All political parties now acknowledge the importance of more integrated – or person-centred – care. This essay collection discusses how we can develop a system that responds to the needs of a patient in the round – whether in the hospital or the home. With contributions from leading politicians, experts and those on the frontline, the paper sets out views on the future role of commissioners, providers, patients and family carers, and sets out alternative perspectives on future funding for the NHS and social care.

Katie Evans
Emran Mian
A Problem Shared?

Essays on the integration of health and social care

Edited by Nigel Keohane

Kindly Supported By
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notes on contributors</td>
<td>5</td>
</tr>
<tr>
<td>Introduction</td>
<td>6</td>
</tr>
<tr>
<td>Integrated care: opportunity or threat?</td>
<td>11</td>
</tr>
<tr>
<td>Rt Hon Stephen Dorrell MP</td>
<td></td>
</tr>
<tr>
<td>Making integrated care the default setting</td>
<td>15</td>
</tr>
<tr>
<td>Rt Hon Paul Burstow MP</td>
<td></td>
</tr>
<tr>
<td>Apart at the seams: The challenge of integrating dementia care</td>
<td>21</td>
</tr>
<tr>
<td>Jeremy Hughes</td>
<td></td>
</tr>
<tr>
<td>Caring for an ageing population</td>
<td>26</td>
</tr>
<tr>
<td>Caroline Abrahams</td>
<td></td>
</tr>
<tr>
<td>Carers and Integration</td>
<td>30</td>
</tr>
<tr>
<td>Heléna Herklots</td>
<td></td>
</tr>
<tr>
<td>Collective commissioning</td>
<td>34</td>
</tr>
<tr>
<td>Sir John Oldham</td>
<td></td>
</tr>
<tr>
<td>Unleashing the power of people: why transparency and participation can transform health and care services</td>
<td>39</td>
</tr>
<tr>
<td>Tim Kelsey</td>
<td></td>
</tr>
<tr>
<td>Joining up health and care – a provider’s perspective</td>
<td>44</td>
</tr>
<tr>
<td>Richard Bowden</td>
<td></td>
</tr>
<tr>
<td>Integrating locally</td>
<td>48</td>
</tr>
<tr>
<td>David Pearson</td>
<td></td>
</tr>
<tr>
<td>Funding a future health and social care service</td>
<td>53</td>
</tr>
<tr>
<td>Richard Humphries</td>
<td></td>
</tr>
<tr>
<td>Endnotes</td>
<td>57</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

I would like to thank the contributors to this essay collection. I would also like to thank Bupa for sponsoring this publication.
### NOTES ON CONTRIBUTORS

**Caroline Abrahams** is Charity Director at Age UK.

**Richard Bowden** is the Managing Director of Bupa UK.

**Paul Burstow** is the Liberal Democrat MP for Sutton and Cheam. He served as Minister of State in the Department of Health between 2010 and 2012.

**Stephen Dorrell** is the Conservative Member of Parliament for Charnwood. He served as Chair of the Health Select Committee between 2010 and 2014 and Secretary of State for Health from 1995 to 1997.

**Heléna Herklots** is Chief Executive of Carers UK.

**Jeremy Hughes** is the Chief Executive of Alzheimer’s Society.

**Richard Humphries** is Assistant Director, Policy, at the King’s Fund.

**Tim Kelsey** is National Director for Patients & Information NHS England.

**Nigel Keohane** is Research Director at the Social Market Foundation.

**Sir John Oldham** was the Chair of the Independent Commission for Whole Person Care.

**David Pearson** is President of the Association of Directors of Adult Social Services (ADASS) and Corporate Director of Adult Social Care, Health and Public Protection, Nottinghamshire County Council.
INTRODUCTION

NIGEL KEOHANE

This essay collection explores how we can evolve a health and social care system that captures and responds to the needs of a patient in the round and can sustain itself into the future. Here we call it ‘integrated care’ (though it is variously termed ‘personalised care’, ‘patient-centred care’, ‘joined-up care’ and ‘whole-person care’). Bringing together leading politicians, practitioners and experts, this essay collection debates what we should expect of integrated care and how we should pursue it.

1. Changing needs and the case for reform

The integration of health and social care is fast becoming the holy grail of policy making, and some of the personal stories related in these essays explain just why. As Jeremy Hughes elucidates, the situation of dementia patients exemplifies the rationale for reform. Alzheimer’s is a long-term condition that does not fit well into the traditional medical model of care that evolved in the twentieth century. Many patients have other conditions concurrently; many rely on an intricate mix of health and social care support, professional and unpaid, for a significant number of years. Many patients also find that the services they require do not fit into the basket of ‘free-at-the-point-of-use’ health services and have to cover many care costs themselves.

What is true for dementia is true often more generally for older people. Those aged over 65 account for two in three of all NHS patients. But, as Caroline Abrahams argues, our current system ‘might be fine for people of working age who are fundamentally fit and well, but it doesn’t work for older people with multi-morbidity, some of whom are already frail.’ Seventy per cent of people aged over 75 have a long-term condition such as arthritis or diabetes, and a quarter have two or more. We need greater co-ordination between specialisms within the NHS, and between primary care, secondary care and mental health services. Given that those with the greatest need for social care support are the over 85s, we must also think wider – about housing and how we support the independence of someone in their home.
But, the problem goes beyond the artificial separation between different care disciplines. Stephen Dorrell speaks of ‘institutional dysfunction which corrupts the heart of the care sector’. Under this diagnosis, not only is the system partitioned; but each part is looking in the wrong direction. This leads to a system where, rather than ‘investing in health, we rely on rationing the treatment of disease.’

If the system struggles to capture the full needs of the patient, it is even less effective at understanding the support systems around that individual. As Heléna Herklots argues, the carer – rather than the professional or commissioner – is often the person who does the coordinating of care for the patient. But, joining the dots can be exhausting. While the family carer is often the fundamental prop around which formal care and medical help can be built, too often the carer’s needs and their ability to support are not given attention.

2. Commissioning, delivery and innovation

Responding to such a huge change in the shape of demand is a colossal undertaking but optimism comes in many forms in the essays – whether this is through pilots on the ground in Cornwall, new digital and technological practices or new commissioning approaches. The challenge appears to be how to move from patches of excellent performance to new types of care at scale.

Commissioning all care services in the round for a patient’s needs and putting the focus on health and well-being outcomes are fundamental common denominators. Sir John Oldham reports from the independent Whole Person Care commission that he led for the Labour Party and takes this head on. The existing tariff structure whereby providers are paid for each episode of care comes in for particularly strong criticism, dampening, as it does, the incentive to innovate and reducing the ability to shift resources from reactive secondary care to preventative care in the home and the community. Current approaches should be abandoned in favour of ‘collective commissioning’ he suggests. There are some interesting parallels between some of his suggestions and the new care models being mooted by Sir Simon Stevens in NHS England’s Forward View.
From the provider side, a similar frustration emerges. In contrast to the current situation where ‘we still see fragmentation running right through the system’, Richard Bowden of Bupa calls for ‘joined-up budgets which pay for the care people need regardless of what part of the system that care comes from’. Such a step would enable a provider to join the seams for the patient. Bowden also sets out other practical steps that could help, such as establishing a ‘key contact’ for the patient, an idea that is currently being trialled by Age UK in Cornwall with its ‘care co-ordinators’ and proposed for dementia patients.

New forms of commissioning also open up opportunities for innovation in the digital and technological sphere. Tim Kelsey details some of the shifts we want to, and are starting to, see with the aim of being ‘the most revolutionary health service on our planet’: better sharing of data between professionals, which can save lives; real time online access to records that can help patients self-manage their conditions and reduce emergency admissions to hospital. Ultimately, this data revolution could lead to new developments in the sequencing of human genomes and digital personal care plans.

Three final points might be noted about the ‘how’. First, the essays contain a refreshing open-mindedness towards ‘who’ provides: there are no proposals here to close down the market in care services. Indeed, both Paul Burstow and John Oldham note the potential that may exist through external providers (or consortia) being made responsible for achieving a wide range of care outcomes.

Second, there is significant consensus on the thorny question of where accountability for commissioning needs to sit, namely locally. David Pearson describes Health and Wellbeing Boards as a ‘once in a lifetime opportunity to integrate commissioning’. While such agreement is reassuring, past experience suggests we are likely to encounter significant professional as well as political opposition. Professional because the partitions that separate disciplines will necessarily have to be dismantled; political because it is hard to envisage a locally-commissioned service co-existing with the level of national controls and oversight that we have currently.
Third, the opportunities for innovation are tantalising. The data revolution can break down professional divides, revolutionise people’s experience of care, and empower them as consumers and ‘co-producers’. Beyond this though, via genomic sequencing, it can help us develop the next generation of more personalised drugs and treatments. Joining up this innovation cycle seems crucial.

3. The funding question

The NHS Five Year Plan showed a mismatch between resources and patient needs of nearly £8 billion a year by 2020/21 even under very optimistic assumptions. There should be no cant that integrating care could deliver us from this reality. Any savings are unlikely to do more than reduce the necessary budget growth in the long-term. Two aspects of the funding debate get covered in the collection: the flow of the money through the system; and, the amount of money being put in.

A number of contributors discuss the Better Care Fund, which emerges as having both some theoretical benefits if also some practical failings. Incentivising (often reluctant) commissioners to pool their funding surely must play a bigger role over the next parliament. However, as David Pearson argues, we are likely to need ‘double funding’ in the short-term so that we can spend on preventative services as well as existing services.

As Paul Burstow acknowledges, ‘the inevitable conclusion is that the next government will have to commit more cash for health and care’. He suggests two radical prescriptions: first, the government should ‘commit to staged funding increases as the economy allows – equating to £8 billion by 2020’. But this money should be conditional on a 2% productivity gain. Second, Burstow calls for ‘a Fundamental Review of NHS and social care finances’ ahead of the next spending review, which should be followed up by annual reviews by the Office for Budgetary Responsibility.

In the final essay of the collection, Richard Humphries elaborates on the proposals made by the Barker Commission late last year. He starts with the principle of ‘equal support for equal need’ across health and social care. He goes on to argue in favour of increasing public funding. The latter
should include changes to national insurance, and a review of property and wealth taxation including possible reforms to inheritance tax, a possible wealth transfer tax and property taxation.

Given the inequities in funding across health and social care and the looming shortfalls, the paucity of serious debate on such fundamentals is alarming. But, arguably, the debate needs to go wider still – to discuss the question of whether individuals as well as the state should shoulder some of the costs into the future.
INTEGRATED CARE: OPPORTUNITY OR THREAT?

STEPHEN DORRELL MP

The concept of “integrated care” is in danger of sounding like “apple pie and motherhood”. It is the new religion; everyone endorses it; no-one is against it.

It represents both a threat and an opportunity.

The threat arises from the danger that the phrase becomes so widely used and so little thought about that it becomes a cliché which has no real meaning. If this happens no-one should waste time writing essays about it – still less reading them.

The opportunity is that integrated care (which, translated into English, means joined up care) becomes the rallying cry for reform.

If that is to happen we must be clear what it means. Rather than succumb to soft focus and good intentions, the champions of integrated care must define what they mean and, just as important, they must be clear what they are against.

It is, sadly, all too easy to be clear what we are against. It is the daily experience of too many individuals and their families who believed that the principles of the welfare state, which they have always supported with their votes and their taxes, included the principle of compassion, but who find when they need its services that their experience is dominated by system, process and rules – operated with depressingly little humanity – rather than by compassion.

It is the experience which Sir Robert Francis had in mind when said that staff at Mid Staffordshire were “doing the system’s business” – rather than delivering care to individuals.

The care failures at Mid Staffordshire were particularly egregious and it is
important not to overgeneralize but it is also important not to understate the issue.

In far too many cases the quality of care delivered by the care sector feels uncaring; it does not manifest the human quality of compassion.

**Why is that?**

It is not because the care sector employs bad people. On the contrary, the vast majority of people who work in the sector do so because they want to be involved in caring for the sick and the vulnerable. It is a motivation which deserves the respect, in particular, of those who have not chosen to commit themselves in this way.

Sometimes, however, there is a straightforward failure of professional standards. When staff deliver care which falls short of their professional obligations it is the responsibility of the individual professional and, failing them, their professional colleagues to ensure that proper action is taken to protect the standards of care provided. There is no substitute for professional commitment to high standards.

But important as this principle undoubtedly is, it is not the whole story. It is not good enough to deliver homilies about the importance of high professional standards and joined up care and then avert our eyes from the institutional dysfunction which corrupts the heart of the care sector.

I believe this dysfunction has two fundamental causes.

First we are living with a system inherited from history which creates institutional boundaries which partition services in highly disruptive ways. To wonder why hospital services, primary health services, community health services and social care services don’t deliver integrated care is like wondering why Berlin didn’t function as an integrated city when it was divided into zones administered by the Russians, the Americans, the British and the French.

Partition – as the word implies – delivers separate administration; it is the
polar opposite of integration. We run partitioned services and wonder why we fail to deliver integrated care.

But the problem is even worse than that.

Not only are our services partitioned; they are looking in the wrong direction.

When we speak in shorthand we speak of “the health service” or “the NHS”; when we are trying to be correct we speak of “health and care services”. But all of these formulations imply that our core activity is to deliver curative care to patients who, in addition to their medical needs, need care and support – typically to assist recovery and rehabilitation.

Such patients are of course an important part of the activity of the care sector; but they are a minority and their needs are a declining proportion of overall activity.

The core and growing requirement of users of care services is the provision of care and support to individuals whose need for such services is long term and for whom the requirement for medical intervention is simply part of the service required.

Against this background the tendency in our system to “default to doctor” is an important source of failure. It creates demands on doctors’ time which they are ill-equipped to handle and it entirely misses the point about the requirement for joined up compassionate care, which lies at the heart of effective care services.

By concentrating so much resource on rationing access to medicine we enter an entirely self-defeating vicious circle. We reduce the resources committed to health and wellbeing which leads to an avoidable increase in illness which leads to even more restrictive rationing and so on.

Although the National Health Service benefits from widespread and articulate political support, the record of our actions contradicts our rhetoric about the importance of health. It shows that when presented
with the choice between committing resources to underwriting health and wellbeing or to the development of new treatments for disease, we almost always choose the latter over the former.

Rather than investing in health we rely on rationing the treatment of disease. The cry for integrated care is a cry for reform, and this time we need to mean it.

Reforming care does not mean changing the management structure. Indeed, over a long period, repeated tinkering with management structures has become a displacement activity which has obstructed real reform.

Real reform means changing the way care is delivered so that care services really are built around the needs of the people who rely on them.

For far too long we have been content to talk of “collaboration” in a system which is fundamentally dysfunctional. It has made us feel better, but it has allowed us to accord greater respect to structures and organizational jealousies than we have to the needs of vulnerable people.

We must face into the need for change.

We must be prepared to challenge old shibboleths and insist on our right to bring new ideas to the table which can improve the care provided to vulnerable people.

Above all we must ensure that we develop a care sector which delivers services which are built around the needs of the individual rather than inviting individuals to mould their needs to the services available from the inherited institutions. If a disruptive innovator has a better solution for vulnerable people, we have no right to obstruct innovation because it challenges orthodoxy.

As so often in human affairs, the case for reform is a case built partly on the belief that the future can be better than the past, but partly also on a rising sense of anger about the injustice of the present.

The anger is rising; it is our good fortune that we can change the future.
MAKING INTEGRATED CARE THE DEFAULT SETTING

PAUL BURSTOW MP

By 2020 the NHS will be looking at a £30 billion blackhole.¹ Social care is on track for a £7 billion shortfall.² They are being crushed under the inexorable pressures of rising demand, technological change, new medicines, non-communicable disease, an ageing population and public finances still in intensive care – we’re standing at a cliff edge, staring at the waves crashing on the rocks below.

What is to be done?

The 2012 NHS reforms focused on commissioning. Placing clinical leaders at the heart of commissioning was the right thing to do. Barely a year old clinical commissioning groups and their health and wellbeing board partners deserve time, support and space to prove their worth.

The Act also shifted the focus towards health outcomes, speaking for the first time in the language of what services deliver for patients, not only in the language of the ‘system’.

Reform must now turn to the ‘why’ and the ‘what’.

Integrated or co-ordinated care has been the holy grail of health and care for decades. Our health care system is designed to fix body parts rather than the whole person. Given the majority of health and care spending goes on the management of long term health conditions not on episodes of care due to illness or accident, the model is out of step. The ‘diagnose and cure’ model we see depicted on Casualty or Holby City is not the reality for most of those who use the NHS. Most people will not be ‘fixed’, their condition will not be ‘cured’. It’s about helping people to maintain their wellbeing and recover social functions that allow them to live as well as possible. In my report to Government on the draft Care Bill³ I recommended that integration become the legal default. Budgets, commissioning, service delivery each should be in scope of the integration ambition. Health and
Wellbeing Boards, with the right support and capacity building should hold the budget and sign off local commissioning plans. Not a smash and grab raid by local government, but a pooling of sovereignty between NHS and local government to match resources to local priorities, to set those priorities based on local need.

But commissioning for what? I believe the promotion of individual wellbeing should become the organising principle around which budgets are pooled, services commissioned and performance measured.

The Care Act 2014 defines wellbeing by placing the individual right at the heart of decision-making about how best to achieve it for them. It goes further by giving family carers, the hidden treasure of our health and care system, an equal standing. Integration legends like Torbay would translate wellbeing as improving care for Mrs Smith.

Commissioning for what matters to people, their wellbeing, means focusing on outcomes. Tentative steps in Oxfordshire and Sheffield are revealing the power of this approach. Taking a whole population perspective, using data to map and redesign patient pathways can yield productivity and healthcare gains.

To realise the potential we need provider-side reform too. The creation of integrated care organisations, like the Alzira model in Valencia, Spain or the alliance based contracting in Christchurch in New Zealand, offer routes to sharing the risks and rewards of signing up to delivering an outcomes-based contract.

There is no reason in domestic or EU competition or procurement law why this approach cannot be adopted. Monitor and NHS England should do more to lay to rest the myths about competition and procurement law. CQC could help nudge things in the right direction by inspecting and rating integrated services, something I raised during the Care Bill’s scrutiny.

In addition politicians and decision-makers, as well as those in the health service, need to have an open and honest debate with the public about how we uphold the NHS founding principle: free at the point of use based on need, while helping to plug that blackhole.
What should be pooled?

When the Better Care Fund goes live in 2015 it will be bigger than the £3.8 billion mandated by Whitehall because some areas have decided to pool more. In fact, the total value of funds pooled has reached £5.3 billion. As this local enthusiasm demonstrates, pooling of funds is absolutely the right direction of travel and Liberal Democrats have now set out our ambition that by 2018 NHS and care budgets should be fully pooled, with commissioning reflecting local models of joined up care. Public health, social care, primary care, community care, mental health, acute care: all are better done as one co-ordinated, population based commissioning activity.

And pooling should go further. It should be possible to pool housing-related budgets – a critical and often overlooked part of the health and care jigsaw. Last year I was privileged to chair a Commission on Residential Care with Demos and experts from across the sector, and as that work reinforced to me, with an ageing population we cannot afford to leave it too late to recognise the critical importance of housing for older people in local plans. And we can go further still, others such as Police and Crime Commissioners and Job Centre Plus should be encouraged to join in and pool their budgets too.

Getting integration right and delivering the ambition of the Better Care Fund will make better use of resources. But this leaves unanswered the question of how to meet future cost pressures.

Again the Care Act contains part of the answer: prevention.

The Commonwealth Fund last year ranked the NHS 1st for efficiency and 2nd for equity, but 10th for healthy lives when compared to the health systems of 11 leading nations.

As recommended by my CentreForum Commission on mental health, we need a national wellness or wellbeing programme to map, network and build-up the hidden social assets in communities. There is strong evidence for the benefits of wellness services and of informal networks of support. At a local level some GPs are embracing this asset-based
approach using social prescribing to connect people to the social support they need. A focus on social assets can build personal and community resilience but it is not a short-term fix. Raising the health and wellbeing literacy of the nation will take time.

Can the NHS survive another five years on flat cash? The forecasts from NHS England make grim reading.

So there is a need to address productivity. Commissioning for outcomes and enabling the formation of integrated care organisations will turn the spotlight on the productivity of NHS provider organisations. In alliance contracts all providers share in the risks and rewards. This can concentrate minds and force collaboration.

Recent work by Monitor\(^7\) has highlighted between £10.6 and £18 billion of recurrent productivity gains through changes to existing services, delivering the right care at the right place at the right time and implementing new ways of delivering care. The report also argues for resources to be allocated in relation to disease burden, which must mean rebalancing funding towards mental health.

This will not be sufficient to close the funding gap.

The inevitable conclusion is that the next Government will have to commit more cash for health and care. But the conditions attached to extra funds must be robust.

As set out by Simon Stevens in NHS England’s Five year Forward View, new money is desperately needed, but could and should be made conditional on achieving at least a 2 per cent productivity gain. This will mean delivering integration, promoting wellness services, and improving efficiency across the system.

In exchange Government should commit to staged funding increases as the economy allows – equating to £8 billion by 2020, which, combined with improved productivity would bridge what is currently seen as a “black hole” in NHS finances. And the Liberal Democrats are the only party to
have yet signed up to meeting this sum in full – as Nick Clegg announced this month, we have a clear funding commitment for the life of the next Parliament. We have committed to deliver the £8 billion Simon Stevens has called for, to give the NHS and care services the funding and the certainty they need and the ability to plan with multi-year budgets. The Lib Dems will wipe out the NHS shortfall.

**But what of social care?**

In government we have achieved much in social care – we have reformed outdated and disparate legislation and established a long-sought-after, but little attended to, solution to the funding of long term care costs. But to isolate social care and its funding from that of the NHS is disingenuous. It will come as a surprise to very few that the social care system has been underfunded for decades and that lack of social care provision inevitably has a knock on impact on the NHS and demand for its services.

In this Parliament we have allocated additional funding to social care but with an ageing population and the dramatic rise in co-morbid long term conditions, demand is at risk of further outpacing provision and will increasingly create a threat to the viability of the NHS, even once the £8 billion funding promised is delivered.

So, before the next Spending Review, we will need a Fundamental Review of NHS and social care finances to establish the scale of current and projected demand, and explore how they will be met. And to support this and ensure that due diligence is paid in regard to trends in health status, demographic change, demand for health and care services, and the costs of new health and care technology – as well as new drugs – the Office for Budgetary Responsibility should conduct annual reviews, reporting to Parliament, to ensure Government is able to respond and take suitable steps to adapt resources and provision as required.

Whoever is in power in the next Parliament will not be able to muddle through. Getting to the election after next without a crisis is inconceivable without a new settlement. Business as usual will not do.
The funding gap can be closed, but it requires bravery and vision to deliver a new settlement.

Integrated or co-ordinated care must become the default way of working within the NHS and with social care and housing. The promotion of individual wellbeing should become the common purpose, a healthy population the measurable result.

But in exchange for above inflation increases in the funding of health and care the public will expect no stone to be left unturned to make the most of the money the NHS receives. Productivity and Prevention will be the watch words of the next five years.
APART AT THE SEAMS: THE CHALLENGE OF INTEGRATING DEMENTIA CARE

JEREMY HUGHES

David’s and Matthew’s mother, Judy, was diagnosed with vascular dementia 6 years ago, and her husband was her carer before he died.

After this happened, Judy received visits from carers each day. There used to be a different carer at each visit, which didn’t work well. Apart from causing anxiety and confusion for Judy there was little or no communication between carers, which led to her being hospitalised after she was given a double-dose of medication one morning.

Support from social services was sparse, as once the initial referral was deemed to be dealt with the case was closed. The family had a contact social worker but rarely saw her. Every year, they had to urge the agencies and organisations involved in their mum’s care and support to meet and review her case. The family believed that this should have happened as standard – but it didn’t.

Eventually, they employed a carer who came in and helped three times per day, every day of the week. The carer was excellent and did lots of extra (unpaid) things to help. Most of all, it meant Judy received care and support that was familiar and consistent.

Judy was initially hospitalised following a fall, but her hospital stay was prolonged and she died in hospital from medical complications. Even though she was in excruciating pain, her X rays weren’t read for eleven days and consequently, she was being mobilised on a fractured hip. It was only during a conversation about discharge that the fracture was uncovered.

Care within the hospital was uncoordinated between specialties,
each of which seemed to make decisions in isolation. The care was not coordinated with social services, despite pressure from Judy’s social worker during both her admissions. Without severe pressure from both the family and social services there would have been little or no discharge planning.

Again, Judy’s needs were assessed on a medical basis only with no regard for what she might need when discharged to her home or into residential care. The hospital did not recognise her needs as a person with dementia.

There are currently 850,000 people living in the UK with dementia, facing a condition that slowly robs them of their memories, their sense of self and their familiarity with loved ones and friends. Dementia also retains a level of stigma that means people and their carers also lose friends and become increasingly isolated in their own communities, compounding the difficulties of managing a serious and progressively deteriorating condition. Worse still, at present only just under half of people with dementia have a diagnosis, and even fewer have access to the support that a formal diagnosis should give them, even at a time when dementia has been recognised as a high priority through the National Dementia Strategy, and the Prime Minister’s Challenge on Dementia.

‘Once you’ve met one person with dementia… then you’ve met one person with dementia’ (carer)

People living with dementia have very individual levels of need, right from the time they develop the condition, through to ongoing management and support at the end of their lives. They want to experience care and support that is tailored to their individual needs and delivered safely and effectively.

The experiences of people with dementia depict a complex web of health and care services and staff with who they have to interact and navigate in order to get the care and support they need. Much of this complexity stems from the differences between the types of care and the range of services they need, from day-to-day care, to managing personal
budgets or direct payments, accessing out-of-hours doctors, and other things like equipment services. This complexity in navigating services is compounded by the fact that many people with dementia may have up to six other health conditions.

At Alzheimer’s Society we hear many examples of poorly integrated care. All too often people with dementia and their carers find themselves repeating their story over and over to different people, undergoing multiple assessments, or receiving multiple visits from paid carers due to poorly organised and overburdened services that simply don’t or can’t communicate with each other properly.

Behind the closed doors of services, the systemic problems within health and social care that prevent or stifle integration can be due to poor communication or working relationships between organisations, a lack of resources or even a lack of willingness to integrate. One significant issue is the funding gap between health and social care, with the latter having suffered a real terms drop in funding of £210m. Just to keep pace with demographic changes, spending on social care on older people would have needed to rise by £1.6bn over the last five years.

Many end up lurching from one part of the service to another. This creates more confusion, stress and anxiety, causing their condition to deteriorate and also having a detrimental effect on the health of their carers and family, who may already have their own health needs.

The effect on the system is that a lack of integration incurs greater costs and pressures, through an increase in avoidable admissions and longer stays. Better integrated and funded support in the community would help in addressing this, with effective individualised care planning enabling people to avoid inappropriate admissions. Where admission to hospital does become necessary, continuation of that support with proactive discharge planning could help reduce length of stay and get people back to their homes with the appropriate assistance.

‘Care is care is care. People don’t know the difference between services’ (Carer)
Integration is defined in various ways, but most commonly and, most importantly for people with dementia and their families, the needs expressed are that it is holistic, meeting people’s physical, mental, social, psychological, emotional and spiritual needs. It also has to recognise and meet the needs of the family and carers. This is how a carer expressed how their care could have been better delivered

*If only...*

- we’d been at the centre of thinking, choosing, planning and delivery of care
- we’d known who we could turn to when there was a problem
- we’d received good guidance that informed our choices
- we’d had an agreed care plan, easily accessed by all health and social care professionals
- we’d experienced cooperation between professionals that ensured timely action
- we’d been valued as true partners in care, and had an expert dementia care co-ordinator who respected our preferences
- I’d had practical and emotional support in my role as carer

*Then the outcome would have been...*

- a contented patient and carer, receiving quality care and support
- working together with professionals to achieve good quality of life and sense of well being

Closer integration of health and social care has been a recurrent goal of public policy for at least the last forty years made all the more pressing by an ageing population.

The current drive for better integrated care is based around the development of a culture of cooperation and collaboration, focussed on supporting individual need, better prevention of deteriorating health and avoidance of unnecessary hospital admission.
It is difficult to put these attributes into practice. In reality, implementing integration requires the highest level of commitment from the organisations' leaders, in order that this filters down to all levels of staff and becomes an organisational goal, rather than being restricted to pockets of good work. It takes determination, innovation and above all a willingness to 'stick at it'. Research suggests that it can take up to seven years to transform a service so that it becomes fully integrated, a significant time period that transcends both parliamentary terms and the changes in health policy that they may introduce.

We have argued that Dementia Leads should be in place locally, not only as clinical experts on dementia, but as leaders who will forge those essential links between the Clinical Commissioning Groups and Health and Wellbeing Boards, and between NHS and local authority services, developing joint strategies and relationships that can ensure a local joined up approach.

The government has committed to the development of integrated services through the integration pioneers programme launched in November 2013 and while these are encouraging, and dementia has been highlighted as a priority, it can’t be ignored that the major stumbling block in achieving the goals is the drastic underfunding of social care services, and the need for effective linking together of health and social care staff who have agreed common objectives and goals to provide the very best care for people with dementia. The Better Care Fund could and should be used by Clinical Commissioning Groups and Local Authorities in a variety of approaches to achieve innovative and effective integration, driven by Dementia Leads.

These are the seams that need to be joined and then to become invisible, before integration can become a widespread reality.
CARING FOR AN AGEING POPULATION

CAROLINE ABRAHAMS

The ‘Integration aspiration’ is not new, but with our rapidly ageing population it is an idea whose time has now surely come. Older people have a great deal to gain from a more integrated approach to planning and delivering health and care.

This, briefly, is why. About one in five of the population are aged over 65 and they account for two in three of all NHS patients. Seventy per cent of people aged over 75 have a long-term condition such as arthritis or diabetes, and a quarter have two or more. Longevity means the number of people aged over 60 is expected to pass 20 million and the numbers of over 85s to double by 2031. So the numbers of older people living with multi-morbidity are going to grow very significantly over the next twenty years and to remain fit for purpose the NHS and other public services will have to change to offer the joined up provision many older people will need.

‘Long-term condition’ refers to the fact that these problems cannot be cured, only managed (and self-managed). Coping with multi-morbidity is undoubtedly draining and undermines resilience. It also makes it likely that you will be on a complex drugs regime, which can be burdensome and also carry risks of side effects.

Older people living with multi-morbidity need health and care services that can help them in the round and support them to manage their long term conditions, replacing what would otherwise be an often frustrating series of disconnected encounters with health professionals with something that is much more holistic and that aims, above all, to help them to maintain a good quality of life.

Yet the traditional model of medical care in this country is that patients present with a single problem, such as a broken leg, and are fixed up so they can hopefully go on pretty much as before. This model might be fine for people of working age who are fundamentally fit and well but it doesn’t work for older people with multi-morbidity, some of whom are already frail.
This is why we have situations such as that of a woman in her mid-eighties who was living with several serious conditions, including Chronic Obstructive Pulmonary Disease. Her adult daughter was at one point struggling to co-ordinate six different specialists and their teams who seemed never to communicate with each other, plus the GP and various community health practitioners as well. Life for Mum was an endless, dispiriting catalogue of hospital appointments during which a lot of the same information was sought each time. No single professional was in charge with an overview, and no one seemed especially interested in maximising her overall quality of life. This woman was however lucky because her daughter was highly committed and was helping to sort things out, but what happens to all the older people who are on their own?

This demonstrates the need for more co-ordination between specialisms within the NHS, and between primary and secondary health care and mental health services too, but older people often require other forms of integration as well. Those with the greatest need for social care to sustain their independence are ‘the oldest old’ – the over 85s. So integration has to happen between Health and Social Care as well as across Health. And given the significance of the physical environment for an older person – for example, the role home adaptations like grab rails can play in reducing falls, which is a major cause of hospitalisation and poor health outcomes in older people – Housing should be part of the mix too.

So, greater integration is the way to go. But big questions arise about how best to drive this process of transforming services and where the focus should be. Much of the debate to date has concentrated on system issues such as the feasibility of pooling budgets between Health and Care. This may be entirely necessary, but we worry that a lot of time could be spent in trying to do this – it is not a new aspiration and it is notoriously hard to do – and that even if it is achieved, it will not in and of itself ensure that Health and Care services are integrated on the ground. And that’s what really matters to us: that individual older people and their families experience high quality, personalised, responsive and joined up services that genuinely meet their needs.
It was partly because of these concerns that Age UK decided to develop our own Integrated Care Programme. The vision is of a much more integrated, personalised approach. The programme is bringing together voluntary organisations and statutory health and care services in local areas to provide an innovative combination of medical and non-medical support for older people living with multi-morbidity. The multidisciplinary team that supports an older person is rooted in primary care, with their GP at the heart.

The pathfinder for the programme has been underway in Cornwall since 2012 and is now one of the Government’s fourteen Integrated Care Pioneers. It is early days but so far the results are highly promising: in the first year, of the 100 older people helped 23% reported improved well-being, saying the programme had given them a purpose in life again; and there was a 30% reduction in non-elective hospital admissions and a 5% reduction in social care costs. Projections suggest that with a £500 service investment for each older person, £2,000 could possibly be saved to be reinvested in the local health system. We are also modelling a new approach to evidencing cashable savings in order potentially to secure a Social Impact Bond. The programme currently holds a Health Services Journal national award.

Key to this approach is a ‘care co-ordinator’; a trained Age UK employee who is part of the clinically-led multidisciplinary team. Care co-ordinators work with an older person to help them to identify their goals and then broker a wide range of support so they can achieve them. The older person is also assigned a volunteer who works intensively with them for three months to connect them to on-going sources of support, so they can sustain the advances they have made.

Here is an example of how it works. ‘Mrs N’ is 74 and lives alone. Her diabetes is not well managed. She is also very breathless, anxious, has suffered a stroke, is partially sighted and in constant pain. This led to a high dependency on services and professional carers for most daily tasks. Age UK arranged for tele-health support to help manage her diabetes and for an ‘exercise buddy’ who visited Mrs N, first at home and then as part of
a group, to encourage and support her through an exercise programme. It has taken a while to build Mrs N’s confidence but she has recently taken the big step of coming on an organised shopping trip and now not only attends a ladies’ coffee morning with other older people, but is confident and able enough to have hosted one in her home.

These gains may seem fairly modest but from Mrs N’s point of view they are truly life enhancing, even transformational. They show what can be done when services are organised around an older person in a joined up way. It is not surprising that 87% of the health professionals involved with Age UK’s Cornwall pathfinder said it made their work more meaningful: by turning the traditional way of working on its head and starting with the fundamental question, ‘what would make life better for you?’ they are able to make so much more difference.

During 2014, we worked to expand the Cornwall pathfinder to cover 1,000 older people and we are now taking the pathway to several other areas of the UK. Making integration real is tough, but hopefully we are showing that it can be done by working ‘bottom up’, and that doing so is thoroughly worthwhile.
CARERS AND INTEGRATION

HELÉNA HERKLOTS

There are 6.5 million carers in the UK caring, unpaid, for family and other loved ones. It might be parents caring for a disabled child, a husband caring for his wife with dementia, a daughter caring for her mum with cancer, or a sister caring for her brother with learning disabilities. There is a great diversity of caring roles and experiences and each year 2.1 million people take on a new caring role, and almost the same number come to the end of their caring experience.¹⁸

Caring is a near universal experience – most of us, at some point in our lives, will either become carers or need the help of someone close to us. Many of us will also need care and support from health and care services, as well as other help such as supportive and understanding employers if we are juggling work and care; suitable housing; and financial security. We will need those services to recognise and understand our caring role, and recognise also the needs we might have because of that caring role. For example carers caring for more than 50 hours a week are twice as likely to be in bad health than non-carers.¹⁹

Being a carer brings with it many responsibilities and also leads to the development of expertise and skills. They are skills that we expect in trained professionals but family members often have to develop them quickly and with little support at a time of emotional stress. One of those skills is integration. So when we ask the question what do carers want from integration, we should also ask what can carers teach us about integration?

John cares for his wife at home who has MS. He works part-time and is supported by a team of care workers who stay with his wife when he is at work. John manages all the care arrangements as well as visits to the GP and hospital (planned and unplanned), and also provides care through the night when needed. It is John who integrates the health and social care support for his wife. He advises the care workers of changes in his wife’s condition or medication; he changes appointment times at the hospital.
– or tries to – so that he can go with his wife and not miss another day's work. He keeps each of the care workers updated on care arrangements and sorts out rotas; he keeps in touch with the GP and practice nurse and lets them know if there are changes in his wife's condition. On top of all this, he tries to sort through the maze of the charges he has to pay for the services his wife receives, and manage a household budget under severe strain from the costs of caring. When things go wrong – such as a hospital stay being followed by a poorly planned discharge without enough notice – it falls to John to try to pull the different parts of the fragmented system together to ensure his wife gets the care and support she needs. John is an integrator, a negotiator, an expert in his wife's care. But what if something happens to John? What if he becomes ill and unable to carry on the caring role?

A key outcome from integration must be to support carers like John, and to make that caring role easier to manage – so John can spend more time with his wife in the role of a husband, and less time (and strain) having to be the integrator and care manager. For this to happen integration needs to deliver at three levels – system level; service level; and what might be called street level.

System level integration has to tackle the fissure between health and social care caused by the charging regime in social care. The provisions in the Care Act 2014 go some way to recognising the principle of pooling risk and helping people to avoid the 'catastrophic' financial costs of care, but we should be more ambitious than just trying to avoid catastrophe. If the positive intent of the Care Act to promote people's well-being, to introduce a more preventative approach to care, is to be realised then any charging regime has to reflect this, and crucially there needs to be a realistic funding settlement for social care. At a time of rising demand for care, it is unsustainable for social care budgets to be cut. The pressures from this fall on families and the NHS. So for integration to work at a system level, we need funding for social care that enables people to access help at 'moderate' levels of need, rather than 'substantial'.

At service level there is much to learn from positive initiatives and integrated approaches happening across the country. One example is in
Hertfordshire where the local authority leads a multi-agency commitment to carers via a strategic commissioning group. The Hertfordshire Joint Strategic Needs Assessment has a very clear commitment that ‘carers should be identified and offered support at the earliest opportunity to help them stay healthy and carry on caring, if they want to, and to avoid or help them through a crisis’. Hertfordshire is taking forward initiatives on ‘carer friendly communities’ and ‘carer friendly hospitals’. Outcomes from these initiatives include earlier identification of carers and referrals for support and reduced hospital re-admissions.²⁰

Looking at tangible outcomes for individuals who are caring for their loved ones brings us to the importance of street level integration. Nearly half of the 6.5 million carers are juggling work with caring. Combining work and caring can be too much without the support of an understanding, flexible employer and the right health and care services in place that can respond to the care and support needs of the family. In the Carers UK State of Caring survey 2014²¹ we asked carers who had given up work or retired early why they did so. 62% of carers said it was the stress of juggling everything and 35% of carers gave expensive or lack of suitable care services as one of the key reasons. In addition 33% of those who have used health or social care services have refused a service because of concerns over quality.

For integration to have a positive impact on families who are caring, the quality of the services and support being integrated is key. If services are not of a good quality – if they are unreliable or inconsistent – then whether they are integrated or not will make little difference – the carer will not feel able to entrust the care of their loved one to those services. For John the reliability and continuity of care from the care worker team is crucial in enabling him to get to work, and to be free, or fairly free, of worrying about his wife when he is at work.

It is impossible to integrate, at a system level, all the various elements that carers may need in order to care for their loved one – health, social care, benefits, housing, employment, transport. Whatever systems and services are integrated there will always be services that fall outside of this. The culture must therefore be one in which wherever the boundaries
exist between services, the approach is to seek to work across these boundaries so that at street level people experience the benefits of an integrated approach. This would mean that carers are not left to do all the integration, but rather that those whom the carer is relying on do this as a core part of their approach. The outcomes from this are that carers would feel better supported, less stretched by needing to hold all the pieces of a fragmented system together, and better able to care and have a life of their own. This benefits carers, their loved ones, and wider society.
COLLECTIVE COMMISSIONING

SIR JOHN OLDHAM

The fragmentation of care experienced by people with multiple needs has its roots in the fragmentation of both provision and commissioning. This essay focuses on the changes required in commissioning to achieve a co-ordinated integrated approach to care. However, just changing the financial system is insufficient on its own. In our report *One Person, One Team, One system*, we made clear the necessity of tackling a number of parameters simultaneously, to create truly integrated care; information flows, training and education, research, tackling biases in the system. These are as crucial.

‘Whole person care’ requires care itself to be collaboratively commissioned across health and care: ‘combined commissioning’. A vision of ‘collective commissioning’ starts from the perspective of the person, and asks how the care system can collectively respond to meet their needs, defined by them, and delivered as outcomes that matter to them. Personalised care planning is a key component of this – identifying individuals’ personal goals and support needs and aggregating these to produce a commissioning plan for the community.

For this to happen, much needs to change. Yet it is our view that the forced merging of organisations to achieve this would be inadvisable, expensive, and would delay the benefits achievable through a more collective commissioning approach. Instead, we should build upon existing commissioning arrangements. This could be done by collective commissioning between existing organisations across the system, underpinned by a legal obligation to adhere to a jointly-agreed collective commissioning plan.

At a high level, ‘collective commissioning’ would mean that:

- Revised health and wellbeing boards (or analogous arrangements) become responsible for developing a collective commissioning plan for their local population with long term conditions, disabilities and frailty.
• The collective commissioning plan is based absolutely on the expressed need and desired outcomes of the users of the services, in terms meaningful to them.

• The collective commissioning plan is enacted by Clinical Commissioning Groups (CCGs) and Local Authority commissioners, with common outcomes tracked.

• Primary Care commissioning is aligned with these local system objectives

This vision for ‘collective commissioning’ centres upon whole system leadership which takes a whole person view. Budgets for this population cohort need to be treated as a whole across health and care, and commissioners must work collectively to align incentives around joint population group outcomes; the roles, responsibilities and governance arrangements of the community commissioning process must therefore reflect this holistic necessity.

Health and wellbeing boards, or analogous arrangements, are a natural vehicle to take overall responsibility for whole person care, involving as they do the leaders of existing organisations working together to coordinate care across their geography. Health and wellbeing board, or analogous arrangements, should be at the centre of the commissioning process for people with long term conditions, disability and frailty (including mental health) – people whose care is often most fragmented and who are heavy users of health and care services. The health and wellbeing board would be responsible for creating a local collective commissioning plan for this group of people – within a nationally defined outcome framework for the development of whole person care. Meaningful public involvement, not simply ‘consultation’, must be introduced as a necessary step in the development of the plan. The caveat of "analogous arrangements" recognises the geographic and structural differences between a metropolitan area e.g. Leeds, and a county area with district councils and CCGs in double figures. In counties one can envisage a subsidiarity arrangement to a more local level.

Within this overall model, existing local health and care commissioners should be given a statutory duty to enact the health and wellbeing board’s
collective commissioning plan for people with long term conditions, frailty and disabilities. The separate health and care budgets would be viewed as a whole: the “locality pound”, encompassing the totality of local resources available for this cohort of the population. Scotland has done some excellent pioneering work on what is useful, and what is unhelpful to include in such budgets, and the governance, itself drawing on exemplars elsewhere.

Whilst some Health and Wellbeing boards across the country are operating well in a new environment, the experience so far suggests that most boards as currently constituted would not yet be ready to take on the role described above. In particular, their failure to include providers as non-voting members is likely to hinder integrated care. Without provider input, system change just isn’t possible. The role of housing is also insufficiently recognised, and the important leverage that, say, ensuring a proportion of new housing is elder friendly. In short, development for this role would be needed and the learning from early adopters like Plymouth embraced.

**Tariff and contracting**

A discussion of commissioning would be irrelevant without considering analogous necessary changes to the tariff and the associated contracting mechanisms. Episodic payments per activity are an incorrect way of creating the longitudinal care required by people needing integrated care. Payment by results, whilst useful for other aspects of healthcare (e.g. elective procedures), should be replaced by a capitation tariff for the cohort of the population that has multiple needs. This tariff should be risk stratified, and conveniently the cost bands can be positively correlated to the number of long term conditions, and a category for frailty. This tariff would apply for all care for a year.

This then leads to different, more collaborative, forms of contracting. Outcome based care is something which is receiving growing interest both nationally and internationally; while in their infancy, a number of forms of outcome based contracts have been let or are being developed in a number of places across the country. These contracts require providers
of care to collectively achieve outcomes for defined population groups. The challenge is to make this shift towards outcome based care the norm. The effective management and delivery of these contracts will require a different overall organisational and governance structure than is currently seen in care economies across England. This will require a fundamental change in the nature of provision.

The main organisational forms emerging to support the delivery of outcome based care in England are the accountable lead provider model and the alliance group of providers. Both of these models aim to improve outcomes through aligning organisational incentives across the health and care economy. The successful delivery of both models requires local health and care providers to work collectively to deliver services which provide the best outcomes while optimising resources; for example, this will likely mean investment in the social aspects of care, including services carried out by the voluntary sector, to avoid costly acute activity.

The central tenet of alliance contracting is that organisations can achieve better outcomes – particularly in the delivery of complex services – by working collaboratively within a single overarching contract. An alliance contract aligns incentives between these organisations through the construction of a common set of outcomes, encouraging collaboration to enable the delivery of coordinated services while sharing risk and accountability between alliance partners. Organisations within the alliance only gain if the alliance as a whole achieves the outcomes asked of it; they must therefore work collaboratively to deliver services which work with each other to achieve their common aim.

The lead provider (or prime contractor) model offers an alternative means to overcome this fragmentation, through the appointment of a single party responsible for the delivery (and coordination) of these services and for achieving commissioner defined outcomes. It is not expected that the accountable lead provider will provide all services which they are accountable for – indeed, in the delivery of complex services this will be rare. However, the prime provider is incentivised to coordinate the delivery of services between all organisations involved in providing that
care around defined outcomes. It may also be the case that a number of organisations are able to form an appropriate commercial and governance structure to jointly become the accountable lead provider (as a consortium) for a given contract.

And finally

All of this is potentially academic unless the projected deficit in the funding of health and social care is addressed politically. Taking the NHS alone, even with real term increases and ring fencing, there will still be a deficit in 2020 equivalent to the whole of the defence budget today. Political honesty is needed with the public about this challenge. The solution needs reform and a rigorous drive to reduce unwarranted variation and waste in the system, but also a new compact with citizens about the scope and funding of health and social care. Just focussing on funding for the NHS is a false reassurance; there is no point in refurbishing the house if you don’t mend the roof (social care).

And finally, throughout all the talk of commissioning, and tariffs and all that goes with it, we should never forget to start and end with a clear vision of the people this is intended to serve; to ensure we really are addressing their wishes and needs.
UNLEASHING THE POWER OF PEOPLE: WHY TRANSPARENCY AND PARTICIPATION CAN TRANSFORM HEALTH AND CARE SERVICES

TIM KELSEY

In the heart of London’s Olympic village is another symbol of transforming social leadership: a new health centre, home to a pioneering general practice which is offering some of the most challenged communities in East London a new standard of personalised care.

Patients here are offered a range of digital services – of the sort they would expect as 21st century consumers in other areas of their lives: they register online from home, for example, which most do by preference. But the real innovation is in the way in which Dr Arvind Madan and his colleagues at the Hurley Group have developed a service which allows patients to consult their own GP from home or work using an online tool that captures a safe, structured history which the GP can use to triage remotely.

I spent the day with Arvind and he has some preliminary results to share which suggest that 24,000 patients have used the service in 6 months, of which 14% reported planning to visit a walk in centre had the service not existed. More than 60% of 1,250 patients who opt to consult online solve their problem without the need to visit their GP, and 78% of the patients who have participated (from the Olympic village practice and other participating practices around London) said that it saved them time – ‘Pretty important for the self-employed in deprived communities,’ he comments.

There is evidence that it also saves GPs time and actually improves the safety of their diagnosis, just because of the systematic nature of the patient questionnaires, which have now been developed for more than 100 conditions.

When I met him, Arvind told me he plays cricket with his sons, but in the
week he is an NHS leader – a clinician who has just got on with making a difference for his patients, putting data and technology to work to deliver a safer, better service, galvanising his colleagues with an ambition for better healthcare.

This is an experiment – for the most part the NHS does not show such person-centred digital behaviour.

The evidence from other sectors is increasingly robust: a combination of transparency (professional and/or public data sharing) and participation (giving the customer more control and voice – especially the opportunity to feedback) has resulted in improved customer satisfaction and (often) dramatic reductions in cost. Industry agreement on data standards, widespread adoption of digital technologies and a focus on personalised internet services has seen the numbers of people opting for online banking rise from zero in 1998 (when Cahoot, the first online bank was launched) to more than 22m. We have taken on some of the costly, administrative work of our banks in return for greater real time control over our financial affairs.

In healthcare, transparency and participation have the potential to do more than just transform value: they can save lives and improve quality. The power of routine data sharing is increasingly well evidenced: cardiac surgeons have reduced mortality rates for some procedures by as much as a third because of transparency of individual results (that data is published through NHS Choices, www.nhs.uk), for example. Yet, despite that evidence, data sharing is not routine in health and care services. Business in the NHS is still largely transacted on paper, by telephone or by fax (the NHS is the world’s largest purchaser of fax machines). Current forecasts suggest there are more than 20,000 avoidable deaths in the NHS each year. Modern inter-operable digital data flows – at the bedside, in the ambulance, in the emergency department – will reduce harm.

We also know that participation – giving people more control over their health and care – improves outcomes, often by reducing hospital admissions for treatment. In the US, the Veterans’ Administration which cares for military personnel has empowered its patients in a range of
digital ways – including real time online access to their records – and they have reported significant improvements in self-management of long term conditions and reductions in emergency hospital treatment.

In the NHS, research indicates that comprehensive adoption of these data and digital strategies will have a significant impact on improving the productivity of services, as has been the case in other industries. The National Information Board, which brings together all national public sector bodies involved in health and care, is reviewing that evidence.

Meanwhile, NHS England has made data access and digital services central to its approach to integrated, personalised health and care. Programmes like care.data – which will link patient data across the care journey so that outcomes can be fairly measured and compared – aim to develop a shared knowledge economy which will help clinicians manage improvement for their patients, commissioners design new models of care and science develop new medicines and treatments.

But hang on: surely the NHS knows what happens to its patients? In most cases it doesn’t. It doesn’t know why a quarter of cancer patients are diagnosed late in the treatable course of their disease in A&E, rather than by their GP – reducing their life expectancy, as MacMillan cancer support recently revealed. Tracking their data over time is a big part of the answer, and understanding local trends in clinical behaviour.

Care.data was delayed last Spring because of concerns about the safeguards for handling of potentially sensitive data and patients’ awareness of their right to object. Since then new legislation – which puts these safeguards on a statutory basis – has received royal assent and the NHS now plans a phased roll out with a group of pathfinder GPs to test new approaches to public information. The NHS needs a professional data revolution – but the internet society wants transparency of why and how: a new information standard that public services at large will need to respect.

The NHS also needs a public data revolution – transparency of a different sort in which aggregate, anonymised information is shared. By the end of 2015, thirteen professional associations will have published individual
consultant level outcomes on NHS Choices (www.nhs.uk), and comparative scorecards for hospitals, GPs and others are already available. Citizens in England have more access to more data about health and care services than any others. More informed patient choice may – or may not – follow. But the professional nudge is irresistible: the first argument for transparency is positive peer pressure.

I would single out a third act in our data revolution – real time publication of patient feedback – as key to promoting better outcomes in healthcare. The NHS launched the Friends and Family Test in April 2013 and since then more than 5m people have rated their local hospital service – and many have also provided free text comments on their experience. It will be rolled out across the NHS later this year but what we already know (a review will be published this summer) is that this new conversation – so effective in other consumer environments – has galvanised real improvements in local services.

Participation is the other side of our modern care equation – giving patients and citizens better information and more control. NHS England has worked with the British Medical Association and the Royal College of General Practitioners to transform digital access for patients. From this spring, GPs have agreed to offer online access to records, appointments and repeat prescriptions. Some, like Arvind, have already taken the initiative and grasped the digital future.

Digital is an enabler: not an human outcome. There are many ways in which technology can assist the NHS harness the power of people for its future sustainability. The case for digital is not just the potential for improving clinical outcomes – but also the extraordinary opportunity offered by emerging science to enable people to take charge of themselves: developing new tools that will allow us to forensically investigate our own data.

A genomic sequence now costs less than $1,000. The first sequence took 13 years and cost £2bn. The NHS, in partnership with Genomics England, has been tasked by the prime minister to sequence 100,000 whole human
genomes by 2017. This heralds a data revolution that is unprecedented in human history. We don’t know yet where precisely this science will take us – but we need to make sure that we are making the right investments in digital technology in our NHS now to maximise its future benefits.

In these ways, transparency and participation – data sharing and digital services – will be a powerhouse for economic growth, as well as patient outcomes. The NHS is at a turning point: we can be the most revolutionary health service on our planet, offering digital services at scale to our citizens and giving them the opportunity to explore their own data. The future is open.
JOINING UP HEALTH AND CARE TO MEET EACH PERSON’S NEEDS – A PROVIDER’S PERSPECTIVE TO BEING PATIENT-CENTRED

RICHARD BOWDEN

At Bupa we do not want to rehearse the familiar arguments about whether health and social care across the UK should be integrated, or for that matter better integrated. As a leading provider of social care, out-of-hospital care, health insurance and clinical services, we are already approaching present and future healthcare challenges through the lens of what our customers want: a truly integrated provider. However, like others, we still have much to do to be truly patient-centred and indeed there is a lot to do system-wide.

We have been working with the NHS and local authorities for many years to deliver high quality care and support to people with care needs, throughout the UK. We run 280 care homes and 70% of our residents are funded by their local authority. We coach NHS patients with chronic diseases to help them self-manage their condition. We also look after NHS patients who are ready to leave hospital but need additional care before they are ready to return home independently by supporting them, either in our care homes or in their own home.

We know that there are many examples of excellent care in the system, where services are designed to meet patient needs and people experience seamless, joined up, high quality care. However, this integrated way of working remains very patchy and inconsistent throughout the system, and is not operating at scale. We need to look at the opportunity as it stands and overcome the barriers standing in the way of joining up health and social care by implementing practical solutions.

If we are to have a health service fit for the future the focus should be on the quality of care and what is right for the individual, not on where the care is provided and who is providing it. Care can be delivered to a high standard outside of hospital and can be provided by the state, third sector,
a social enterprise, an independent provider or a partnership made up of these providers. In the future, it is likely to be a combination of these - bringing together expertise from each and focusing on what is truly best for the person.

In Valencia in Spain for example, where Bupa runs healthcare services on behalf of the regional government, healthcare is truly integrated, so that the patient receives care in whatever setting is most appropriate, whether that’s in hospital, in the community or at home. This approach allows new models of care that focus on prevention and early intervention to thrive, which is crucial to help reduce the burden of demand on the system. That’s not to say that we want to transport the Spanish system to the UK, but there are aspects of care in many other countries were we operate that we can learn from.

What people really care about is that when they are ill they can be treated in the best possible way in the most appropriate place. By starting with the individual and creating and designing healthcare services around their needs, we are likely to improve people’s experience of care, rather than expecting them to fit into the system as it is currently designed. This is particularly important for older, vulnerable people trying to navigate services that are fragmented and disconnected – we see this first hand, constantly.

Currently, people using services don’t always experience choice and flexibility in how and where they receive care. This can be for a range of reasons, including a lack of information sharing between local health and care services, fragmented decision making and tight, siloed budgets across healthcare organisations.

We need to work towards a future when person-centred care for older people and those with long-term conditions is the standard, not the exception. Integrating care to provide a coherent and connected service that is focused around the individual, involving them and their families in all decisions, can deliver good quality care for the patient and a better experience.
Joining up different parts of the system so they work more effectively together can create an opportunity to reduce unnecessary hospital admissions and help more people to stay independent in their own home, provided of course it is safe for them to do so. By creating the right incentives and a culture of collaborative working across health and care, we can support people to access the support they need when they need it, whether that’s care in their own home, intermediate care in a residential setting or access to local primary care or physiotherapy services. By providing people with more support and options in the community and at home, we can reduce unnecessary hospital admissions and help take pressure off NHS hospitals.

There are lots of things that can be done within the existing system to create services that work better for patients and their families. For example, establishing a ‘key contact’ for the individual service user who coordinates and helps navigate local health and care services on their behalf could reduce confusion and create a more seamless experience. Better management of care and more preventative measures in the community can help prevent conditions escalating to hospital as frequently, and provide patients with more options to turn to for support, with less reliance on services like A&E. Care coordinators could make use of more ‘step-up’ facilities as a bridge between home and hospital for less acute needs.

In spite of the momentum towards increased coordination of care, we still see fragmentation running right through the system. The reality is that if we are to design services for the long-term around the needs of patients, we need to address the question of funding. We need joined-up budgets which pay for the care people need regardless of what part of the system that care comes from. Combining these budgets just makes practical sense and budget holders can then make more assured, long-term investments in health and care.

Currently, funding for health and care services come from different sources and budgets, and services are commissioned through a range of bodies locally and nationally. Provision of care can be similarly fragmented with
no one organisation truly responsible for an individual’s care. Because of this, genuinely integrated services are hard to get up and running and people continue to come into contact with disjointed local services. If we are to link up services around patient needs, local commissioners and providers need to work together across traditional boundaries and ensure that funding follows patient needs. There needs to be a single local budget for health and care services, so that individuals can easily access the services they need regardless of which part of the system the service comes from. There needs to be one organisation accountable for managing people’s care needs in a given area, managing the different providers spanning the NHS, independent sector, charities and social enterprises, who all bring different expertise.

Incentives must be aligned to support coordinated care across traditional health and social care boundaries. Currently, the payment system is structured so that trusts receive money for treating people in hospital, which isn’t always the choice of the patient or medically the best place for them to be. By joining up incentives and sharing out risk across primary and secondary healthcare, and between health and social care, we can give people access to joined-up services, personalised for them.

It is clear that the status quo in the UK is not sustainable and making services work better for patients will require a change in culture. It will also require strong national and local leaders who are willing to try new approaches, find new partnerships across organisations and sectors, develop new ways of working, sharing risk and delivering care. Otherwise, we will keep falling back into traditional silos and older, vulnerable people in our communities will not get the care they need or deserve.

Simply pouring more public money into the NHS alone will not allow it to keep pace with changing demand and rising expectations. It’s only by working together across the public and private sector that we can drive quality and innovation and relieve pressure on funding and services. That’s the way to ensure we have a healthcare service that is fit for the future.
INTEGRATING LOCALLY

DAVID PEARSON

The main drivers of health and social care integration have been the development of ‘seamless’ services and the wide recognition of the performance and financial links between the NHS and social care. A recent EY report on whole-place community budgets argued that the net annual benefit from joining up funding across public services to health and social care might be between £2.8bn and £7.9bn. While this comes with a large number of caveats, the sums being discussed are very large.

So are the human sums. As Dr Martin McShane, NHS England’s director for people with long term conditions, has put it: ‘The NHS faces tackling an issue which is the healthcare equivalent to climate change’ as the number of people with long-term conditions grows rapidly.

Lord Warner, a member of the Dilnot Commission, said that directors of adult social services should ‘cosy up’ with Clinical Commissioning Groups. Even though the health service has its own £20 billion or so challenge, the NHS budget is approaching ten times that of Adult Social Care nationally. Its protected status in terms of reductions in public spending means it has the capacity to support social care beyond the very welcome current NHS support to social care funding.

So what do we mean by integrated care? In reality, it is a variety of arrangements from close coordination of commissioning and provision to organisational merger. Previous governments have looked to joint posts or pooled budgets as a proxy for effective arrangements. However, real success must be measured by improved outcomes for citizens as a result of integration and by the financial benefits. Integration is not an end in itself, but only a potential means of improving outcomes and value.

Joining up commissioning or providing?

The Health Select Committee has proposed one commissioning system. This does not necessarily mean that those carrying out the task have to
belong to one organisation, but that the whole of the health and social care spend for older people is considered together. This makes a great deal of sense.

Integrated commissioning has been characterised in many places by considering jointly only those aspects of care where it is difficult to avoid it. This includes adult mental health and learning disability. But for older people it has often been intermediate care, reablement, and areas of service where continuing healthcare and social care butt up against each other.

Nearly half of local health service expenditure is spent on hospital care. But, the National Audit Office has identified that approximately 30% of those in hospital beds at any one time could receive their care outside hospital.

Similarly, social care authorities spend a significant proportion of their funding on residential and nursing care for older people. Integrated commissioning provides the best opportunity of meeting the aspiration of the vast majority of older people to remain in their own homes and the financial challenges facing health and social care. An understanding of the financial and service benefits of investment in social care could lead to a clear commitment to the transfer of funding to meet those objectives.

The best approach to integrating provision is less clear cut. In health and social care there is an increasing number of providers in a mixed economy of care. For example, in Nottinghamshire direct gross public spend on social care services is £283m of which £226m is spent on well over 300 organisations. How do we join up all this provider activity with health? The fact is we don’t need to integrate in all areas. The key is making sure that services are integrated where there is an evidence base of improved outcomes and better financial performance.

The advent of Health and Wellbeing Boards as system leaders provides a once in a lifetime opportunity to integrate commissioning. The key is to be clear about the outcomes, the costs and the benefits.
These factors don’t apply to England alone, although practice in the four constituent nations of the UK has trended to drift apart as a consequence of different statutory arrangements being set up following the creation of different constitutional agreements. But integration has been a steady theme throughout, as a recent publication* from all four UK social care leadership organisations demonstrated.

Research evidence and the practical experience of directors and social services organisations suggested that there are four critical factors for success:

• A clearly articulated and widely shared vision of ‘why, how and for what benefits?’
• A medium to long term financial strategy that is realistic about costs.
• Flexible organisational arrangements that support a common purpose.
• Attention to matters of culture through effective leadership.

Evidence shows that successful integration relies upon more than a structural or contractual relationship with other key public services. Central to success is the integration of organisational and individuals’ outcomes and customer experience across multiple sectors. Many sectors share the commitment to the principle of promoting independence, wellbeing and self-reliance that sits at the heart of social services. We also have different drivers.

Mutual respect and understanding will lead to better contributions from professionals and improved outcomes for the public. While the report acknowledged different organisational boundaries, systems and strategies, many professional values are shared. And it is these mutually held principles that serve to underpin a set of core organisational and practice behaviours that characterise best health and social care integration. In particular, the report strongly advocates that change needs to start from the individual.
Funding integration

The funding challenge was revealed well by the ADASS’s Budget Survey in summer last year. Since 2010, spending has fallen by 12% in real terms at a time when the population of those looking for support has increased by 14%, with councils over the last 4 years making savings totalling £3.53bn from their adult social care budgets. The consequence can only be fewer people receiving support.23

So far as financing integration, the Better Care Fund (BCF) has been established as the means by which NHS funds can be used, under strict conditions, to buttress social care funding. Although the mechanics of the BCF have been questioned by the National Audit Office, the principle that money can be pooled across the care is powerful and should not be lost.

Clearly, many hospitals have been, and are, worried about their long term survival and short term solvency, while others lack confidence that changes can be achieved or the reductions in hospital beds will be tolerated by the public – or ultimately, supported by politicians.

It is perhaps a reasonable concern that such major changes can be achieved in very short timescales or without some degree of double funding to put new services in place. This issue will no doubt continue to be a central debate as we approach the general election next year.

But, we need to remember that the intention behind the BCF is fully consistent with its use to ensure that vital and essential social care services can be provided. Backing up social care services via using BCF is as crucial a part of prevention as are the moneys specifically earmarked for that purpose.

Running with integration, the BCF and all of what Lord Warner again recently described as the ‘raw politics’ of the health and social care divide, will not be easy. We are 152 top tier local authorities and some 211 CCGs tackling these issues from different bases with widely differing economic, geographical and demographic requirements.
What is imperative in these turbulent times is to keep focused on our purpose: to use the available evidence from the many critiques of the health and social care system and to help fulfil the widely expressed desire of citizens to have their care joined up in the community whilst leaving hospitals to do what they do best: save lives.

Perhaps it is this focus that will enable leaders both nationally and locally to be brave enough to take the bold steps necessary to make the changes to a system that is in danger of lagging behind the demands upon it and the expectations of the people who pay for it.

The model for future integration should be built around the patient and user experience. As National Voices puts it:

‘My care is planned with people who work to understand me and my carers, put me in control, co-ordinate and deliver services to achieve my best outcomes.’

The best vehicle for achieving this outcome is services that meet local needs, through planning across health and social care, housing and wider public, community and voluntary services. This should activate the interest and commitment of commercial organisations in contributing to the activity of the state. We need to build community capacity to enable a contribution to the delivery of care and support.

National policy can ensure a coherent approach and ensure that funding and resources are aligned. But they cannot deliver this approach. Local health and wellbeing boards are well placed to provide both the democratic and clinical impetus to achieve these objectives, given the right investment and responsibility.

It will leave people better cared for, with more choice and control – essential factors in ensuring that we have world-class services to help us face the growing needs in our communities.
FUNDING A FUTURE HEALTH AND SOCIAL CARE SERVICE

RICHARD HUMPHRIES

Whilst there is now broad consensus across the political and policy firmament that integration is the right direction of travel for our health and care system, past progress and future prospects are beset with obstacles arising from differences in the organization, funding, governance, accountability and modus operandi of the two systems.

A particular fault line is that whilst the NHS was introduced in 1948 to universal acclaim – a universal service, used by most of the population and free at the point of use – the genesis of today’s social care system lie in the National Assistance Act with its forbidding opening words “...an Act to eliminate the poor law...”. Sixty-five years later, demographic change, improvements in material prosperity and personal household wealth are seeing rising numbers of people responsible for the costs of social care – a prospect that would have been unthinkable to architects of the welfare state – whilst their health care still remains largely free at the point of use. As more of us live longer – with at least one long-term health condition, dementia and frailty in older age – our needs for a mixture of different kinds of treatment, care and support will be much harder to disentangle into separate ‘free’ and means-tested compartments.

Whilst there has been no shortage of reviews, reforms and initiatives in recent years, none have gone back to first principles to re-examine the post-war settlement and ask fundamental questions about entitlements, the compatibility of universal with means tested systems and the balance of responsibilities between the individual and the state. That is why the King’s Fund established an independent commission, chaired by the economist Kate Barker, to consider whether the health and social care boundary should be redrawn; where entitlements to services could be better aligned across that boundary; and whether health and social care funding should be brought together.
The Barker Commission’s report published in September identified three major systemic problems with current arrangements:

Entitlement to health and social care are not aligned – whereas the NHS is used by most of the population, growing numbers of people are falling outside of the publicly funded social care system, either because their needs are not high enough to meet eligibility criteria, or they are not poor enough to qualify for help.

Funding streams are not aligned – with NHS funded largely through general taxation and a budget that is ring-fenced, social care spending is channeled through 152 local authorities whose financial support from central government is reduced by over 40% in the current spending review period;

Organisational and commissioning arrangements are not aligned, and the NHS reforms have introduced further fragmentation and complexity of how services are commissioned across primary care, mental health, acute hospitals and social care.

The Commission identified a further problem to do with adequacy of social care funding, where we appear to spend less than many other advanced countries.

Important steps have been taken to reform social care funding through the Dilnot reforms and the Care Act 2014. The Better Care Fund aims to protect social care services and promote integration. But neither of these measures is sufficient to address the underlying underfunding of social care or tackle the fundamental differences in entitlement and funding between health and social care services.

It concluded unequivocally that England must move towards a single ring-fenced budget for health and social care, which is singly commissioned and within which entitlements are more closely aligned. The prize of this new settlement is a big one – an end to historical and artificial divides and more seamless services that get much closer to the principle of ‘equal support for equal need’ – irrespective of whether that is clinical or social.
It has stopped short of considering how services should be organized and delivered, as these fall outside of its terms of reference, and has focused instead on entitlement and funding. Nevertheless if the case for a new settlement is accepted the question of how the fragmentation of the current commissioning landscape can be replaced with a single local commissioning arrangement without plunging the system into further reorganisation will be a major implementation issue.

A key proposal is that a much simpler path through the complex maze of the current system should be designed, beginning with straightforward non-means tested help for people with relatively low levels of need (through a new care and support allowance), progress, evolving into formal personal budgets as needs change. For people with very high levels of need – currently defined as ‘critical’ or ‘substantial’ the Commission concluded that all care should be free, thus removing the distress, confusion and inefficiency of the current divide between free NHS and continuing health care and means tested social care. With the next general election drawing closer, there are four distinctive features of the Barker Commission’s thinking that are germane to the evolving policy and fiscal climate:

- a clear commitment to aligning social care entitlements with health (by making care for critical and substantial needs free at the point of use) rather than reducing NHS entitlements, based on the principle of equal support for equal need; the inadequacy of social care funding is seen as increasing obstacle to offering people genuinely joined-up care;

- rejection of new NHS charges and private insurance options – on grounds of equity and effectiveness – in favour of public funding options, including changes to national insurance and a review of property and wealth taxation including possible reforms to inheritance tax, a possible wealth transfer tax and property taxation

- A strong argument that greater investment in care and health is both affordable and sustainable if a staged approach is adopted. Although short-term fiscal prospects are bleak, a longer-term view paints a more promising picture. International and national trends signal a public
willingness to devote a bigger share of national wealth on health care and the resumption of economic growth will make projected future spending estimates look less frightening. The Government should plan on the assumption that public spending on health and care will reach between 11 and 12 per cent of GDP by 2025 (comparable with what some countries are already spending today).

- The principle that the biggest beneficiaries of the proposed new settlement – wealthier older people – should make a significant contribution to its costs through limiting certain universal benefits to the least affluent and redirecting the savings to health and care budgets.

The Commission has addressed head on one of the toughest questions of all about health and social care integration – how do we pay for it. The hard choices about this are so difficult that it will be tempting for politicians to duck them in the intensity of a general election campaign (remember the ‘death tax’ row in 2010?). But doing nothing will further weaken the already creaking NHS and social care system – the next government will need to act as soon as it takes up office to address the immediate financial pressures as well as make faster progress in achieving fundamental changes to services that are widely regarded as being needed.
ENDNOTES

1. NHS England, Five Year Forward View, 2014
4. Section 1, Promoting individual well-being http://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted
11. Care Bill [Lords] Deb, 28 January 2014, c448 http://www.publications.parliament.uk/pa/cm201314/cmpublic/care/140128/pm/140128s01.htm#Column448
12. Demos, The Commission on Residential Care, 2014
18. Cares UK, Need to Know (2014)
19. Census data 2011
20. Presentation to State of Caring Conference May 2014 Tim Anfilogoff, Integration Lead, Herts Valleys CCG

A Problem Shared? Essays on the integration of health and social care

All political parties now acknowledge the importance of more integrated – or person-centred – care. This essay collection discusses how we can develop a system that responds to the needs of a patient in the round – whether in the hospital or the home. With contributions from leading politicians, experts and those on the frontline, the paper sets out views on the future role of commissioners, providers, patients and family carers, and sets out alternative perspectives on future funding for the NHS and social care.