‘Who will care?’

Five high-impact solutions to prevent a future crisis in health and social care in Essex

An independent Commission led by Sir Thomas Hughes-Hallett with Dr Paul Probert

How did you find the solutions?

We agreed from the start a clear approach to ensuring we achieve good answers. The Commission's report is based on eight underlying principles:

1. We base all our recommendations on extensive evidence collected throughout Essex and from talking to others in Britain and internationally who have collected evidence to address similar challenges in other places.
2. We place the interests of the people of Essex above the organisations that serve us.
3. We are frank, bold, and honest in our recommendations.
4. We believe that individuals must take responsibility for their own health care and from an early age.
5. We push back against entrenched interest and conflicts and are prepared to recommend adjustments to traditional working practices and use of buildings.
6. We embrace the benefits of modern technology as has happened in all other walks of life but not always in care.
7. We recommend that all are incentivised in ways that complement each other.
8. We welcome all who can contribute to success from pharmacists to schoolchildren.

By 'Essex' we mean the parts of the county covered by Essex County Council, Southend-on-Sea Borough Council and Thurrock Council.

What is this about?

In January 2013, five independent Commissioners began the task of tackling the single largest challenge faced by the people of Essex since the 1960s – how will we care for ourselves and our communities right now and in the future?

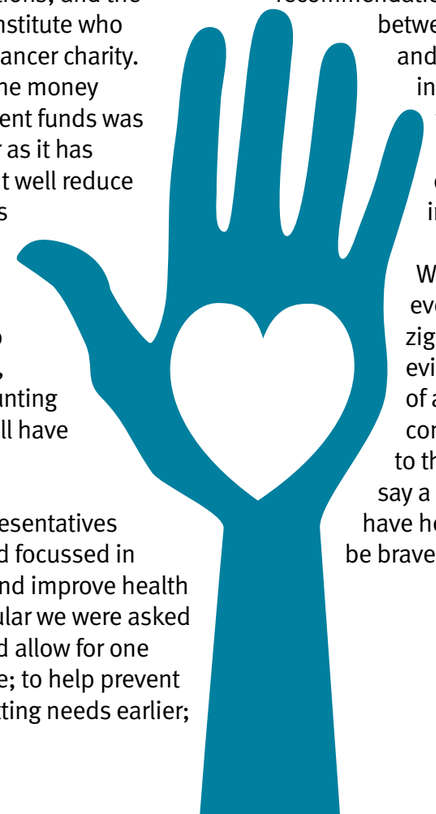
Who will care for us, the people of Essex, when we need support? Our population is getting older, larger in number, and an ageing population has greater and more complex care needs. New government reforms have destabilised and disintegrated further an already complex system of care.

The five of us are a hospital chairman; the chairman of Essex's main community charity; the chief executive of a disability charity; a GP and chairman of one of our new health organisations; and the chairman of an academic health institute who was formerly chief executive of a cancer charity. We recognised immediately that the money available from taxes and government funds was no longer going to grow every year as it has done for the last twenty, and might well reduce just as the need in Essex increases further. In particular we have real concerns about the current political protection of health budgets, which has contributed to cuts in crucial social care budgets, and the likely impact that cost shunting between health and social care will have on citizens.

Our instructions from elected representatives were to be unfettered, creative and focussed in considering how we can sustain and improve health and social care in Essex. In particular we were asked to create the conditions that would allow for one system of care from cradle to grave; to help prevent people needing crisis care by spotting needs earlier; and finally, to understand how all of us in Essex can look out for ourselves and help to support those who need our help most.

We set about this challenge with great enthusiasm and a belief that we would find five high-impact solutions to this very difficult question. We have done that. We believe that each of the five high-impact solutions is practical, and together, if properly carried out, each of you will receive good care when you need it. We have also identified two problems that require urgent further investigation.

There is no option but to take action as otherwise, within the very near future, there will be a real crisis in care for you and your family. Our recommendations set out a new relationship between us as citizens and the state, and explain what needs to happen in order for this relationship to work. It is clear to us that the ability to take more control over our care really is the only game in town.



We have been welcomed everywhere we have visited. We zigzagged across Essex taking evidence from hundreds of people of all ages in libraries, hospitals, community centres, from the young to the most frail. We would like to say a big thank you to all of you who have helped us and encouraged us to be brave, innovative and realistic.

What is this about?

You recognise that there is a shortage of money and you are ready to take on a new responsibility for your healthcare, embrace modern technology, and share your own data for your own good. But you have also said that the NHS, social care, charities and other organisations will have to be bolder, better co-ordinated, easier to access, more convenient, and more flexible with their workforce, if they are to remain supportive of the people of Essex.

You have encouraged us to recommend that if financial resources are constrained that they be targeted to those most in need rather than to 'marginal' benefits such as free spectacles for some. You told us that waste is still common (not least with prescriptions) and services not convenient for you as customers. Many of you now use Google and pharmacists for healthcare advice. You told us that they are available when it is convenient for you, not for them. You wanted pharmacists to receive additional money, while you felt GPs had adequate funding and the wrong incentives.

You want more of the taxpayers' money invested in community services and adult social care and less in hospitals.

You want to know whether we are investing well the significant funding committed to people with learning disabilities.

Many of you have expressed a desire to see stronger, safer, and more supportive communities. This Commission suggests how Essex can embrace a new social movement harnessing the desires that have been expressed to us.

There is much for you to be proud of. We identified so many good examples of great care in Essex, of exciting new innovations, and of communities working together to support each other – but all too often these were in isolated pockets and with little evidence of good practice being shared. But there are encouraging developments taking place including the creation of the Essex Partnership Board to deliver public service reform and an accelerating initiative for collaboration amongst voluntary sector leaders.

As Commissioners, we want to build on the best and the hard work that has already been done by many. No more change for change's sake. We know that Essex is best-placed to be the shining example of care; success will need courage and trust in each other. We hope this report will help Essex achieve that goal.

Sir Thomas Hughes-Hallett

Cllr John Spence, CBE

Mike Adams, OBE

Professor Sheila Salmon

Dr Gary Sweeney

'Who will care?'
Five high-impact solutions to prevent a
future crisis in health and social care in Essex

What are your five high-impact solutions?

Introduction

Our five solutions aim to achieve particular successes:

- a more effective and earlier identification of your needs including support for you to self-identify;
- seamless care and support for all Essex people;
- giving back to you the ownership of your health and care and reducing all of our dependence on the State; and
- value for money.

You told us that crucial to achieving these successes would be making the most of our communities as our most valuable assets. We will need to own and share information about our health and particular needs. We will need to ask the Local Authority and Health commissioners to support achievement of these successes. We need to mobilise Essex's resources to all of our benefit, in a way that is best value for tax payers and rate payers and eliminate unnecessary waste. We need to swap ideas about what works best.

> *'The state, in organising security, should not stifle incentive, opportunity, responsibility; in establishing a national minimum, it should leave room and encouragement for voluntary action by each individual to provide more than that minimum for himself and his family.'*
>
> William Beveridge, *Social Insurance and Allied Services,* 1942

> *'The level of public health corresponds to the degree to which the means and responsibility for coping with illness are distributed among the total population. This ability to cope can be enhanced but never replaced by medical intervention...That society which can reduce professional intervention to the minimum will provide the best conditions for health.'*
>
> Ivan Illich, *Medical Nemesis: The Expropriation of Health,* 1975

The five high-impact solutions

Our first solution:
Agree a new understanding between the public sector and the people of Essex.

The public sector needs to be up-front and honest with us - clarifying the extent of the 'care offer' available to us. We will need to take ultimate responsibility for our own care, becoming key members of the care team – based on the premise that individual care is owned by the people of Essex. The public sector will need to provide core quality services to us, be able to answer questions and to help and encourage us to take on this responsibility whilst guiding us to, and facilitate the provision of, additional sources of support if we need them. You told us that you want to increase your ability to live independently for longer.

To support this recommendation, we call for:

An easy to navigate Citizen's Guide to Care in Essex showing how each aspect of care can be accessed and what the core offering to the citizen comprises. This will be supported by a communication strategy, which will support the desire to create a new contract with the citizen – The "SatNav" of care in Essex.

A new publication, both in hard copy and online, championed by Healthwatch, the body which represents our interests in health and social care. This will give all of us the opportunity to share knowledge about what is best and worst in care services in Essex – The "TripAdvisor" of care in Essex.

The introduction of coaching, training and help lines to allow us to take control of our own health and that of our families. GPs and others will be given the tools to help to support us beyond our physical needs – the "driving lessons" of care in Essex.

A new approach in Essex to the support, acknowledgment, celebration, recognition and reward for informal and unpaid carers and patients who self-manage.

A revolution for the voluntary sector where it reviews, revises and regroups leading to an exciting new offering, supporting us to take ownership of our own care.

Essex to welcome new players and embrace and incentivise greater participation by corporate employers and providers so as to improve accessible, helpful, and customer-focused care services.

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The five high-impact solutions

Our second solution:
Prevent unnecessary crises in care

A new approach to change the focus of care from treating disease and chronic conditions to supporting individuals earlier – preventing crises in care, improving independent living, and creating a responsibility for all of us to identify those most in need of care and support in our communities.

The long term health of families and communities is planned together by us and by those who provide our care and support to ensure that the right care is received in the right place.

To support this recommendation, we call for:

A new record owned by, and accessible to, the individual to be created as a new right for those of us most in need of care and support to allow for advanced planning and improved support at an earlier stage.

The provision of initial intensive care and support when an individual is first identified as being in need of care and support rather than when we reach a point of crisis which in many cases could have been avoided or better planned.

Everyone needing care and support to have the right to choose a co-ordinator/wellness worker to support them in taking responsibility for their care. Communities and the voluntary sector will be encouraged to step into this role but on a new 'person-centred', non-disease based approach.

Essex to support the evolution of Long Term Conditions Centres, nurse led and staffed partly by trained volunteers.

Essex to create online communities to help those of us in need of care and support to live independently and to combat loneliness.

The five high-impact solutions

Our third solution:
Mobilise community resources

A new approach to supporting communities and people – you are Essex's most valuable assets not liabilities! This is not an excuse to make communities deliver care 'on the cheap'. Instead it is an acknowledgement that, alongside occasions when voluntarism can and should play a greater role, there will also be instances where a local approach and local understanding of grass-roots needs can deliver best care, best support, best value, and greater independence for each of us.

To support this recommendation, we call for:

Help for local schemes providing support and care on a voluntary basis – this can include some seed funding, training and information about best practice drawn from other places.

The creation of an Essex-wide organisation embracing paid staff and volunteers so that every household has a team or individual charged with identifying early signs of difficulty, combining concepts such as Health Champions, Neighbourhood Watch, Village Agents, and the current Essex Fire Prevention initiative.

The introduction of a new award scheme for the most vibrant communities in Essex.

Public agencies that commission services to agree longer-term contracts than happen now – one year for pilot projects, but three to five years for services that are proven and essential, subject to annual appraisal of performance. Equally these public agencies should be encouraged to favour consortia of providers to encourage integration of services and better value.

Employers to support staff volunteering.

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The five high-impact solutions

Our fourth solution:
Use data and technology to the advantage of the people of Essex

This needs a new approach to making the most of information and technology. Given advances in recent years, it is surprising that the healthcare economy has not done more to embrace the richness of health and care data as well as technology. Organisations and individuals will welcome the benefits of using data and technology better to support independent living, self-care, and co-ordination and to give more convenient access to good advice. Only one out of more than 700 people we interviewed was unhappy with the concept of total transparency of data between professionals.

To support this recommendation, we call for:

The urgent creation of a simple 'good enough' Essex wide data strategy supported by an IT strategy that enables success and sees the individual as the ultimate owner and custodian of their own health and care record.

Borough, city, district and unitary councils and housing associations to work together to create a housing strategy using assistive technology that will enable people to live independently for longer.

A thorough telehealth and telecare trial in a meaningful population to identify and evaluate the benefits and appropriate design of the packages. This should be in an area of good internet coverage, good mobile signal coverage and with all patients consenting to open sharing of their data.

The five high-impact solutions

Our fifth solution:
Ensure clear leadership, vision and accountability

Clear leadership and accountability are the only ways to deliver better, more co-ordinated care. We recommend that implementation of our suggested solutions should be the responsibility of an Essex care partnership of commissioners and providers operating across Essex. This will bring together key partners from the public, private and voluntary sectors to procure and provide cradle to grave, co-ordinated, and convenient care for each individual. Every incentive must be aligned better to allow this to happen, with a clear vision that brings everyone together. If successful, this care partnership could take on broader responsibilities.

To support this recommendation, we call for:

A care partnership with an independent Chair, governed by the Health and Wellbeing Boards, and operating across Essex to bring together key partners from the public, private and voluntary sectors.

A new culture of collaboration through 'a single pot of money' to deliver the identified outcomes. Permission should be sought from the relevant authorities and regulators to allow for this to be successful.

The partnership to focus with urgency and courage on core areas that pose significant care challenges across Essex:

- *Bringing commissioners and providers together, from hospitals to care workers, to achieve the best care, best access, in the appropriate setting, cared for by the appropriate people and at the best value to the taxpayer;*
- *Allowing us to share our data;*
- *Identifying earlier those most in need and most likely to require care;*
- *Making the most of our communities and all our assets; and*
- *Creating a county-wide strategy to support us to take control of our own health and care and make the most of recent technologies to enhance the support provided.*

Investment in the leadership team and the building of trust between us, including working with non-executive mentors from customer-facing organisations.

The integration of provision – in other words make services less fragmented, easier to navigate, and hence better value for money. Commissioners will incentivise providers to work together rather than driving them apart through divisive tendering processes.

Whenever a new service is commissioned another should be decommissioned. Commissioners should be encouraged to identify non-core services now.

Commissioners should be supported to consider greater flexing of the workforce.

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The five high-impact solutions

Two thorny problems

The Commission also wants to make two recommendations to problems that need urgent answers.

We call for root and branch reviews to be carried out where you have expressed dissatisfaction with services and concern about value for money. These services are:

1. Appropriate hospital discharge - are Essex citizens being discharged properly from hospital? And are they being discharged to the place they want to go?

2. Learning disabilities - are services for people with learning disabilities and their families optimal given the large financial investment made? We heard few if any compliments from families and service providers alike.

We believe the answers to both questions require a radical rethink by bringing together all interested parties to create new solutions. The new care partnership we propose could lead on these issues as well.

	NOW	2014	2015	2016
Understanding	Ongoing: campaign to create a new contract with the people of Essex Autumn 2013: GPs begin to make greater use of social prescriptions, helping us deal with issues beyond the physical Winter 2013: voluntary sector begins to review how it does business, grounded in the principle that our well-being is our responsibility	Spring 2014: launch the *Citizen's Guide to Care in Essex* Spring 2014: extension of coaching, training and helplines to support self-management By mid 2014: introduce a scheme supporting and celebrating carers and those who self-manage By end of 2014: health TripAdvisor Essex launched by Healthwatch Essex	Government changes tax policy to no longer penalise those who save for their disabled children's future	
Prevention	Autumn 2013: begin identifying the 20 per cent of Essex residents most in need of care and support Winter 2013: ensure intensive initial support is in place for those considered most in need of care and support Winter 2013: promotion of online communities to help those in need	Commissioning of new services for those most in need of care and support underway Spring 2014: first nurse-led and volunteer- supported Long Term Conditions Centre opens Spring 2014: introduce a care record owned by Essex residents not public agencies and designed to allow for advanced planning and improved support	Across Essex, every person needing care and support has the choice to appoint their own co-ordinator or wellness worker	
Community	Ongoing: implement community schemes, drawing on local knowledge and appetite - bolstered where apppropriate Winter 2013: consortia of organisations encouraged to collaborate and jointly bid for services By Winter 2013: large employers commit to promoting volunteering and community activity to their staff	Spring 2014: move toward 3-5 year contracts for services commissioned by public agencies Spring 2014: Create village/ town/community groups to care for groups of households End 2014: 1,000 individuals each look out for 600 households End 2014: inaugural '*vibrant communities*' awards for Essex neighbourhoods	End 2015: 1,500 individuals each look out for 600 households	
Data and Technology	In Autumn 2013: begin development of Essex-wide data strategy	Spring 2014: agree telehealth and telecare sites End 2014: housing strategy supporting assisted technologies in place across Essex	Throughout 2015: implement and assess progress at telehealth and telecare sites whilst lobbying for improved connectivity across Essex	Patient-owned records are the default across Essex Early 2016: if appropriate, roll out telehealth and telecare across Essex
Leadership	In Autumn 2013: a Care Partnership is created, develops a common approach to care and begins work on the core health and social care challenges By Winter 2013: business leaders begin mentoring health leaders in Essex - part of the development of a trusting leadership team	January 2014: integration plans agreed Early 2014: 'permission to innovate' granted September 2014: begin measuring success Throughout 2014: integration of provision begins - an ongoing drive to make services less complicated Throughout 2014: decommissioning of non-core services alongside commissioning of new activity Throughout 2014 and ongoing: those providing services are incentivised to work better together	By January 2015: clear progress and improvement in the Care Partnership's areas of focus A culture of measurement, comparison, learning and improvement is in place April 2015: one pot of money alongside one set of outcomes By Winter 2015: a common, collaborative leadership across the Essex health economy	Cradle to grave co-ordinated and convenient care is the norm in Essex

What is the problem and how serious is it?

The problem is a simple one. More people need care and there is not enough money to go around.

> *'In the past 50 years, spending on the NHS in the United Kingdom has increased from 3.4 per cent to 8.2 per cent of gross domestic product (GDP). If the next 50 years follow the same trajectory, the United Kingdom could be spending nearly one-fifth of its entire GDP on the public provision of health and social care.'*
>
> John Appleby, *Spending on health and social care over the next 50 years. Why think long-term?*, The King's Fund, January 2013

Across Essex, publicly-funded health and social care organisations are facing budget pressures. In plain English, some organisations' budgets will reduce, for others the amount of money they have will increase but not quickly enough to meet the increased demand for services.

The money in the system needs to go further. The number of us who make use of health and care services is increasing. Why is this?

For one thing, we are living longer. More people than ever before are living well into retirement. The average baby born in Essex today can expect to live to 80 if they are a man or 83 if they are a woman. This compares to 66 and 71 for men and women born in 1948.

But averages can be misleading. Essex is already home to some 300,000 over-65s – and many people will live long beyond the *'average'*. There are around 36,000 over-85s in Essex. That number is equivalent to a large market town and the figure will more than double in the next twenty years.

We might wish for an active, healthy retirement, but for most of us, the last years of our lives – whether they fall in our fifties, sixties, seventies, eighties or beyond – will see us increasingly frail and increasingly unwell.[i] The average Essex resident in their mid-80s will have three to five illnesses when they die.

Whilst NHS health care is free, many of us pay for our own social care.[ii] Those that don't, look to local councils to provide care. This care is paid for through general taxation. Some have suggested that public spending on social care alone will need to triple over the next twenty years to keep pace with our ageing society – at precisely the same time as the number of us in work is reducing.[iii] There is little evidence to suggest that this is possible. A declining number of taxpayers are being asked to fund health and care services – it is a burden they may struggle to bear.

But this isn't just about people *growing old*. It's about people *getting older* as well. Advances in public health and in medical technology alongside improvements in baby units mean that illnesses and conditions that, as recently as the 1960s, saw babies, children and teenagers die, no longer lead to as early a death. There are men and women alive in Essex today who would not have reached adulthood even a generation ago. Improvements in battlefield medicine also mean that more young men are returning from tours of duty to garrison towns like Colchester with significant physical disabilities.

We should welcome these improvements in medicine. However it does comes at a cost – one that few Essex residents are aware of. For example, the average annual cost to the taxpayer of caring for someone with Learning Disabilities is more than £50,000. This compares to £10,000 typically spent each year on an older person receiving social care.

This difference is significant both in cost and in duration. An older person may receive social care for four years. A child with Down's syndrome can now be expected to live into their 60s – compared to a life expectancy of only twelve years a century ago. It is not unusual for some children with learning disabilities to receive more than £2,500,000 worth of care over the course of their life.

> *Learning Disabilities - a learning disability affects the way a person understands information and how they communicate. This means they can have difficulty:*
>
> - *understanding new or complex information;*
> - *learning new skills; and*
> - *coping independently.*
>
> *Up to 4,000 people in Essex have severe learning disabilities. This figure is increasing.*

We expect the number of us in Essex needing social care support to grow from 35,000 now to more than 137,500 by 2030. The increasing number of older people needing care, and the cost of supporting a smaller but growing number of children and adults with care needs are two difficult challenges. To these we can add the consequences of us living less healthy lives.

Although there is some frustration at public health messages - *'we've had it pushed down our throats for so long'* as one Basildon resident put it – poor personal choices will likely catch up with those of us who over-eat, drink too much, or smoke (or all three) sooner rather than later.[iv]

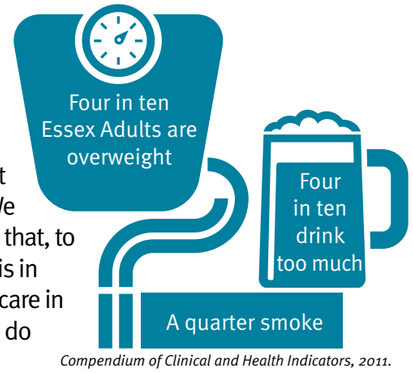
> ***Co-morbidities*** *– co-morbidity means having more than one long-term health problem - for example, high blood pressure and diabetes, or high blood pressure, diabetes, and heart failure.*
>
> *One disease may make another worse, and the combined effect of all the diseases may be more than each on its own.*

It is not a given that if someone is obese they will also have Type 2 diabetes and heart disease, but there are a growing number of us whose personal choices make it more likely that they will suffer from two or more diseases – diseases that are often avoidable.

More people living into old age, more people living longer and more people living unhealthily are creating a real problem for Essex.

We need to recognise that, even if public spending were to increase, it would struggle to keep pace with the scale of the challenge posed by our changing population.

We need to recognise that, even if we wanted to, we could not spend our way out of the problem. We need to recognise that, to avoid a future crisis in health and social care in Essex, we need to do things differently.



Compendium of Clinical and Health Indicators, 2011.

Almost one-fifth of 10-11 year olds in Essex are obese
(source: NHS Information Centre, 1st June 2012)

What can we all do to help?

Failing to care for yourself is, in the hard-hitting words of one Brentwood resident, a *'self-inflicted wound'*. Our health is our responsibility – or to put it another way: your health is your responsibility.

This is a straight-forward way of recognising that public agencies can play an important role in *helping* individuals to live well but they cannot *make* individuals live well. The primary responsibility for leading a healthy life rests with us as individuals. Although this transfer of control and ownership may trouble some professionals, the evidence we have taken across Essex has convinced us that the residents of Essex believe that their health is their responsibility.

> *'The person is responsible – not the government, not the local health system.'*
>
> Essex resident,
> Pitsea, June 2013

We need to think about our wellbeing and how we can live better. We should focus not on what we can't achieve, but rather on what we can. Each of us has the power to improve not only our own life but also the lives of others.

Importantly, we are not alone. We should be supported by the state, by business, by the voluntary sector, by our communities and our neighbours. Ensuring our health and wellbeing is not a task for local authorities alone, any more than it is the sole preserve of GPs, of Clinical Commissioning Groups (groups of GP practices responsible for commissioning many health and care services for patients), or of hospital trusts (bodies managing NHS hospital care and providing hospital-based services). Our health and wellbeing is best ensured by us as people, communities, and public, private and voluntary sector organisations working together across health and social care.

Those public bodies responsible for taxpayer-funded health services need to take the principle of *'our health, our responsibility'* to heart. The services they offer must meet the needs of the people, not the preconceptions of those who draft current tenders for services. The Commission is convinced that we, the people, own our health.

Employers, as a whole, need to promote not only the health and safety, but also the health and wellbeing of their staff. People spend much of their time at work, and wellness at work matters. Generally, healthy employees are more productive than unhealthy ones; their wellbeing contributes to business success.[v]

The Commission calls on organisations across the county to do whatever they can to promote the health and wellbeing of their people, convinced that there is a strong business case – and a moral imperative - for keeping employees healthy.

It is not only at work and at home, but also in our immediate neighbourhoods, that we can make a difference. We should encourage schools to create voluntary street schemes for those of us most in need of care and support in their catchment area and to provide basic health training for students.

Through the work of the Commission, we have already been able to bring about two neighbourhood pilots in Canvey Island and North East Chelmsford – grass-roots community programmes designed to make a difference on a street-by-street basis.

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What can we all do to help?

Speaking to a group of Essex teenagers who were either at work or studying, we asked if they would consider helping someone in need. One, concerned about the potential long-term commitment, said *'I'd like to think I would, but I wouldn't … after getting in from work there's too much to do';* another, recognising the disproportionate value of small-scale acts of kindness, justified her willingness to help by comparing what else she might have done instead: *'half an hour a month … that's only one episode of EastEnders'*.

We all need to make choices about the extent to which we help each other, but we are convinced that if we want our local area to be better, we are the people best-placed to make the change.

> *'They, Rita and Bob, my father's neighbours, always look out, keeping a really good eye on him. We're really grateful to them … I work, I do shifts at Broomfield hospital… I can't be there all the time, knowing there is someone just over the road keeping an eye, it's a great comfort. My brother and I really appreciate what they do.'*
>
> Ann, Great Totham
> *Dave Monk Show,* BBC Essex,
> 16 July 2013

Health and Social Care - a beginners' guide

For many of us, it is difficult to understand what aspects of our wellbeing are health-related and which are social care-related. We have yet to meet any citizen who welcomed (or understood) a health and social care split. However, the system operates on two distinct models, one dealing with health, one dealing with social care, so it is helpful to understand what happens where.

Health – although many private companies provide healthcare for those willing to pay for it, for the vast majority of us, the NHS is our health service. Founded sixty-five years ago, the NHS provides a range of services from ante-natal screening (before the cradle) to end-of-life care (very nearly the grave). GP surgeries, operations, out-patients' clinics and most hospitals are all part of the health system.

Leaving aside some charges – such as prescriptions, spectacles and dentistry – we do not pay for the NHS when we use it. Instead NHS services are funded through general taxation – at a cost, in Essex, of more than £3 billion last year.

Whilst a majority of Britons view the NHS as the *'envy of the world'*, as we move further away from 1948, there is growing concern that the NHS is primarily focused on dealing with 'illness' rather than promoting 'health'.

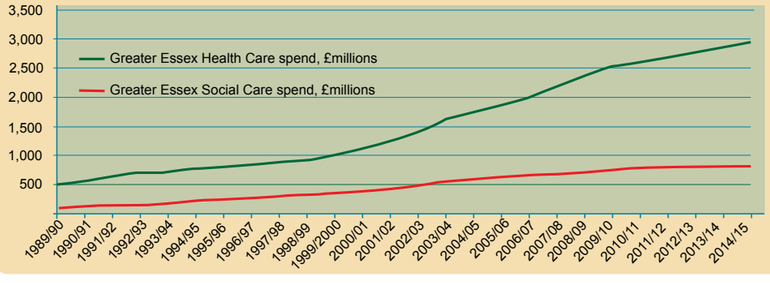
Social Care – by contrast, there is no simple definition of social care. It covers a wide range of services - like help with washing, dressing, feeding, or assistance in going to the toilet, meals-on-wheels, day centres, and home-help for people with disabilities. Councils, charities and companies provide social care services to frail older people, to those with mental health problems, to those with physical disabilities and to those with learning disabilities.

Unlike the *'free at the point of delivery'* NHS, and unlike children's social care, adult social care is means-tested – in other words, the amount you pay for care depends on the amount of money you have, with those with savings of over £23,250 having to pay for all their care. From 2017, there will be a limit of £75,000 to the amount of money an individual will need to pay for elderly care before receiving free social care support from their council, funded by tax payers.[vi]

Although spending on social care has increased significantly over time, the number of us receiving services has reduced - the result of stricter eligibility criteria and more complex care needs.

Regardless of the sector, spending on both health and social care has increased significantly over recent years:

Health and Social Care spend over 25 years



For the foreseeable future, public spending increases will be less pronounced. The government has committed to protect NHS spending, whilst reducing local government funding. Although not the full picture, this means that NHS budgets will increase by 4.2% between 2010/11 and 2015/16, compared to a 35% reduction in grants received by local government.[vii]

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How you would allocate public funds – creating a People's Care Budget for Essex

The background – In June, 100 Essex residents came together in Basildon and Braintree to debate the future shape of care in Essex. These residents, chosen to be representative of Essex communities as a whole, then decided how they would spend almost £3.4 billion of public money currently spent within the health and social care system in Essex.

The process – Across high-level categories – covering both health and social care services – participants were given an overview of the service provided, the associated budget, the cost per resident and the cost per recipient of service. In groups, participants then began the process of discussing and agreeing Essex's care budget. They were not asked to cut budgets, and instead focused on re-allocating money between services.

The result – There was significant agreement that a care system across Essex should focus more on community activity and preventative work than is currently the case.

GPs were viewed as increasingly unresponsive and difficult to see at times that worked for residents – by contrast, budgets for pharmacists were increased given the improved customer-focus they offered. Prescription costs were considered too high and there was surprise and frustration that cheaper generic drugs were not more widely prescribed.

Increased expenditure on public health, a range of social care services, and community health services gave residents the confidence to reduce hospital budgets (aside from maternity and A&E services) reassured that preventative services were in place.

Activity	Current spend	New spend	Difference
	£m	£m	% change per category
Public Health	64	79	23.44%
Older People Social Care	317	360	13.56%
Mental Health	261	270	3.45%
Learning Difficulties	253	253	0.00%
Physical Impairments Social Care	64	70	9.38%
GP Services	249	235	-5.62%
Prescribing Costs	266	219	-17.67%
Dentistry	94	94	0.00%
Opthalmic Services	16	19	18.75%
Pharmacies	68	85	25.00%
Maternity	79	89	12.66%
General and Acute	1,323	1,217	-8.01%
Accident and Emergency	59	66	11.86%
Community Health Services	263	321	22.05%
	3,376	3,377	

figures may not sum due to rounding

What is the detail behind your high-impact solutions?

Our first solution: Agree a new understanding between the public sector and the people of Essex

Whilst discussing health and care with the people of Essex over the last nine months, we have taken evidence from hundreds of people. They ranged in age from teenagers to nonagenarians - some were in rude health, others were living with chronic illnesses. They represented the public, professionals, practitioners, and a range of organisations, statutory and voluntary, national and local.

Whilst the people were diverse, two things united them. Firstly, although many praised the health and care system, everyone believed it could be improved. More worryingly, not one of them understood what the health and care system could and would provide.

> *'People don't have a clue. They really don't know what care and support is out there.'*
>
> Charity worker, Benfleet, May 2013

People didn't know what was available or who provided it. A Basildon resident summed up a common belief when he said *'we've all paid into the National Health Service and we expect to get something back in the later years of our lives'*. Yet if we confuse the 'free' NHS with the means-tested social care system, the financial reality of paying for our own social care can come as, at best a shock, at worse an impossibility.[viii]

If we do not make some provision for our own future care, our old age will be much bleaker than it need be.[ix] If we spend everything and leave the state, in the memorable words of one Leigh-on-Sea resident, *'to pick over the bones of my carcass'* then no-one will win: as individuals we will receive care only if we are truly frail; as taxpayers we will be faced with an ever-increasing social welfare bill.

This matters enormously. If we do not understand what is available to us, we will struggle to make the right decisions. The health and care system is too complex by far and the reality is that most of us give more thought to our new mobile phone contract than we do our health. This means that the first time we think about health is at the moment of crisis – precisely when we are least able to make effective decisions.

Luckily, all is not lost. One Essex resident who attended a session at Broomfield Hospital hit the nail on the head: *'a lot of people can make informed choices, if they have the information'*. We are more than capable of understanding our wellbeing and deciding what would work for us. We simply need the public sector to help us navigate the system.

The state needs to be clear and up-front with us about the realities of health and care. This is why we call for the production of an easy to navigate *Citizen's Guide to Care in Essex* showing how each aspect of care can be accessed and what the core offering to the citizen comprises. This will set out:

- what we can expect the state to provide for us all;
- what the state will provide for those who are in specific need;
- what other organisations can offer; and
- what we – as individuals – can do for ourselves.

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Our first solution: Agree a new understanding between the public sector and the people of Essex

To show how the idea of a *Citizen's Guide to Care in Essex* might work, we look at three areas: wound care, reablement services and end of life care.

	Wound Care	**Reablement services**	**End of Life Care**
What we mean	*Dressing of wounds, frequently for older people with co-morbidities such as dementia or diabetes – preventing potential loss of limbs or death through septicaemia*	*Service to help people get 'back on their feet' following a medical episode*	*Care and support for those who are dying*
What we can expect the state to provide for us all?	• Dressing and undressing of wounds at specific intervals – typically at a GP surgery, hospital or district nursing centre	• Nothing – service based on likelihood of benefitting from reablement, rather than a universal right	• Regular assessment of patient's needs • A coordinator for the patient to guide them through their journey, signposting patients and families to the full range of services • Social care needs of a patient after they are added to an end of life locality register
What the state will provide for those who are in specific need?	• If you are considered housebound, the service will be provided in your home - but frailty can mean greater risk of infection	• Interim service limited to maximum of six weeks – free to anyone who could benefit from reablement • Support could range from grab rail to microwave oven	
What other organisations can offer?	• Voluntary sector can provide assistance	• Voluntary sector can provide assistance	• Bereavement care • Spiritual care • Complementary therapies • Support for carers and families • Information and advice • Respite care for adults • Play therapy, and other similar interventions
What we – as individuals – can do for ourselves?	• Pay for private care at a place and time of your convenience	• Supplement the state package, by purchasing more / longer care visits • Buy general care, physiotherapy, occupational therapy, specific equipment or 'nice to haves' such as massage	• Pay for additional nursing care • Provide support and care

Our first solution: Agree a new understanding between the public sector and the people of Essex

To ensure that this understanding becomes part of the fabric of Essex life, **Essex must create a communication strategy, which will support the desire to create a new contract with the citizen.** This strategy will provide signposting advice and information about services from all sectors and highlight best practice from across the county and elsewhere. This strategy should take maximum advantage of all forms of media and be accessible to all.

The *Yellow Advertiser* for Southend, Leigh-on-Sea and Shoeburyness ran a fantastic supplement in March 2013 highlighting how people can avoid going to A&E and giving self-management, and pharmacies as possible alternatives and Southend Clinical Commissioning Group have published an excellent and comprehensive guide with the same aim.

We have been struck by the way in which you find out about your options for care. Too often guidance is given at the wrong time and in the wrong place. Deciding appropriate care when someone is at their lowest ebb can lead to the wrong care. Instead guidance should be available not only at the moment of crisis but whenever it is needed.

There is plenty of evidence to prove that self-management can work – reducing costs and improving quality of life. Professionals need to give us the tools to manage our own health. **We want to see the introduction of coaching, training, and help lines to allow us to take control of our own health and that of our families.**

This isn't fanciful. In Mexico more than one million households already pay $5 per month to access a health advice hotline before setting foot in a doctor's office. Facilitated networks like www.patientslikeme.com help patients monitor and manage their own conditions, sharing information about what works well. [x]

> **Self-management** – extensively monitored patients with chronic illnesses can learn to manage their life better and cope with their disease.
>
> Participants reported improved health, less distress, less fatigue, more energy, and fewer perceived disabilities and limitations in social activities after the training. Healthcare costs also fell.
>
> *BMJ,* 2011

As individuals we have a responsibility to care for ourselves. This is fundamental if we are serious about our health. We need to acknowledge this responsibility and do much more to make it easier to self-manage. This means **giving GPs and others the tools to help support us beyond our physical needs** (such as the social prescription scheme run by the Colchester CVS in North East Essex and the Reading Well Books on Prescription scheme run through Essex libraries). It must also mean a greater acknowledgement of the role of carers who do so much to care for friends and family but are frequently overlooked and overburdened.

Professionals can provide guidance and expertise but we, as the people of Essex own our own health and wellbeing - it is up to us, not professionals, to decide what will work for us.[xi] **Healthwatch Essex should champion a consumer 'magazine', in print, online and across other media that will give all of us the opportunity to share knowledge about what is best and worst in care services in Essex** – if

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TripAdvisor why not health TripAdvisor Essex?

The concept of patients as partners isn't a new one,[xii] but all too often the professional continues to take a medical / clinical perspective that sees us as a series of conditions to be dealt with rather than us as the primary owner of our health and wellbeing and a co-producer of our own care. Financial and demographic pressures provide added impetus for professionals to make the cultural leap from patient to person-centred care. In 2008, Lord Darzi warned that:

'If the NHS remains a primarily reactive service, simply admitting people into hospital when they are ill, it will be unable to cope with the increased demands of an ageing population. Our longer life spans require the NHS to be forward-looking, proactively identifying and mitigating health risks.' [xiii]

Five years on, this assessment is more valid than ever.

We believe there should be **a new approach in Essex to the support, acknowledgment, celebration, recognition and reward for informal and unpaid carers and patients who self-manage.** The Commission wants to see self-management and informal caring become a new social norm as we take greater responsibility for ourselves, our families and our friends.

We were surprised that efforts to take greater responsibility often ran up against unintended consequences. In Canada it is possible to take advantage of Registered Disability Savings Plans, contributions to which do not affect disability benefits and are also match funded by the federal government. In Britain, by contrast, any investment in a trust fund for a disabled child would be taxed once income exceeds £10,900. It seems peculiar that an individual can make a donation to the UK disability charity SCOPE and claim tax relief but when they set up a trust fund for their own disabled child they pay tax.

> **Registered Disability Savings Plans** - in 2008, Canada became the first country to introduce plans to provide security, independence and quality of life for a disabled person, with no loss of benefits.
>
> The plan is owned by the individual beneficiaries. Family and friends can contribute up to $200,000 over a lifetime, with earnings growing tax-free.
>
> Government adds up to $3 for every $1 privately invested. 75,000 people have accounts with a total of $1 billion in savings.

The voluntary sector could be encouraged to identify how it too can best support Essex people to take responsibility for their own healthcare – an opportunity for the voluntary sector to review, revise and regroup, leading to an exciting new offering, supporting us to take ownership of our own care. We were delighted to learn that a group of voluntary sector leaders has been formed and meets regularly - this could be the perfect forum to carry out a mapping exercise of additional services that are required to enable good 'whole-person' care to be provided for all.

We were struck by the willingness of Essex residents to consider new ways of meeting their health and care needs. Commissioners must follow suit. There was a strong support for the principles underpinning the NHS, but an equally pragmatic

Our first solution: Agree a new understanding between the public sector and the people of Essex

approach to using providers from a range of sectors – be they public, private and voluntary.[xiv] Given the demographic challenges facing us we need to use everything at our disposal to ensure health and care services are as good as they can be.

The role of the pharmacist and of Google is seen as key by many Essex people – and increasingly more accessible, helpful, and customer focused than many existing services. **Essex should welcome new players and embrace and incentivise greater participation by corporate employers and providers so as to improve accessible, helpful, and customer-focused care services.**

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Our second solution:
Prevent unnecessary crises in care

One Braintree resident summed up the reason behind this recommendation in a single sentence: *'prevention is not only better than cure, it is also more cost-effective'*. Unnecessary crises are both expensive and unpleasant. We should avoid them wherever possible.

The problem is that we spend much more dealing with acute episodes and chronic conditions (long-lasting conditions that can typically be controlled but not cured) than stopping, or at least delaying them.[xv] One Colchester charity went so far as to say that *'there is no preventative work – only crisis intervention.'* We need to change this focus from treating disease and chronic conditions to supporting individuals earlier, whilst also emphasising the responsibility for all to identify those of us in our communities who are most in need of care and support.

What price a bed? - having the right care in the right place matters enormously.

Taking evidence, there was considerable frustration from relatives who saw family kept in hospital unnecessarily.

What is more, these stays are also much more expensive than caring for someone in a more suitable setting - as these figures for weekly costs show:

- *Hospital* - ***£1,750***
- *Residential care* - ***£525***
- *Home* - ***£140***

Keeping someone in the wrong place can cost the taxpayer twelve times as much whilst reducing individual quality of life at the same time - an unwanted double whammy.

When we asked Essex residents to reallocate almost £3.4billion spent on health and social care in Essex last year, so as to create their own health budget, the logic of prevention was quickly understood. A greater focus on keeping people in our community and away from expensive medical settings resonates clearly with our budget makers.

Your gut instincts are supported by academic research. One example, looking at end-of-life care, demonstrated that home-based nursing can reduce hospital use at the end of life and help more people die at home.[xvi]

Long before there is a need for end-of-life care, one way to help limit health crises is to know who is likely to experience a crisis. At present, the state does not know who is most in need of care and support. Individual public agencies know their clients, but there is limited sharing of intelligence between agencies. Essex Fire and Rescue Service has told us that while they install and check smoke alarms, they are unable to know who the people are who are most likely to burn to death in their homes. The reason? A reluctance from GPs to share this information based on the belief that legislation prevents them from doing so.

We call for **a new record owned by and accessible to the individual to be created as a new right for those of us most in need of care and support to allow for advanced planning and improved support at an earlier stage.**

Our second solution:

Prevent unnecessary crises in care

'International best practice suggests that control by a patient is best achieved through the agreement of a personal care plan. In Germany, nearly two-thirds of people with long-term conditions have a personal care plan, whereas the same is true for only a fifth of people in this country. Care planning creates packages of care that are personal to the patient. It involves working with professionals who really understand their needs, to agree goals, the services chosen, and how and where to access them.'

High Quality Care for All, Department of Health, 2008

Access will be given to all approved professionals including fire officers, flood defence teams and police, by the individuals themselves - bureaucratic concerns about data sharing must not be allowed to stop this early identification.

Essex should make increased use of predictive models of health and care needs – we know certain factors (falls, for example) are often early indicators of future needs.

This early identification of the 20% of us most in need of care and support will require services to be commissioned to provide care to this newly mapped picture of vulnerability. What's more, it will bring about a new emphasis by **initial intensive care and support when an individual is first identified as being in need of care and support rather than when we reach a point of crisis which in many cases could have been avoided or better planned.**

The pilot scheme being conducted at Mountnessing Court in Billericay for dementia patients aims to reduce the need for going to acute hospital or reducing the stay there, and enables patients to return to their home environment and prevent premature long term care.

Everyone needing care and support shall have the right to choose a co-ordinator/wellness worker to support them in taking responsibility for their care. Communities and the voluntary sector will be encouraged to step into this role but on a new 'person-centred', non-disease based approach. The Commission thinks this could be fertile ground for a more adventurous use of focussed personal budgets.

There is a clear role for both public health and community-based services to work to keep us away from the wrong part of the care system (typically Accident and Emergency departments) and to provide better support after leaving hospital. Certainly the case for intensive care and support is as equally valid immediately after hospital discharge as it is upon initial identification as someone most in need of care and support.

There is great scope and need for a new skilled workforce to support this recommendation. Our engagement with Essex residents suggests that this is an area where the voluntary sector can have real impact but only on a co-ordinated basis.

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Prevent unnecessary crises in care

Health Champions - in North East Essex, some 400 Health Champions work alongside employed Health Trainers to support local communities and individuals to make healthier choices.

Anglian Community Enterprise recruits Health Champions from the communities in which they work.

The Health Champions initiate, develop and run local projects, supporting individuals to access support and services, attend community events to promote healthy choices, and, through Youth Health Champions, volunteer in local schools.

The Commission has also been struck by the potential for schemes like the Long Term Conditions Centre under development in Castle Point. This approach would create an environment where personal responsibility, with targeted support, would seek to educate and improve both the health of patients with long-term conditions, their carers and their families.

By adopting an approach that sees health as primarily the responsibility of the individual, the Centre would be able to work with the individual to improve their wellbeing, whilst reducing the demands they would otherwise have placed on more costly acute services. We believe **Essex should support the evolution of Long Term Conditions Centres, nurse-led and staffed partly by trained volunteers**, which blends a flexed workforce and community support to prevent unnecessary crises.

Speaking to the people of Essex, we have been made aware of a paradox. By making it difficult for you to help each other, public agencies are gradually weakening our confidence, as individuals, to do the right thing and look out for each other. The result, as one Clinical Commissioning Group Chair put it, is that we *'end up a million miles from self-sufficiency'*.

Clearly, we cannot rely on the state alone to look out for our neighbours most in need of care and support. This responsibility must rest with anyone who wants to live in a compassionate society. We need a new relationship between state and citizen where we plan together the long-term health of our families and communities knowing the limits of the core offering.

We outline ways to help communities play a greater role in the next section of our report but want to emphasise the part we can all play in helping those of us most in need of care and support. We need to use whatever tools we can to look out for each other. By way of example, **Essex should create online communities to help those of us in need of care and support to live independently and to combat loneliness.**

By way of examples, Tyze and Rally Round are both personal on-line networks controlled by the patient/client, close family member or friend and all network members have to be invited to participate. A network could be built for an elderly adult who has suffered a stroke so that care providers and a large circle of family and friends can provide companionship, monitoring and system navigation. NESTA and others have demonstrated such networks can combat loneliness and offer independent living to those who might otherwise be in residential care.

Our third solution:
Mobilise community resources

Again and again across the county, the Commission heard from people wanting to return to a time when neighbours knew and helped each other.

There is a problem, though – we cannot go back to *'the good old days',* assuming they ever existed. Times have changed. So have our neighbourhoods. We need a solution that will work in 2013, not one which made sense in 1953.

Luckily, across Essex, the Commission has seen what it considers to be a possible solution - a real desire for our streets and communities to be better places to live. What's more, the people of Essex recognise where the buck stops – in the words of one Basildon resident who spoke of the need for more neighbourliness: *'it's only us, the people who live in our communities, who can do this.'*

This is fortunate because we do not have an alternative. Having set out its core care offer, the state needs to look at what happens in communities and within neighbourhoods as valuable and complementary to its own provision. Local and national government needs to be careful that it does not throttle voluntarism at birth by excessive regulation.

Little acts of kindness - working with the 'Who Will Care?' Commission, individuals have come together in Canvey Island and North East Chelmsford to make a difference in their neighbourhoods.

On a street-by-street basis they will test a new concept of neighbourhood watch - CareWatch. Their experience to date suggests that what matters isn't organisations and structure but the commitment of people within their communities to make a difference.

We have been told that the NHS is free at the point of delivery but have often mistaken this to mean that healthcare is free. It isn't. What's more, there will likely be less to go around as demand for services grows. The voluntary sector needs to pick up some of the slack. And so do we as individuals.

Formal volunteering has a role to play but we are convinced that the formality of being a 'volunteer' can get in the way of community action. As one Rochford resident put it, many local volunteers have *'never been near a volunteer bureau... they just want to help their community'*. Individuals need to cherish this independent civic pride. Public agencies need to find ways to nurture it –and with eight out of ten local associations unknown beyond their local patch, local knowledge is critical.

To support this civic pride, we want to see **a new award scheme for the most vibrant communities in Essex.** These awards should be financial to help local schemes grow and will be replicated in other communities. Healthwatch should award prizes in partnership with borough, city, district and unitary councils - Essex's (largest) employers could be encouraged to fund these awards.

'We know that loads of really good things happen in communities. And these examples show everybody - from young professionals, to gap year students to older people themselves - wants to be involved in supporting their community.

Governments by their nature must think big. But the challenge of supporting well-being through care and support is to think small, think local. It is in the small places that the greatest triumphs of social care take place.'
Norman Lamb, Health Minister, July 2013

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Employers to also support staff volunteering. We heard that Essex employees would welcome protected employment time to allow them to participate in care in their local communities. Staff from statutory services will be given protected time to work in voluntary care services and local communities – other businesses, not just large corporates but smaller businesses as well, should look to do the same.

Just because something is done by a community or by a charity doesn't mean that it is done for free. Of course, there will be some things – such as the 'little acts of kindness' currently happening through our community action pilots – that don't come at a cost, but for many other activities, funding will need to be found.

West Essex Mind's Befrienders are a dedicated team of volunteers who are an invaluable source of extra support when people's plans for recovery require that bit extra. There are currently 45 Befrienders supporting people with their person-centred plan.

Although Befrienders are volunteers and therefore this is a low cost intervention, it should be remembered that there is a cost involved in delivery. The success of projects such as this is down to having the appropriate training, policies and procedures, expenses and on-going support for the volunteers involved.

This money might not come from the state – there is much greater scope for individual and corporate philanthropy – but the Commission believes that if public agencies value a specific project or activity, they should consider funding it. What is more, this funding should be sufficient to make a difference.

The Commission believes there should be **help for local schemes providing support and care on a voluntary basis – this can include some seed funding, training and information about best practice drawn from other places.** District councillors, mayors, faith leaders, school governors and other local leaders have a critical role to play here.

The other side of the coin is that where there is no taxpayer funding, the role and influence of the state is reduced. Different places will have different approaches – politicians, professionals and public will need to be comfortable with this.

Village Agents - providing free independent information about local services, clubs and groups and a link to the support, Village Agents look to keep people safe and healthy, increase social interaction and help anyone in need. By way of example:
"Mr X has Motor Neurone disease and is unable to leave his home. He asked Chelmsford (City) Council for help with his garden, they passed it onto me. I asked Guiness Trust for help... The garden has now been tidied up. Customer happy. Whilst visiting Mr X I also found out that he is having trouble accessing his bathroon due to his lack of mobility. I have referred him to Social Care Direct to get him a seat with wheels on, to move around small spaces. He is also looking at the telecare leaflets I gave him as he is prone to falling and is unable to get up."
Source: Village Agent case study

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The Commission would like to see **the creation of an Essex-wide organisation embracing paid staff and volunteers so that every household has a team or individual charged with identifying early signs of difficulty, combining concepts such as Health Champions, Neighbourhood Watch, village agents, and the current Essex Fire Prevention initiative.** This organisation would identify those most in immediate need, and help households to manage their own health and the new ownership of their care needs.

The Commission was impressed with the Village Agent model, the Health Champions in North East Essex, and the Community Builders programme and believes Essex should create a countywide scheme similar to these – trained co-ordinators who recruit and train volunteers – with a specific emphasis on improving health and care – to be the face of community action in their neighbourhoods, be they urban or rural.

Whichever organisation runs this scheme has the opportunity to become one of Essex's premier charities. It will need to work with all obvious partners, including Age UK and the Red Cross amongst others. This approach will require great courage and resolve from the voluntary sector. The Commission recommends that statutory bodies provide the core funding for the first five years. This Essex-wide scheme would be responsible for collecting data on those of us most in need of care and support.

Services need to be based on people's local needs. By looking to spend money on people not organisations, commissioners should ensure that their procurement processes support this aim and take into account social value, social capital and local knowledge. We have heard of a number of examples of poor procurement undermining commissioners' aspirations. Providers must be challenged so as to reflect the needs of their people. They must also work to secure collaboration between organisations rather than competition.

> *'Why are we still looking at this in silos? If we look at the journey of the individual - it's about time professionals stopped doing what they've been doing for years and start working for the benefit of the people who pay their salaries.'*
> Essex Resident, Braintree June 2013

A good example is the work in Worcestershire delivering early intervention service for dementia.[xvii] In 2010 the NHS Trust in partnership with Dementia UK and the Alzheimer's Society began to provide a co-ordinated service to assess, diagnose and support people identified with early signs of dementia. Partners have contributed their particular expertise to an overall package, comprising occupational therapy, psychology and memory strategies; local dementia advisers; Admiral Nurses, who provide information, practical advice and emotional support for carers; access to a range of local support services; and onward referrals to other services and to other community groups for advice.

By doing this, commissioning organisations may find themselves pushing at an open door. Our conversations with the people of Essex suggest real frustration when services aren't built around them. Those delivering services are also up for the challenge – as one third sector chief executive said: *'it is a total waste of public money that commissioners are not pulling together organisations that they commission services from.'*

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We were excited by the model being explored in Thurrock around the use of existing state-owned premises to create Community Hubs. The South Ockendon project could be a beacon for the rest of Essex and brings together all services in one building including library, children's services, voluntary services, GP cover, a crèche and 'E-citizen kiosks'.

> **Community Builders** - supporting three trial areas in Southend, Harlow and Tendring, Community Builders will work with neighbourhoods as they identify what would make a difference in their local patch. This isn't a case of 'doing to' a place, but rather an approach that looks to develop local assets, whether active community groups, individual skills and expertise, or community-owned buildings in a way that makes a sustainable difference to neighbourhoods.

Many organisations have expressed frustration with twelve-month pilots and year-long funding agreements. **Public agencies that commission services should agree longer-term contracts than happen now – one year for pilot projects, but three to five years for services that are proven and essential subject to annual appraisal of performance. Equally these public agencies should be encouraged to favour consortia of providers to encourage integration of services and better value.**

Short-term funding can prevent innovation – twelve months is seldom long enough to create, staff, run and assess something new, so why take the risk? Given that the unprecedented challenges we face call out for new thinking, this is a real problem. When a public agency resorts to stop-gap measures such as extending year-long pilots, it does nothing to help medium-term planning. If it is done too often, there is a real risk that providers will leave the market.

Our fourth solution: Use data and technology to the advantage of the people in Essex

Over the last three decades, technology has changed the way we live our lives beyond recognition. Yet it has had less of an impact on day-to-day health and care than in any other sphere. As we listened to Essex residents, we heard time and again the incredulity people felt when they could order groceries on-line and have them delivered to their house at a time that suited but then relied on the manual and sluggish transfer of pieces of paper amongst GPs, consultants, and pharmacists when something as important as their health and care was concerned.

Some definitions

Telecare uses alarms, sensors and equipment to help us live independently for longer. Examples could include a bed sensor which monitors when someone leaves their bed and raises an alarm if they don't return to bed. Telecare is particularly used for people who require social care and health services.

Telehealth helps us manage their long-term health issues. Equipment monitors vital signs - such as blood pressure, oxygen levels, and weight - and share this electronically with health professionals. This helps clinicians monitor progress and take action if necessary. It also prevents avoidable hospital admissions and reduces surgery visits.

Together they allow you to access your medical records, manage your medication, monitor simple health measurements at home and book appointments with your GP and get repeat prescriptions and all while you are at home or at work.

There is real scope to make better use of technology. This isn't science fiction. Technology that can make a real difference to our lives already exists but needs to be better understood, by users and professionals, and better supported.[xviii] If Estonia, with a population similar to that of Essex, can store citizens' health records in the digital cloud, why can't Essex citizens enjoy the same technological benefit? Basic technologies, such as alarms are used, trusted and valued (*'it really is essential'* said one participant at a session hosted by Age UK Essex) but there is a recognition that across Essex we don't make the most of technological innovations.

The Airedale telehub at Airedale hospital is staffed 24 hours a day by experienced senior nurses who provide clinical support to patients. Most of the patients using telemedicine in their own home have one or more long-term conditions and can call the hub if they have any concerns - preventing hospital admissions as well as providing reassurance to them and their families. We are not aware of an Essex equivalent.

Evidence from the dallas programme (delivering assisted living lifestyles at scale – a telecare and telehealth trial site) in Scotland suggests professionals can view technology as a threat to both their judgement and their jobs. We believe this concern is misplaced. Technology complements professional skills. What's more, the scale of the increase for the very services professions provide is growing – technology is a way to manage this pressure; without it, professionals will face a tidal wave of demand.

We know of the statistic that seven million people in the United Kingdom have not used the internet.[xix] This is a very narrow definition. Speaking to the people

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Our fourth solution: Use data and technology to the advantage of the people in Essex

of Essex, we came across a handful of people who had not used or did not have direct access to, the internet, but none of these people were unable to access the web. Family, friends, and public libraries all played a role in connecting people when they needed to be connected.

There is a school of thought – typically one put forward by professionals – that holds that something should not be used because it is not universal. We disagree. Everyone may not want to use technology but it is wrong to limit its use for this reason. Its life-changing potential should not be ignored.

Housing has been a consistent concern in the background of our taking evidence. **Borough, city, district and unitary councils and housing associations should work together to create a housing strategy using assistive technology that will enable people to live independently for longer.** This is a sensible way of keeping Essex residents in their own homes. We were impressed by the excellent plans in Thurrock for the specialised housing units being developed at Derry Avenue designed to be 'care-ready' so that new and emerging technologies can be easily installed.

A bigger challenge is the infrastructure required to support telehealth, telecare, e-health and m-health. Poor broadband capacity across parts of Essex will limit the potential of much telehealth technology to make a real difference to independent living and self-care. This deficit needs to be addressed.

With time, we are hopeful that infrastructure will improve. Until then, we should continue to learn how technology can help self-management. The commission advocates **a thorough telehealth and telecare trial in a meaningful population to identify and evaluate the benefits and appropriate design of the packages. This should be in an area of good internet coverage, good mobile signal coverage and with all patients consenting to the open sharing of their data.**

> *'There appears to be little or no sharing of information about families. This is especially true when a parent has a mental health problem.'*
>
> Family Charity, Colchester

The differences between what we want and what professionals are willing to provide is nowhere greater than the issue of data sharing. Essex people want their data shared so as to help them experience better quality care. Compare the comment from a lady in Brentwood - *'how fantastic it would be that someone could log into me ... I see that as a benefit'* – with the reluctance of professionals to share data between agencies, let alone directly with the individual.

Whether this reluctance flows from a hesitancy to let us see our records, entrenched professional interests, or a real concern about data protection is unclear. We take the same view as a former anaesthetist in Basildon who summed it up like this: *'people not wanting to share their information is a red herring ... there isn't a bother about it'*. In fact, we go further and state that individuals should be the ultimate owner and custodian of their own health record - as with their money, so their health. In the Isle of Wight data owned by the individual is now the norm.

Our fourth solution: Use data and technology to the advantage of the people in Essex

Patient-held records - by transferring the ownership of data from professionals to individuals, patient-held records are a symbolically significant shift.

Eclipse provides patient record services across the Isle of Wight. A credit card sized patient record can be shared with GP, pharmacist or anyone else the patient elects to share their information with - the information can range from the medical to the personal, from medical history to who should care for the patient's dog if the individual is taken ill. Whilst the principle of patient-owned records is important, the systems can go much further.

Patient records can be updated in real time, providing an accurate and contemporary assessment of a patient's health. More importantly still, the system can prevent harm - as the number of drugs taken increases, and the patient's health changes, potentially unintended results can occur. While GPs may not have time to review the totality of prescription medications a patient takes, Eclipse's system can.

By way of example, the system can automatically review the results from GP blood tests showing anaemia levels (stored on the patient's record) and cross-reference these results with individual prescriptions (again on the record). This can point to individuals whose iron levels are falling and who are taking aspirin - people whose condition is being worsened by the very medication they are being prescribed.

Eclipse can flag the problem and the GP can stop the problematic drugs, reducing cost by withdrawing the use of medication that is, at a minimum, ineffective and at worse dangerous, while, most importantly, improving the health of the patient.

Across the Isle of Wight, GPs have welcomed the system and the number of patients receiving inappropriate or unsafe combinations of prescriptions is falling.

This is happening elsewhere in Britain. In South London, myhealthlocker has been set up as a personal health record which includes hospital and GP records. People can choose who their information is shared with – based on the principle, summed up by one participant, that *'it really plays an important part in taking your control back which is important for making any kind of recovery.'*

To support this commitment, the Commission calls for the **urgent creation of a simple 'good enough' Essex wide data strategy supported by an IT strategy that enables success and sees the individual as the ultimate owner and custodian of their own health and care record.** There should be no barriers in the way of exchanging data in the interests of the people of Essex. A default position on the exchange of data between recognised professionals should be considered. Data transfer and the ability to interface with the customer are crucial. We encourage Essex to consider the work of Eclipse Systems and others in this field.

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Our fifth solution: Ensure clear leadership, vision and accountability

A greater role for communities and individuals is one of the two fundamental requirements if we want Essex to have a health and care system that works. The other is clear leadership, vision and accountability. Without both of these, nothing else will work.

Talking to others outside of Essex about how they improved health and care, we kept hearing about the importance of those who run parts of the health system working well together. We also heard candid criticisms of a system in Essex which *'incentivises us into a turf war'*. A senior figure in one of Essex's seven Clinical Commissioning Groups spoke of a *'commissioning system [which] has a thread of madness through it... as commissioners, we are doing as we are told ... we are doing exactly as the system tells us to, there are significant penalties if you don't'*. The over-riding perception was one of good people in an imperfect system. As one politician put it: *'I draw a line from cradle to grave: that's care ... to have two different systems, two different philosophies: that's crazy'*.

We think there is real merit in bringing together the key players in the health economy. Clear leadership and accountability are the only way to deliver better, more co-ordinated care. **A care partnership with an independent chair, governed by the Health and Wellbeing Boards, and operating across Essex should bring together key partners from the public, private and voluntary sectors** to procure and provide cradle to grave co-ordinated and convenient care for each individual. Every incentive must be aligned better to allow this to happen with a clear vision that brings everyone together. Ideally the leadership must include providers as well as commissioners and, through Healthwatch, the voice of the Essex people. Critically, you need to move at the speed of the most willing.

The Essex care partnership - a membership drawn from the key health and care organisations across the county:

- Clinical Commissioning Groups;
- NHS England;
- County and Unitary Councils;
- acute sector clinicians, for acute trusts;
- larger care providers;
- city, borough and district councils;
- Healthwatch representing residents; and
- the voluntary sector.

> *'No system trapped in the continuous throes of production, exisiting always at the margin of resources, innovates well. Leaders who want innovation to spread must ensure that they have invested people's time and energy into it.'*
>
> Don Berwick, *Escape Fire: Designs for the future of health care*, 2005

The care partnership has a critical role to play. For it to work we need to **invest in the leadership team and build trust between us, including working with non-executive mentors from customer-facing organisations.** If we need to change the way health and care happens in Essex – and we do – we need a care partnership that takes calculated risks. More importantly we, the people of Essex, local public agencies and national government, need to reward courage and accept mistakes. If we fail to do so, we will only get more of the same – and more of the same will not be good enough.

Our fifth solution:

Ensure clear leadership, vision and accountability

> *'It is important as innovations diffuse to harvest and then routinely and widely publicise the benefits. Successes need to be showcased and celebrated to build momentum for the on-going journey of system transformation.'*
>
> G.Parston et al., *From innovation to transformation,* Institute of Global Health Innovation, Imperial College, forthcoming 2013.

The Essex care partnership will develop a common vision of, and a co-ordinated approach to, care. This approach should be made clear to the people of Essex as well as the professionals and practitioners who work in the health system. Healthwatch must play a crucial role in the crafting of this on behalf of Essex people. Without imposing additional burdens on already hard-pressed commissioners and providers, a culture of comparison, acknowledgement, value, learning sharing and improvement should be encouraged – learning from each other to achieve more.

The Health and Wellbeing Boards will allow the Essex care partnership to co-ordinate the design, commissioning, procurement, and provision of a range of services that will address a small number of significant care challenges. **The Commission recommends the partnership to focus with urgency and courage on core areas that pose significant care challenges across Essex.** These areas of focus should support rather than replace local inputs and could include:

- **bringing commissioners and providers together, from hospitals to care workers, to achieve the best care, best access, in the appropriate setting, cared for by the appropriate people and at the best value to the taxpayer;**
- **allowing us to share our data;**
- **identifying earlier those most in need and most likely to require care;**
- **making the most of our communities and all our assets; and**
- **creating a county-wide strategy to support us to take control of our own health and care and make the most of recent technologies to enhance the support provided.**

We were struck by the unprecedented challenges all public agencies were facing. We were particularly surprised at the scale of the task facing the county's new Clinical Commissioning Groups.

We have been told many times that *'the incentives are in the wrong places'*. Improved accountability can help improve the way money and incentives flow across the system. **A new culture of collaboration through a 'single pot of money' to deliver identified outcomes** – combined with pragmatism about how to deliver will help achieve the best possible wellbeing for Essex residents, whether they are in Chigwell or Clacton, Southminster or Saffron Walden. This would help address the situation outlined by a hospice chief executive who said that *'people are too narrow-minded, too focused on their own budgets ... they are all looking at their own budgets rather than over-all value for money.'* This approach is not the norm, and **permission should be sought from the relevant authorities and regulators to allow for this to be successful.**

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Our fifth solution:

Ensure clear leadership, vision and accountability

The care partnership will look to bring together commissioners and providers. Of equal importance, it will also look to **integrate provision – in other words make services less fragmented, easier to navigate, and hence better value for money. Commissioners will incentivise providers to work together rather than driving them apart through divisive tendering processes.**

> *'I find it confusing that I have recorded 28 organisations which provide support for carers. This must mean overlap, duplicaton and confusion of effort.'*
>
> Carer, Chelmsford, June 2013

Those who know the system admit it is difficult to navigate; those who have to use the system are more critical still. This will require tough decisions and mean people and organisations acting in new ways.

It is clear that the face of health and care will need to change over the coming years - budget pressures and increased demand for services will see to that. The services we will use will be different, based increasingly on professionals working with people to develop individual services. The commissioners, Healthwatch and Health and Wellbeing Boards should work together to identify and decommission services the state will no longer fund. Indeed, **whenever a new service is commissioned another should be decommissioned. Commissioners should be encouraged to identify non-core services now.**

Those who buy services will need to look to joint or combined tenders, funding collaborations rather than individual organisations – for example, why not look to the twenty-eight carers' organisations to provide a single common service for carers rather than twenty-eight different services? Those who provide services will be asked to bid together and to consider the whole system – a *'service-plus'* offer – and **commissioners should be supported to consider greater flexing of the workforce.**

What happens now?

The 'Who Will Care?' Commission was asked to consider how care could be improved for the benefit of all. With the publication of this report, the Commission has fulfilled its side of the bargain. As five Commissioners, we cannot deliver the change Essex needs. That responsibility rests with the people of Essex, with public agencies and health professionals, with business, and with you. We look forward to watching your success in the years that follow this Commission's publication.

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Who are you?

Sir Thomas Hughes-Hallett is our Chairman. Tom was Chief Executive of Marie Curie for twelve years until taking on this Commission. He is now Chair of the Institute of Global Health Innovation at Imperial College, London. Tom lives in East Anglia and his son was a surgeon at Broomfield Hospital. This is the third Commission he has chaired.

John Spence CBE is Tom's Vice Chair. John worked for Lloyds Banking Group for twenty-two years and has also chaired a range of charities, including Action for Blind People, Vitalise, and Blind In Business. A resident of Chelmsford, he was elected to Essex County Council in May 2013.

Mike Adams OBE is Chair of Healthwatch Essex and Chief Executive of the disability charity ecdp. He is also a non-executive director of CareTech, a private sector social care company. Mike has held a number of senior management positions at the Disability Rights Commission, the National Disability Team for higher education and Coventry University.

Professor Sheila Salmon is Chair of Mid-Essex NHS Hospital Trust. A midwife by training, Sheila has more than three decades of health and social care experience and has served as a Foundation Trust governor and a Non-Executive Director. Sheila is Emeritus Professor of Health at Anglia Ruskin University. She lives in Danbury.

Dr Gary Sweeney is a GP in Clacton and Chair of the North East Essex Clinical Commissioning Group. He has worked in Tendring for almost thirty years, twenty-six of those in his Pier Ward surgery. A former student of St Bart's in London, Gary spent eight years in hospital medicine in Anaesthetics. Gary is also deputy Chair of the Essex Health and Wellbeing Board, which brings together councils and Clinical Commissioning Groups to develop a shared understanding of our health needs.

The Commissioners were supported by a secretariat consisting of **Sara Ismay**, **Julie Leigh** and **Dr Paul Probert.**

Notes

You can read *'Who will care?' Five high-impact solutions to prevent a future crisis in health and social care in Essex* without having to read these notes. However, if you want to know more about the issues we raise and the sources we used when coming to our recommendations, you can find out more here.

[i] Office for National Statistics, *Statistical Bulletin: Health Expectancies at Birth and at Age 65 in the United Kingdom, 2008-2010*, August 2012. Available online: **http://www.ons.gov.uk/ons/dcp171778_277684.pdf**. See also Seshamani & Gray, 'A longitudinal study of the effects of age and time to death on hospital costs', Journal of Health Economics, vol. 23, (2004), pp. 217-35.

[ii] Local Government Association and ADASS, *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market*, January 2011, p23. Available online at: **http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Localmilestones/People_who_pay_for_care_-_report_12_1_11_final.pdf** Accessed July 2013.

[iii] All Party Parliamentary Group for Housing and Care for Older People, *Living Well at Home Inquiry*, (2011), p. 7. Available online at: **http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/living-well-at-home.pdf.** Accessed July 2013.

The alternative could require another £50 billion of efficiency measures needed over the next 50 years to cope with the increasing cost of health care and supporting Britain's ageing population. See Office of Budget Responsibility, Fiscal Sustainability Report, (July, 2013). Available online at: **http://cdn.budgetresponsibility.independent.gov.uk/2013-FSR_OBR_web.pdf**. Accessed July 2013.

[iv] See, for example, the reporting of recent research on childhood heart health: 'The unhealthy generation who could die before their parents Millions of British children risk heart disease by shunning vegetables and watching too much television, campaigners warn', *Daily Mail*, 12th August 2013. The original analysis is Townsend *et al*., Children and Young People Statistics 2013, British Heart Foundation Health Promotion Research Group and Department of Public Health, University of Oxford, August 2013. Available online at: **http://www.bhf.org.uk/publications/view-publication.aspx?ps=1002326** Accessed August 2013.

[v] See, for example, Department for Work and Pensions, *Working for a healthier tomorrow. Dame Carol Black's Review of the health of Britain's working age population*, March, 2008, especially chapter three. Available online at: **https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209782/hwwb-working-for-a-healthier-tomorrow.pdf**. Accessed July 2013. Given the UK's emerging demographic profile of an ageing population, with a smaller proportion of working-age residents, the Chartered Institute of Personnel and Development's *Managing a Healthy Ageing Workforce. A National Business Imperative*, March 2012, is also relevant. Available online at: **http://www.cipd.co.uk/NR/rdonlyres/2778DBAC-B375-4CB5-B5C9-FFD866C7597A/0/5754ManagingageingworkforceWEB.pdf**. Accessed August 2013.

[vi] These figures will change in 2016/17.

[vii] Institute for Fiscal Studies, 'We shall squeeze until the pips squeak', *Post-Spending Round Briefing*, 27 June 2013. Available online at: **http://www.ifs.org.uk/budgets/sr2013/gemma_tetlow.pdf**. Accessed June 2013. Clearly local government delivers a range of services beyond social care but directly comparable national social care figures are not readily available to show changes to budgets in real terms. HM Treasury budgeting and administrative structures fodus on organisations not services – hence the clarity on the NHS budget administered from Richmond House but less certainty on the proportion of local government grant from central government which will be used to provide social care. The Local Government Association in its *Funding Outlook for Councils from 2010/11 to 2019/20: preliminary modelling*, June 2012, cites the King's Fund analysis of a £1.2 billion social care funding gap by 2014/15. Available online at: **http://www.local.gov.uk/web/guest/publications/-/journal_content/56/10180/3626323/PUBLICATION** Accessed August 2013.

[viii] This blind spot isn't Essex-specific, see Wellings, 'Health and Social Care Funding – Public Perceptions, presentation to the King's Fund, January 2013. Available online at: **http://www.kingsfund.org.uk/sites/files/kf/dan-wellings-health-and-social-care-funding-kings-fund-jan13.pdf**. Accessed July 2013.

[ix] Government can do much more to make this easier, see the National Audit office, *Government interventions to support retirement incomes*, July 2013. Available online at: **http://www.nao.org.uk/wp-content/uploads/2013/07/10153-001-Government-Interventions-to-support-retirement-incomes-Book-ES.pdf**. Accessed August 2013.

[x] Macdonnell and Darzi, 'A key to slower health spending growth worldwide will be unlocking innovation to reduce the labor-intensity of care', *Health Affairs*, April 2013.

[xi] On this see The King's Fund, *Patients' preferences matter. Stop the silent misdiagnosis*, 2012. Available online at: **http://www.kingsfund.org.uk/search/site/publications%20patients%20preferences%20matter** Accessed July 2013.

[xii] See Holam & Lorig, 'Patients as partners in managing chronic disease', *BMJ* 2000; 320:526.

[xiii] *High Quality Care for All*, Department of Health, 2008, p. 7.

[xiv] In this respect, Essex residents' attitudes are not markedly different from those of the British public at large – see Bidgood, 'The NHS: the Envy of the World?', Civitas, March 2013.

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Available online at: **http://www.civitas.org.uk/nhs/download/NHS_Envy_of_the_World.pdf**. Accessed August 2013.

[xv] For example, The King's Fund, *Transforming our health care system: ten priorities for commissioners*, revised edition, March 2013. Available online at: **http://www.kingsfund.org.uk/publications/articles/transforming-our-health-care-system-ten-priorities-commissioners** Accessed August 2013.

[xvi] Chitnis, Georghiou, Steventon & Bardsley, *The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life*, (November 2012). Available online at: **http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/121114_marie_curie_summary-final_0.pdf**. Accessed August 2013.

[xvii] Addicott, *Working together to deliver the Mandate. Strengthening partnerships between the NHS and the voluntary sector,* The King's Fund, July 2013. Available online at: **http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/working-together-to-deliver-the-mandate-jul13.pdf**. Accessed August 2013.

[xviii] See, for example, Deloitte, *Primary Care: Working Differently. Telecare and telehealth – a game changer for health and social care*, 2012. Available online at: **http://www.deloitte.com/assets/Dcom-UnitedKingdom/Local%20Assets/Documents/Industries/Life%20Sciences/uk-ls-telehealth-telecare.pdf** Accessed July 2013.

[xix] The seven million figure comes from the Office for National Statistics. For a recent example of its deployment, see 'Tenants without internet access don't care, landlord survey reveals', *Inside Housing*, 31 May 2013.

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