IMPRESS

Improving and Integrating Respiratory Services

Shaping the Future of Care Together
The Big Care Debate - Response by IMPRESS

Improving and Integrating Respiratory Services in the NHS (IMPRESS) – IMPRESS is a joint initiative between the two leading respiratory clinical societies in the UK: the British Thoracic Society (BTS) and the General Practice Airways Group (GPIAG). Its mission is to provide the clinical leadership required to drive improvements in the support and care of the population with, or at risk of, respiratory disease so that everyone gets the best care for their needs in the right place at the right time by the right people. It aims to stimulate provision of:

- improved support and care including improvements in integration of services across social, primary and secondary care boundaries;
- increased personalisation of care taking account of the changing financial and policy context;
- more accurate identification of the size of the population to be served.

For more information, please visit the IMPRESS website at www.impressresp.com.

Introduction

IMPRESS, with the support of the British Thoracic Society, has brought together the opinions and experiences of its members to prepare a submission to the response to the Big Care Debate. The response also draws heavily on input from the Long Term Conditions Delivery Support Team.

The Long Term Conditions Delivery Support Team – The Team aims to improve the services for people with long term conditions by supporting the implementation of Long Term Conditions policy and strategy. They work with and are sponsored by the Department of Health. For further information and to become part of the LTC Community, please visit the website at www.ltc-community.org.uk.

In responding to this consultation we have decided to concentrate on the first two questions in the consultation as these are the areas that we have experience in and therefore we feel most able to add to the debate on these questions.

Consultation Questions

Question 1: We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- **prevention services**
- **national assessment**
- **a joined-up service**
- **information and advice**
- **personalised care and support**
- **fair funding.**

a. Is there anything missing from this approach?

- **Integrated staff training –** Only by ensuring that health and social care staff understand how the two systems operate and how they can work together will integration ever be achieved. Therefore, staff training for health care staff should include developing an understanding of the how funding works in both the health and social care systems, the language used (IMPRESS has developed a Jargon Buster including social care terms, and also a separate social care glossary with assistance from the Long Term Conditions Delivery Support Team) and staff training for social care workers should include developing an understanding of health care principles.
- **Flexibility –** We would suggest adding flexibility to meet variable social and health care needs. Respiratory condition symptoms and care support needs may vary in severity from day to day/week to week due to: weather, stress, activity schedule, other health conditions, as well as any clinical progression of the respiratory condition.
- **A specific example in advanced COPD care –** Having cancer and being on a palliative care register jumps the usual queues for social care and benefits. However, this does not work in COPD because a transition point for palliative care can not be identified. The very slow insidious development of COPD means that needs develop/evolve very slowly over the years and decades and there is a lack of structure – no clear beginning, a middle that's a muddle of (apparently) unconnected crises and an end that is unpredictable and unanticipated. We are suggesting that flexibility is required. Rather than registers we need to recognise 'milestones' (for example, an admission is the obvious one, but also giving up work for health reasons, needing long term oxygen therapy (LTOT) etc.) which should trigger a holistic assessment of clinical, social and supportive needs.
- **Equity in access –** ensuring that people are able to access the health care they need when they need it is the central aim of the UK's health service; this should also be true for the social care system. This can be most effectively achieved by removing some of the barriers that exist between people's health care and their social care and ensuring truly integrated services.

In addition, in relation to information and advice being readily available for people with social care needs, there are examples of this in action on a charitable level which could provide an excellent framework upon which to base development of these services. Two notable examples are the services available through Age Concern (http://www.ageconcern.org.uk/AgeConcern/care_information.asp) and Sixty Plus (http://www.sixtyplus.org.uk/htm/services.htm).

a. How should this work?

- In terms of introducing flexibility into the systems, by having more control over their services people can increase or decrease the level of care they need, rather than too much support one day and not enough the next. The net input may be approximately the same but the health improvement outcomes including patient quality experience

would be much improved. Changes may be supported via access to a bank of carers or individual social care or health budget schemes.
- Access to seven day services (referral and assessment) are needed so care packages can be set up through weekends and bank holidays and hospitals can achieve safe discharges on weekends which is a precursor to self care which will also need support systems available 7 days / week.
- A reduction in variation of practices between local authorities would also help with the integration of care services as many health professionals work across a range of local authorities. They therefore have to become familiar with a number of different models and practices, which can impede integrated care and be confusing for people who access that care.
- Continuity is essential – in health care professionals' experience, social care currently involves lots of handoffs which are out of the control of the person using services – an in-patient social worker or occupational therapist hands a patient over to a community care worker, for example. In addition, in many local authorities, the social care workforce includes a large number of temporary staff, which means that even at a community level people are handed over to new care workers regularly. This can be very unsettling and confusing for people with long-term conditions. Ensuring greater continuity in care will help people to feel confident in the care they are receiving and comfortable with the people who are caring for them. It also makes establishing professional shared care relationships between social care and health care staff and learning how the others work very difficult.
- It is worth noting at this point that one of the reasons for the lack of continuity in care is the temporary nature of the care workforce, in part due to the low status of care work in the UK. In Dame Denise Platt's 2007 report for the Department of Health, *The Status of Social Care – a review 2007*, she said that "Working in a service that is not clearly understood, or experienced as being poor is not a great motivator of the workforce!" She went on to say that registration of the social care workforce was "important to provide a proper reassurance to the public that people not fit to practice would not be allowed to. Registration also reassures the public that staff have an appropriate qualification for the job they do and that they are continually challenged to improve."
- Co-aligning career structures and payscales with health will help to reduce chronic shortage of social workers nationally in order to deliver the care. Social workers' career structure and payscale is very limiting and unattractive especially in light of recent high profile cases.

Question 2: We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

a. Do you agree?

We support the proposal to give people more choice and control over their services and therefore their lives for the following reasons:
- Having control over service provision will mean that people with respiratory conditions feel and are more in control of their condition. Patients/service users will choose the services that work best for them and their respiratory condition, shaping the market and introducing competition, including generating a specialist market.
- Travelling can be a struggle for people with respiratory conditions and also picking up a hospital bugs as an inpatient can pose people with respiratory conditions real problems. Specialist respiratory health care delivered closer to home or in the home would be easier and prevent unnecessary health exacerbations. Maximum use of telehealth or remote monitoring would enable people with respiratory conditions to be in close contact with health professionals, providing early detection and averting the need for hospital admission.

- Please note telehealth is only as good as the service that supports it. Telemonitoring data need to be reviewed regularly (daily in the case of COPD) by someone with appropriate training and allocated time, who has, or has access to, the clinical skills needed to respond to changes in the data.
    - Patient and service user engagement in commissioning processes is very useful to drive personalisation changes but adequate funding and support needs to be provided to make this more than tokenistic.
- Perceived quality of staff, trust of staff and continuity of staff coming into people's homes are all three essential for people to agree to professionals they don't know coming into their homes. All three are very common reasons patients with COPD tell us that they will not accept help at home even when health professionals and social care professionals assess that they need help. This is often detrimental to the health of family and friends who provide care (more information about the needs of carers is available from the Carers UK website at http://www.carersuk.org/Information).

However:

- It is essential that the National Care Service model stimulates the market and prompts market competition.
- If people have cognitive, communication or physical access difficulties they will need more support to exercise choice and control, a failure to offer more support may disenfranchise this group even further. This is a particular problem where barriers co-exist, for example, alcohol dependence and smoking addiction make intervening to reduce breathlessness from COPD much more difficult. Furthermore, people with mental health problems often have unrecognised long-term conditions, for example, ischemic heart disease and peripheral vascular disease, which are made worse by smoking, drug use and alcohol dependence. Even if underlying long-term conditions are recognised they can be hard to treat if individuals do not see why they should engage with services or take medication.
- Control can only be exerted if there is real choice in the market place. Choice and shaping the market requires clear signposting of services. The problem with the increasingly complex world of health and social care provision is that neither the patients nor the professionals know what is available.
- Robust systems need to be put in place to safeguard the interests of people who are vulnerable.
- Solutions need to accommodate the needs of different communities and user groups. For example, many older people may not be able access IT based support systems. Interestingly, there have been COPD trials which have shown that inability to use the telemonitoring system has not been a major barrier in recruiting, however some people need support in the early stages as they get used to the system.
- Addressing inequities in health and social care provision is a must but the needs of communities differ and a uniform approach to delivering health and social care provision may not reflect either local demographic needs or the wishes of the local community. This will need to be managed carefully.
- Services need to specifically address social isolation; a significant proportion of people in inner cities with breathlessness from COPD live alone and in accommodation above the ground floor with only unmanageable stair access.
- Quality is important. Carers broadly fall into two categories with very different training needs that need to be addressed:
    - Middle aged women with limited formal training but lots of life experience and skills – they will often stay around for many years as they are part of the 'community';
    - Young people with little or no experience who see it as a (not very well paid) job – they will often only remain in this role for months/a few years before moving on.

We agree that services should be joined up for the following reasons:

- People with respiratory conditions do not distinguish between health and social providers and their needs cross these areas of care.
- Despite a plethora of statutes and pieces of guidance health and social services still don’t systematically work together well enough to provide a genuinely seamless service. Something else is needed to make this happen (and for people who are breathless, having to repeat oral information to a number of carers is a tiring and frustrating challenge).
- The boundaries between health and social services are becoming increasingly blurred, with funding streams pooled (section 75) and tasks delegated across authorities via section 256 and 76 payment systems.
- Some health tasks could be completed by social care staff if they receive appropriate training and ongoing supervision, this may be cheaper, will create capacity for health staff to focus on meeting clinical needs and reduce the number of carers traipsing through people’s homes.
    - We need to overcome some of the barriers about what carers can do. Examples told to IMPRESS include reluctance to learn to check a blood sugar for a diabetic patient, and not being ‘allowed’ to help a patient who was confused about how to adjust the head of their electronic bed which was in an upright position – this resulted in the patient being stuck sitting up in bed all night until a district nurse called the next day who was qualified to adjust the bed.
    - A good example: the Reablement Service in NHS Islington. Patients who are discharged from hospital or are being supported with admission prevention receive up to 6 weeks of enabling care free. Carers are trained with basic therapy skills and implement rehabilitation programmes planned by senior enablers (OTs) aiming to encourage function and reduce long term need for care packages
- Information is power, broadening out the DH Choice’s website to include more health condition Information Prescriptions for respiratory conditions would be very useful, and even more so if they were joined up with local social care provision.
    - Information should include, for example, books on prescription – doctors can prescribe books on stress, relaxation etc. The prescription is then presented at the local library to be ‘filled’.
- Self care as an approach to enabling people to manage their respiratory conditions most effectively works well, but leading self care arrangements are predominantly regarded as a health task. Joining forces with social care would give this approach greater impact. Joining forces with social care would give this approach greater impact and seven day access to non-emergency social care will help achieve this.
- Joint care plans, information prescriptions, assessments (Common Assessment Framework) will assist the joining up of health and social care organisations.
    - In health alone IT systems get in the way of sharing information/using same care planning tools and even when different services have the same clinical systems permissions are not always granted to share records (e.g. GP practices to community respiratory team).

b. What would this look like in practice?

- Same level of health and social care support is available wherever people live, but the allocation of resources would need to be different to reflect local markets and demand.
- Health and social care organisations – joined-up pooled services and pooled budgets with truly integrated teams.
- Integrated care records - There are some good examples of integrated care records that sit on top of existing and separate systems but these have been built and funded locally and are not widespread. Sometimes these are disease specific (e.g. Lambeth and Southwark COPD and Hampshire diabetes) which is not ideal.

c. What are the barriers to making this happen?

- Social care and health's approach to categorising patients/service users is often at odds and serves as a further barrier to joining up services. I.e. Social services separates services for younger physically disabled adults 18-65 from those for people 66 and over. Health refers to people with long term conditions of any age.
- It is worth emphasising the basic distinction that social care services categorise according to assessed need (which is better at recognising health and social care needs and also at including health co-morbidities) and healthcare services categorises according to diagnosis – commissioning for pathways tends to encourage this, for example (even though primary care is more holistic than this) and so there needs to be some solution to this. (See below the problems of the assessment system.)
- Lack of organisational structures that support shared working between social care and health care professionals.
- Allocation of social care resources are subject to democratic public opinion, where as health services are not.
- Current provision is focused on serving people with critical and substantial needs, which results in fire fighting rather than supporting people with low and moderate needs. Prevention work is vital to releasing capacity, keeping people healthier for longer or preventing respiratory conditions in the first place.
- The same level of health and social care support is available wherever people live, but the allocation of resources would need to be different to reflect markets and local demand.
- Health and social care organisations have different cultures and have developed very different budget management, accounting and style of provision.
- Competition between health and social care for scarce resources.
    - Continuing care is a good example of where the systems don't always work together. Disputes arise between health and social care through the assessment process about which organisation funds what part of a patient's care, for example, whether or not the need is deemed a health or social need.
- Health and Social Care services are seldom coterminous and this is still resulting in many boundary issues and may present inequality in provision.
- The lack of infrastructure (IT - Knowledge management and People - Networks) prevents the sharing of best practice and lessons learned across a region. We recommend a national infrastructure e.g. Map of Medicine free at point of use) adaptable to local practices and the product, care pathways, are live documents that can be updated, peer reviewed and shared.

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