 pages of explanation. It is important that management and clinicians are constructively involved in service improvement so that best care models can be delivered.

Information and coding

Tariff disincentives
These disincentives remain a significant barrier to the development by clinicians of creative patient-centred care such as telephone consultations with patients and clinical colleagues and other community patient-centred initiatives. We understand some forward-thinking PCTs have achieved local agreements to encourage this, but it needs national attention.

Patient level costing
As we said above, we have many well-established examples of hospital at home care for people with respiratory disease. They have well-defined timeframes, human resources and published Integrated Care Pathways that make them ideal for a patient-level tariff. However, further development of these programmes is severely hampered by the current lack of guidance regarding patient-level costing and, without some standardisation and better quality of coding, it will remain difficult to rely on derived tariffs and subsequent bench-marking.

Patient information
The smooth and timely flow of information between primary and secondary care is essential, work in Salford shows the benefit of this.[xx] Competition between providers increases the risks of information being withheld to the detriment of patients.

Conclusion

To conclude, we are supportive of the principles in the interim report. We advocate more involvement of clinicians in decisions about models of care, more incentives and fewer disincentives for creativity and innovation; sufficient investment in R&D, training, education and continuing professional development to achieve a world class clinically-led and personalised NHS.

We look forward to hearing about progress, and discussing with you any of the ideas contained in this letter.

Yours sincerely

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Attachments:
Pulmonary Rehabilitation standards
Community consultants
Respiratory competences – a guide for commissioners (to follow)

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