

Stroke Disease Management—A Framework for Comprehensive Stroke Care

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Abstract

Disease management is an approach to patient care that coordinates medical resources for the patient across the entire healthcare delivery system throughout the lifetime of the patient with the disease. Stroke is suitable for disease management as it is a well-known disease with a high prevalence, high cost, variable practice pattern, poor clinical outcome, and managed by a non-integrated healthcare system. It has measurable and actionable outcomes, with available local expertise and support of the Ministry of Health. Developing the programme requires a multidisciplinary team, baseline data on target populations and healthcare services, identification of core components, collaboration with key stakeholders, development of evidence-based clinical practice guidelines and carepaths, institution of care coordinators, use of information technology and continuous quality improvement to produce an effective plan. Core components include public education, risk factor screening and management, primary care and specialist clinics, acute stroke units, inpatient and outpatient rehabilitation facilities, and supportive community services including medical, nursing, therapy, home help and support groups for patients and carers. The family physician plays a key role. Coordination of services is best done by a network of hospital and community-based care managers, and is enhanced by a coordinating call centre. Continuous quality improvement is required, with audit of processes and outcomes, facilitated by a disease registry. Pitfalls include inappropriate exclusion of deserving patients, misuse, loss of physician and patient independence, over-estimation of benefits, and care fragmentation. Collaboration and cooperative among all parties will help ensure a successful and sustainable programme.

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Introduction

Disease management (DM) is an approach to patient care that coordinates medical resources for patients across the entire healthcare delivery system.¹ It requires a shift in focus from viewing patient care as discrete episodes or fragmentary encounters with different parts of the healthcare system,² to provision of high-quality care across the continuum³ of the lifetime of that patient with the disease. As opposed to a “patient-solution”, DM

programmes provide a “system-solution”,⁴ where the burden of care of the patient is not borne by the physician alone, but by a comprehensive and integrated system. The patient needs to be responsible for his health.⁵⁻⁷ An imperative is to optimise health outcomes while controlling resource utilisation and healthcare costs.³ The face of major diseases in Singapore has changed over the last 50 years, mirroring similar patterns in more developed countries—principal causes of death have shifted from infections to the

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“big three”: cancer, myocardial infarction and stroke.⁸

Stroke as a Target for DM^{2,9,10}

Diseases suitable for DM programmes share the following characteristics:

1. Well-known disease entity: The pathophysiology, mechanisms, risk factors, prevention and treatment options for stroke are well-described in all textbooks of internal medicine;
2. High prevalence: Stroke prevalence in developed countries ranges from 500 to 600/100,000. With our rapidly ageing population (presently those aged >65 years comprises 7.1%, projected to reach 20.1% by the year 2030), rising hospital stroke admissions (more than 10,441 in 2000 alone), and falling age-standardised mortality rates (99/100,000 in 1976 falling to 42/100,000 in 2000), the prevalence of stroke survivors is expected to rise.¹¹
3. High cost: The direct cost of hospital care for a single patient with acute stroke is \$7547, a fraction of the lifetime total cost of stroke care.¹¹ The cost of care for patients admitted for stroke to hospitals of the National Healthcare Group in the year 2000 was in excess of \$17 million.
4. High variability in practice patterns: Stroke is managed by a large number of family physicians, internists, geriatricians, neurologists and neurosurgeons, resulting in variations in management philosophies. Variations in acute stroke care may have been reduced by the development of stroke units and stroke carepaths in some hospitals championed by stroke physicians.
5. Easily developed evidence-based clinical practice guidelines (CPGs): The Ministry of Health published the CPG for acute stroke management in 1999, drawing on the expertise of a broad range of specialists.¹²
6. Poor clinical outcomes, high risk of recurrent events: At 3 months post-stroke, 63.3% are moderately or severely disabled.¹¹ The risk of stroke recurrence ranges from 5% to 15% annually.
7. Preventable disease: National Health Surveys¹³ have shown the high prevalence of hypertension (27.3%), hyperlipidaemia (25.4%), smoking (15.0%) and diabetes (9.0%), many previously undiagnosed or poorly controlled.
8. Non-integrated, inefficient and ineffective delivery systems: Care is provided by numerous private and public sector doctors, hospitals, rehabilitation centres, including services provided by a number of voluntary welfare organisations, with gaps in certain geographical areas. There is a shortage of stepdown facilities. The clustering of healthcare facilities of 3 hospitals and 9 polyclinics in the Western Cluster run by the National Healthcare Group (NHG) offers an opportunity for limited coordination of care.
9. Measurable outcomes: Data on trends in hospital admissions (e.g. 10,441 in 2000), mortality rates (e.g. 1632 in 2000);¹⁴ data on incidence is less readily available.
10. Actionable outcomes: Specific treatment strategies have been proven to favourably affect outcomes, e.g. the use of antiplatelet drugs to reduce ischemic stroke recurrence.¹²
11. Availability of expertise: Singapore in general and NHG specifically has a number of stroke-trained clinicians, supported by family physicians with advanced training and a range of healthcare personnel.
12. Commitment: Healthcare providers should assume responsibility for DM programmes. The Ministry of Health has indicated the need for further attention to stroke. NHG has established a Disease Management Task Force, which includes a Clinical Champion for Stroke who heads a Stroke Disease Management Workgroup (the authors of this paper). This team is multidisciplinary and draws upon the resources of the acute hospitals, polyclinics and community-based providers.

Developing a Stroke DM Programme^{2,3,9,10,15-17}

The development of a stroke DM programme requires the following:

1. Formation of a multidisciplinary team: The team should be led by a “champion” who has the support of the member organisations. Members may include doctors, nurses, case managers, patient educators, social workers, therapists and administrators, all providing the required expertise to make the programme a success.
2. Determination of baseline epidemiological, clinical and related data of the target population and healthcare facilities: The target population will include the healthy public, those with stroke risk factors, the acute stroke patient, and the stroke survivor and his family. The availability of the various healthcare services in the private and public sector will also need to be known.
3. Identification of core components and services: These could include public and patient education, risk factor screening and monitoring, acute stroke treatment, rehabilitation, and community care.
4. Collaboration with key stakeholders: These could include family physicians, specialists, clinics, hospitals, rehabilitation facilities, voluntary organisations, support groups and governmental agencies. Tools may have to be developed to positively influence behaviour.

5. Formulation of the plan: Based on the above information, the team can then define overall framework and core components, develop and implement acceptable and workable plans, monitor progress of the programme, perform evaluations and audits, and re-evaluate and re-prioritise objectives as the programme progresses. The plan has to be patient-centred, outcome-focused, objective, evidence-based, flexible, pragmatic, dynamic, realistic, and designed to maximise benefits while minimising difficulties.
6. Development of evidence-based CPGs, carepaths: While guidelines do exist for the acute management of stroke, similar guidelines will need to be developed for prevention and rehabilitation of stroke. These can then be translated into locally-applicable and acceptable carepaths. Analysis of variances will provide useful information on compliance with and shortcomings of the carepaths.
7. Institution of care coordinators: Case managers will be needed to ensure active and sustained follow-up, to monitor patient progress and complications, if any.
8. Use of information technology (IT): This is critical in enabling healthcare professionals from different facilities to share a common coordinated care plan; by linking the various healthcare components, it allows sharing of data, tracking patient progress and audit. Technology is also needed to create a clinical database or registry of patients with stroke. This will enable the stroke care team to evaluate outcomes over a period of time.
9. Continuous quality improvement and formulation of audit measures: Audit measures will need to be developed of both processes and outcomes. Outcomes and goals should have clear and measurable clinical, humanistic and financial components. In particular, focus should be made on critical processes that impact on significant outcomes.
10. Involvement of the patient as a partner: By empowering the patient with information and access to services that teach skills needed to carry out medical regimens, guide health behaviour and provide emotional support, it is hoped that the individual patient will be pro-active in issues relating to his or her personal health. However, despite our high literacy rate, there is a surprisingly low level of compliance with healthcare advice (e.g. 53% of hypertensives detected during a national survey were previously undiagnosed¹³) and disease knowledge. The DM programme will thus need to overcome this obstacle by other means so that patient enrollment and compliance is enhanced.

Components of a Stroke DM Programme

The spectrum of DM extends from health promotion and disease prevention, through diagnosis, treatment and rehabilitation, to long-term care.² The programme will need to be patient-centred, with a horizontal integration of services (Figs. 1a & 1b). Coordination of these services will be needed so that seamless care is provided. The processes at each level will need to be defined, responsibilities assigned, and quality control monitored so that care is adequate and of a high calibre. If these services are lacking, they will need to be developed in collaboration with appropriate agencies.

1. Public education about stroke, its risk factors, symptoms and preventability: This may be best organised and funded by governmental agencies, e.g. the Health Promotion Board. The programme may further enhance these efforts by developing educational pamphlets, videos and panels that are prominently displayed in suitable locations, organising public forums and talks in work places, use of the press, radio and television.
2. Screening for risk factors: Mass screening may be better organised and funded by governmental agencies. Screening of high-risk patients [e.g. older age, hypertension, diabetes mellitus, hyperlipidaemia, atrial fibrillation and other cardiac diseases, previous strokes or transient ischaemic attacks (TIAs)] as well as opportunistic screening can be performed whenever a person presents to a medical facility for an unrelated illness such as a minor respiratory infection. Annual screening for those above 40 years old should be encouraged. Cost-effective screens include blood pressure, pulse rhythm, blood sugar and blood lipid examinations.¹⁸
3. Management of risk factors/post-stroke follow-up: This is done in the primary care setting by family physicians. Readily available evidence-based

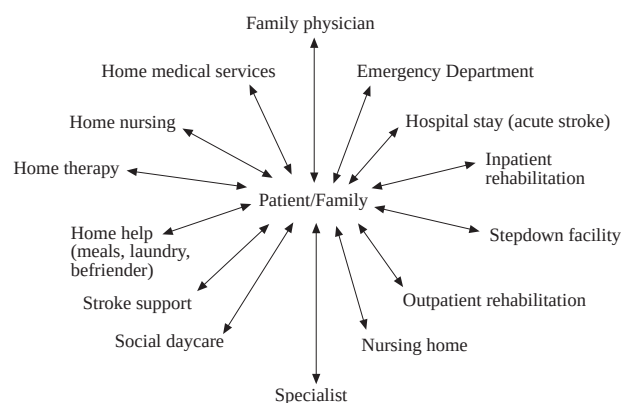


Fig. 1a. The stroke patient and components of the healthcare system: Before disease management.

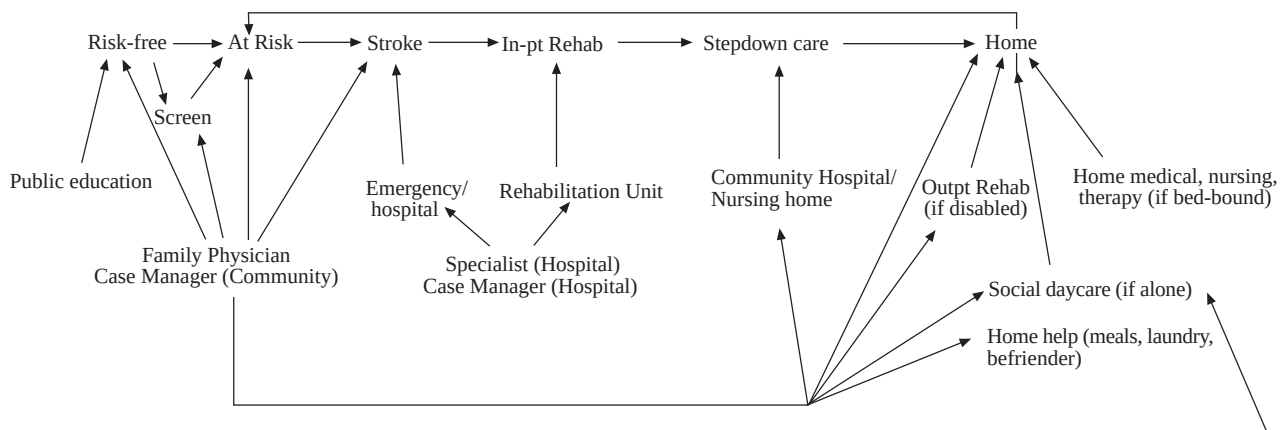


Fig. 1b. The stroke patient and components of the healthcare system: After disease management.

algorithms¹⁹ will make it easier for the doctor to make appropriate treatment decisions. Well-designed carepaths will ensure that important issues are not overlooked. Active and sustained follow-up will be needed to monitor health status, identify complications, and check on compliance with and adequacy of treatment (Fig. 2).

4. Rapid access specialist clinics/emergency departments: These will be needed for the urgent evaluation of cases not easily managed at the primary care level, such as TIAs and atrial fibrillation. Second opinions can be obtained for patients suspected to have a stroke. In NHG, the direct access scheme for family physicians to urgently refer patients with TIAs to the hospital specialists within the same day is an example of how a DM approach could help to improve the standard of care and prevent strokes. Emergency departments are needed for the urgent evaluation of acute stroke patients, and part of a hospital-based stroke clinical pathway is provided to illustrate the initial management of acute stroke patients presented to the emergency department (Fig. 3).
5. Acute stroke units: As stroke is unpredictable in the early hours to days after onset, acute stroke patients are best managed in hospital in a stroke unit. Stroke unit refers to a geographical co-location of stroke patients, or care by a mobile multidisciplinary stroke team of healthcare professionals trained and interested in stroke who manage patients anywhere in the hospital. Stroke units have been shown²⁰ to reduce mortality by 17%, morbidity, length of stay, cost of care, need for institutionalisation, while improving efficiency of services, allowing audit and facilitating research. Some of these benefits may be due to the use of carepaths²¹ and reduction in complications. Caregiver identification and training should be performed in a stroke unit.

Patient and family education on stroke should also be provided.

6. Inpatient rehabilitation: This should be started as soon as possible after stroke, with the patient's family encouraged to participate actively. Those who would benefit from intensive rehabilitation should be transferred to a rehabilitation unit. Those who are unable to cope with an intensive programme may benefit from slower stream rehabilitation at stepdown facilities such as community hospitals or nursing homes.
7. Outpatient rehabilitation: These should be available for mild stroke patients in centres close to their homes. These centres could be co-located with or be part of the polyclinics, and manned by full-time physiotherapists and occupational therapists.
8. Day care services: This will be beneficial for those who are mobile but alone at home.
9. Home care services: For the bed-bound stroke survivor, this may include home medical, home nursing and home rehabilitation services to assist the caregiver. Medication can be prescribed, urine catheter changed, wounds dressed and therapy advice given. In Singapore, there is still a relative lack of home-care services, with varying standards and scope.
10. Other social services: This may include home visits by befrienders, meals services, laundry services, and house cleaning services.
11. Stroke support groups: The Singapore National Stroke Association²² organises regular social and educational activities for stroke survivors and their families. Stroke clubs have been established in hospitals and community to encourage self-help among stroke patients and families. Bedside counselling of acute stroke patients by stroke survivors has already started in some hospitals.

Stroke Carepath - NHG Polyclinics				
Patient's sticker _____				
Source of referral _____				
Type of stroke - ischaemic/haemorrhagic/not known, Comments _____				
<u>Risk factors</u>				
Hypertension - yes/no Comments _____				
DM - yes/no Comments _____				
Hyperlipidaemia - yes/no Comments _____				
Smoking - yes/no Comments _____				
<u>Secondary prevention</u>				
Cardioembolic stroke - warfarin, target INR 2.0-3.0 - yes/no				
Comments _____				
Non-embolic ischemic stroke - antiplatelet - yes/no				
Comments _____				
<u>Complications</u>				
Pneumonia	Urinary Infection	Bedsore	Contractures	Depression
Incontinence	Dysphagia			
<u>Other Measures</u>				
Dietary advice - yes/not needed Comments _____				
Therapy - yes/not needed				
Outpatient at _____				
Home therapy by _____				
Comments _____				
Informed about stroke support group (SNSA) - yes/no Comments _____				
Home nursing - yes/not needed Comments _____				
Social day care - yes/not needed Comments _____				
Home meals service - yes/not needed Comments _____				
Other issues _____				

Fig. 2. Carepath for follow-up of the stroke patient at the primary care level.

12. Nursing homes: While it is preferred that stroke patients return home to the care of their family, it is inevitable that some families will not be able to cope with a disabled elder at home. Adequate and affordable nursing homes will be necessary to meet this need.
13. Staff training: Continuing medical education of healthcare workers is needed to ensure that they are up-to-date with current developments in stroke care.

Coordination of Services—The Case Manager Network

The patient and family can expectedly feel overwhelmed by the range of activities needed to support the stroke patient. The mildly disabled patient will be able to return

home, visit his family physician and attend an outpatient rehabilitation centre; if he is alone at home in the day time, he may benefit from social day care services on his non-rehabilitation days. The bed-bound stroke patient, however, may need caregiver identification and training before discharge, and medical, nursing and rehabilitation services to visit him at home. Coordination of these services is probably beyond the capacity of most lay people, and is best performed by a case manager.

The hospital case manager is ideally suited to perform assessments of the patient's and family's needs while still in hospital, in consultation with the other members of the multidisciplinary stroke team. Referrals and appointments can be made before hospital discharge, and the family

NATIONAL NEUROSCIENCE INSITUTE / TAN TOCK SENG HOSPITAL Clinical Pathway					
Case Type : Stroke (Emergency Department)			Patient's Sticky Label		
DATE		Team Initial	Nurses' Shift		
TIME FRAME			AM	PM	ND
CONSULTS	Neurologist / Neurosurgeon	Dr			
TEST/ PROCEDURES	FBC,Platelets,PT/PTT,U/E/S,GXM,CXR if ill, drowsy				
	ECG (for all patients)	Dr/Nurse			
	Blood sugar (finger prick) for all patients				
	CT Scan - Head (if ill, drowsy)	Dr			
TREATMENT	Oxygen therapy, if hypoxic				
MEDICATION	I/V Normal Saline 1 L/24 h (if ill, drowsy)	Dr.'s order			
	Anti-hypertensive therapy only if SBP persistently >200 mmHg on 3 consecutive readings in 2 hours without a downward trend, unless in heart failure, AMI, hypertensive encephalopathy, aortic dissection, haemorrhagic stroke, for thrombolytic therapy				
ACTIVITY	Maintain bed rest till CT scan is done	Nurse			
NUTRITION	Nil by mouth if patient is ill, drowsy and risk of aspiration present				
	Can feed if patient is post-stroke >3 days and GCS 15	Dr/Nurse			
	Swallowing screening before feeding				
OBSERVATIONS	Elevate head of bed at 30 degrees	Nurse			
	GCS and vital signs 2 hourly (15 mins if patient ill & drowsy)				
	Aspiration precautions				
	Falls risk assessment				
EDUCATION	Give stroke information sheet to patient/family				

Fig. 3. Carepath for the management of suspected stroke in the Emergency Department.

advised accordingly. On discharge, further coordination of care can be undertaken by the community case manager.

The community case manager, possibly co-located with the family physician will be able to follow-up on appointments made to visit doctors and rehabilitation centres, and to ensure that home services do attend to the patient at home. She is also able to initiate new services or terminate existing services, based on the patient's needs. She may visit the patient's home if needed to make accurate assessments, or attend to each patient when he or she turns up to visit the family physician. The responsibilities of the community case manager should be listed in the clinic carepaths, and may include related tasks such as patient education and screening for stroke complications.

The success of case management will depend on the commitment and proactiveness of the case managers, and their being able to provide accurate information of available resources. A booklet listing the resources would be immensely helpful, which will need to be updated regularly as new services are developed. One such service directory has been developed by the Care and Counselling Department of Tan Tock Seng Hospital.

Coordination of Services—The Call Centre

A call centre with expertise in stroke offers the opportunity to do the following:

1. Triage²³: The traditional function of call centres, the centre will be able to advise the caller of self-help

measures (e.g. for mild neck pain) or the need to see a family physician (e.g. for fever) in non-stroke benign conditions, or the need to rush to the nearest emergency department for evaluation of the symptoms suggestive of acute stroke (e.g. slurred speech with weakness of the face, arm and leg on one side).

2. Education: Callers can request for information on stroke or its risk factors (e.g. what is a TIA). Call centre personnel may also routinely give a health message to all callers (e.g. stop smoking).
3. Appointment reminders: Reminders can be made by mail, telephone call, e-mail and fax to visit the doctor or to attend outpatient rehabilitation. Defaulters can be identified and encouraged and assisted to comply.
4. Coordination of services: The centre will be able to centrally coordinate the required services when informed about the needs of a patient by the case manager. These may range from outpatient rehabilitation services to home nursing visits to nursing placements.

Coordination of Services—The Family Physician²⁴

The family physician is usually involved with risk factor screening, management of risk factors, referral to the specialist for the more complex cases, and the long-term follow-up of the post-stroke patient. He is thus well-positioned to coordinate the overall care of the patient. However, the clinical workload is usually too heavy to allow this. Collaboration between the family physician and the case manager/call centre will allow the family physician to retain control of patient care, and be saved the need to be involved in the nitty-gritty details. Involving the doctors in DM programme will allow them to better understand the roles others play in healthcare delivery, the need to balance competing priorities, and the full ramifications of their clinical decisions. Provision of government subsidies to family physicians in private practice will further encourage their participation.

Pitfalls of a Stroke DM Programme^{4,5,9,25}

All programmes will have their drawbacks, no matter how well-intentioned. They are:

1. Benefits few: Selecting only a small group of non-disabled cooperative patients would yield falsely positive results. The programme should encompass all stroke patients; as most are disabled and have risk factors, there is a need for service coordination.
2. Misuse: DM programmes developed by pharmaceutical firms, home care companies and supermarket chains may be seen to be self-serving, used as a way of selling services or patented (non-generic) drugs, as a marketing or publicity tool, or as a means of reducing their risk by targeting only low-risk individuals to enter their programmes. Thus, DM programmes are best run by

governmental organisations, or developed in-house, and not out-sourced to specialised organisations.²⁶

3. Loss of physician and patient independence: DM programmes may begin to resemble managed care systems, where physician selection and treatment options are dictated by the organisations. There may be a change in the dynamics of the doctor-patient relationship. Patient demands may conflict with protocols. Treatment options may become restricted. Encouraging the participation of physicians and patients in the development of the programme will reduce anxiety of loss of independence.^{7,15}
4. Over-estimation of benefits: DM programmes hold the promise of enhancing efficiency and provision of holistic care while keeping costs down. Start-up costs may be high. The benefits gained may not be as spectacular as is hoped. Cost savings may be realised only some years after implementation of the programme. However, profit should not be a measure of the success of the programme.
5. Care fragmentation: This may occur if only the disease is managed, excluding attention to the accompanying issues such as risk factors. Thus, care has to be comprehensive and holistic.

Audit, Quality Control^{27,28}

Continuous quality control is a core philosophy of DM.³ It is important to ensure that standards are maintained and plans are followed. Performance measurement and quality improvement are essential ingredients of chronic DM. The success of a DM programme can be measured by its success in clinical, humanistic and financial arenas. Each process can be audited, either assessing process or measuring outcomes (Table I). However, it may be difficult to decide whose outcomes should prevail—the professionals or the patients.² The best measures of a successful programme would include falling stroke incidence and case fatality rates, lesser disability of survivors, and better quality of life of patients and caregivers. A stroke registry is likely to provide such information as well as help monitor trends.²⁹

Conclusion

This paper has outlined what a DM programme could compose of and what are the essential elements for success. DM programmes for stroke need to be population-based, and to be responsive to individual patient's needs, respecting patient preference and advocating joint decision-making. The NHG stroke DM workgroup has spent the first year gathering baseline information, developing public and patient educational materials, organising public education forums, fine-tuning risk factor screening in collaboration with the Vascular Risk Factor Workgroup and Cardiac Workgroup, setting up stroke and TIA clinics, and refining stroke carepaths in hospitals including review of carepath

TABLE I: AUDIT PARAMETERS FOR STROKE

Process/audit measure	Process measure	Outcome measure
Public education	Presence of educational programme Presence of educational materials	Proportion attending educational programmes Proportion receiving educational materials Knowledge, attitudes and practices survey
Risk factor detection	Presence of screening programme	Proportion screened National health surveys Incidence surveys
Risk factor control	Presence of risk factor control protocols/algorithms	Proportion attaining treatment targets National health surveys Incidence surveys
Acute stroke treatment	Presence of carepaths Presence of multidisciplinary care team Presence of stroke physician	Proportion on carepaths Carepath variances Proportion attended to by multidisciplinary care team Disability at 3 months Recurrent stroke rate Case fatality rate
Rehabilitation	Presence of rehabilitation services	Proportion receiving rehabilitation Disability at 3 months
Education	Presence of patient education programme Presence of staff education programme	Proportion receiving education Knowledge survey Proportion of staff attending education programme Knowledge survey
Community resources	Presence of medical, nursing and therapy services	Proportion receiving services Quality of life surveys

variances. The second year will be spent in the challenging task of engaging with community services to build up a support base for stroke patients after they go home. A pilot project of community case managers linking with hospital case managers is being planned. A booklet on community resources is being finalised and will be available on-line soon. Collaboration with the Health Promotion Board will be needed to continue with education and screening programmes. The support of the Ministry of Health is crucial, especially in the issues of funding, and the development of adequate stepdown facilities and community resources.

Problems encountered during this initial phase of the running of the NHG stroke DM workgroup include difficulty in getting enough physicians and healthcare specialists in other disciplines to be actively involved in the group, coordination of the efforts especially in patient education and primary prevention among different DM workgroups (stroke, vascular risk factor and cardiac) and the Health Promotion Board, and working under tight schedules and budget.

Evaluating the stroke programme will be difficult, especially in an operational setting. The presence of a clinical database or disease registry will help facilitate this. The issues of funding, resistance to change by physicians

and administrators will continue to pose challenges to the programme. Only by forging partnerships within and across the healthcare system, supported by information technology and research, can a stroke DM programme truly deliver.³⁰

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