NHSScotland

NATIONAL FRAMEWORK FOR
SERVICE CHANGE IN THE NHS IN SCOTLAND

Care of Older People

Action Team Report

May 2005
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Annexe. Members of the Care of Older People Action Team
0. Executive summary

General

- By 2024, as Scotland’s population ages and diminishes, older people will become by far the major users of health and social services.
- The goal must be to provide for Scotland’s older people services that are safe, of high quality and delivered as near home as possible.
- Policy and services should aim at supporting wellbeing and the individual’s ability to play a greater role in self-management.
- Introducing a more pro-active anticipatory approach which identifies those older people with the most complex needs would allow for their health and social care needs to be co-ordinated.
- Care provision must focus much more on the optimal management of continuing illness and disabilities, with less emphasis on the current ‘default option’ of episodic unscheduled care.
- Unscheduled care, evolving via technical advance and more cost-effective provision, must meet the special needs of older patients – its main users – and provide for them the best possible journey of care.
- Health and social services in Scotland – functionally integrated at all levels – must respond to these challenges, adapting organisation and practice, and working seamlessly in the services of individuals and communities.
- The challenge is great, but it seems likely that developments in IT and health technology, together with improvements in housing, transport and communications, will facilitate the necessary changes in service provision.

Context

- Care of older people is already the central task of health and social services, and the task will grow as Scotland’s population ages.
- The nature of this challenge, and how it is met, will be determined by:
  - Health trends and social conditions for older people.
  - Likely changes in health technology, communications and IT.
  - The response of the research community to an age-related research agenda.
  - Developments in the organisation and infrastructure; and in local/regional government in Scotland.
- Already there are encouraging trends and sporadic examples of relevant good practice; but only sustained, creative (and perhaps politically difficult) efforts will deliver the change necessary to meet the challenges of 2024.
Governing principles: the case for a whole systems approach

- Much of the current pressure on health and social care services relates to the care of older people
- Historically based provisions have adapted only slowly to changing need, and are now unbalanced in relation to their main task
- With more and more of the health and social care task relating to chronic and recurrent ill-health and dependency in older people, a change of focus from episodic to sustained co-ordinated care is overdue
- A pro-active and supportive approach to care of frailer older people – based on ‘whole-system’ redesign of health and social care is required
- Substantial resource shift, and serious investment in training and services away from the current acute sector, is needed; and resistance is to be expected.

Enabling well-being and function: self care, carers and volunteering; partnership and empowerment

- Patients, their carers, and volunteers already willingly provide a high proportion of the social and health care needed by older people, and will continue to do so.
- Many carers and volunteers are themselves older: the ‘well elderly’ who constitute a major and growing resource for their frailer relatives and friends, and are key to effective community-based volunteer initiatives
- Active partnerships between formal and informal care can promote and maintain the health and independence and extend care at home; training and education, carer and volunteer support, and respite provisions have all proved effective, and should be extended as Scotland’s population ages
- Older people are already major providers of their own health care; and if self-care and self-management – particularly for chronic/long-term conditions - can be supported by formal health and social care providers, with information, education and empowerment, better health and health care outcomes will result
- The community-based, lay and professionally led condition-specific self-management ‘Braveheart’ project for CHD exemplifies the kind of approach which could be extended more widely
- Scotland’s Health White Paper of 2003 ‘Partnership for Care’ offers a basis from which to build on success and extend evaluated practice in self-care and carer and volunteer involvement – as numbers of both the well and the frail elderly rise over coming decades.
Redressing the balance of care: Providing more care closer to home

- Current difficulties in the care of older people reflect misprovision, with a costly, misplaced and inefficient emphasis on acute care
- Countervailing initiatives – improving the availability, flexibility and effectiveness of responses to frailty and illness at home – have been piloted
- Improving care for older people depends on managing long-term illness and debility far better, with much more emphasis on proactive, sustained care at home and in local settings
- Further developments in health and social care, with closer integration and best use of emerging technologies, are required
- Developments in health screening and in ICT could not only promote cost-effective care and support but also provide service planning and evaluation data
- As mortality is compressed in old age, enhanced palliative services could provide better – and also more cost-effective – care towards the end of life, much of it at or near home
- Substantial workforce issues – in education and training, in career flexibility and life-long learning – must be addressed with a new focus on competencies rather than traditional labels

Care of older people other than at home: unscheduled, post-acute, continuing and palliative care

- Acute sector care for older people in Scotland is unsustainable over the next 20 years in its present form
- Future trends in demand are to some extent predictable, though biomedical and other advances may mitigate their service impact
- Older people must continue to have full access to treatments and technologies from which they as individuals might benefit
- The unscheduled care system may be vulnerable if the journey of care for older patients is not well-managed, with
  - closest possible integration of health and social care
  - optimal management of chronic illness/disabilities
  - as much diagnosis, treatment and care as possible provided near home
  - minimal use of remote unscheduled care centres
  - optimal acute rehabilitation in such centres
  - ready access to post-discharge rehabilitation at home
  - post-acute inpatient rehabilitation nearer home for those who need it
- Developments in healthcare, IT and communications technology may serve to facilitate any necessary concentration of aspects of unscheduled and planned services and the necessary associated service change
- Inpatient services for respite, palliative and continuing care will – like those for post-acute rehabilitation – be provided locally
“The best response to concerns about ageism in NHS Scotland is simply to achieve a widespread and visible improvement in the quality of service for older people.” (Chief Medical Officer, 2002)

Policy Implications

By 2015 (high level goals)

- Integrated and coterminous health and social services focussed largely on the care and support at home of Scotland’s frailer older people, with a commitment to optimal management of chronic, long term illness, impairment and disability
- Unscheduled health services similarly redesigned around the major client group – older people – to provide for them, in conjunction with the above, optimal journeys of care
- Fit-for-purpose ICT to facilitate, support and monitor care of older people: at home; in and through unscheduled and post-acute care; through long-term and recurrent illness; and towards the end of life
- Systems of clinical governance and performance management that ensure quality, cost-effectiveness and equity in the delivery of support and such care
- A health and social care workforce that reflects demography and need, increasingly community-based and less focussed than at present on acute and unscheduled care: with changes delivered via training, education and career paths; knowledge, skills and attitudes; with more people working in teams and away from hospitals; and making maximum use of emergent ICT and other technology

By 2008 (to support progress towards above)

- Central and regional planning of tiered and cost-effective patterns of care provision to reflect the many drivers of change in both primary and acute health sectors, including clinical and other workforce issues, technological change, economies of scale, and remote and rural service provision
- Substantial developments, jointly with health and social care, in rehabilitation – through unscheduled care, in post-acute care and via community-based services to ensure older people’s access to unscheduled care and their maximum benefit from it
- Increasing integration of health and social care, with eventual common boundaries and systems, aiming to ensure seamless patient-centred care from a single accountable organisation focussing largely on care and support at home or near it whenever possible
- Workforce developments in health and social care – in training, continuing education, joint learning and working, and team-working – in parallel the above; with care of older people a central feature in all developments
• An R&D agenda that matches the realities of demography and need in order to encourage: increased health services focused research; age-specific biomedical research in acute care and in drug development; the development and evaluation of initiatives in health and social care at or near home; and the evaluation of emerging biomedical, IT, telemedicine and communication technology to support the above goals in the care of Scotland’s older people

**Short term actions: urgent/overdue**

• Provide clear central direction on expected targets/outcomes for services provided to older people by the Community Health Partnerships; consider the use of financial incentives; and ensure robust evaluation of impact/outcomes

• Ensure that the forthcoming review of the Quality Outcomes Framework associated with the new General Medical Services contract includes indicators specific to an anticipatory and co-ordinated approach to management of older people with co-morbidity and complex needs.

• Ensure that the new Pharmacy contract reflects the extended role that pharmacists and in particular community pharmacists could play in the monitoring and review of older peoples medications and health status

• Procure and implement a national integrated IT system based on a uniquely identified single shared record that covers all health and social care sectors within three years.

• Utilise the Chief Scientist’s Office to ensure that the Research & Development Agenda of NHS Scotland, including that of the Health Services Research Unit, reflects more closely the realities of Scotland’s current and future demography and need.

• Promote closer working between health and social services, explore the feasibility of building on the current commitment of social services to implement care management after April 2005 and include the currently missing dimension of health.

• Ensure that the Scottish Executive’s Workforce Planning Initiative considers and responds to the implications of this report.
1. Context

Main points

- The care of older people is already the central task of health and social services, and the task will grow as Scotland’s population ages
- The nature of this challenge, and how it is met, will be determined by
  - Health trends and social conditions for older people
  - Likely changes in health technology, communications and IT
  - The response of the research community to an age-related research agenda
  - Developments in the organisation and infrastructure; and in local/regional government in Scotland
- Already there are encouraging trends and sporadic examples of relevant good practice; but only sustained, creative (and perhaps politically difficult) efforts will deliver the change necessary to meet the challenges of 2024.

1.1. General

1. The need for healthcare rises sharply with age, and Scotland’s population is ageing rapidly. The implications for NHS Scotland are both clear and urgent, and are at present only beginning to be addressed.

2. Already around two thirds of acute beds in NHS Scotland are used by patients aged over 65; and over 75s (7% of population) account for 22% of admissions and a similar proportion of acute health expenditure. Current acute sector pressures (emergency admissions, waiting lists, bed crises and delayed discharges) involve mainly older patients, with serious implications for their quality of care and their access to it.

3. Older people are also major users of primary care, with contact rates per year rising from around 9 per person in the 65 to 74 age group to around 16 in the over 85’s (compared to around 4 per annum in the 25 to 44 age group). Approximately 60% of the spend of Social Work departments is devoted to the care of older people.

Older people’s health care needs differ from those of the younger because they are:

- More likely to live alone.
• More likely to have functional dependency and sensory impairment
• More likely to have chronic disease.
• More likely to have co-morbidity (ie multiple medical problems, perhaps a mixture of acute and chronic).
• More likely to be on multiple medications, with greater risks as a result
• More likely to have cognitive impairment and other mental disorders.
• More likely to develop complications of acute illness and its management; and more likely to develop hospital acquired infection.
• More likely to stay longer in hospital; and more likely to require rehabilitation following acute illness and trauma.
• More likely to die.

By 2024 Scotland’s over 65s will be:

• On average older.
• More numerous – absolutely and proportionately.
• More at risk in relation to bullet points 2 to 9 above – because on average older.
• And, because of their increasing numbers and age, even more at risk from current patterns of healthcare provision/misprovision – unless these are seriously, urgently and explicitly addressed in terms of the needs of older people.

4. Over 2001 – 2031 Scotland’s over 65s will rise from 15.9% to 26.6% of the population; with over 80s (whose health and social care needs are highest) rising from 3.8% to 8.2%  (Figure 1). To ensure quality of care for them 20 years from now, and indeed to enable NHS Scotland then to avoid a state of perpetual crisis, a radical review and restructuring of older people’s health and social care is needed.

5. Care of older people has recently been recognised as ‘the central responsibility of NHS Scotland, with good mainstream care as a goal of current and future efforts in the health service reform’ (Chief Medical Officer, 2002). However, such reforms are slow: current challenges are not being met, and the scope and scale of reform to ensure adequate delivery of the ‘central responsibility of NHS Scotland’ in 2024 remains daunting.
1.2. Looking ahead
Health care needs and health care delivery for Scotland’s ageing population in the year 2024 will be influenced by many factors, of which demography is the least uncertain. The health of the older people, their attitudes and expectations, technological advance, the R&D agenda, health service organisation, and infrastructure will all – with varying degrees of uncertainty – contribute.

### 1.2.1 Demography and health

1. Recent upwards revision of the estimates for numbers of the very old, with the number of over 85s now predicted to treble by 2040, adds urgency to the search for an appropriate response: but raw numbers might be misleading: demand is determined also by the fitness of the older population.

2. Most health care is needed by those ‘between the health curve and life curve’: in effect the caseload of the frailest elderly who make greatest use of health services. Better health in later life may diminish this zone of vulnerability/dependency and its consequences for health and social care.

3. Health in old age in the future will be dependent on both current and future lifestyles. Early and mid-life health-related behaviours both contribute and may show generational change over relatively short periods.

4. It is possible that the current and near-future old are the fittest that there ever will be. However, social trends may favour increasing health-consciousness and fitness. The currently middle-aged are the relevant target group, both for ascertainment studies and possible intervention.

5. There is also good evidence that ‘It’s never too late to exercise’: a substantial return of measurable fitness can be achieved by bearable amounts of exercise even late in life. This may amount to a rejuvenation effect as fitness levels rise towards the average for a younger cohort, with improvements in health, well-being and independence.

6. The geographical distribution of our ageing population – which is currently uneven and loaded towards rural/retirement areas and declining inner cities – may change: with considerable consequences for its health care.

7. Useful research is already available on the views and needs of a predominantly rural older population (Highland Senior Citizens Network 2004). Further such work might be used to help shape services.

8. The ethnic composition of our older population will also change, with the predictable ageing of established minority populations (predominantly south Asian) whose cultural and religious expectations and sensitivities must be provided for throughout health and social care services.

9. The likely – but less predictable – emergence of new and younger minorities, as a result of migration within an expanded European Union, will probably favourably influence the dependency ratio of Scotland’s population.
10. There is a need to adopt an anticipatory approach based on the identification of those older people with the most complex needs. This would involve: the co-ordination of care in terms of delivery, support and monitoring; the stratification of need; the tracking of changing patterns of need; resource and service planning locally and nationally; and evaluation of measures designed to minimise unnecessary unscheduled admission and to minimise unnecessary permanent institutionalisation.

11. Health and social care should work closely together in both the gathering of information and in its use in planning care at the individual and service level. Building on work such as Single Shared Assessment and other emerging joint information systems, local and national databases on Scotland’s older people might provide an invaluable resource in terms of mapping need and providing and monitoring their care.

1.2.2 Expectations, Attitudes and the NHS

1. Today’s older Scots are on the whole very easy to please in matters of health care. Reaching adulthood via war and austerity, and with direct or handed down memories of pre-NHS provision, they demonstrate a sometimes remarkable tolerance that will fade as quickly as they do.

2. Subsequent generations will expect more in terms of: immediacy and flexibility of access; quality of care and the surroundings in which it is delivered; and patients’ rights as consumers, including the right to participate in decision making. (The kind of patients who currently say ‘Just do what you think’s best, son…’ will be few and far between)

3. Far better-informed older consumers of health care (‘I’ve just been on the internet, doctor, and….’) will appear in increasing numbers.

4. Scotland’s traditionally left-leaning social consensus on public services may also fade.

5. The distribution of wealth may be reflected in the distribution of health: affluence in retirement may well minimise dependency or ill-health in old age.

6. Much of the health inequality in Scotland, including that among older Scots, involves differing attitudes to health and health-related behaviours, with a strong correlation between social deprivation, poor diet, alcohol and tobacco abuse, and resulting ill-health.

7. The 2024 older population will include many survivors of lifelong deprivation and its health consequences. If social inequalities can be diminished, this will be reflected in eventual better health for older Scots – though we are faced with to some extent with an inevitable ‘Rab C Nesbitt at 70’ syndrome.

8. Housing is a major determinant of the health and wellbeing of older people, and housing need and provision must be addressed in ways that take account of the increasing numbers of older households. More
and more of Scotland’s housing stock will need to be ‘age-friendly’ in terms of access, design, and security.

9. Patterns of housing tenure are unpredictable, but older people are likely to be major users of the rented, social and sheltered housing stock, much of which must therefore be adapted – ideally with optimal use of emerging technology – to ensure warmth and safety, IT access and possibly monitoring facilities.

10. Whatever happens in terms of pensions and home ownership, there will continue to be large numbers of older poor people in Scotland: because ‘the poor get old and the old get poor’.

11. With their major health care needs increasingly compressed into the pre-death months and years, poorer aged Scots would be a very doubtful commercial proposition for insurers; and it seems unlikely that a residual ‘safety-net’ NHSScotland would serve them well

### 1.2.3 Technology

1. Developments in diagnostic, intervention and communication technologies will be major determinants of the nature and shape of the health care provided for older people.

2. Smart housing and electronic systems monitoring safety and care in the home will allow more and more older people to remain at home in an electronically supported environment.

3. Newer imaging techniques such as USS, CAT and MRI have, alongside endoscopy and developments in the laboratory specialties, facilitated accurate and minimally traumatic diagnosis for older patients in ways unpredictable 20 years ago. More will be delivered.

4. Increasing capabilities in remote imaging – and even remote intervention: a transatlantic cholecystectomy has already taken place – might allow greater (and more cost-effective) concentration of expensive expertise and technology on fewer sites while at the same time serving even the most remote/rural populations better.

5. Minimally invasive interventional techniques have likewise transformed procedures formerly big and bloody, with particular benefit to older people by reducing physiological insult, length of hospital stay, and need for post-operative rehabilitation. These trends will continue.

6. Trauma surgery – important for older people: e.g. for hip fracture – is more likely to remain ‘big and bloody’, though potential developments in bone substitutes – e.g. a quick-setting bone cement later forming a substrate for bone re-growth – might transform the current problem of ‘doing great operations on lousy bone’.

7. Stem cell research and related developments may offer dramatically effective solutions for common diseases of late life, and for age-related organ failure – and, if they do, will also raise a number of interesting ethical questions, at least for the first few years following each advance.

8. There is great potential to use existing modern technology to improve communication with patients, and within and between clinical teams, to speed up the delivery care and improve its quality (e.g. in the transition form acute to primary care).
9. Wellbeing and informed self care of older Scots could also be enhanced by potential IT/communications developments: in terms of the provision of valid health and wellbeing-related information; in facilitating support groups; in promoting ‘virtual exercise clubs’; and in replacing current community alarm arrangements with something much more sophisticated.

10. There is huge potential too in NHS internal IT and communications: while the NHS still struggles to use information to facilitate and improve care, particularly when it does so with other agencies, some health providers (e.g. Kaiser Permanente) have already achieved substantial efficiencies far in excess of outlays.

11. **NHS Scotland currently fails to make best use of existing ICT.** There must be doubts about its ability to benefit maximally from the advances of the next twenty years. However rapid adoption of fit-for-purpose ICT systems will be a vital underpinning for the delivery of optimal care for Scotland’s older people.

### 1.2.4 An R&D agenda fit for demographic purpose?

1. If care of older people is a central responsibility of NHSScotland, then its research and development agenda in both health and social care should reflect that. At present it fails to do so.

2. As the need for joint initiatives in health and social care is increasingly recognised, the evidence base for such service developments must be strengthened. This requires a research agenda involving social work and the voluntary sector as well as health.

3. **The R&D agenda must reflect not only the demographic realities – many more old and very old people – but must address also the need for an evidence base for the management of long term and recurrent illness and disability.** This too will involve close cooperation between health and social care researchers.

4. Biomedical research in older, frailer patients with multiple diagnoses is challenging in the extreme. Much of the evidence guiding the treatment of older people has in fact been derived from work on younger patients, resulting in levels of risk and damage which are higher than necessary.

5. As admissions of older, frailer patients rise over the years, optimising their medical care by means of a focused research effort assumes increasing importance.

6. Geriatricians, clinical pharmacologists and a range of ‘single organ doctors’ should work with the pharmaceutical industry to ensure that older patients benefit maximally – and suffer minimally – from successive advances in drug therapy.

7. Large hospitals dealing with larger numbers of acutely admitted older patients should rise to the research opportunities associated with their care with common acute presentations in the frail elderly as a focus of their research efforts.

8. **Health service research – like biomedical research – encounters special difficulties in relation to care of older people (case-mix and biodiversity in old age; multiple impairments; functional and**
social complexity; fuzzy multidisciplinary inputs etc). However, 
Health service research must respond to the demographic 
imperative.

9. Already service change based on health services research has 
demonstrated its utility in the care of older people. The sequence of 
ascertainment study, evaluated pilot development, wider adoption of 
change and eventual roll-out across the service is a proven but under-
used model for evidence-based change to promote quality and 
effectiveness in health care.

10. Encouraging examples include rapid response teams, early supported 
discharge for older trauma patients, and alternatives to admission in 
acute exacerbation of chronic bronchitis (Felix et al., 2004) with the last 
offering a particularly good model of improved chronic disease 
management.

11. Common themes of such work are: patient focus; multidisciplinary and 
interagency working; and the provision of better care away from 
hospital. Patient satisfaction and economic evaluation are alike 
positive.

12. **Looking after older people well seems therefore to be cheaper 
than looking after them badly.**

13. Further such HSR-based improvements in care will meet individual, 
societal and cost-effectiveness goals; and the challenge for the next 
twenty years is to maximise such gains via a national programme of 
age-related health service research: which Scotland – with its strong 
traditions in public health, geriatric medicine and inter-agency working 
– might do rather well.

14. However, the potential of HSR is currently under-exploited in the NHS 
(Dash et al, 2003). Researchers, managers and policy makers have 
failed to connect around tasks and goals, and mutual disillusionment is 
common.

15. **Within Scotland, the researchers who generate the knowledge, the 
managers and clinicians who see the need for action, and the 
policy makers who want change, should – as part of the work of 
adapting NHS Scotland to changing demography – identify 
priorities and develop a strategy for HSR in an ageing Scotland.**

1.2.5 **Organisation and Infrastructure**

1. Primary, secondary and social care are not currently well organised for 
the delivery of care to older people in the communities they serve. In 
many instances, multi-agency systems unnecessarily complicate 
multidisciplinary working. In primary care the doctor-led model 
encouraged under the new GMS contract does not provide incentives 
to empower patients (BMJ 2004: 329: 1197-8) or to provide pro-active, 
co-ordinated care at home for the frailest elderly.

2. **Ideally single-system working - encompassing unscheduled, 
primary and social care - should evolve.** Care should be 
accountable as a single system – an optimal arrangement towards
which the CHP’s are a first step. However, many issues relating to
culture, organisation, incentives and funding will require to be
addressed.
3. Today’s over-complex, anomalous and non-coterminous
patchwork of local authorities and health board areas is a
historical burden which adds greatly to the current task of
providing health and social care for Scotland’s older people.
4. Current organisational arrangements have only partially succeeded in
meeting the challenges of providing care for older people in remote and
rural areas.
5. Various models of care for remote and rural populations have evolved
here and in Northern Europe, and will continue to evolve with growing
experience and – importantly – with technological advances as outlined
above, which may greatly facilitate improvement of care for scattered
populations in the south, west and north of Scotland.
6. While the necessary but politically sensitive task of rationalising health
and social care organisational boundaries in the interests of scale and
simplicity is beyond the remit of the group, a radically simpler and
uniformly coterminous solution would serve to make the
implementation of its recommendations much easier.
7. The legacy of board- and trust-based planning decisions
demonstrates a clear need for a national strategy for tiered
services – national, regional, and local – in health care (Currie and
Toft, 1997)

2. Governing principles: the case for a whole systems
approach

Main points

- Much of the current pressure on health and social care services
  relates to the care of older people
- Historically based patterns of provision have adapted only slowly to
  changing need and are now unbalanced in relation to their main
  task
- With more and more of the health and social care task relating to
  chronic and recurrent ill-health and dependency in older people, a
  change of focus from episodic to continuous and sustained care is
  overdue
- A pro-active and supportive approach to care of frailer older people
  based on ‘whole-system’ redesign of health and social care is
  required
- Substantial resource shift, and serious investment in training and
  services away from the current acute sector, is needed: and
  resistance is to be expected.
2.1 Current issues and pressures.

1. Acute sector pressures (rising emergency admissions, high levels of delayed discharge and waiting times) relate largely to the care of older people. However, a case can be made that the acute sector dominance that has characterised the NHS throughout its life hitherto has not served older people well, and has served the frailest of them least well.

2. Previously fit older people with a single diagnosis may of course be served quite well by the current pattern of provision, but for patients with co-morbidity, long term illness, frailty or confusion serious difficulties can arise such as: loss of mobility, increasing confusion, prolonged length of stay, prolonged loss of function, permanent loss of function and loss of home.

3. Frailer older people – especially those with cognitive and/or sensory impairments - are at most risk on the boundaries between the acute sector, primary care and social care provision. Although current organisational reforms (the introduction of Local Health Care Cooperatives now to be succeeded by Community Health Partnerships) and innovative multidisciplinary interface services (such as Rapid Response Teams and Early Supported Discharge) have mitigated some of the problems, there are continuing concerns about the vulnerability of frail older people in a complex system of care.

4. One unexplained and problematical aspect of acute sector dominance is the rise of emergency admission of older people (Figure 2) in excess of demographic change and in the absence of broadly measurable increased morbidity (ISD Scotland, 2003).

5. Various societal, attitudinal and service change reasons have been postulated in explanation, but it is arguable that the explanation might be rooted in the problem of acute sector dominance (“to the man with a hammer, every problem looks like a nail”). Recent trends are perhaps slightly encouraging.

Figure 2.
6. Progress towards tackling this issue will depend on explicit recognition of the specific health care needs of older people and developments throughout health and social care designed to meet these needs, including:

- better early recognition of dependency and need (case finding)
- flexible and responsive community provision to facilitate early intervention and support the frail elderly at home (case management)
- ready access to diagnostic technology and expertise
- improved ‘interface’ services to minimise the adverse consequences of contact with unscheduled services such as A&E departments and Assessment Areas
- awareness and response throughout the acute sector to the vulnerability of the frail elderly, with adequate functional assessment and readily available and effective rehabilitation services – both in-patient and community – to meet their needs (NHS QIS, 2002).

7. In addition, the full impact of recent changes in out of hours cover on the care of the frail elderly at home has yet to be assessed. The quality of out of hours care will be crucial to the care of older people over the next twenty years - in controlling avoidable unscheduled care, in optimising end of life care and perhaps even contributing to case finding.

8. Organisational structures and barriers are not the whole story in accounting for the often fragmented nature of care of older people. Changing organisational structures is not a panacea.

9. However, our conclusion is that the current organisation and infrastructure of both health and social care – with health still split into acute and primary sectors and social care managed as a traditionally separate entity – is far from ideal for the necessary development of the whole-systems approach essential for the good care of older people, both individually and at a population
level. The introduction of unified NHS Boards and the implementation of Community Health Partnerships will provide a better context for flexible and innovative models of organisational integration.

2.2 Misunderstanding need, understanding misprovision.

1. As NHS care, increasingly and perhaps still reluctantly, focuses on the care of an ageing population, chronic disease/long term illness looms larger, and current systems are ill equipped to deal with it.
2. In the words of Robert Kane “the predominant acute disease paradigm is an anachronism… in fact modern epidemiology shows that the prevalent health problems of today (defined both in terms of cost and health impact) revolve around chronic illness” (Kane, 2002)
3. “The failure of NHS Scotland to adapt to the changing needs of a changing population could also be seen as ‘structural ageism’. In other words, a traditional service designed around isolated episodes of care within well-defined specialities and agencies cannot fully meet the needs of increasing numbers of older patients, especially those with chronic current, multiple and recurrent medical problems” (Chief Medical Officer, 2002)
4. Broadly speaking, much of the current acute sector crisis might be best understood as a crisis of misprovision and in relation to long term illness lacks strategic direction, cohesion and efficiency.

2.3 Moving forward – towards a whole systems approach.

1. This whole system agenda for the provision of care for older people will be a major undertaking which will involve: reducing misprovision; shifting the balance of care; reproviding services that are local, patient/person focused and take into account the complex inter-relationships between health, frailty, dependency, formal and informal support and health care. However the relevant principles are broadly agreed and some encouraging examples exist.
2. According to the Audit Commission, a successful whole system of care, in which services are organised around the older person, requires three key elements: “a shared vision.. rooted in the views of older people; a comprehensive range of services, including prevention services, which are delivered by flexible, multi-professional teams; and a way of guiding/accompanying older people through the system to make sure that the receive what they need, when they need it.” (Audit Commission, 2002)
3. Services are then “organised around the user” with all contributors recognising their interdependence and sharing vision, objectives, action (including redesigning services), resources, and risk. Users thus “experience services as seamless and the boundaries between organisations are not apparent to them.
4. Characteristics of the organisational culture leading to success include: a genuine commitment to place the older person at the centre of all
efforts; a “can do” approach; risk taking (within sensible boundaries); a flexible pragmatic working style; openness to new ideas and ability to customise to meet local needs; an entrepreneurial ability to take advantage of any new source of funding to support localised priorities (Audit Commission, 2002)

5. The report cites many examples of a whole system approach involving social work and primary and secondary care; recognises that these will be diverse and context-specific (though drawing general lessons about the elements, leadership style etc) and suggests indicators of local progress.

6. In Scotland, the Joint Performance Information and Assessment Framework (JPIAF 10) captures whole system performance information for individuals over 65 years at a local partnership level covering: the number admitted to hospital as an emergency; the number of delayed discharges; the number supported in hospital long stay beds and in care homes; the number supported at home in receipt of more than 10 hours home care per week and the number of single shared assessments.

7. This whole system indicator framework is an attempt to assess changes in patterns of health and social care service provision and usage are related to partnerships’ ability to support older people in the most appropriate setting matched to assessed needs.

8. The Scottish Executive’s document Better Outcomes for Older People makes the case that developing high quality, integrated care provision for vulnerable older people, and their carers, is one of the key objectives for measuring successful joint working across agencies and organisations (Scottish Executive, 2004)

9. For older patients with a single dominant chronic or recurrent illness (for example chronic bronchitis or congestive heart failure) single-diagnosis, inter-agency initiatives have demonstrated clinical effectiveness, cost-effectiveness and patient satisfaction. However, they are not uniformly available and, in the interest of equity, should be extended across Scotland in the coming decade.

2.4 Potential resistance to a whole systems approach – and can anything be done about it?

1. The “structural ageism” of NHS Scotland is deep-rooted in service provision, in education and training, and in a regrettable and persistent tribalism. However, growing recognition of obvious functional limitations offer increasing leverage on the status quo.

2. Similarly, disquiet about the consequences for care of older people of persisting divisions between acute and primary care, and health care and social work may facilitate the emergence of the professionals concerned from the “silo mentality” which currently too often impedes reform – despite the facilitating environment increasingly provided by unified NHS Boards and Community Health Partnerships.

3. On a more positive note, there is some evidence from the Audit Commission report (Audit Commission, 2002) and from the highly
successful Integrated Frontline Network Scotland within NHS Scotland, (which brings together a broad range of participants in innovative interface services) that professional involvement in innovative whole systems initiatives offers high levels of job satisfaction – though not, perhaps, to the fainthearted.

4. **In the longer term, only a sustained effort – through education and training of health and social care professionals – will bring better awareness of changing demography, changing need and the value and professional satisfactions of responding to such need.**

5. **Efforts will be required at under- and post-graduate levels with a far greater emphasis on multi-professional training and learning and team working. This is a formidable challenge involving a transformation of traditionally held views.**

Main points

- Patients, their carers, and volunteers already willingly provide a high proportion of the social and health care needed by older people, and will continue to do so.
- Many carers and volunteers are themselves older: the ‘well elderly’ who constitute a major and growing resource for their frail relatives and friends and are key to effective community-based volunteer initiatives.
- Active partnerships between formal and informal care can promote and maintain health and independence and extend care at home: training and education; carer and volunteer support and respite provisions have all proved effective, and should be extended.
- Older people are already major providers of their own health care; and if self-care and self-management – particularly for chronic and long-term conditions - can be supported by formal health and social care providers, with information, education and empowerment, better health and health care outcomes will result.
- ‘Braveheart’, the community-based, lay and professionally led condition-specific self-management project for CHD exemplifies the kind of chronic disease management initiative that could be developed more widely.
- Scotland’s Health White Paper of 2003 ‘Partnership for Care’ offers a basis from which to build on success and extend evaluated practice in self-care and carer and volunteer involvement – as numbers of both the well and the frail elderly rise over coming decades.

3. 1. Introduction.

1. In terms of the health care of older people - as more generally - the NHS forms only one part of the system of health care. A high proportion of the health care needed by older people is provided by individuals themselves, their carers and by voluntary activity on the part of others in the community.
2. The future rapid growth in numbers of older people has often been referred to as a ‘demographic time bomb’ whose implications in terms of the demand for health care will swamp the NHS. In these circumstances it becomes all the more important that the NHS works in active partnership with all the ‘informal’, unpaid elements of the healthcare system so that the effectiveness of each element is maximised and most importantly the healthcare system in the widest sense operates in harmony. The most important allies of the NHS in
facing up to future pressures related to an ageing population are older people themselves – whether as patients, carers or voluntary helpers.

3. Scotland’s Health White Paper of 2003 was entitled ‘Partnership for Care’. A central theme running through the White Paper is the need to work in partnership with patients, carers and volunteers in delivering health care.

4. Older people are already major providers of their own health care. By providing support and training for self care and self management among older people the NHS can help produce better levels of health and better outcomes of care and increase the sense of empowerment and confidence among older people. Older people will benefit and the NHS will benefit.

5. Similarly, unpaid carers (mainly family members and especially partners) provide a high proportion of the health care of older people. Adequate respite, support and training will help maintain the health and psychological well-being of carers themselves and help them fulfil their caring role more effectively. Again patients, carers and the NHS itself will benefit.

6. Finally, older people have a great deal to contribute as volunteers in health. Not only can this provide a much-needed contribution to care services but there is growing evidence that there are health and other benefits from being involved in volunteering (Community Service Volunteers, 2004).

3.2. Self care and self management.

1. Self care covers a vast range of activities and behaviour. It can range from relatively casual activities to deal with occasional events e.g. buying painkillers to deal with a headache to the acquisition of high levels of expertise in coping with and managing a long term condition. To the extent that self care is regarded as including everything an individual does to maintain their health then it would include aspects of lifestyle such as exercise and maintaining a good diet. Self care in this broad sense is just as important for older people as it is for younger age groups.

2. There is growing evidence to show that programmes to support self care have a range of positive outcomes: better health and quality of life (overall life expectancy; impact on specific symptoms such as pain, anxiety, depression); improved patient satisfaction; significant impact on use of care services (reductions in GP visits, outpatient attendances, A&E visits, inpatient admissions) (Department of Health, 2005)

3. Self management is often regarded as a sub-category of self care which tends to take place in the context of a recognised medical condition. It will normally include a level of formal health service input often with elements such as patient education, monitoring of disease indicators and skills mastery.

4. A key aspect of the challenge which an ageing population poses to the NHS is the need to deal with a much higher burden of chronic disease or long term conditions in the population. Better support for self care
and self management are increasingly recognised as key components in any strategy to deal with long term conditions. In particular, encouraging patients to become active participants in their own care is a key element in the original Chronic Care Model which has been immensely influential in informing strategies for dealing with long term conditions.

5. Older people are more likely to experience long term conditions. Hence any strategy which makes the NHS better at dealing with long term conditions will mean better care for older people. This applies equally to the self management elements of a chronic disease management strategy.

6. The body of knowledge and practical expertise relating to self care and self management has been growing rapidly in recent decades. Among the themes which are emerging as central to a successful strategy for developing self management are:

   • *Collaboration and partnership*. In contrast to the traditional view of the patient-professional relationship in which doctors and other health professionals are regarded as experts with patients expected simply to obey their instructions, a new paradigm is emerging in which health care professionals and patients work in partnership (Bodenheimer et al., 2002)

   • *Empowerment and self-efficacy*. Although training in specific medically-oriented aspects of managing a long term condition is often a key element, there is increasing recognition that psychological elements of the self-management role are equally important. Appropriate methods such interactive educational methods and the involvement of mentors who themselves have experienced long term conditions need to be employed to help patients develop coping skills and a sense of self-efficacy in managing their condition.

7. In recent years there has been particularly rapid growth in lay-led self management approaches. Lay-led self-management programmes share several characteristics with professionally led programmes: they are evidence based; have measurable effects in terms of outcomes and include medical management of the condition. However they have additional characteristics reflecting the enhanced role of the patient: they are driven by the patient rather than the health professional; there is an emphasis on self-efficacy as a major factor in the patient's control over the condition; the programmes are lay delivered in community settings. (Cooper and Clarke, 1999)

8. Some self-management programmes are condition specific, others are generic. A particularly influential implementation of the latter model has been the Chronic Disease Self Management Course developed at Stanford University. This has been the basis of the Expert Patient Programme currently being adopted in England.

9. A notable initiative in Scotland combining elements of the lay-led and professionally led approaches to self-management is the Braveheart Project. The project was initially developed as part of the Ageing Well
UK national health promotion programme. Participants are patients aged 60 and over with a clinical diagnosis of ischaemic heart disease. They participate in a series of meetings of a mentor-led support group over a period of a year. Mentors are not health professionals but individuals with experience of the same or similar conditions who undergo specific training for the project with input from a range of health and other professionals. Sessions cover a wide range of issues relating to the management and self-management of cardio-vascular disease and the promotion of general well-being. A randomised controlled trial showed significant improvements in exercise, diet and physical functioning as well as reduction in outpatient attendances. (Coull et al., 2004)

10. Finally it must be stressed that in many instances self care or self-management in the context of an older person with a long term condition (or long term conditions) must not be seen as involving solely the individual concerned. Wherever there is a carer (or carers) involved, the carer must be regarded as an integral part of the self-management exercise.

3.3 Carers: unpaid carers of older people.

3.3.1 General

1. Unpaid carers form Scotland’s largest group of care providers – a careforce whose qualitative and economic contribution to health and social care provision is difficult to quantify but which has been estimated as equivalent to the entire budget of the NHS.

2. Unpaid carers are particularly important partners for the NHS in the care of older people. Approximately 50% of carers look after someone over 75 and 71% care for someone aged 65 or over. 29% of carers themselves are retired. (2001 Census). As the numbers of older people increases in future years, so will the role of unpaid carers become all the greater.

3. Along with this increase in the overall volume of unpaid care, a trend towards an intensification of caring relationships has been identified with a higher proportion of carers having sole responsibility for the person they look after and an increase in the proportion of carers providing the more demanding forms of care (Hirst, 2003). There is also evidence that an increasing proportion of unpaid care is being provided by relatively close family members – adult children or, especially, partners (Hirst, 2001; Pickard, 2002). These trends may well be leading to a greater likelihood of stress and ill-health among carers (Hirst, 2003). A recent analysis showed that people providing high levels of care are twice as likely to be in poor health as non-carers (Carers UK, 2004)

4. These continuing and probably increasing pressures on carers mean that it is all the more important that the NHS does everything it can to acknowledge and support the role of carers for older people.
5. In recent years the legislative and policy context for such support has been transformed. The Community Care and Health (Scotland) Act 2002 and subsequent Scottish Executive guidance formally recognise carers as “key partners in then provision of care” and for the first time defined a legislative duty on NHS Boards to identify and support carers through the development of local NHS Carer Information Strategies.

6. In describing the kinds of information, training and support which carers need it is difficult to separate out the roles of the NHS and other agencies involved, local authorities in particular. This reflects the need for close partnership working in this area. In what follows, given the overall focus of this report, the emphasis is on elements of information, training and support relating to health care.

3.3.2 Information and advice for carers.

1. Unpaid carers require appropriate information and advice at every level of the caring journey. According to carers’ own preferences they prefer information directly from NHS contact points or from ‘one-stop shops’ such as local Carer Centres, rather than having to piece together information from a wide range of sources and agencies.

2. They require information and advice on the health and medical condition of the person they care for. For example understanding the gradual impact, symptoms and processes of dementia and Alzheimer’s, or the causes and patterns of schizophrenia, epilepsy, stroke or kidney dialysis, goes a long way to understanding and planning appropriate care support and predicting and preventing crisis interventions.

3. They require information and advice on health promotion and healthy living. There is increasing evidence that the pressures of caring lead to stress and mental ill-health and a neglect of people’s health and dietary needs. The NHS needs healthy carers in the community as much as healthy nurses on every ward – protecting the health of Scotland’s largest careforce is a public health issue.

4. They require information and advice on the range of support agencies who can help them with financial advice and benefits for themselves and the person they care for; short breaks and breaks from caring (respite); equipment and adaptations to support daily living; practical and emotional support

3.3.3 Training for carers.

1. Appropriate training courses on different aspects of caring, preferably early in the caring role, plays a significant part in building carer knowledge, expertise, confidence and peer support. Early training intervention can prevent the drift into social isolation as early peer contact supports the development of self-help coping strategies.

2. NHS research has shown that systematic training support produces a better quality of life for carer and person cared for, as well as tangible economic savings from reduced NHS and social care intervention, and
prevention of repeated hospital admission. For example, a recent randomised controlled trial looked at the effects of providing unpaid carers of disabled stroke survivors (patient median age 76) with training in basic nursing techniques relating to stroke and hands on training in such areas as lifting and handling and continence issues. Improvements were shown across a range of outcomes for both carers (e.g. quality of life, anxiety and depression scores) and patients (e.g. quality of life, burden of care) (Kalra et al., 2004) An economic evaluation showed significantly reduced costs of care (Patel et al, 2004).

3. Training programmes should be free to carers, with financial support for alternative care arrangements to allow particularly those with the heaviest caring responsibilities to participate. Training courses should cover carers’ rights; sources of information and advice; support agencies and access to breaks from caring, including leisure, recreation; pathways to assessments and NHS and social care support; use and effects of medication; moving and handling; emotional aspects of caring; healthy living and health promotion; work-life balance for carers in employment.

4. Training programmes should provide a balance of professional speakers and tutors from a range of relevant agencies and time for peer support and the exchange and development of personal coping strategies.

5. Ideally, carers should have the opportunity to choose from a mixed programme of generic courses, specialist courses and group work programmes (on emotional aspects of caring) to opt into appropriate training support for their specific needs at different stages in the caring journey.

3.3.4 Carers: a new paradigm.

1. It essential that health and social care services adopt a fundamentally different paradigm when considering their approaches to carers. Despite the contribution made by carers, despite their integral role in supporting disabled and older people in the community and despite recent improvements in the high-level statutory and policy framework they continue to have to make a case for inclusion in the care planning process and to receive appropriate information services and supports.

2. The general shift in orientation which health care is currently experiencing in recognition of the growing importance of chronic diseases or long term conditions should provide a highly favourable environment for an increased level of partnership between the NHS and carers. It has been pointed out that as the population ages and there is an increase in the incidence and prevalence of chronic conditions there is a need for a shift in the basic paradigm of healthcare from the isolated episode of treatment to ‘care based on the continuous healing relationship’. (Institute of Medicine, 2001)
3. Such a health service will be one in which continuous and collaborative relationships with carers are essential.

4. As various methods and levels of care and case management are progressively adopted as part of the move towards a more preventative and proactive model for dealing with long term conditions, carers will play an increasingly important role as partners in these initiatives. Conversely these developments are likely to be of great benefit to carers in to the extent that they reduce fragmentation and duplication in the provision of care.

5. As pointed out in a recent Australian report: “Care co-ordination and case management, often viewed as primarily a service to care recipients, carries direct benefits for carers, particularly carers of people with impaired decision-making capability. Primary carers have been likened to ‘bridges’, connecting their care recipients to health and community care networks. Case management … can relieve carers from the time consuming detail of investigating alternative services etc …. Case management is a necessary rather than optional form of support for the ‘bridging role’ of primary carers ….” (Australian Institute of Health and Welfare, 2004)

6. A strategy is required to translate the statutory requirement that carers be seen as partners in care to the reality of working with carers to design, develop, deliver and review health care services. This is predicated on the view of carers as net providers of care.

4. Volunteering in the healthcare of older people.

1. Future demographic trends will mean an increase in the amount of health care required by older people. The scale of this increase should not be exaggerated. The fact that age for age, older people are, on average, becoming healthier means that the increased burden of ill health will not grow as quickly as the numbers of older people. However, just as there will be increased numbers of older people in relatively poor health there will be greater numbers of older people in relatively good health. Older people will be better educated and in possession of a widening range of skills and knowledge. Retirees will increasingly look for meaningful and rewarding ways of using the extra years which increasing healthy life expectancy will give them.

2. Older people will thus constitute an immense and expanding potential resource. The challenge will be to mobilise this resource in ways which are of benefit to patients and carers, of benefit to the NHS and, most importantly of benefit to those older people who can be encouraged to volunteer their care and their services.

3. The unique contribution of volunteers to health care is being increasingly recognised and encouraged. Not only can volunteers make a valuable contribution to making health care a more human and caring process but the health and psychological benefits to the volunteers themselves are becoming ever more apparent. The range of contributions made by volunteers in health care is vast: from highly generic services such as driving or running shops and tearooms...
roles which involve an irreplaceable level of empathy and expertise such as mentors in patient-led self-management programmes.

4. 2004 saw the adoption of a Volunteering Strategy by the Scottish Executive aimed at embedding and expanding the culture of volunteering in Scotland. In healthcare this policy drive is able to build on a long established tradition of volunteering in the NHS where significant numbers of individuals contribute their time in a variety of settings - hospitals, hospices, health centres and community and local projects. Many volunteers provide “direct” assistance to the NHS and link with a Voluntary Services Managers or another member of staff. Others volunteer with voluntary organisations – Friends Associations, large organisations like WRVS or Red Cross, or with self help or condition specific groups.

5. Older people form a high proportion of volunteers in the health care sector. The Retired and Senior Volunteer Programme of Community Service Volunteers has a significant representation in the health care field with a particularly significant contribution in primary care settings (Community Service Volunteers, 2003).

6. As well as the contribution made by older volunteers, evidence is accumulating about the benefits to the volunteers themselves. A recent study in Scotland looked in particular at the effects of volunteering on older people. It found a range of health benefits; psychological benefits such as confidence building and a restoration of a sense of purpose and a sense of achievement; social benefits involving creating new networks and lessening social isolation. (Community Service Volunteers, 2004)

7. As we move towards implementing better strategies for supporting people with long term conditions, a crucial component of these strategies will be support and training for self management. A high proportion of people with long term conditions are in the older age groups. Older people will play an increasingly important role as volunteer lay mentors or trainers in courses and programmes aimed at giving older people with long term conditions the skills and confidence to cope with and manage their conditions. As the involvement of volunteers in specific initiatives such as Braveheart and Challenging Arthritis becomes more widespread there is a strong case to be made for ‘mainstreaming’ the involvement of volunteers by including this as an option in the development of individual care plans. This could have particular relevance in the context of planning services for the elderly.
4. **Redressing the balance of care: providing more care closer to home**

Main points

- Current difficulties in the care of older people reflect misprovision, with a costly, misplaced and inefficient emphasis on acute care
- Countervailing initiatives – improving the availability, flexibility and effectiveness of responses to frailty and illness at home – have been piloted
- Improving care for older people depends on managing their long-term illness and debility far better, with much more emphasis on pro-active, sustained care at home
- Further developments in health and social care, with closer integration and best use of emerging technologies, are required
- Developments in health screening and in IT could not only promote cost-effective care and support but also provide service planning and evaluation data
- As mortality is compressed in old age, enhanced palliative services could provide better – and also cheaper – care towards the end of life
- Substantial workforce issues – in education and training, in career flexibility and life-long learning – must be addressed.

4.1 **The current challenge**

1. It is highly likely that much of the current crisis in acute care is a “crisis of misprovision” (see 2.1, 2.2 above) resulting in the regrettable combination of avoidable service pressures and inappropriate and sometimes harmful care of some of Scotland’s frailest older people.
2. “The rapidly rising trend in multiple emergency admissions among older people is a reflection precisely of a system attempting to cope by providing increasing numbers of isolated episodes of care rather than providing the integrated and supported care which is so often needed” (National Framework, 2005).
3. Acute services under pressure show signs of prioritising throughput, to the detriment of provision of all but the most acute care. As a result functional assessment and rehabilitation issues suffer, with the worst consequences – in terms of lost function – for the frailest.
4. “Effective prevention and management of chronic conditions requires an evolution of health care, away from the model that is focussed on acute systems towards a co-ordinated, comprehensive system of ongoing care. Without this type of change, health care systems will grow increasingly inefficient and ineffective as the prevalence of chronic conditions rises. Health care expenditure will continue to escalate but improvements in population health status will not” (Epping-Jordan et al, 2003).
5. The ‘co-ordinated, comprehensive system of ongoing care’ prescribed above is still a long way off; and – given the demographic changes
predicted for the next 20 years, together with foreseeable changes in NHS organisation and hospital provision, and rising expectations – the challenge of providing greatly improved care and rehabilitation for long term and recurrent illness is a substantial one.

6. Given the risks to older patients arising from their exposure to multiple medications for multiple medical problems, much work is required to improve for them in all settings their medicines management, in order to increase patient safety and minimise the current – unacceptable and avoidable – caseload of unscheduled admissions resulting from therapeutic misadventure.

7. However, there are some grounds for optimism. A high proportion of the oldest patients admitted as emergencies have no new specific diagnosis (diagnostic category: 'symptoms and signs') (Figure 3), and have few needs that can be met only in the acute sector. Their use of acute beds is high and arguably harmful to them.

Figure 3.


8. Their better management, by improving anticipatory care - both in terms of diagnostic uncertainties and the support/dependency issues involved - and by the provision of effective community-based rehabilitation, will bring about care at home and in local settings that is acceptable to them and their carers, and should also be both cost-effective and of high quality.

9. It is likely that continuing developments in biomedical technology and IT/communications will result in easier and earlier access to much more powerful diagnostic facilities by community base healthcare professionals, with most benefit for the frail elderly wishing to remain at home through acute illness.
4.2 Optimising and generalising current best practice.

10. Two recent reports - *Adding Life to Years* (Chief Medical Officer, 2002) and the NHS QIS national overview of older people in acute care (NHS QIS, 2004) have focused attention on the potential of clinically appropriate alternatives to admission: the former setting policy goals, the latter reporting on a nation-wide survey in which 14 of the 36 sites visited demonstrated “multidisciplinary, multi-agency teams able to respond within 24 hours and provide co-ordinated packages of care and rehabilitation” so that older people could remain at home when this was clinically appropriate.

11. *Adding Life to Years* reported on a range of initiatives designed to: identify and monitor frail older people at home; provide support at home through exacerbation of acute illness; and assess, rehabilitate and support older people who had attended an A & E department. Examples include the Rapid Response Teams in Aberdeen and the IRIS (Intensive Rehabilitation Integrated Service) in North Glasgow.

12. The same document identified initiatives that had improved the management of exacerbations of chronic conditions (e.g. the Acute Respiratory Assessment Service (ARAS) in Edinburgh for people with chronic bronchitis; and an integrated service for people with heart failure in West Lothian) and schemes that had improved monitoring and care of older people in nursing homes (with avoidance of unnecessary admission, or shortening of acute stay when admission was necessary).

13. However, the NHS QIS report expressed concerns that such initiatives, though welcome, were not widely enough available. In the short term there is a strong case for ensuring that such initiatives are encouraged, properly evaluated and – where cost effectiveness and quality of services is proved – made much more widely available.

14. In the longer term, the rollout of such schemes, tailored appropriately to local conditions, has much to offer Scotland’s frail older people. If they are properly accountable and quality-assured (e.g. by NHS QIS), and evaluated in terms of service outcome, they will bring benefits in terms of efficiency and effectiveness, a shift in the balance of care and genuine advance in the care of long-term illness.
4.3 Improving the management of chronic/long term illness in a changing NHS

1. Improved management of chronic/long term illness demands a shift away from the common current default option of recurrent episodic and sometimes dysfunctional unscheduled care to a new more and effective model of care – emphasising partnership between patients and care agencies, the empowering of patients, and meeting their needs by providing earlier, better care at home wherever possible.

2. Given likely trends in hospital care over the next 20 years, and the rising numbers of older Scots who would both appreciate and benefit from optimal care at home, emerging structural/organisational change in NHS Scotland and in social care must be directed towards achieving this.

3. LHCCs offered some opportunities to develop LHCC-wide and cost effective expertise and systems to improve the monitoring and care of older people in their own homes, and some did so. PMS contracts similarly encouraged such developments.

4. More promisingly, Community Health Partnerships (CHP’s), by bringing together coterminous area-based NHS Primary Care and local authority social work resources, offer the basis for “whole system” working (see above).

5. Given the uncertainty and unevenness of CHP development across Scotland, it is clearly far too early to draw conclusions about their eventual contribution to improved care of older people at home (though optimism remains). CHPs should be given clear direction in terms of the expected outcomes for the care of older people.

6. The Single Shared Assessment offers encouraging evidence of practical collaboration between health and social work, with the principal beneficiaries being older patients/clients. Further organisational and funding developments of the kind JPIAF seeks to foster will support improved management of chronic/recurring illness at home.

7. Developments in identifying those with the most complex of needs through functional screening or risk stratification, early case finding and shared/joint health and social care records, designed to be comprehensive but in confidentiality terms secure, will facilitate the effective co-ordination and management of care for people with chronic conditions/long-term illness. This will ensure continuity of care, continuous monitoring of need and resource use, and provision of prompt additional care as required. Care co-ordination must be ‘hard-wired’ so that no case is ever – as can happen at present – ‘closed’ when a crisis occurs.

8. Additional details of the recommended approach to the introduction in Scotland of care co-ordination and case management for long-term conditions is set out in Chapter 4 of the National Framework’s Guide for the NHS. (National Framework, 2005)
4.4 Knowing more about older Scots to serve them better: anticipatory and co-ordinated care

1. There are no means at present of consistently monitoring the health of older Scots. Evidence from outwith the UK shows the value in being able to identify those most at risk and adopt where appropriate a more structured assessment for case-management.

2. However, the introduction of a proactive, systematic and standardised anticipatory approach – with an emphasis on functional dependency, cognition, falls, and use of community support – might be regarded as a minimal essential first step towards improving the care of older people in the medium and long term.

3. Such an anticipatory approach could: identify those in need of further assessment and possible case management; allow the development of a rolling epidemiology of dependency, cognition, residential status, service uptake etc by older people (with implications both for CHP and higher level planning); and have the potential for use as a monitoring tool to assess impact of service change and development (using outcomes such as recurrent admission, institutionalisation rates etc).

4.5 Nearing the end of life

1. With the “squaring of the life-curve” and the resulting compression of morbidity into the extreme decades of survival, the care of older Scots in 20 years time will include a large and increasing component of end-of-life and near end-of-life care.

2. Many older people express the wish to remain at home as long as this is clinically appropriate, and there are many excellent examples of the provision of home-based care (e.g. the Dying at Home scheme in Dumfries and Galloway)

3. Currently, in health economics terms, overall lifetime health care costs are markedly ‘end-loaded’: one UK study showed that the 5% of patients in their last year of life generated approximately half the hospital expenditures for the population aged 65 and over (Seshamani, 2004)

4. In a proportion of cases this too may represent misprovision: such costs may not always reflect patients’ wishes and/or value for money. Sensitive ethical issues arise in relation to the appropriateness or otherwise of various more strenuous interventions late in life: and the increasing popularity of living wills designed to limit such possibly futile care may reflect changing attitudes.

5. In clinical terms, as life nears its end, diagnostic and treatment goals change, with greater emphasis on support, palliation and quality of life: goals that require forms of care and treatment that are in many instances compatible with life at home until the end, or very near it.

6. Impressive advances in the delivery of palliative care, and in related technology, have been seen in the last twenty years: more can be
expected. It will become ever more feasible to satisfy older Scots’ preferences for high quality end-of-life care at home or as near to home as possible (Taylor and Carter, 2005)

7. Making available the best possible end of life care to those who need it in the settings they prefer should be a major policy and organisational goal of NHS Scotland – with potentially considerable benefits in patient satisfaction, quality of care and cost effectiveness too.

4.6 Workforce issues; changing working practices

1. The radical shift in the balance of care from institution to home as outlined above will require very substantial changes in the way the NHS and social care in Scotland recruit, train and support their workforce. All health and social care professionals will need to know a lot more about the care of older people, and all their education and training should accordingly reflect current demographic reality: with care of older people as a mainstream element of the curriculum.

2. It is vital that such training is expert, authoritative and enthusiastic, promoting evidence-based practice and enriched by relevant high-quality research; and that the image projected of the care of older people is a positive one for all health and social care trainees. The current status of the care of older people in the curriculum, and its image in the minds of young professionals, give cause for some concern. These issues must be addressed: to improve skills, attitudes, knowledge and career-long professional satisfaction.

3. Nursing in particular, as the largest profession involved in care of older people, faces special challenges as the current workforce ages (the average age of registered nurses is now mid 40’s) and many other occupations compete for a shrinking pool of school leavers. However, the nursing profession has responded positively, developing new roles and taking on new responsibilities, many in relation to care of the elderly.

4. A particularly useful development would be the emergence of a generalist model of advanced gerontological nursing practice. This would focus on the multiple complex needs of the very elderly and frail and give equal priority to physical and mental health. Such nurses would be particularly effective in care home and community settings.

5. The traditional roles of AHP’s are already being extended: for example through leadership roles in primary and social care and participation in outreach, interface and admission-preventing multidisciplinary initiatives. There is scope for considerable further expansion of such roles. The training and professional development of AHP’s should reflect this potential. Organisational barriers (between hospital and community; between social work and the NHS) to the spread of such initiatives should be addressed.

6. Substantial changes in the medical workforce, as foreshadowed in the Temple Report (2004) will lead to earlier and more narrow specialisation for hospital doctors and extended training for general practitioners – who
will continue to manage the vast majority of care episodes for older people.

7. The New General Medical Services (nGMS) and Consultant Contract arrangements afford considerable opportunity to incentivise medical staff in providing high quality care for older people. Likewise the Quality Outcomes Framework of the nGMS should also be used as a powerful mechanism through which high quality services for older people are encouraged, valued and rewarded.

8. A new flexibility in NHS and social work working practices – of the kind already tentatively acknowledged in Agenda for Change – will be essential in the new context of structural change (and probable fluidity, as emergent solutions are influenced by technological advance and revision of structure and accountability). A commitment to a rolling review of workforce needs and related changes might be prudent.

9. The new pharmacy contract will also provides a mechanism through which pharmacists roles could be enhanced to the benefit of older people particularly in community and local settings.

10. Many more personnel than at present will work flexibly in teams. Multidisciplinary and inter-professional education should be the norm, so that all health professionals know and understand each other’s roles and learn to work together in teams in a flexible way with incremental blurring of role boundaries.

11. Recognition and reward will increasingly relate to team rather than individual outcome and performance and this should be explicitly stated and practiced by management at all levels.

12. New working practices in both health and social care, more focussed on chronic/recurrent disease and care management, will emphasise communication and IT skills. High levels of IT literacy should become the norm for all skilled health professionals.

13. Traditional assumptions about disciplinary boundaries are already becoming obsolete in both the NHS and social care. As they fade further and working practices change, discipline-based assumptions about roles, skills and careers will be challenged.

14. It is likely that lifelong learning and new and more responsive career paths - dependent on assured/certificated competences rather than on the basis of original professional training - will become commonplace or indeed the norm. This will be accompanied by flexible working hours and career pathways to maximise – in the context of a shrinking workforce - participation by those with family commitments.
5. Care of older people other than at home and local settings: unscheduled and planned acute care; post-acute care; continuing and palliative care

Main points

- The current pattern of acute sector care for older people in Scotland is unsustainable over the next 20 years
- Future trends in demand are to some extent predictable, though biomedical and other advances may mitigate their service impact
- Older people must continue to have full access to treatments and technologies from which they as individuals might benefit
- A more centralised unscheduled care system will be highly vulnerable if the journey of care for older patients is not well-managed, with
  - closest possible integration of health and social care
  - optimal management of chronic illness/disabilities
  - as much diagnosis, treatment and care as possible provided near home
  - minimal use of remote unscheduled care centres
  - optimal acute rehabilitation in such centres
  - ready access to post-discharge rehabilitation at home
  - post-acute inpatient rehabilitation nearer home for those who need it
- Developments in medical, IT and communications technology may serve to facilitate such centralisation of unscheduled services and the necessary associated service change
- Inpatient services for respite, palliative and continuing care will – like those for post-acute rehabilitation – be provided locally
- “The best response to concerns about ageism in NHS Scotland is simply to achieve a widespread and visible improvement in the quality of service for older people.”

5.1 The current challenge

1. Serious shortfalls in management of chronic or recurrent illness and disability for older people (see 4.1 above) have resulted in care that could be characterised as ‘too little at home; too much in acute hospitals’.
2. Much of this imbalance reflects a reluctance of health and social services to work together in the identification, support, and (where appropriate) case management of the frailest elderly at home.
3. The acute (in the broader sense) sector of NHS care in Scotland is currently dominated by the emerging demography: with older people as the main users of acute medical and surgical beds following emergency admission; and the bulk of elective care taking the form of disability-reducing surgery for older patients.
4. Convergent and rising age-related demand for both unscheduled and elective care is reflected in much of current NHS dysfunction (bed crises, waiting list problems etc).

5. This is graphically illustrated in orthopaedic care, where elective hip replacement increased from 2000 per year in Scotland in 1978 to 5000 in 1998, with the great majority of the increase involving over 65s. Over the same period a gradual rise in osteoporotic fractures – most notably hip fracture – was at the same time competing for a limited – or indeed falling – number of orthopaedic beds.

6. Throughout the acute sector, and most particularly in its high-volume inpatient services, older patients form a majority of the caseload: yet it is noteworthy that – despite pressing day-to-day realities – there is a reluctance on the part of many acute sector specialist clinicians to recognise this, adapt for it, and engage wholeheartedly in the ‘central task of the NHS’

7. While service misprovision and resulting service dysfunction (see 4.1 above) are together already sufficient cause for concern, there is clearly also a massive educational challenge to be addressed. At worst threatened and resentful, at best simply bewildered, a substantial proportion of acute sector clinicians need to be persuaded of the need for change and the reasons behind it.

8. This might prove a formidable political and organisational task, but it is already overdue. Perhaps the best evidence of ‘acute provision as misprovision’ drives from trends in repeat admissions, with the fastest rise seen in the oldest – and hence most vulnerable – age groups (Figure 4).

Figure 4.

Patients with 3 or more emergency admissions within 1 year by age group. Per 100,000 population. Scotland 1981 to 2002.
5.2 **Trends in demand and provision?**

1. In elective care, projections of future demand for hip and knee replacements currently verge on the alarming – probably reflecting both an increase in the population at risk and a rise in expectations. In the absence of major technical advance (e.g. joint resurfacing) such projections pose a formidable challenge.

2. Similar trends may be seen in cataract surgery. Here however, technical advances and a shift towards day-surgery provision allow cheaper and easier treatment than formerly and thus more hope of meeting future demand.

3. In general surgery, there have already been major advances in atraumatic diagnosis and minimally traumatic interventions that have shortened stay and diminished rehabilitation need. Future developments might result in further such gains.

4. Osteoporotic or fragility fractures appear to have shown a one-off increase in age-specific incidence (perhaps reflecting the secular loss of the protective effect on bone mass of hard physical work in younger women). The number of such fractures is likely to continue to rise at a rate reflecting the increase of the population at risk, though this trend may be offset by improved pharmacological, health improvement, preventative and physical interventions.

5. Management of such fractures may change greatly in the fairly near future with bone substitution/graft technology improving fixations and hence promoting early mobilisation – with useful consequences for rehabilitation and length of stay.

6. Around one third of all cancers are diagnosed in the over-75s, who form only about 7% of the population. Overall incidence of cancer will therefore rise quite steadily simply as a result of increasing longevity (Figure 5).

**Figure 5.**

![Incidence trends and projections. All cancers (with 10 most common identified) Scotland. 1961-65 to 2016-2020](image-url)
Many of the cancers which are more common in older people are already easily treatable if detected early. For more serious cancers, advances in early diagnosis and less traumatic or toxic treatments may substantially benefit older people. In a proportion of cases, however, frailty will inevitably point towards an essentially palliative approach to care.

Although the age-specific incidence of stroke appears to be falling slowly, this is probably largely offset by the rising numbers of older people at risk. Early interventions for acute stroke are of growing utility, and again further useful developments can be expected over the next few decades.

A similar ‘incidence vs. population at risk’ effect may be seen in coronary heart disease. Again, both surgical and – especially - medical interventions have improved greatly in recent years, and further advances are likely.

In summary, it is highly likely that over the next 20 years:
(i) older people will form an even higher proportion of unscheduled care service users than at present;
(ii) further technological advances will further benefit them and facilitate their care; and
(iii) even with the best unscheduled care, highly effective acute and post-acute rehabilitation will be required if they are to benefit maximally from such care.

5.3 Rehabilitation during and after unscheduled care

1. Optimal rehabilitation is a necessity if older people are to benefit maximally from clinical, medical and surgical care. By 2024, the context in which that rehabilitation is provided will have changed greatly. For certain conditions requiring highly specialised treatment, care is likely to be concentrated on fewer sites, so more will experience it further – or much further – from home.

2. For the previously well and independent elderly such a change in the locus of care may cause no difficulties. Many acute interventions may be more benign and delivered nearer to home than at present: with a correspondingly lower requirement for rehabilitation.

3. However, many older people (particularly those with needs in the context of chronic illness, and those with cognitive impairment) will require rehabilitation, and new structures and processes will be needed that take account these needs.

4. In essence, only for the most specialised care should patients have to travel far from home. Such a more centralised system for specialised care will work well only the only patients only in this way. Local services, for example satellite clinics, remote pre- and post-assessment, often making use of tele-medicine will all help in achieving the new configuration of services.

5. Rehabilitation – involving needs assessment, functional assessment and documentation, rehabilitation input, monitoring of progress, and assurance of quality and cost-effectiveness –
must therefore have greater prominence in twenty years time than it does at present: professional education, training, and staffing should reflect these changed priorities.

6. Rehabilitation, still sometimes seen as a lower priority activity than acute care, will become a more equal partner, and an indispensable and integral component of the care of all but the fittest of older patients throughout the journey of care.

7. In future, even minor illness at home will be assessed in terms of associated functional dependency and rehabilitation need.

8. Older people attending unscheduled care and A&E departments will in future always and everywhere (not, as currently, sometimes and in some places) be screened in terms of dependency and their need for rehabilitation and support in order to: optimise their overall care, minimise inappropriate admission, and provide safe and supported care at home on discharge (Currie, 2005).

9. Older patients being assessed for scheduled care will likewise be systematically pre-screened - in terms of their fitness, their available support, their home circumstances, their likely rehab and support needs at home – as part of the routine assessment. This will facilitate their post-op progress, ensure their quicker return home and maximise the efficiency of resource use centrally.

10. Older patients admitted to acute or unscheduled will also be screened on admission: their levels of dependency, support and cognition and likely future needs for support and rehabilitation will be assessed and documented; throughout unscheduled care they will have ready access to as much rehabilitation – directed towards mobilisation and self-care – as they are fit for according to clinical circumstances.

11. Multidisciplinary specialist rehabilitation for older patients, backed up by middle-tech medicine, tele-medicine and (where necessary) readmission to inpatient care, will ensure: maximal rates of return home for all patients with that potential; assessment of future care needs and placement for those unable to return home; and terminal care nearer home for those requiring only that.

12. There is already a strong evidence-base and a wide range of good practice in this area, as documented in the NHS QIS national overview of older people in acute care (NHS QIS, 2004). However, also documented is wide variation in the quality of rehabilitation services amounting to a post-code lottery. Removal of this by the implementation of services of a uniformly high standard must be a priority.

13. Developments in transport, communications and IT should combine favourably over coming years to facilitate such advances in the coordination, integration and effective delivery and monitoring of rehabilitation across large and complex health systems. A rigorous and integrated approach to quality assurance and clinical governance, perhaps using case-mix adjusted outcome methods, should be pursued to ensure both equity and value for money.

14. Given the vulnerability of older patients to unwanted side-effects of polypharmacy, optimal management of their medications at all stages in the journey of care is vital. These concerns are
increasingly recognised. Advances in ICT should be exploited to support 'e-pharmacy' involving: better information more swiftly and securely transmitted; semi-automatic vetting for drug interactions; and compliance monitoring supported by in-home and remotely checked ‘e-dosette’ boxes.

5.4 Trends in Technology and Clinical Governance

1. Given the substantial and unpredictable advances in biomedical technology generally, and diagnostic and interventional technologies in particular, predictions for further advances are intrinsically risky.

2. However, future advances might clearly include or greatly exceed some of the developments outlined in 2.3 above, with substantial implications for the provision of unscheduled care for an ageing population 20 years hence.

3. Developments with the greatest potential to transform the way we provide unscheduled care for older people would include: adoption of an anticipatory approach to care using functional screening, risk stratification and case-finding to identify and monitor those with the most complex needs; earlier and more accurate diagnosis; more effective and less traumatic interventions; developments in organ transplantation and stem-cell related advances; and a range of distance-transcending developments in ICT, remote imaging, remote consultation and remote intervention.

4. Yet there remains a grave duty of scepticism in relation to such developments. Rigorous evaluation for effectiveness and efficiency, and of the scale and locus of provision, must precede wider adoption of all new structures, processes and technologies. Scottish scepticism may serve us well in this – particularly if expensive lessons can be learned and paid for elsewhere.

5. Clinical care should be subject to a comparable scrutiny which is much more rigorous than that generally practised today. Real-time electronic records, routine audit, case-mix adjustment and continuous feedback to clinicians should be the rule rather the exception.

6. With acknowledged achievements in national data sets and substantial developments in national audit, Scotland is currently well placed to make the necessary advances in clinical governance of care for common serious conditions affecting older people.

7. NHS QIS already has a substantial track record in clinical standards and should – taking advantage of developments outlined above – assume further responsibilities in clinical governance including: quality assured audit data; continuous feedback; and progress towards routine implementation of statistical process control in clinical care (Mohammed et al, 2001).

8. The above emphasis on improving clinical governance should be an integral part of improving care of older people in Scotland. Potential benefits include: an ability to demonstrate that care across Scotland is equitable (or not); that care is cost-effective (or not); that care is
accountable, and that information is available to clinicians to help them scrutinise and continuously improve the care they provide.

5.5 Access, ageism, and the suspicion of ageism

1. Survey work carried out for Adding Life to Years showed that, while anxieties about ageism in relation to access to health care were present, personal experience of discrimination on grounds of age was unusual.

2. However, as noted above, today's older people may be less assertive than the aged baby boomers of 20 years hence. Rising expectations and increasingly consumerist attitudes may put considerable pressure on all services and this must be planned for. Even if services improve markedly in volume, quality and convenience, public education and debate about access may still be necessary.

3. Not all acute treatments will be clinically appropriate for all older people: for example, the frailest are currently spared inappropriately drastic surgery and/or chemotherapy for many malignancies. In general terms, all proposed treatment should clearly be considered on an individual basis and discussed with patients and carers in terms of individual risks and benefits.

4. Another area where there is a risk of perceptions of ageism is that of staff attitudes. Particularly for staff untrained in the care of older people, dealing with older patients whose needs and care they do not understand can be difficult and sometimes frustrating, with such feelings sometimes surfacing in unacceptable ways. The challenge here is one of education.

5. However “in the long term, perhaps the best response to concerns about ageism in NHS Scotland is simply to achieve a widespread and visible improvement in the quality of service for older people” (Chief Medical Officer, 2002): a challenge that will grow substantially over the next twenty years.
6. Policy implications

6.1 By 2015 (high level goals)

- Integrated and coterminous health and social services focused largely on the care and support at home of Scotland’s frailer older people, with a commitment to optimal management of chronic, continuing illness and disability
- Unscheduled health services similarly redesigned around the major client group – older people – to provide for them, in conjunction with the above, optimal journeys of care
- Fit-for-purpose ICT to facilitate, support and monitor care of older people: at home; in and through unscheduled and post-acute care; through long-term and recurrent illness; and towards the end of life.
- Systems of clinical governance and performance management that ensure quality, cost-effectiveness and equity in the delivery of support and such care
- A health and social care workforce that reflects demography and need, increasingly community-based and less focussed than at present on acute and unscheduled care: with changes delivered via training, education and career paths; knowledge, skills and attitudes; with more people working in teams and away from hospitals; and making maximum use of emergent IT and other technology

6.2 By 2008 (to support progress towards above)

- Central and regional planning of tiered and cost-effective patterns of care provision to reflect the many drivers of change in both primary and acute health sectors, including clinical and other workforce issues, technological change, economies of scale, and remote and rural service provision
- Substantial developments, jointly with health and social care, in rehabilitation – through unscheduled care, in post-acute care and via community-based services to ensure older people’s access to unscheduled care and their maximum benefit from it
- Increasing integration of health and social care, with eventual common boundaries and systems, aiming to ensure seamless patient-centred care from a single accountable organisation focussing largely on care and support at home or near it whenever possible
- Workforce developments in health and social care – in training, continuing education, joint learning and working, and team-working – in parallel the above; with care of older people a central feature in all developments
- An R&D agenda that matches the realities of demography and need in order to encourage: increased health services focused research; age-specific biomedical research in acute care and in drug development;
the development and evaluation of initiatives in health and social care at or near home; and the evaluation of emerging biomedical, IT, tele-medicine and communication technology to support the above goals in the care of Scotland’s older people

6.3 Short term actions: urgent/overdue

- Provide clear central direction on expected targets/outcomes for services provided to older people by the Community Health Partnerships; consider the use of financial incentives; and ensure robust evaluation of impact/outcomes

- Ensure that the forthcoming review of the Quality Outcomes Framework associated with the new General Medical Services contract includes indicators specific to an anticipatory and co-ordinated approach to management of older people with co-morbidity and complex needs.

- Ensure that the new Pharmacy contract reflects the extended role that pharmacists and in particular community pharmacists could play in the monitoring and review of older peoples medications and health status

- Procure and implement a national integrated IT system based on a uniquely identified single shared record that covers all health and social care sectors within three years.

- Utilise the Chief Scientists Office to ensure that the Research & Development Agenda of NHS Scotland, including that of the Health Services Research Unit, reflects more closely the realities of Scotland’s current and future demography and need.

- To promote closer working between health and social services, explore the feasibility of building on the current commitment of social services to implement care management after April 2005 and include the currently missing dimension of health.

- Ensure that the Scottish Executive’s Workforce Planning Initiative considers and responds to the implications of this report.
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**Annexe. Membership of the Care of Older People Action Team.**

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