

Report of the Long-Term Conditions Clinical Working Group

Introduction

This report is the output from two meetings of the group (for group membership see Appendix B) on 17 January and 7 March, the clinical conference on 19 February and sharing of evidence and best practice examples within the group. It draws particularly heavily on work by the National Primary Care Research and Development Centre in Manchester on the potential for replacing hospital outpatient appointments and a more general review of the evidence for shifting care into the community carried out by the Health Services Management Centre at Birmingham.¹

This report both sets out the group's diagnosis of what needs to change to improve the care of people with long-term conditions (LTCs) and sets out recommendations to achieve better care. Figure one summarises how the group envisages LTC care will be provided in future:

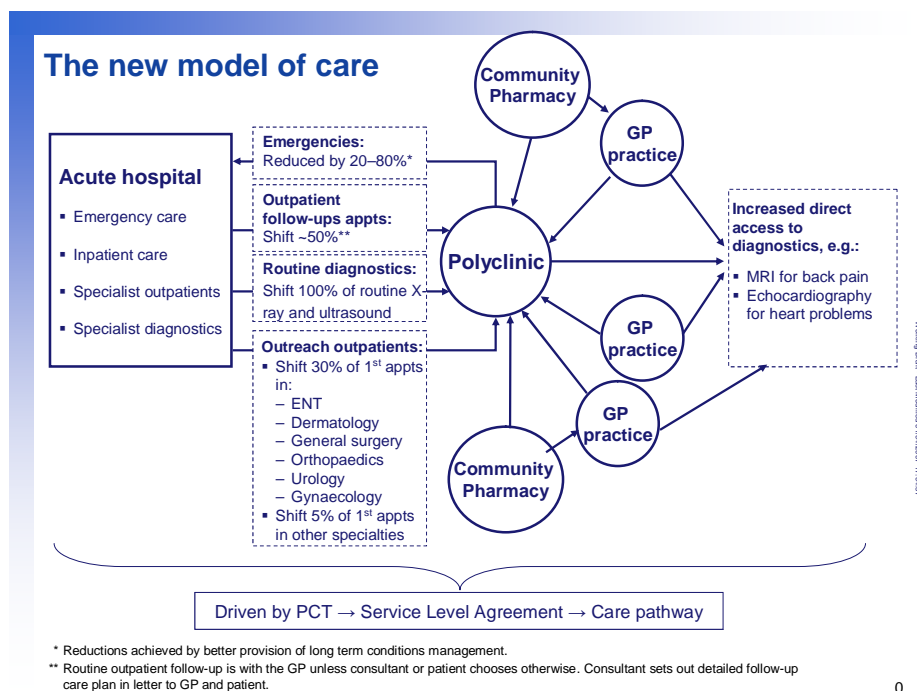


Figure one – new model of care for LTCs

¹ National Primary Care Research and Development Centre, *Can primary care reform reduce the demand on hospital outpatient departments?*, <http://www.sdo.lshtm.ac.uk/files/adhoc/82-research-summary.pdf>, March 2007 (this is a summary of a longer report on outpatients and primary care) and University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

The report considers the full range of LTCs, including common mental health problems (but not the care needed for people with severe mental health issues such as schizophrenia). This is because mental health problems are prevalent in London and their effects can be long lasting – 50 per cent of people with depression have symptoms that last longer than a year.

It does give some thought to the needs of children with LTCs. We recognise that the improvements in organisation of care in this report will result in better treatment of children with LTCs, but they may have a lesser impact on hospital attendance than for adults with LTCs, as a higher proportion of children with LTCs will need specialist input.

1. THE LTC CASE FOR CHANGE IN LONDON

People with LTCs are the most intensive users of health services. Over fifteen million people in England have an LTC. Patients with an LTC account for 80 per cent of all GP consultations.² Analysis by Dr Foster found that so-called "frequent flyers", the 14.1 per cent of patients (most of whom have LTCs) who are admitted to hospital four or more times a year, are responsible for 36.5 per cent of bed days.³ This means that any improvement in LTC care will both benefit a lot of people and have a major impact on the NHS.

The prevalence of LTCs increases with age. More than 70 per cent of those over 75 have one or more LTC compared with 20 per cent of the 16-44 year-old age group.⁴ Therefore London, with its comparatively young population, actually has a lower prevalence of many LTCs than other areas of the UK.

However, some LTCs are increasing amongst the young – Diabetes UK have recently published research showing how the number of under-fifteens with type 1 diabetes had doubled over the last twenty years.⁵ In addition, for some LTCs London has above average prevalence rates. For instance, London is home to 57 per cent of those diagnosed with HIV in the UK.⁶ And in London 1.2 million people have a common mental health problem such as depression or anxiety.

Figure two shows the number of people (both absolute and in percentage terms) in London diagnosed with four of the major LTCs:

LTC	No. of diagnosed Londoners	Percentage of London population
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² *Chronic disease management: a compendium of information*, Department of Health, May 2004

³ S. Williams et al., "Frequent Flyer" patients, *BMJ* 2005, 303

⁴ *Chronic disease management: a compendium of information*, Department of Health, May 2004

⁵ See report at http://www.diabetes.org.uk/About_us/News_Landing_Page/Dramatic-increase-of-Type-1-diabetes-in-under-fives/

⁶ London Healthcare Observatory, *Health & Healthcare in London: Key Facts*.

Congestive Heart Failure	111,548	1.5
Asthma	390,128	5.2
Chronic Obstructive Pulmonary Disease (COPD)	72,382	1.0
Diabetes	295,877	4.0

Figure two – LTC prevalence in London⁷

Significant numbers of Londoners have LTCs and they are already major users of health services. Our modelling analysis shows that if the status quo continues, the biggest proportionate growth in hospital activity for London will be in dealing with LTCs.⁸

Looking beyond the prevalence of particular LTCs, the issues of health inequalities and poly-morbidities (people with more than one long-term condition, sometimes called co-morbidities) need to be addressed. Poly-morbidities are common – 26 per cent of people with LTCs have three or more conditions. And conditions can affect each other. For instance, people with diabetes are three times as likely to suffer from depression as those without diabetes. The two conditions are inter-related, as if depression is managed effectively this can improve a person's ability to self-care for their diabetes.

There is also a health inequalities aspect to LTCs. Those with lower incomes, living in deprived areas, are much more likely to suffer from LTCs than their wealthier neighbours. For instance women and men in the least wealthy twenty per cent of the population are respectively 50 and 30 per cent more likely to suffer from coronary heart disease than their counterparts in the most affluent quintile.⁹ In addition, those in deprived areas are less likely to access care. Figure three shows how diabetes is most prevalent in deprived areas and/or areas with high black and minority ethnic (BME) populations, as some BME groups are more susceptible to developing diabetes:

⁷ Disease prevalence numbers from Quality and Outcomes Framework data for 2005/06 (applied to GP registered populations for percentage prevalence)

⁸ HES 2005/06 data forecast with demographic and prevalence projections.

⁹ ONS, *Key Health Statistics from General Practice* (2000)

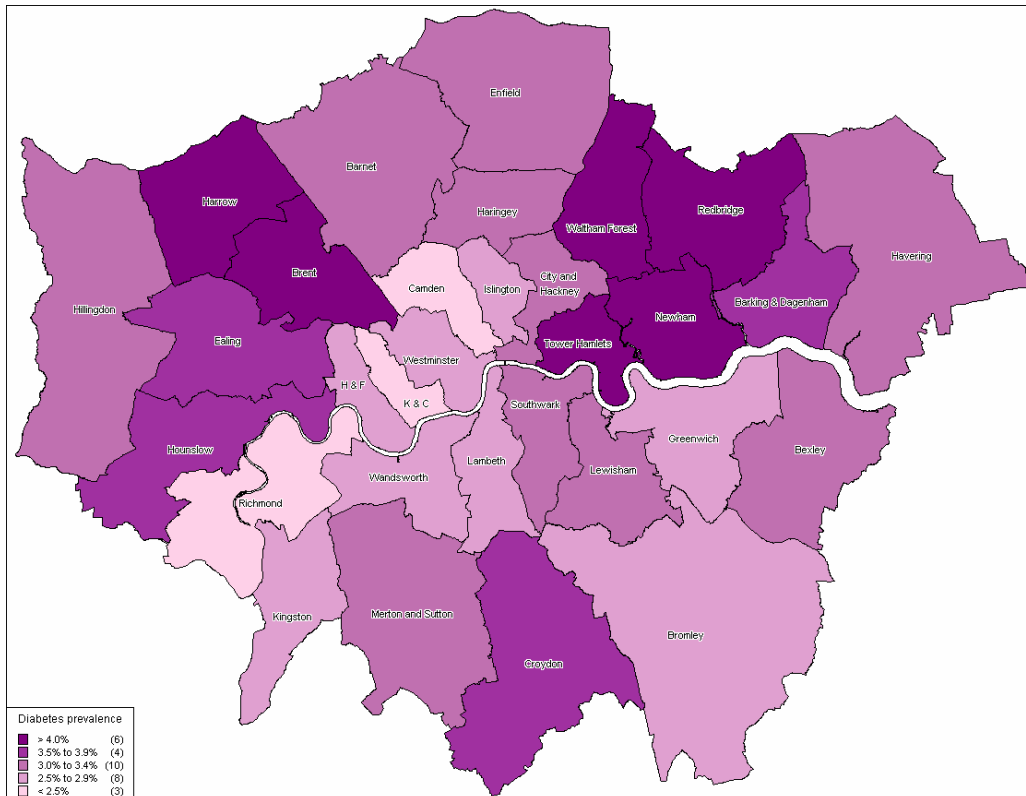


Figure three - map of diabetes prevalence across London

In recent years there have been significant improvements in care for some of the most prevalent LTCs such as rheumatoid arthritis, diabetes, asthma, heart disease and cancer. Developments such as Quality and Outcomes Framework (QOF) disease registers have increased diagnosis and proactive care for people with LTCs. However, much more can be done, as was made clear in the *Our health, our care, our say*¹⁰ White Paper.

- 1 There is often poor co-ordination both between health and other public services (for instance social care and education) and between community and hospital health staff.
- 2 There are also still too many people in need of emergency care because their day-to-day care has broken down.
- 3 There is not enough support to help people manage their own condition through self-care, taking the correct medication or accessing therapies etc.
- 4 Half of all people with LTCs were not aware of treatment options and did not have a clear plan that laid out what they can do for themselves to manage their condition better.

¹⁰ "Chapter 5," *Our health, our care, our say*, Department of Health, January 2006

In London, Wandsworth primary care trust (PCT) has looked at common issues for older people with LTCs and for all age groups with the conditions of chronic obstructive pulmonary disease (COPD), heart failure and diabetes (see Appendix A for more detail). They found the following problems.

- 1 **Diagnosis.** Many people remain undiagnosed or under-diagnosed for COPD, heart failure and diabetes. It is estimated that up to 33 per cent of people with diabetes may be undiagnosed and up to 41 per cent of people with COPD. For mental health, people with generalised anxiety disorder are often undiagnosed for five to ten years. In addition, if diagnosis is made in the acute hospital this information may not be received in primary care and, as a result, people do not receive optimal care.
- 2 **On-going care.** Four key issues:
 - 1) There is a lack of sufficient patient understanding/education to manage their conditions.
 - 2) There are sometimes difficulties in communications between primary and secondary care which can lead to greater morbidity, admission and expenditure.
 - 3) Patients ask for consistent care and a key contact point which the health system is not currently in a position to deliver.
 - 4) There are significant variations in the protocols used to govern patient care.
- 3 **Specialist input.** There are significant variations in admission rates in each of COPD, heart failure and diabetes which are not well understood. Once patients are admitted to the acute hospital there may be prolonged stays for elderly patients.

2. PRESENT LTC HEALTHCARE PROVISION

Present healthcare for people with LTCs is not how we want it to be.

Hospital-based. Much LTC care is unnecessarily hospital-based. 97 per cent of outpatient appointments take care in hospital, when there is good evidence that GPs and other primary care clinicians can replace the need for outpatient follow-up appointments with local ongoing care for adults with LTCs.¹¹

Diagnostics. There is not enough direct access to diagnostics. Direct access to diagnostics has been found to be effective. For instance, direct access spirometry has been found to improve diagnosis of COPD and hence the treatment of the previously undiagnosed patients.¹² And direct access also

¹¹ University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

¹² P. P. Walker et al, "Effect of primary-care spirometry on the diagnosis and management of COPD," *European Respiratory Journal* 2006, 28: 945-952

reduces the need for hospital outpatient appointments.¹³

Estates. Part of the reason why LTC care is hospital-based and there is little direct access to diagnostics in the community is that the primary care estate is not good enough. A BMA survey found that 59 per cent of practices in London would like to offer additional services but that they cannot due to the physical size of their practice.¹⁴

Communications. Communication between primary and secondary care is often poor. This makes the co-ordination of care difficult. In one primary care trust, a single patient attended A&E 250 times with minor issues (eg need for a new inhaler) without the GP practice ever being aware of this. This seems to be a particularly British problem - 65 per cent of doctors in the UK report problems due to care not being co-ordinated across sites/providers compared to 22 per cent in Germany and 39 per cent in Australia.¹⁵

Inconsistency. There is inconsistency in treatment of LTCs across London. For instance research has shown that COPD admissions can be reduced by 25 per cent if patients have access to a community respiratory nurse specialist and A&E are able to refer patients to these nurses.¹⁶ However, only a few of the London PCTs are making use of these nurses. There is not a systematic use of protocols for LTC care. This may be due to a combination of factors, including local differences in agreed protocols, a lack of awareness of or compliance with these protocols, lack of incentives or monitoring tools and the lack of electronic decision support tools to help guide protocol use.

Information. Patients lack information and understanding of where to get health care and how to self-care. In the absence of clear and easily understandable information about where to go to receive care, patients may turn up at A&E where they know they can now get care within four hours. Lack of understanding of the need for self-care makes it less likely that LTC patients will manage their care effectively. This is seen by the example of how only 50 per cent of medicines are taken as prescribed.

3. IDEAL CARE AND EXAMPLES

The evidence from Wandsworth PCT and nationally¹⁷ suggests that the best practice for LTC management is remarkably similar across the major disease conditions. Therefore, this section of the report looks at the components of ideal

¹³ NPCRD, *Can primary care reform reduce the demand on hospital outpatient departments?*, March 2007

¹⁴ BMA Health Policy and Economic Research Unit, *Survey of GP practice premises*, London 2006.

¹⁵ 2006 Commonwealth Fund International Health Policy Survey of Primary Care Physicians.

¹⁶ F. Ram et al., *Hospital at home for patients with acute exacerbations of chronic obstructive pulmonary disease: a systematic review of evidence*, BMJ July 2004, 329.

¹⁷ See *Supporting people with long term conditions*, Department of Health, January 2005

care rather than focussing on specific conditions. Many of the aspects of ideal care draw on proposals set out in the *Our health, our care, our say* White Paper and the *NHS and social care model* for supporting people with LTCs and we recognise the potential benefits that implementing these two policy documents will bring for people with LTCs.

Prevention

Obviously preventing LTCs in the first place is preferable to managing the conditions when they emerge. The two biggest areas for preventative activity are reducing smoking (which kills one Londoner an hour) and decreasing obesity through better diet and more physical activity.¹⁸

This could be achieved by ensuring all health professionals ask about diet, smoking and activity in their consultations with patients and can direct people towards appropriate support. Some outreach would be required, as deprived populations who are less likely to use traditional services are the groups who are more likely to smoke and have a poor diet.

There is also huge potential for building the maintenance of health into all sorts of community institutions. This could include schools, which can educate children about good health, reach out to parents and the local community (eg by opening up their sports facilities) and effectively use school nurses to connect with children who may not use other health services.

For people with mental health problems, secondary prevention can improve symptoms, such as greater exercise – both physical and mental.

London good practice

Exercise on prescription/bibliotherapy: In Kensington and Chelsea PCT a programme to provide exercise on prescription and bibliotherapy for people with depression and anxiety has had great success. People who otherwise would have required medication are treated drug-free, in line with NICE guidelines.

Diagnosis

Ideal care means easy and fast diagnostic access to tackle under-diagnosis of LTCs. This should be achieved through rapid access in the community, rather than requiring patients to travel to the acute hospital for routine tests to be performed. The evidence on this is good. One trial in the UK found that direct access sigmoidoscopy clinics reduced the NHS and patient's combined costs by £105 compared to a standard outpatient appointment.¹⁹

¹⁸ See analysis in Derek Wanless, *Securing Good Health for the Whole Population: Population Health Trends*, December 2003

¹⁹ S. Mackenzie et al., "Randomized clinical trial comparing consultant-led or open access investigations

The ability to perform diagnostic tests in the community needs to be built, including:

- 1 Phlebotomy in every practice
- 2 Locally improved access to spirometry, with means to interpret data
- 3 Local MRI (but see caveat below)
- 4 Local access to echocardiography and ultrasound

For local diagnostics to be effective, accreditation and quality control will be needed to ensure that any diagnostic activity off the hospital site can be relied upon for clinical judgment. In addition a clear set of protocols will be needed to govern what tests are needed, under what conditions (for instance research has shown that in some cases radiography can be as effective as an MRI scan whilst being considerably cheaper²⁰ and interpreting an MRI scan for a child would need a specialist opinion) and when patients should be referred on to specialists. Training and education will be needed for staff in the community to ensure they are aware of protocols and the availability of diagnostics. Finally, diagnostic results should be available quickly.

London good practice

Direct access spirometry: Hammersmith and Fulham PCT and Imperial College set up a nurse-led Community Respiratory Assessment Unit.²¹ This provided local access to spirometry and helped to ensure that national guidelines were followed. 88 per cent of GPs involved thought their patients had benefited or greatly benefited from the service. Without the Assessment Unit there would have been more referrals to hospital outpatients and more prescriptions of courses of drugs.

Empowering the patient

Ideal care means putting the patient at the centre, in control of their care. Such patient accountability lies at the core of effective management of LTCs. The patient needs to be personally responsible for their own health and to be the expert for the management of their condition. This requires them to have the information about their condition and the strategy for managing it, supported by and developed in partnership with the clinician.

An informed patient who knows when to self-care and when to seek clinical

for large bowel symptoms," *Brit J Surg* 2003, 90, 941-7

²⁰ Jarvik JG, Hollingworth W, Martin B, Emerson SS, Gray DT, Overman S, Robinson D, Staiger T, Wessbecher F, Sullivan SD, Kreuter W, Deyo RA. "Rapid magnetic resonance imaging vs radiographs for patients with low back pain: a randomized controlled trial," *JAMA* 2003; 289: 2810-8.

²¹ Hassett R, Meade K, Partridge MR, "Enhancing the accuracy of respiratory diagnosis in primary care: a report on the establishment of a Community Respiratory Assessment Unit, *Primary Care Respiratory Journal*(2006), 15, 354-361

support can control their LTC much more effectively. For instance, a study showed that people with COPD who were suffering an exacerbation of their condition who went to see a doctor early could receive therapy (eg antibiotics) and were less likely to need hospitalization or for their condition to worsen than those who delayed visiting the doctor.²²

The best means for doing this are not particularly clear from the available evidence. Self-management education programmes do seem effective²³ (although the Expert Patient Programme is still being evaluated) whilst the evidence on written care plans and self-monitoring is mixed.²⁴ There are a number of national developments on self-care that London should seek to take advantage of, such as the provision of information prescriptions and the development of Healthspace, allowing people to register their treatment preferences.

Recent national guidance also highlights the vital role community pharmacies can play in helping people self-care.²⁵ Pharmacies are well used – it is estimated that 1.2 million Londoners visit one every day. In particular, community pharmacies can support people with LTCs to correctly take their prescribed medication as problems with medicines may be the cause of as many as fifteen per cent of hospital admissions²⁶

Any patient empowerment methods in London need to take account of language and cultural issues. Proper patient education would also tackle one issue that we know is common in London - self-medication by people coming back with drugs from abroad.

London good practice

Using technology. The NEAT diabetes project, funded by the London Borough of Newham Social Services, involves the use of t+, a text messaging service developed by E-San, allowing patients to download blood sugar readings and text it through their mobile phones. This is read by a diabetes specialist nurse based in hospital, who texts/calls back with appropriate advice. The project is aimed at improving care for women with antenatal diabetes by reducing the

²² Wilkinson TMA, Donaldson GC, Hurst JR, Seemungal TAR, Wedzicha JA. "Impact of Reporting and Early Therapy on Outcome of Exacerbations of COPD," *Am J Respir Crit Care Med* 2004; 169: 1298-1303

²³ See the joint DH and Diabetes UK report on structured education for people with diabetes at http://www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Patient_education/Structured_Education_Care_Recommendation/

²⁴ University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

²⁵ *Supporting people with long term conditions to self care: A guide to PCTs in developing local strategies and good practice*, DH, 2006

²⁶ Healthcare for London joint response from the London Local Pharmaceutical Committees Forum and the National Pharmacy Association

frequency of outpatient attendances and providing aggressive management of blood sugar levels by the diabetes nurse. The clinical and biochemical outcomes are being evaluated, but one interesting finding was that most women from ethnic minority groups had the latest mobile phone with GPS required for this service.

Diabetes education for non English speakers. This is being funded by the NHS Service Delivery and Organization Research and Development programme (SDO) to develop the role of bilingual health advocates (BHA) who provide diabetes education in the community for patients who do not speak English. The BHA are community workers who are offered six months of accredited training and then provide group education, with input from health professionals as required, for patients with diabetes (though this model could be rolled over to other LTCs, if successful). This is being compared to standard health professional led education and clinical, biochemical, wellbeing and organisational impact is being measured. Further details at:

www.newhamuniversityhospital.nhs.uk/poseidon

Managing Care

Ideal care for people with LTCs is effectively-managed care. Protocols need to be used to deliver against standards of care that have been demonstrated to be clinically and cost effective, spelling out clearly under what conditions care is needed in the community versus in the hospital. Few studies have been conducted into the efficacy of formal care pathways, although there is some evidence that they reduce hospital use. There is good evidence that referral guidelines help GPs and these could be built into the care pathway.²⁷

Greater use of patient segmentation on the basis of severity/attribution allows the health service to provide the right kind of interventions where they are needed. Computerised decision support tools would provide a way to ensure coherent protocols are available and used by clinical staff.

Case management should occur for the patients with the most complex needs. The evaluation of the Evercare pilots suggested that case management on its own does not reduce total emergency admissions.²⁸ Qualitative analysis suggested it did reduce particular admissions, but total admissions were not affected, perhaps due to better case-finding and more treatment as a result of the Evercare model. However, other case management approaches have reported a drop in emergency admissions. In addition, regardless of the effect on admissions, case management does improve patient satisfaction.²⁹

Many of the most vulnerable people with LTCs have considerable social care as

²⁷ University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

²⁸ NPCRD Centre, *Evercare Evaluation: Final Report*, September 2006

²⁹ NPCRD Centre, *Evercare Evaluation: Final Report*, September 2006

well as health needs and their care will need to be jointly managed by health and social care professionals.

Primary and Secondary Care Working together

Ideal care means close co-operation between specialists and primary care teams. This means good information sharing - the district nurse needs to be able to see what the COPD nurse said, did and prescribed. For children, there needs to be good communications between school nurses and the GP practice team. Specialists can pass on their knowledge to primary care staff and care can be "shared" between primary and secondary care. We are aware that the evidence on shared care is inconclusive³⁰ and any expansions of it within London should be evaluated thoroughly.

London good practice

Community diabetes consultant. Newham have used a community diabetes consultant for about eight years, who supervises and supports the GPs with special interests (GPwSIs) and community specialist nurses who provide diabetes clinics closer to patient's homes. There is a central referral triage system and referrals are allocated according to guidelines to community clinics or secondary care specialist services. The community clinics are staffed by GPwSIs and specialist nurses, and teaching, training and supervision is done by the GP diabetes lead and community consultant. This also allows clinical mentoring and governance.

Shared Care. Hammersmith Hospitals NHS Trust has an innovative strategy that "shares care" between primary and secondary care. Four years ago they developed a multidisciplinary multiple sclerosis (MS) clinic in the community. Without any additional funding, all the relevant healthcare professionals got together as a group to discuss patients they would have normally have seen separately. Just breaking down primary/secondary care barriers in this way has brought big gains in patient care. A recent audit has demonstrated that inpatient bed occupancy for MS patients has reduced by 34 per cent. The clinic was awarded a national innovation award for patient care by the UK MS Society in 2005. The trust is now looking to develop a similar approach for other chronic neurological diseases.

Reducing hospital use

Ideal care means that LTCs should be treated by doctors and nurses closer to patients' homes unless exceptional circumstances require treatment in the hospital.

³⁰ University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

Outpatient care for LTCs should be performed closer to patients' homes; hospital visits should only occur for truly exceptional circumstances. Many hospital outpatient follow-up appointments could be replaced by continuing primary care. Clear guidelines are needed for when follow-up appointments are no longer required and telephone consultations could be used instead of hospital attendances. Patient-initiated outpatient access appears effective and could be explored.³¹ Specialists could provide more outpatient appointments locally although there would need to be careful consideration of this to ensure that they have sufficient volumes of work and time is not wasted by travelling round the capital to see a small number of patients in different locations.

A&E needs to divert patients from the hospital to primary care to ensure continuity. For instance rather than admitting a patient with an exacerbation of their COPD, the A&E could alert the specialist COPD intermediate care team to treat the person at home. Doing this requires agreed care package to handle acute deteriorations in a chronic illness.

There is good evidence that the use of specialist nurses has benefits for people with LTCs such as asthma, COPD and heart failure in reducing emergency admissions and improving care. Evidence on the efficacy of 24/7 available Intermediate care (step-down and step-up) in order to permit timely discharges from the acute setting or to avoid an acute admission is mixed.³²

The majority of care for people with common mental health problems is already provided locally - 90 per cent are managed entirely in primary care. There is potential for this to increase even further, with the current psychological therapy demonstration site in Newham reporting positive results in helping people back to work and reducing depression, anxiety and the GP consultation rate.

London good practice

An effective care model in the community. The Brent integrated cardiology model combines case management, easy access diagnostics, local clinics and patient support. Particular aspects include:

- A 'community cardiologist' currently provides three general cardiology clinics and one cardiovascular risk and hypertension clinic in two venues in different parts of Brent. A third venue will become operational in the near future.
- The heart failure clinic at Wembley has its own echocardiography service ('Echotech').
- Specialist cardiac nurses case-manage patients in the community, which includes telephone consultations and home visits. Cardiac rehabilitation is coordinated by the nurses and they provide support and guidance to the two patient support groups.

³¹ NPCRD, *Can primary care reform reduce the demand on hospital outpatient departments?*, March 2007

³² University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

- A training programme was implemented at the end of 2005, coordinated by the community cardiologist whose remit includes one training session per week. Initially aimed at GPs, the training programme is now attended by members of the wider multidisciplinary team and patients. There are two sessions per month, one in the afternoon and one in the evening, in order to reach a wider audience. Speakers have included local clinicians, both doctors and nurses and 'international' speakers. Sessions are very well attended and the feedback has been excellent.

4. QUANTIFYING CHANGES TO CARE

Following on from explaining what ideal care will look like, this section attempts to quantify some of the changes we would expect. Figure four looks at four LTCs and demonstrates from the evidence how better LTC care would reduce both admissions and length of stay, as well as improving the quality of care:

Condition	Intervention	Impact on unscheduled activity:				Impact on outcomes:		Core references
		A&E	Adm*	LOS	OP	GP	Mortality	
Congestive heart failure	Multi-disciplinary managed care**		↓23-85%***				↓21-58%	<ul style="list-style-type: none"> Heart,2005,91,899-906 (74 trials);JGenInternMed,1999,14(2),130-4 (7 trials); Chest, 2005,127;2042-8 (4yr study) BMJ,2001;323;715-8 (1 RCT) JAMA,2004,291,11 (18 RCTs) CHD NSF Chapter 6 Euro Heart Journal, Guidelines for the diagnosis and treatment of CHF, 2005
	Specialist nurse interventions		↓58%	↓54%				
	Discharge planning and post discharge support		↓25%				↓13%	
Asthma	Active case management****	↓18%	↓36%			↓32%		<ul style="list-style-type: none"> Cochrane,2003(1) (36 trials); BTS Asthma Guideline, 2004 (25 trials) DH Compendium of CDM citing BMJ,2004,328,144;Thorax,2001,56,68 7-90;Pub Health Med,2002;25;258-60
	Specialist asthma nurses		↓10-38%				↑29% QOL	
COPD	Early discharge planning and hospital-at-home		↓10-30%	↓50%			↓40-70% Costs	<ul style="list-style-type: none"> Thorax(NICE),2004,59,39-130 (2 RCTs; 1 for each intervention) NHS Institute Directory of Ambulatory Emergency Care for Adults (citing NICE guidance)
	Multi-disciplinary pulmonary rehab for 6-12 weeks		↓10-30%	↓50%				
Diabetes	Active disease management		↓25%	↓40%			↓45%	<ul style="list-style-type: none"> DH CDM Compendium citing Cochrane (41 RCTs) & 3 RCTs Diabetes Med, 2003(1),32-8 (1 study)
	Specialist primary care (GPwSIs)				↓25%		Improved HbA1c; glycaemic control	

* Hospital readmission (inpatient)
 ** Best evidence for programmes of ≥3m including education, lifestyle advice, exercise, home visits, nurse case managers and regular monitoring.
 *** Weighted average = 27%.
 **** Including written care plan, supported self-monitoring and regular practitioner reviews.

Figure four – quantifying better care for LTCs

Figure five then quantifies for the same four conditions the increased resources that would be needed in primary care to achieve such changes. The current consultations per year figures (one GP consultation for each person with an LTC) are based on the one annual review that is required as part of the QOF, not on the additional consultations patients have on an ad hoc basis as part of the core GMS contract. These extra consultations would be the key to the reduction in emergency admissions and attendances envisaged in figure one.

Condition		Total		Mild	Moderate	Severe
		Diagnosed cases	Consultations/year %	% of diagnosed cases	Consultations per patient	
Congestive heart failure	London prevalence	111,548	1.5	32	29	39*
	Consultations/year:					
	– GP	274,000 (+163,000)		1 (+0)	2 (+1)	4 (+3)
	– Practice nurse	71,000 (+0)		2 (+0)	0	0
	– Specialist nurse/GPwSI	477,000 (+326,000)		0	4 (+2)	8 (+6)
Asthma	London prevalence	390,128	5.2	63**	19	18
	Consultations/year:					
	– GP	675,000 (+285,000)		1 (+0)	2 (+1)	4 (+3)
	– Practice nurse	492,000 (+0)		2 (+0)	0	0
	– Specialist nurse/GPwSI	858,000 (+570,000)		0	4 (+2)	8 (+6)
COPD	London prevalence	72,382	1.0	50	37	14
	Consultations/year:					
	– GP			0	0	0
	– Practice nurse	130,000 (+57,000)		1 (+0)	2 (+1)	4 (+3)
	– Specialist nurse/GPwSI	261,000 (+114,000)		2 (+0)	4 (+2)	8 (+6)
Diabetes	London prevalence	295,877	4.0	na***	na	na
	Consultations/year:					
	– GP	683,000 (+391,000)		1 (+0)	2 (+1)	4 (+3)
	– Practice nurse	195,000 (+0)		2 (+0)	0	0
	– Specialist nurse/GPwSI	1,171,000 (+781,000)		0	4 (+2)	8 (+6)

* NYHA functional classifications 3 and 4. ** Of which split 70/30 between mild intermittent and mild persistent.
 *** Assumed 3-way split for calculating total number of consultations required.

Source: Disease prevalence numbers from QOF data for 2005/6 (applied to GP registered populations for percentage prevalence), NHS Information Centre; Decision Resources Patient Base for CHF prevalence and severity breakdowns between conditions; Department of Health (for GP registered populations)

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Figure 5 – increased resources needed in primary care

5. RECOMMENDATIONS

Figure one outlined a new model of care and we are making a number of recommendations to achieve this, as well as some recommendations that go beyond shifting care more locally to consider issues such as joint working.

Recommendation one. Routine follow-up outpatient care for LTCs should be done in the community. The best model for doing this needs to be explored – depending on the individual and the severity of their condition, outpatient appointments could be requested by the patient themselves, be done on a recall

basis by GPs and specialist nurses or be done by consultants at a polyclinic (see recommendation three).

Recommendation two. Allow all GPs to have proforma-driven access to diagnostics. There is good evidence that direct access to diagnostics can reduce hospital outpatient appointments.³³ Direct access is particularly effective when GPs have referral guidelines, which the proforma would offer.

Recommendation three. For specialist outreach clinics to take place in the community, specialist doctors and nurses must be able to see a sufficient volume of patients. Otherwise, too much of their valuable clinical time will be wasted. The population coverage required to generate sufficient volume will vary from condition to condition. For the most common LTCs, clinics for populations of around 50,000 would be feasible, as this population segment would typically include 1750 diabetics and 450 patients with COPD.

Recommendation four. There should be the development of more one-stop polyclinics/health centres based on the wider determinants of health – education, environment, creativity, employment etc. This would be convenient and effective for patients – for instance people with common mental health problems often need access to social care, housing and employment services.

This might involve using existing hospital sites and would require co-ordinated primary care development across a PCT. Primary care practices would need to co-locate together to give large enough volumes to justify, for instance, more community diagnostics. Transitions paths should be put in place for the gathering of primary care practice together in more suitable facilities. Access to capital for building facilities that allowed the relocation of traditional hospital services (diagnostics, outpatients etc) would also be required.

These one-stop health centres or polyclinics would serve a sufficient population for specialist outreach clinics, as called for by recommendation three. Many would provide the base for community mental health teams, who typically serve populations of between 50-100,000.

Recommendation five. The workforce should be developed to deliver these recommendations. There will need to be better use of consultant time (eg, teaching, training, population-based service, specialist input for complex case) and additional roles needed to deliver must be developed (eg clinical nurse specialist). The diversity of the workforce should be used as an advantage (eg bilingual health assistants to communicate with London's diverse population).

Recommendation six. London-wide guidelines for all long-term conditions should be established, with a "plain English" version for hospital practitioners,

³³ NPCRD, *Can primary care reform reduce the demand on hospital outpatient departments?*, March 2007

GPs and patients. Patient access to the guidelines would lead to patient-led audit of care – they would know if care is not up to the standard they should be receiving. Use should be made of existing work wherever possible. Guidelines would include details on:

- 1 Which diagnostics should be accessed and when
- 2 Self-care options and support, including education and skills training for patients
- 3 Sources of information and advice
- 4 When specialist input is required
- 5 Annual review interventions
- 6 Management of a crisis

These would be developed over several years, starting in 2007/08 with COPD, asthma, diabetes and rheumatoid arthritis.

Recommendation seven. There should be a designated consultant/nurse specialist and community lead for each major long-term condition in each PCT area. They would be clinically accountable and would champion the guidelines and lead their application within their PCT. The clinicians would also work together to reduce the barriers between hospital and community care. The consultant/nurse specialist would be contracted with the PCT and have a population responsibility based on practice populations. The specialist would be contracted to provide training to those practices and specialist advice to all practitioners by mobile phone, e-mail and letter, webcam etc.³⁴ This would involve the identification of consultant time in the community as part of the contracting process.

Recommendation eight. Underpinning the LTC guidelines would be care pathway service level agreements (SLAs). The SLAs for hospitals would have the care pathways inserted and performance monitoring should be introduced using selective case note audits.

Recommendation nine. The financial incentives behind the SLAs must also stack up correctly to ensure the care pathway is followed. For instance some of the money freed up from a reduction in outpatient follow-up appointments needs to be invested in improved primary care, such as more specialist community nurses or psychological therapists. In Wandsworth there are 2,652 patients on the COPD register. If each patient had one fewer follow-up outpatient appointment per year then £182,000 would be saved and this could be used to fund four respiratory nurse specialists. Another example is mental health. Mental health problems may be a major factor in as many as 50 per cent of outpatient attendances and many of these patients could be treated locally by psychological therapists, through investing the money from the saved appointments.

³⁴ There is good evidence for having educational outreach by specialists. See for instance NPCRD, *Can primary care reform reduce the demand on hospital outpatient departments?*, March 2007

Recommendation ten. Use patient-held records until electronic records are fully in use.³⁵ Patient-held records would be a folder of any letters about their care, any test results and summaries of primary care consultations. They should be more than just patient records but also contain the care pathway so that patients know what to expect from their care givers. They could incorporate useful health information and symptom diaries.

Recommendation eleven. Make increased use of telephone consultation. There is some evidence to show that telephone follow-up of patients does not reduce the quality of care. An agreed tariff would need to be developed locally to ensure appropriate payments.

Recommendation twelve. Greater use of intermediate care to prevent admissions to hospital and to facilitate early discharge. The evidence on inpatient intermediate care is mixed, but it has potential in some cases. There is also good evidence for the greater use of hospital-at-home type approaches.³⁶

Recommendation thirteen. Primary care teams (GPs, practice nurses, case managers etc), should work with public health colleagues to seek out people at high risk of smoking and obesity (eg through deprivation indices). They should then provide tailored advice and support to people to improve their diet, exercise and stop smoking. This is likely to require effort to reach out, recall and follow people up who may be reluctant to access services or keep up with the programmes. Any programmes (eg smoking cessation) must be appropriate to the different ethnic groups served. This could be achieved by each PCT implementing a Local Enhanced Scheme to target smoking cessation and obesity management at the most deprived.

Recommendation fourteen. PCTs and practice-based commissioning groups should ensure through their contracts that any contact with a health care professional (eg. outpatients, inpatients etc) includes brief advice on smoking and weight with simple referral routes to adequately-resourced weight management and smoking cessation programmes. The health workforce would need to have the skills, training and confidence to do this.

Recommendation fifteen. All education, disease prevention work and care pathways must be language and cultural specific, reflecting London's diverse population.

Recommendation sixteen. Local authorities and PCTs should have joint action plans for the management of long-term disease, building on White Paper commitments around joint teams.

³⁵ Newham PCT already does this for diabetes, with a combined health information guide and hand held record

³⁶ University of Birmingham Health Services Management Centre, *Making the Shift: Key Success Factors*, July 2006

Underpinning assumptions

As well as these recommendations the group makes assumptions that in implementing these recommendations:

- 1 Research, teaching and training needs will be preserved.
- 2 The impact of the recommendations will be rigorously evaluated because evidence on proposals such as substitution of face-to-face clinics with telephone consultations is mixed.
- 3 There is the political will to improve services
- 4 Any changes will be cost-effective
- 5 Care will be personalized and centred on the individual.

Conclusion

The LTC clinical working group believes that the implementation of these solutions would continue the improvements that are being made in the care for people with LTCs.

Appendix A

Conclusions about issues with LTC care: Wandsworth

	Diagnosis	On-going care	Specialist input
COPD	<ul style="list-style-type: none"> Many people undiagnosed COPD. When diagnosis made in acute hospital information may not be received in primary care. Even if it is, it may not be properly recorded. As a result, people do not receive optimal care 	<ul style="list-style-type: none"> Patients need to understand condition to self manage it. Need access to named contact Outpatients could be managed equally well and more cost effectively within primary care. The treatment of COPD in primary care is compromised, resulting in poorer quality of life, greater hospital use, more A&E attendances 	<ul style="list-style-type: none"> Variations in admission rates for COPD patients among GP practices are not well understood.
Heart Failure	<ul style="list-style-type: none"> Under-diagnosis and recording exists Demands on acute hospital care could be reduced if consistent primary care and diagnosis 	<ul style="list-style-type: none"> Good communication is important to HF patients Poor communication between secondary and primary care lead to great morbidity, more admissions and expenditure Management in accordance with protocols could reduce demand on acute 	<ul style="list-style-type: none"> Variations in admission rates for HF patients among GP practices are not well understood
Diabetes	<ul style="list-style-type: none"> Significant progress to be made to improve diagnosis 	<ul style="list-style-type: none"> Patients are asking for good communication and consistent care in secondary and primary care Improved structure and processes to improve diagnosis and management will reduce complications and acute OP activity 	<ul style="list-style-type: none"> Variations in admission rates for Diabetes patients among GP practices are not well understood
Older People	<ul style="list-style-type: none"> Efforts need to be made in younger age groups to prevent the complications of LTCs in later life. 	<ul style="list-style-type: none"> Availability of a key contact point is important to older people. Poor communications lead to sub-optimal care and greater anxiety Older peoples' admission to acute hospital care could be reduced if more timely out of hospital care was available. 	<ul style="list-style-type: none"> Acute hospital care admissions are prolonged due to lack of service model and timely delivery model

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Source: *Wandsworth Long Term Conditions*; team analysis

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Appendix B

MEMBERSHIP OF THE LONG-TERM CONDITIONS CLINICAL WORKING GROUP

Tom Coffey (Chair)	Wandsworth Primary Care Trust
Tracey Baldwin	Haringey Primary Care Trust
Alan Cohen	GP and London Development Centre for Mental Health
David Elliman	Great Ormond Street Hospital for Children NHS Trust
Ursula Gallagher	Ealing Primary Care Trust
Sandra Howard	London Borough of Waltham Forest
Stephen Jefferies	Hammersmith and Fulham Primary
Kay Lewis	Enfield Primary Care Trust
Martin Lindsay	Haringey Primary Care Trust
Anne Mackie	NHS London
Anita Macro	Lambeth Primary Care Trust
Stephen Nussey	St George's Healthcare NHS Trust
Martyn Partridge	Imperial College
Samantha Prigmore	St George's Healthcare NHS Trust
John Riordan	Retired Consultant (NW London Hospitals NHS Trust)
David L Scott	Arthritis & Musculoskeletal Alliance/ Kings College Hospital NHS Trust
Debarjit Sen	University College London Hospitals NHS Foundation Trust
Shanti Vijayaraghavan	Newham Healthcare NHS Trust
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