



**Patient, manager, expert: individual.
Improving the sustainability of the healthcare
system by removing barriers for people with
long-term conditions**

**A report from the Sustainable Healthcare
Steering Group**

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COLLEGE OF MEDICINE
CREATING HEALTH TOGETHER

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About the initiative

The scale of the challenge facing our healthcare service is stark. If funding remains flat, the NHS in England could have shortfall of up to £54 billion by 2021¹⁷. Making up the shortfall is the equivalent of having to make a saving of over £1,000 for every man, woman and child in England¹⁷.

Nearly a quarter of people in England (15 million) have a long-term condition such as diabetes, heart disease, dementia or asthma and this number is set to rise¹⁰. Over 70% of the NHS budget, £7 out of every £10, goes on care for people living with chronic conditions¹². Already half of GP appointments and two thirds of outpatient and A&E visits are for people with long-term conditions¹¹.

The UK is not alone. Healthcare systems across Europe are struggling with similar demographics and financial imperatives. Recognising this, in May 2013, AbbVie, together with the European Public Health Association and Philips, invited healthcare stakeholders from around Europe to discuss how healthcare systems could become more sustainable and meet the challenges of managing long-term conditions.

The conclusions were clear: lifelong prevention, early diagnosis and effective intervention all have a key role. Furthermore, it was agreed that if we want to achieve healthcare sustainability, then governments, stakeholders, people living with illness and companies must work in close partnership to change the way healthcare is delivered in Europe.

This led AbbVie and long-standing partner the College of Medicine to convene a steering group of multidisciplinary healthcare experts to explore how NHS healthcare delivery in England can be made more sustainable and outcomes for people living with long-term conditions can be improved. The College is committed to championing a culture of innovation, prevention and patient collaboration in medicine, towards the goal of a sustainable 21st century NHS and a better health future.

The Steering Group debated the challenges facing the UK, reached out to a wide range of other healthcare stakeholders to seek their views and perceptions, and distilled the findings and recommendations into this report.

This report will feed into a pan-European White Paper, looking at the wider European situation and addressing commonalities and potential shared approaches to sustainability in healthcare. However it is also intended to act as a catalyst for UK discussion and action, as we call on everyone with an interest to consider the question: what can I do to make our NHS sustainable for the future?

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Introduction from the Co-Chairs of the Sustainable Healthcare Steering Group

The Sustainable Healthcare Steering Group has come together to explore how the quality of healthcare for people living with long-term conditions in England can be improved in the context of a health and care system which is under sustained pressure. Experts from a range of disciplines are working together to stimulate thinking and identify the practical actions that can be taken across healthcare from prevention, to treatment and self-management.

Sustainability in healthcare relies upon realistic expectations about what can be delivered effectively within constrained financial resources. Decisions for the future need to be imaginative. New ways must be found to work more efficiently, to spread innovation and harness our assets better: the reach of the NHS, its dedicated workforce and, most importantly, patients themselves.

The Steering Group's work shows that commissioners and providers of health services are concerned about the sustainability of healthcare. They are prioritising sustainability and are striving to find and implement solutions that will work for their local population. Across England, there is a clear need to fund high-quality care in cost-effective ways. The Steering Group has identified three areas where, if greater attention is focussed, there are opportunities to improve the sustainability of healthcare services:

1. **Embedding a person-centred approach, which considers the individual rather than a siloed focus on their condition(s)**
2. **Helping individuals to navigate the healthcare system and manage their condition with confidence**
3. **Using technology to improve the delivery of services and care closer to home and equipping individuals to self-manage**

This report is intended to act as a catalyst for discussion and action both nationally and locally in England. The Steering Group's vision is for a system that equips, empowers and supports all individuals with long-term conditions to acknowledge their abilities, embrace opportunities for change and understand their rights and responsibilities so that they can actively manage their health needs.

Baroness Julia Cumberlege and Dr Michael Dixon
Co-Chairs of the Sustainable Healthcare Steering Group

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Membership

The following individuals are members of the Sustainable Healthcare Steering Group and have contributed to its work:

- **Chairs: Baroness Julia Cumberlege and Dr Michael Dixon, College of Medicine**
- **Professor Sir Mansel Aylward, Public Health Wales**
- **Dr Tim Ballard, Royal College of General Practitioners**
- **Neil Betteridge, Neil Betteridge Associates**
- **Professor Stephen Bevan, The Work Foundation**
- **Charles Gore, The Hepatitis C Trust**
- **Carrie Grant, Patient representative**
- **Phil Gray, Chartered Society of Physiotherapy**
- **Laura Guest, British Society of Rheumatology**
- **Susan Oliver – Nurse Consultant Rheumatology, Member of the British Society for Rheumatology International Strategy Group, Fellow of the Royal College of Nursing**
- **Mark Platt, Royal College of Nursing**
- **Matt Regan, AbbVie**
- **Professor John Weinman, King's College London**

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For more information about the Sustainable Healthcare Steering Group please contact:
len.gooblar@abbvie.com

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Executive summary

The NHS is under strain to meet the challenges of an ageing population, increasing numbers of people living with multiple chronic conditions, and financial pressures. At the same time, the NHS is striving to sustain high quality, evidence-based care. This report sets out a series of recommendations to help the NHS to meet these challenges.

The members of the Sustainable Healthcare Steering Group share a desire to see health and care providers enabling people with long-term conditions to understand their abilities, opportunities, rights and responsibilities in actively managing their health. By creating an environment in which people are empowered and equipped to better support themselves, the healthcare system can be made more sustainable.

In this report, the Steering Group sets out a vision for change based around three themes: embedding a patient-centred approach and treating the individual; navigation and coaching; and harnessing technology to support self-management. Around each theme, the Group has examined examples of care and made recommendations for change in the NHS.

Considering the individual rather than the condition will require a fundamental shift in thinking across the NHS. It will necessitate a change in the way in which clinicians are trained, and in which patients are supported, in terms of what health services can provide and what patients can contribute. At the heart of this theme is the desire to encourage individuals to move from being passive recipients of care and advice from ‘expert’ professionals, to being more involved in directing their own care and being recognised and respected as experts in their own condition.

Supporting individual patients to get the most out of their contacts with healthcare professionals will enable them to make best use of the healthcare resources available, and help them to achieve better outcomes. In practical terms, there are two key ways to deliver this. The first is the adoption of a ‘coaching’ approach, supporting individuals to consider, set and achieve their healthcare goals. The second is achieved by helping people to access and use the healthcare system itself, and connect with other useful non-NHS services, for instance community resources. These two very different challenges require two different functions to support individuals: the ‘coach’ and the ‘navigator’.

The coaching approach to enabling supported self-management means equipping people with the confidence and skills to set their own goals and manage their condition as far as they feel able to. The second principle sees ‘navigators’ being embedded within services bringing local knowledge of healthcare services and support services to individuals with long-term conditions.

Technology must be harnessed better to empower patients and allow them to engage with their healthcare professionals in ways which are more convenient to them. In many areas, appropriate technology has already been developed which could be adapted to support individuals in their care. It is important to state that although the effect of a particular technology could be transformative on individuals and on healthcare systems, the technological leap does not necessarily have to be that great. This means that greater adoption of such technology need not be complex or costly.

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The opportunities for using greater technology must be flexible, however, so that individuals are not left behind but also so that others are not held back. This will require working with individuals – both healthcare professionals and patients – to assess their level of digital and cognitive skills, confidence and desire to use such tools.

In addition, the impact of personalised care plans and individuals having access to their own healthcare records also present opportunities. These issues raise justified concerns around privacy and data security but the Steering Group recommends that individuals should be the ‘owners’ of their health records rather than the healthcare system. This would mean that individuals would be able to add to and control the information contained within it, and with whom it can be shared.

Across these three themes, the report’s 12 recommendations are intended to be both practical and forward-looking. We do not believe that implementing the recommendations across the NHS in England would require disruptive change, and in many ways feel that the recommendations build on existing work and evidence.

The strength of the Steering Group’s ideas and proposals can ultimately only be demonstrated by their application, but if they were to be implemented, we believe that they would result in individuals receiving earlier, more appropriate interventions and support to meet their health and care needs. This would help to transition the healthcare system from being overstretched and strained to one that can safely and effectively meet the needs of the people it endeavours to serve.

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Summary of recommendations

The Sustainable Healthcare Steering Group has made these recommendations to improve the sustainability of the healthcare system in England to benefit people with long-term conditions:

Recommendation 1: The Department of Health should work with NHS England and Public Health England to establish a shared healthcare sustainability resource for local commissioners, bringing together good practice examples of evidence-based initiatives.

Recommendation 2: All individuals with a long-term condition should have a named healthcare professional with the appropriate expertise to support the coordination of their care.

Recommendation 3: All individuals, and their carers, newly diagnosed with a long-term condition should have the name and contact details for a designated person who they can contact and who can direct them to local health and support services.

Recommendation 4: Commissioners should explore the potential of expanding pilot projects of individuals with long-term conditions being able to self-refer to services and evaluate further the impact on the quality of experience, outcomes and efficiency of these individuals' care.

Recommendation 5: More evidence is needed on the impacts of changing the relationship between healthcare professionals and individuals with long-term conditions on quality, experience and safety of care. Researchers investigating innovative approaches should look to include measures of these in pilot design.

Recommendation 6: Studies and surveys of patient experience and satisfaction with healthcare professionals should capture whether individuals are having a full share in consultation and decision-making about their care and having opportunities to self-manage.

Recommendation 7: Commissioners should examine the potential for existing technologies, that tap into digital systems that people already use, to be expanded across the country to enable more people with long-term conditions to benefit from them.

Recommendation 8: Commissioners and providers should explore the potential for trialling e-consultations, to determine whether they improve individuals' satisfaction with their healthcare services and yield efficiency benefits (such as reduced non-attendances).

Recommendation 9: Commissioners and providers should ensure that systems using new technologies are built taking into account the needs of those who are not yet digitally enabled, but that this does not prevent progress in increasing the use of technologies to improve care.

Recommendation 10: Commissioners and providers should explore the potential for cloud computing to enable better information-sharing and rapid decision-making in long-term, as well as acute, conditions.

Recommendation 11: Royal Colleges, Health Education England and universities should examine the curricula for professional training to identify opportunities to embed coaching skills and shared decision-making. Providers should also encourage healthcare professionals to develop coaching and shared decision-making skills as part of their continuing professional development with a quality indicator set against which performance can be benchmarked.

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Recommendation 12: Commissioners and providers should explore pilot programmes to establish the value of care-coordinators in supporting individuals to navigate the healthcare system. These programmes should include evaluation of the impact on individuals' satisfaction with services, use of resources and wellbeing.

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The Steering Group's approach

The Sustainable Healthcare Steering Group met three times as a group and once at a consultation event with stakeholders from across the health community in England. The details of these meetings are set out below.

July 2013 – Terms of reference and scope agreed

The Steering Group established its terms of reference, the scope and desired outputs of the project and identified areas for further research.

The Steering Group determined that the project would focus on exploring three areas where the experts felt there was full potential to change mind-sets and behaviours had not been fully exploited, namely:

- Taking a person-centred approach to care, rather than a siloed focus on their condition(s)
- Coaching and supporting people not only to self-manage their condition but also to confidently navigate the complexities of the system
- Increasing the use of technology to support better engagement between people and healthcare services

The Steering Group agreed that some form of validation would be required to assess whether the term 'sustainable healthcare' resonates at a local level. The Steering Group began to identify national and international case studies which could be more closely examined for relevant lessons which could be applied to England.

The Steering Group then recommended that a plan should be drawn up for a consultation event with a wider group of healthcare stakeholders encompassing commissioners, providers, policymakers, professional associations and patient advocacy groups.



September 2013 – Initial research and planning for stakeholder consultation

The Steering Group reviewed project plans for the consultation event and examined the case studies identified through desk research. Initial findings were presented from field research carried out with Health and Wellbeing Boards (HWBs) and local Healthwatch organisations (given their increasing salience in the new healthcare system). This research explored these organisations' understanding of the concept of 'sustainable healthcare' and identified local initiatives in line with the three themes.



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November 2013 – Stakeholder consultation

The stakeholder consultation event was held in November 2013 and attended by around 60 participants from a wide range of disciplines and organisations.

Speakers were invited to give short presentations to the three themes, and these were followed by facilitated roundtable discussions in five groups, followed by feedback on emerging consensus and recommendations.



November 2013 – Review of findings

At the third and final meeting of the group, the findings of the stakeholder consultation event were discussed, case studies examined and recommendations for each of the three topic areas reviewed.



2014 – Publication of report

This report brings together the Steering Group’s discussions, research and findings around the three core themes and recommendations for change. Supported by AbbVie, colleagues in other European nations are examining the same questions and insights from each country. This work is being brought together in a pan-European White Paper for publication.

The Steering Group looks forward to determining where there are common challenges with other countries and to sharing recommended solutions.

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The context and case for change

“Sustainability is about avoidance of waste. People like myself who are long term in the system have assets that are going to waste. That is what needs to be addressed.”

Alison Cameron, a patient leader and speaker at the Sustainable Healthcare panel debate

When the NHS was founded in 1948, it served a population of over 49 million¹. In 2011, that had grown to over 63 million². Across those 63 years, life expectancy has also increased. In 1948, life expectancy at birth for men was 65.9 and for women was 70.3³, while today, those figures are 78.5 and 82.4⁴. At its inception, the NHS was chiefly seen as there to manage ill-health and some public health but it did not have a vision in place for managing chronic conditions.

The impact of long-term conditions

Improving health and increasing age has come as the nation has (broadly) become wealthier, and people have enjoyed healthier lifestyles, better nutrition and benefited from medical advances. However, now, around one in four people – some 15 million people in England – are living with one or more long-term conditions⁵. This number is set to rise.

Estimates suggest that by 2025, as many as 18 million people will be living with at least one long-term condition⁶ and many people will be living with multiple conditions. Indeed, the number of people in England with three or more long-term conditions is expected to rise from around 1.9 million in 2008 to 2.9 million in 2018⁷. These may either be physical or mental health conditions, and there is an established correlation between the two.

At least 30 per cent of all people with a long-term physical condition also need support with managing a mental health condition⁸. People with severe mental illnesses experience significantly higher rates of physical illness which affects their life expectancy⁹. Multi-morbidity is more common among people living in deprivation, and the more long-term conditions a person has, the greater will be their use of health services and resources^{8,10}.

Long-term conditions are more prevalent in the elderly as more people are now living long enough to develop a long-term condition. However, long-term conditions are not purely a function of our ageing population. Some of the most common conditions – such as rheumatoid arthritis – show signs of onset between the ages of 40 and 60¹¹, and many others – such as asthma, diabetes, epilepsy and allergies – are frequently diagnosed in childhood. The need to take a life-course approach to long-term conditions, and to diagnose early, is therefore clear.

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Spending on the NHS as a share of national income has more than doubled since 1948, rising by an average of four per cent a year in real terms: now, around £7 of every £10 spent by the NHS goes on managing long-term conditions⁶.

In 2010, the Department of Health estimated that long-term conditions in England accounted for more than⁶:



50% of GP appointments



65% of outpatient appointments



70% of inpatient bed days

However, as recent analysis by the Nuffield Trust sets out, if funding levels continue to be flat, the NHS in England could experience a funding gap of between £44 billion and £54 billion in 2021/22¹². The Nuffield Trust suggests that to avoid cuts in services or reduced quality of care, either growth in funding must return to historic averages (unlikely in the current fiscal environment even with an economy showing signs of recovery) or “unprecedented, sustained increases in health service productivity” must be made¹².

Furthermore, data from the Work Foundation (funded by AbbVie) show that over 35 million work days are lost each year to sickness absences in the UK – costing the economy £15 billion¹³. Musculoskeletal condition, such as back pain, are the leading cause of absence from work¹³. Many people with long-term conditions want to work, and could return to work if they had early support to help them manage their condition. The Work Foundation (funded by AbbVie) has estimated that an additional 60,000 adults with musculoskeletal conditions could be at work each day if earlier interventions were more available¹³.

In addition, more than one in eight adults – some 5.43 million people in England – are informal (unpaid) carers¹⁴. Carers UK estimate that, over the next 20 years, this invisible workforce will need to increase to 40% to keep pace with demand¹⁴. Caring can take a toll on the carers’ own physical and mental health, with around eight in 10 carers reporting that caring has had a negative impact on their own physical health¹⁵ – creating a vicious cycle.

The imperative for action

The focus on long-term conditions and patient-centred services has been maintained by the Coalition Government. From the outset of announcing its healthcare reforms in 2010, the Coalition Government has championed the concept of ‘no decision about me, without me’ – the principle of

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placing patients' goals, needs, and preferences at the centre of clinical decision-making. *Equity and Excellence*, with its central tenet of devolving decision-making closer to patients, clearly identified¹⁶:

- The power that shared decision-making can have in improving patient outcomes and reducing costs, with the expectation that this would become the norm
- A commitment to provide choice in care for people with long-term conditions as part of personalised care planning
- The importance of general practitioners as coordinators of care, especially in supporting people living with long-term conditions
- The need to coordinate health and social care services to reduce avoidable hospital admissions
- That new technologies can be harnessed to improve both quality and efficiency

Increasingly, there is a recognition that people with long-term conditions – and indeed all users of healthcare services – can use their expertise and ‘assets’ to contribute to the sustainability of the system as well as drawing from it to meet their needs. This is not a new theme, however, and has long been recognised, but now there is momentum behind unlocking this potential.

The reforms introduced through the Health and Social Care Act 2012 have led to significant structural change, the impact of which on services is still only just starting to be understood. As the system becomes used to the new structures, the imperative for the NHS is still the same: how to direct expenditure to make sure that services provide high quality support to keep the general population healthy and provide correct levels of care for individuals who fall ill.

Set out below is an indication of the services that a patient with rheumatoid arthritis will encounter and interact with under the new NHS. This is similar for patients with other long-term conditions, and shows how a long-term condition has an impact on a number of different areas. This clearly demonstrates the challenges patients face in understanding who they should engage with.

The new NHS – local leadership in sustainable healthcare

The new NHS landscape creates an opportunity for – and indeed demands – local leadership and action. A top-down, ‘command and control’ model does not reflect the separation between the Department of Health and NHS England, and the multiplicity of commissioners in clinical commissioning groups and local authorities.

The Sustainable Healthcare Steering Group wanted to understand to what extent issues around sustainable healthcare and potential solutions to challenges are being considered and prioritised at a local level. Research was undertaken with two of the main actors in the new landscape: Health and Wellbeing Boards (HWBs) and local Healthwatch organisations.

Encouragingly, the Steering Group’s exploratory research with HWBs and local Healthwatch organisations suggests that the importance of building sustainable systems is being recognised at a local level.

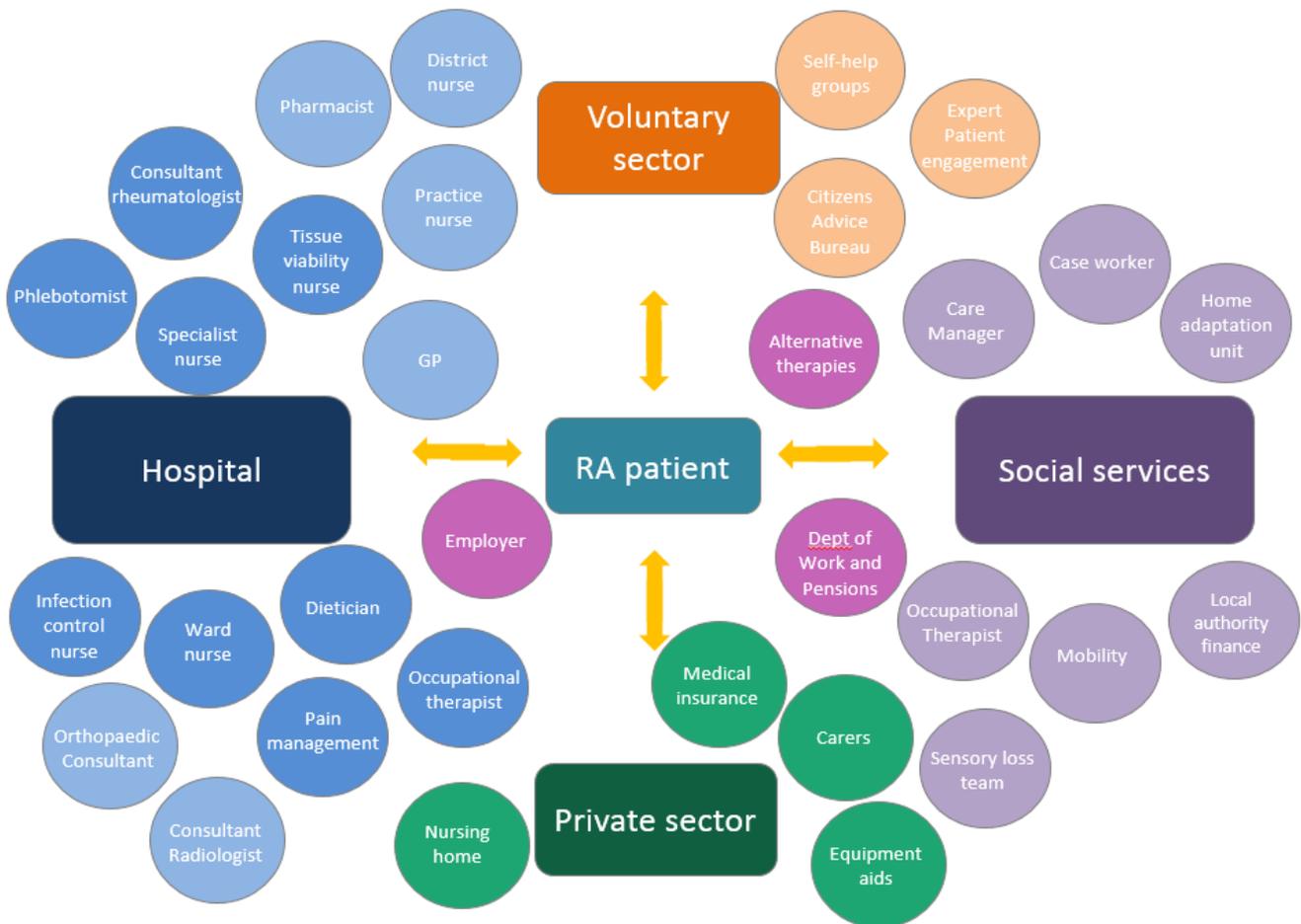
During September and October 2013, the Sustainable Healthcare Steering Group conducted in-depth interviews with members of eight local HWBs from across the country, to understand: what

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sustainable healthcare means to them; whether sustainable healthcare has been raised at board level within their organisations, and in what context; and to understand their views on the potential for sustainable healthcare to become a common thread of the work of HWBs.

Interviewees suggested that HWBs are responsive to the increasing importance of sustainable healthcare, sometimes as a priority in its own right and sometimes as a contributory factor to success in other policy areas¹⁷. For most of the HWBs which responded, sustainable healthcare meant providing affordable and cost effective care that focuses on preventative medicine and person-centred care – potentially through greater service integration such as that being explored by the new integration pioneers¹⁸.

HWBs see a role for themselves in being part of the solution to meeting the challenges of creating a sustainable system. Financial constraints were seen as presenting the biggest challenge to sustainable healthcare. However, other challenges include ensuring that the quality of service is maintained as well as the relatively new nature of the boards. HWBs are still interpreting their roles and boundaries, but believe that they could contribute in coordinating and facilitating the provision of sustainable healthcare services.



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A key theme emerging from the interviews was the need for examples of good practice in sustainable healthcare from other localities, ideally packaged into a single easy-to-access, information resource, such as those developed by NHS Improving Quality (www.nhs.uk). One councillor said:

“A particular issue for Health and Wellbeing Boards is the ability to find information and independent analysis that outlines the best return for investments to achieve sustainable healthcare outcomes. A systematic and national information resource, which highlights new initiatives and sustainability issues would also be useful.”

All local Healthwatch organisations were surveyed during September to October 2013 on the extent to which they believed sustainable healthcare was prioritised locally and the different ways in which people with long-term conditions are being supported to participate in making the system more sustainable. Despite being nascent organisations, responses were received from 32% of local Healthwatch organisations¹⁷.

Most respondents believed that sustainable healthcare is highly prioritised on a national level, with nine out of 10 believing it to be a ‘very high’ (75%) or ‘quite high’ (15%) national priority. However, respondents felt this prioritisation was not reflected at a local level¹⁷. Only 35% of survey participants believed local decision-makers prioritise issues around healthcare sustainability ‘a lot’ or ‘quite a lot’, and 15% indicated that they did not believe it to be a ‘very high’ local priority¹⁷. This may signal a disconnect between the national and local priority-setting; further research would be needed to interrogate this.

Respondents highlighted a number of different approaches which are being taken by local authorities to improve healthcare sustainability. For specific conditions, coaching from the point of diagnosis schemes and support to self-manage initiatives have been implemented in 40% and 38% of local areas respectively¹⁷. Initiatives to coach patients when they reach a crisis or turning point have been established in 37.5% of local areas¹⁷. It would be helpful to understand the lessons from these schemes, to help spread them to locations where they are yet to be established and to test whether similar approaches would be successful in supporting people living with other long-term conditions.

However, there was little evidence of approaches being taken that enable people with long-term conditions to self-refer to services. Further, the improved use of technology to support long-term condition management was only being considered in around a quarter of local areas¹⁷. It is not clear whether these are areas where innovation is yet to be spread, or whether knowledge that such approaches are being taken is not being disseminated.

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Recommendation 1: The Department of Health should work with NHS England and Public Health England to establish a shared healthcare sustainability resource for local commissioners, bringing together good practice examples of evidence-based initiatives.

Putting a human face to the challenges – Gerald, Jean and Hannah

Each of the 15 million people living with a long-term condition is a person, with individual needs, hopes and wishes. They expect and deserve a high quality of care from our healthcare system, but increasingly they understand the pressures it is under and can be encouraged to contribute to its sustainability.

To illustrate how changing mindsets and behaviour in the three identified themes could make a difference, the Sustainable Healthcare Steering Group has created three portraits of people living with a long-term condition. These stories are fictional, but not untypical of the situation faced by millions of people in England. In each of the chapters that follows we will summarise how change could make a difference to these people's healthcare journey.

Gerald

Imagine Gerald. At 86, he is just about managing to live independently with increasing support from his family and neighbours. He should be taking a beta-blocker to lower his blood pressure, and he has hearing aids in both ears.

Recently, he has become more forgetful, so his family persuaded him to see his GP. Following referral to a memory clinic, he has been diagnosed with dementia and given more daily medication. However, his family are worried that he is not taking all of his tablets as they keep finding them around the house. They are also worried that he is not eating enough as they have found old and partly eaten meals in the fridge for several days. He has fallen several times in the last few weeks and the family need guidance and support on how to keep him safe and cared for.

Jean

Imagine Jean. At 48, the joint pain she had been living with for years has worsened, and she has finally been referred to a rheumatologist and been given a diagnosis of rheumatoid arthritis. In some ways, the diagnosis is a relief – with a diagnosis she can at least start on treatment – but it has thrown up many questions. Will the medication help with the pain? What about side-effects? Will she be able to carry on working? Jean and her husband were planning to rely on both of their pensions to enable them to cope financially.

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Hannah

Imagine Hannah. After a year of pain, sickness, and exhaustion, she has been diagnosed with Crohn’s disease. At 17, when her friends are talking about going to university, she is wondering if she is ever going to be able to complete her A-levels – she has had so much time off college – never mind the thought of leaving home.

She is losing weight and confidence and has resorted to staying at home rather than visit friends or socialise. Her mum and dad are obviously upset and that is causing her stress. The doctors are talking about surgery to give her a colostomy bag – but she thinks that is something for old people. She is finding the situation unsettling and frightening.

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Theme 1: taking a person-centred approach to health and care

“When I was first diagnosed I saw myself as a victim, and then I felt like a patient. Gradually, I made the massive journey to ‘self manager’, and then beyond to become a leader, taking control of every aspect of my mental and physical well-being. In 30 years I have made a massive journey.”

Carrie Grant, advocate and Sustainable Healthcare Steering Group member

The Sustainable Healthcare Steering Group has identified a need to shift attitudes in health – from a siloed approach looking at just the condition to an approach that recognises the needs of the individual as a whole. This shift will be increasingly important as the healthcare system cares for more people with a multiplicity of sometimes interrelated comorbidities.

A person-centred approach

The concept of ‘patient-centredness’ or ‘whole person’ approaches can be defined in a variety of different ways. The Sustainable Healthcare Steering Group has based its view on eight fundamental principles set out by the Picker Institute¹⁹. These are set out below.

Respect for patients’ values, preferences and expressed needs

Coordination and integration of care

Information, communication and education

Physical comfort

Emotional support and alleviation of fear and anxiety

Involvement of (and support for) family, friends and carers

Smooth transitions and continuity of care

Access to care

These principles are founded on the belief that improvement – either in the achievement of personal goals or systemically – cannot happen unless the views and experiences of individuals with long-term conditions are integral to efforts to change. The eight principles were set out in 1987, but remain as relevant today.

However, these principles must be applied in a way that is sensitive to each patient. Recent work, notably by M. Politi and colleagues, confirmed the importance of clarifying patients’ precise desired role in shared decision-making²⁰. Key aspects of patient-centredness are:

- Ensuring that any approach to care is tailored to the individual and respects that person’s preferences
- Decision-making based on a genuine two-way dialogue between patient and professional

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- The provision of clear information to support decision-making

Achieving these principles consistently across the NHS demands a more fundamental change in attitude and re-education of both patients and clinicians. This should be in terms of both what to expect and what to provide. In order to be effective, such change must work in both directions and must be applied consistently across the care system.

In addition, there is a further complicating factor around shared decision-making. In practice, individual patients' perspectives can still be overlooked and it can be hard to translate complex medical facts into a discussion about the risks that an individual is prepared to take around particular healthcare decisions. Care must be taken with such discussions.

In summary, the shared objective of the Steering Group is for a sustainable healthcare system in which individuals will be able to make a transition from being a passive recipient of advice and treatment to increasingly directing their own care. In enabling this transition, there needs to be an understanding that individuals will want different degrees of power, information and support, but they should have continued encouragement to optimise their ability to negotiate their healthcare needs.

The role of healthcare professionals is to encourage people to move along the path of self-management to a point at which they feel comfortable, supported and in control. This will enable resources – both those of the individual and the system – to be used better in a more sustainable way.

The power of identity

People's behaviours are often affected by the labels ascribed to them – treat someone as a victim and they are likely to accept and behave so. In the context of health services, the way in which someone with symptoms of, or newly diagnosed with, a long-term condition is labelled will shape the way in which they feel about their condition and respond to services.

Further, if the approach taken is solely driven by the medical needs and if the language used by a professional is highly medicalised this can sometimes overlook the wider needs of the person as an individual rather than simply as a patient. Such a medicalised approach could serve to foster reliance on professionals rather than promote individuals' independence.

Two themes were brought to the forefront in this context. Firstly, professionals, services and the media should be scrupulous in avoiding polarising phrases like 'bed blockers', 'heart-sink' patients and 'frequent flyers'. These terms are offensive and lazy and do nothing to encourage a culture of openness and trust between the NHS and the people who use it. Often, they refer more to the failings of an organisation which has allowed a negative situation to arise.

Secondly, professionals should recognise that people do not define themselves by their condition. Their identities as parent, grandparent, sibling or employee will be of importance in understanding their hopes and goals for treatment and care. As Homaira Khan, a speaker at the panel debate stated:

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“I am [seen as] ‘only a patient’, ‘the person with rheumatoid arthritis’. I have other identities that make up who I am as a person and are things that sustain me as an individual and give me the strength to deal with this illness. I haven’t been asked if I need any services as a mother with an illness. I don’t actually need it now because I have a support unit around me. I have a supportive partner, family and siblings. For those that don’t have it, I dread to think what they have to go through.”

If truly patient-centered care is delivered then potentially difficult issues would be apparent during a consultation and not arise later. In this way, therefore, taking the time to understand the identity of the individual – how they define themselves and what matters to them – can mean that they are on a better healthcare trajectory.

Right person, right time, right plan

The Mandate to NHS England sets out an objective for the NHS to become better at involving and empowering individuals and their carers to make decisions about their own care and treatment. To enable this, a commitment is made to offer everyone with a long-term condition (physical or mental) “a personalised care plan that reflects their preferences and agreed decisions” as well as the option of holding their own personal health budget²¹.

Discussions with stakeholders carried out by the Steering Group reinforced the conclusion that individuals with long-term conditions must have the information they need, delivered at the right time, and by the right person. The Sustainable Healthcare Steering Group welcomes the commitments in the Mandate to NHS England, but recommends they could go further.

The Secretary of State for Health recently announced that frail elderly people will be given a named GP to coordinate their care²². The objective underpinning this is to support better coordination of care in the community, and reduce the burden of avoidable admissions of the frail elderly to hospital, particularly during winter months. Given the impact of long-term conditions on acute admissions, the Steering Group recommends that individuals with a long-term condition should also be given a named healthcare professional with responsibility for supporting the coordination of their care. This professional should not necessarily be a GP but must have the responsibilities, skills and experience to deliver this role effectively.

Recommendation 2: All individuals with a long-term condition should have a named healthcare professional with the appropriate expertise to support the coordination of their care.

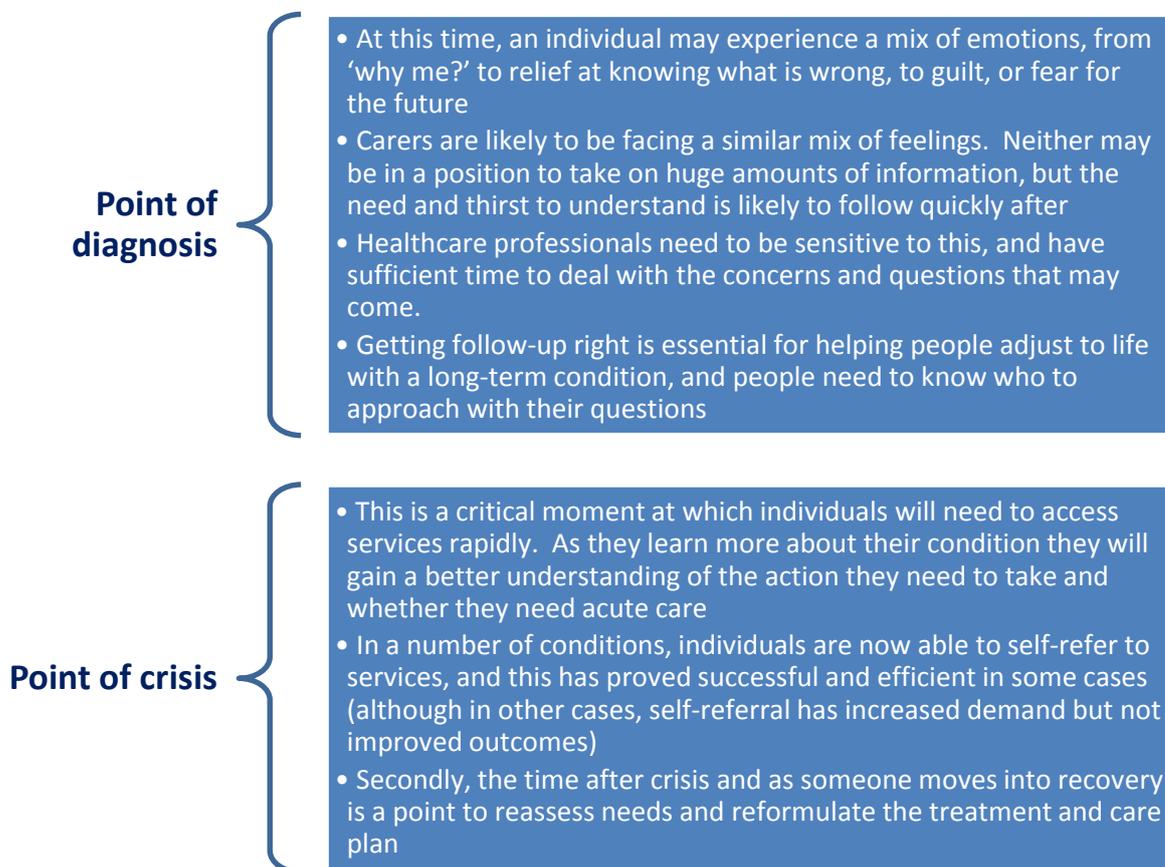
A number of stakeholders who the Steering Group engaged with raised the importance of getting the timing of interventions right. Several individuals spoke of how it took them a number of years to fully understand and adjust to living with their condition. However, there was consensus that there are important moments in the journey of care, where a well-timed intervention can make a significant difference – particularly the point (or just after) a diagnosis is made and also when a crisis or relapse can occur. In this context, members of the Steering Group cited models already in

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operation across England such as telephone advice lines staffed by nurse specialists which have received positive feedback from people.

The considerations at these two points are illustrated in this diagram.



Recommendation 3: All individuals, and their carers, newly diagnosed with a long-term condition should have the name and contact details for a designated person who they can contact and who can direct them to local health and support services.

This directly aligns with the Government’s aim to give every person aged over 75 a named, and therefore accountable GP, who ensures that care given to individuals is coordinated.

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Recommendation 4: Commissioners should explore the potential of expanding pilot projects of individuals with long-term conditions being able to self-refer to services and evaluate further the impact on the quality of experience, outcomes and efficiency of these individuals' care.

Changing relationships

Alison Cameron, a patient leader and one of the speakers at the panel debate, explained the difference that being given back control made to her recovery from trauma:

"I did trauma therapy hanging out at a wheel of a boat and meditation every morning. Standing at the helm of a boat in the storm I realised I was powerless over the weather but when I blew off course I was the person who directed it back onto course. Since I have been able to make my decisions I have not been admitted. I still have problems but live alongside them. I am emancipated."

Enabling individuals to take back control over their care will, in many cases, necessitate a change in relationship between the healthcare professional and the individual. The relationship must change from a transaction (where advice is given and accepted or rejected) to a partnership recognising the learned or lived expertise of each individual.

Case study: expanding understanding of the potential impact of changing relationships

In 2010, The Health Foundation launched its *Closing the Gap through Changing Relationships* improvement programme. As part of this £4m programme, seven teams are working on projects that aim to change the relationship between people and health services through:

- Patient self-administration of medication
- Patient access to online health records
- Addressing complaints about care received
- Involving women in decision making in antenatal care
- Use of peer support workers in mental healthcare
- Improving healthcare services for homeless patients
- Shared decision-making in child/adolescent mental healthcare

The Health Foundation recently reviewed the evidence for how these different interventions may impact on the professional-patient relationship in a positive way, by enhancing individuals' confidence and knowledge, and by recalibrating the system away from one that limits people's ability and opportunity to take an active role in their health and healthcare²³.

The review found a fairly robust level of evidence of effectiveness for patient self-administration of medications, the use of peer support workers in mental healthcare and interventions to improve services for homeless people. Evidence of impacts on person-centredness and quality of care were more mixed.

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The authors concluded that that more research is needed to clarify how the mechanisms for changing relationships may impact on quality of care. However, it was clear that there is a need to take a more user-centred approach that involves end users in all stages of system design and implementation.

Recommendation 5: More evidence is needed of the impacts of changing the relationship between healthcare professionals and individuals with long-term conditions on quality, experience and safety of care. Researchers investigating innovative approaches should look to include measures of these in pilot design.

Benchmarking performance

The impetus of the NHS to deliver a person-centred approach to health and care will come from clear performance measures. Patient experience surveys are one mechanism for benchmarking how well healthcare systems are responding to patient needs.

The NHS has traditionally performed well on measures around communication and experience when compared with systems in other countries, but with room for improvement. For example, the Commonwealth Fund International Health Policy Survey of adults across 11 countries in 2011 showed that in the UK in respect of managing chronic conditions:

- 78% of respondents said that they had discussed their main goals/priorities with their healthcare professional
- 80% reported that they had been given clear instructions by their healthcare professional on symptoms and when to seek care
- 80% reported that their healthcare professional had helped make a treatment plan they could carry out in daily life
- Only 69% reported that their healthcare professional had done all three²⁴

The current GP experience survey asks respondents questions about their experience of their last appointment with their GP and practice nurse, including whether they: gave the person sufficient time; listened to them; explained tests and treatments; involved them in decision-making; and treated them with care and concern. It also asks whether they have a care plan in place, in which they were involved in creating and which reflects their personal goals, as well as their confidence in managing their condition.

The Steering Group recommends that there is scope to further refine these questions while new surveys such as the Friends and Family Test are being implemented, to ensure that individuals are having a joint share in the conversation.

Recommendation 6: Studies and surveys of patient experience and satisfaction with healthcare professionals should capture whether individuals are having a full share

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in consultation and decision-making about their care and having opportunities to self-manage.

Summary of theme 1: how would taking a person-centred approach make a difference to people's lives?

Gerald

- Would have access to a named healthcare professional to support the coordination of his care
- Would have his needs for additional support to maintain independence considered and met
- Would have social care needs assessed earlier and met

Jean

- Would have access to a named GP
- Would be able to self-refer to services

Hannah

- Would have access to a named GP
- Would be able to self-refer to services

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Theme 2: harnessing the power of technologies

“Huge growth in take-up of smartphones and tablets is creating a nation of media multi-taskers, transforming the traditional living room of our parents and grandparents into a digital media hub.”

Ofcom, *The Communications Market Report – UK*, July 2013

Within a short few years, new technologies have transformed our everyday lives. In the UK today:

- 94% of people own or use a mobile phone²⁵ and half of all adults use a mobile phone to access the internet (51%)²⁶
- 83% of households have access to the internet, either via broadband or a mobile phone²⁷
- In 2013, 72% of all adults bought goods or services online, up from 53% in 2008²⁷
- 43% of adults have used the internet to find health information online. Among those aged 25 to 34, nearly six in ten people (59%) have used the internet to find health information²⁷
- According to some estimates, there are around 20,000 ‘medical’ apps available for smartphones²⁸

Many people have embraced digital technology, and now use it to interact daily with friends and family. The speed of which this change has happened signals the potential that technologies have to transform the way in which people interact with healthcare services.

Increased adoption of technology is in line with the direction of national healthcare policy. The *Mandate to NHS England* outlines the Coalition Government’s expectation that the NHS will embrace and increase the use of technology to improve the quality and efficiency of healthcare²¹.

Within 18 months, the Government expects that everyone who wishes to will be able to access to their health records online, as well as having secure communications with their GP practice to enable online appointment booking, ordering of repeat prescriptions and e-consultations. Plans will be in place for secure linking of electronic records, enabling them to follow individuals (with their consent) to any part of the NHS or social care system and give healthcare professionals a full picture of their care.

By 2017, the Coalition Government has stated that it also expects that progress will be made towards its ambition of three million people with long-term conditions being able to benefit from telehealth and telecare²⁹. This will support people with long-term conditions to manage and monitor their condition at home, and reduce need for avoidable visits to their GP practice and hospital – which may be both inconvenient for individuals and more costly to the NHS. It should be noted however, that some of the evidence base for telehealth is still mixed and further technology pilots may be needed to support this case.

An important transition needs to take place. This is through ensuring that the public actively engage in seeing the sense of using their own technology (e.g. devices) to engage with healthcare changes.

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For individuals to buy-in to using technology in this way requires them to see the personal advantages for them such as having a clinical consultation at home.

Controlling healthcare from the home

There is the potential for the ‘digital media hub’ of our living rooms to become the centre for people to control their healthcare and long-term conditions. Already, technologies exist that can support people to monitor their condition from their armchair, with results being fed back to a system that can either reassure them that all is well or alert a community or hospital-based team of the need for intervention.

The NHS Simple Technology ‘Florence’ or ‘Flo’ is an example of this and, in the parts of the country where it has been rolled out, has been improving people’s experience of care as well as saving money. When such models work well, then they attract interest and enthusiasm from other areas and this encourages wider adoption.

Case study: Enabling individuals to monitor and self-manage their long-term conditions

The ‘Florence’ (Flo) system – named after Florence Nightingale – allows people to take an active role in the management of their long-term condition.

People send in daily details of their blood pressure, temperature and pulse readings via SMS to Flo. These are analysed by Flo’s computer system, which responds within minutes via SMS to either reassure them that their results are fine or advise them on action to take. It can also send reminders to take medication, helping to improve concordance with their treatment. The flexibility of the system means people can use it at home – or indeed on holiday – minimising the need for repeated appointments with their GP.

Flo can also share the person’s information with their healthcare team (GP, community matron or hospital team) via the web and mobile apps, and send alerts if results are not received or if there is a potential problem such as unexpectedly low blood pressure. This means that the healthcare team can quickly follow up with a telephone consultation or a home visit, enabling early intervention to avert more serious problems.

More than 1,000 people in the Stoke on Trent area have been helped by this award-winning service, which runs at around 10% of the cost of previous telehealth solutions. One person said:

“Even though I had never used text before, the system is very easy to use and I don't have any problems sending my readings in. Flo found I had a heart problem and my GP was able to quickly see me and then check on my progress. I'm far less worried about my condition; I am less tired and feel much better now because of Flo.”

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One of the clear advantages of technologies like Flo is that they build from mobile phone technology that people already have and are familiar with. As one participant at the stakeholder consultation event put it:

“Everyone has a mobile phone. People buy them themselves – they cost the NHS nothing. We [the NHS] just need to use them.”

However, a number of challenges have been identified, particular in relation to how the benefits of some technologies have been ‘sold’ to people with a perception that they may have been business-driven rather than provided around the needs of an individual. Such experiences serve to reinforce the need to ensure that services and care are shaped around the individual.

Recommendation 7: Commissioners should examine the potential for existing technologies, that tap into digital systems that people already use, to be expanded across the country to enable more people with long-term conditions to benefit from them.

Flexible consultation: the patient will see you now

Increasing use of smartphones and tablets, coupled with face-to-face messaging software such as Skype, means that there is the potential for people with long-term conditions to consult their GP or hospital team without having to physically visit the surgery or hospital – unless they feel that they want or need to.

The Sustainable Healthcare Steering Group saw different scenarios where a more flexible approach to consultations and information-sharing might be appropriate:

- **Pre-referral:** Instead of (or in addition to) written information people referred for an appointment could either ‘meet’ their consultant via video-or tele-conferencing or be emailed a short video setting out what to expect at their hospital appointment, as well as if there’s anything they should do in advance or bring with them. In Ireland, rheumatologists have been trialling sending out a short video message ahead of first hospital appointments and these have been well received and have helped to reduce the rates of non-attendance
- **For routine checks:** In some long-term conditions, there will be a need for ongoing discussions – for example of test results, but no need for a physical examination. In these instances, the person with the condition could be asked whether they wish to have their next consultation in person or via Skype or similar technology. This would potentially save time – particularly for the person with the condition who would not need to make a round trip to hospital or their GP surgery. This approach could be trialled to see if it improves patient satisfaction and experience, as well as the efficiency of appointment delivery

It would, of course, be essential that the person with the condition is in control of how they wanted their consultation to be held – whether virtually or in person – or plan to have their future consultation face-to-face. Flexibility and a choice of technologies is key. While texting suits some

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people, telephone email or face-to-face messaging will be preferred by others. There is also a need to change mindsets and see technologies as being for the benefit and convenience of the individual with the condition(s) and not solely for clinicians. In some cases, however, existing financial models have served to stymie the wider adoption of such technologies in practice and therefore financial drivers must be examined and in such cases amended in order to speed up adoption.

Recommendation 8: Commissioners and providers should explore the potential for trialling e-consultations, to determine whether they improve individuals' satisfaction with their healthcare services and yield efficiency benefits (such as reduced non-attendances).

Security and ownership

Despite the experience of the troubled NHS National Programme for IT, there is consensus in the healthcare community that electronic records are a vital tool for the future. Summary Care Records now exist for nearly 27 million people, or nearly half the population³⁰ and there is potential both to expand the data held within online records beyond that required for the Summary Care Record, as well as to make this more accessible to patients.

The Sustainable Healthcare Steering Group and stakeholders attending the consultation meeting considered two questions in this area: the importance of ensuring that data are secure; and the question of who 'owns' the data.

The example of the banking industry is one from which stakeholders felt the healthcare sector could learn. Around 50% of adults now use online banking, rising to three quarters (75%) of 25-34 year olds²⁷. High street branches still exist and paper statements can be sent to those who do not wish to bank online. However, consumers are increasingly choosing to access their financial information and make transactions online, in a secure space shared with their bank or building society. The need for security, and trust in that security, over personal health records is just as important. The fact, however, that banks can create a secure shared space, accessible to consumers, means that it must be possible for the NHS to achieve the same with integrated care records.

There was consensus among stakeholders consulted that individuals should be the 'owner' of their health data and records rather than the healthcare system – especially where the data have been generated through their own information technology. This would mean that individuals would be able to add and control the information contained within it and who it can be shared with. Importantly, there needs to be continued engagement with individuals and family members, to reinforce trust that they are in control of a system designed around their needs.

The pace of change

Concerns have been raised about the potential for technologies to create new inequalities, and in particular to disadvantage older people. One in five households is not yet online, and there is a group of people who will not be quick to embrace new technologies without significant levels of support. However, with a significant number of people moving to more technological approaches

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this releases resources in terms of time to care which means that appropriate support can be offered to those who are unable to use technology.

It is, of course, important that health services do not only cater for those who have access to the internet and are confident online. Equally, the opportunity to deliver more flexible services and increase self-management must not be held up or blocked by a refusal to go faster than the pace of the slowest.

This will require working with individuals – both healthcare professionals and patients – to assess their level of digital skills and improve those where needed. It will also require increasing awareness about the types of technology that are available; low demand may not necessarily mean that people do not want to access their records online or consult with their GP via Skype, it may be that they do not yet know this is an option for them.

We must also guard against the assumption that people do not have the skills or cannot learn to use technologies. As one stakeholder put it:

“My nan’s 85 and she probably wouldn’t use technology, but her brother is 90 and he absolutely would – he uses Facebook, Skype, all of that. They’re similar ages, but very different people.”

Recommendation 9: Commissioners and providers should ensure that systems using new technologies are built taking into account the needs of those who are not yet digitally enabled, but that this does not prevent progress in increasing the use of technologies to improve care.

An example of the need to look ahead and embrace emerging technologies is the potential for cloud computing to speed up and share access to records.

Case study: Using cloud computing to speed up decision-making in stroke care

Neurologists from hospitals in the North East London Stroke and Cardiac Network now use a cloud system as a secure shared space for remote access to CT scans of stroke patients, enabling faster decision-making when time is of the essence³¹.

Previously, logging into the network and waiting for images to download would take 20-40 minutes, and was limited by the bandwidth of the connection and the NHS internet gateway. Now, the hospitals’ PACS system uploads emergency CT images to the cloud and members of the team can log in and view images within five minutes.

The cloud system also means that a neurologist based in a specialist centre in one part of London can view a CT scan taken in another hospital and rapidly confirm whether or not the individual has had a stroke and needs to be transferred. The receiving unit no longer needs to repeat the scan once the patient arrives, and this means the patient can receive thrombolysing medication without delay.

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Recommendation 10: Commissioners and providers should explore the potential for cloud computing to enable better information-sharing and rapid decision-making in long-term, as well as acute, conditions.

Summary of theme 2: how would harnessing technology make a difference to people's lives?

Gerald

- Would be supported to use technology where he felt able
- Could be reminded to take medication
- Could be assessed for home adaptation to enable him to continue living at home for as long as possible

Jean

- Would have access to her records online
- Would be able to make appointments online
- Would be able to speak to her rheumatologist via Skype

Hannah

- Would be able to access her records online
- Would be able to have e-consultations if she preferred
- Would be able to find peer support online and through social networks

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Theme 3: helping individuals navigate the healthcare system

“The co-production of value in health care is not an alternative to the NHS. It is the NHS working differently with patients to develop greater value. What does this mean in practice?”

“If you are a person with diabetes you are managing your own health care in your own life for about 5,800 waking hours a year. [You] will also be seeing NHS healthcare professionals for about 5 hours in that year. The impact of these five hours upon the 5,800 hours is the crucial issue which determines the amount of health care value that is created. For it is in those 5,795 hours that most health care value is created NOT in the 5.”³²

Paul Corrigan, healthcare consultant and Sustainable Healthcare Steering Group member

The NHS is a complex system. Long-term conditions can be equally complex to manage. For individuals with a long-term condition and their carers – especially when newly diagnosed but also as their needs change – knowing where to turn, for what and when can be difficult.

If individuals can be supported to get the most out of the time they have in contact with healthcare professionals, then each should be able to make best use of the healthcare resources available to them and achieve better outcomes for themselves.

The Sustainable Healthcare Steering Group considers there to be two key areas for exploration under this theme:

- Taking a coaching approach to support individuals to consider, set and achieve their healthcare goals
- The routes and mechanisms to support people to better use and navigate the healthcare system, and tap into community resources

These require two different functions to support individuals: the coach and the navigator.

The coaching approach

Coaching helps individuals improve their performance and skills development, and tends to be task- or project-focused with the coach supporting an individual towards achieving a specific outcome. Widely applied in line- and project-management, a coaching approach is being increasingly explored to support people to achieve healthcare, as well as life, goals.

This shifts the focus from understanding what is important ‘for’ the individual to what is important ‘to’ them. Rather than the healthcare professional telling the patient how to get to a clinical endpoint, they will explore with the individual what they would like to achieve from their treatment and care, and then working with them to determine a route to get there, including identifying potential barriers and how they might overcome them.

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By fully exploring the individual's goals, and co-creating the plan to 'get there', the individual has more 'ownership' of the plan and more likely to maintain behaviour or lifestyle changes. There is an increasing body of evidence to show that a coaching approach can help people achieve good outcomes in a range of areas, from smoking cessation and weight loss to diabetes management and adherence with treatment.

Case study: supporting people with Chronic Obstructive Pulmonary Disease (COPD) to manage breathlessness and anxiety

Funded by the Health Foundation and NHS East of England, the Centre for Self Management Support (CSMS) at Cambridge Hospitals NHS Foundation Trust has been testing the impact of self-management support on quality of life and independence for people with long-term conditions including COPD, Type 2 Diabetes, stroke and heart disease.

For COPD, the team has been exploring how coaching from nurses, supported by online technology (the 'Prevention Plan') can help people with COPD better manage symptoms such as breathlessness and anxiety. The nurses initially provide coaching face-to-face, and then over the phone, to help people feel more confident in understanding how to manage their symptoms, and how to use exercise and breathing techniques to cope when they feel breathless. Follow-up has shown that people using the self-management techniques report improvement in quality of life.

Case study: overcoming issues faced by people with hepatitis C and blood borne viruses

Waverley Care in Scotland has created a life coaching programmes to tackle the issues facing people living with hepatitis C and blood borne viruses such as poor mental health, financial hardship, chaotic lifestyles, stigma and discrimination and issues around medication and treatment.

The programme aimed to support people to gain self-management skills, through: seven weekly sessions of 3.5 hours per week; incentives (food and travel); baseline and impact assessments; independent health checks four weeks post-programme delivery; one-to-one life coaching tailored to the condition the individual has; a supportive group environment; and access to expert peers.

Data collected from participants and facilitators show that the programmes were successful in: raising confidence, motivation and self-esteem; improving participants' ability to cope with symptoms and emotions; encouraging better health; and enabling informed decisions about treatment to be made.

The Sustainable Healthcare Steering Group believes that coaching can be a powerful tool in enabling people to choose and sustain lifestyle changes needed to prevent the development of some conditions, or to manage to adapt to the development of a long-term condition. With the rise of diseases related to lifestyle factors such as smoking, alcohol and obesity, and the general increase of long-term conditions (lifestyle-related or not) these approaches should be more widely utilised.

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Upskilling the workforce for coaching

Healthcare professionals are primarily taught to diagnose, treat and care, though an increasing focus that has been given to how they communicate with patients through that process. In order to facilitate coaching to be embedded in the system, the healthcare workforce will need to be supported and upskilled.

Importantly, this training and development should not be just limited to GPs or specialists in secondary care; a range of healthcare professionals, at different grades and from different disciplines, should be encouraged and equipped to use these skills. Indeed, nurses have trained from bedside to specialist fields and the need to support and educate the patient along the journey is embedded in their work. In practice, this means negotiating or brokering for the people they care for and acting as a hub for access to other aspects of support. The training and development of this work should be enhanced.

Case study: coaching to improve rehabilitation programmes

The team at the Centre for Self Management Support at Cambridge Hospitals NHS Foundation Trust has worked with Band 4 healthcare assistants to use coaching skills to support people who have experienced a stroke. Because they spend more time with the patients, the healthcare assistants have found they are able to openly explore with them what they want to achieve from their rehabilitation.

The team has developed a tool, using structured questions, which enables rehabilitation programmes to be better tailored to individual needs and goals. They have also reported a renewed confidence and sense of achievement among the healthcare assistants themselves.

Recommendation 11: Royal Colleges, Health Education England and universities should examine the curricula for professional training to identify opportunities to embed coaching skills and shared decision-making. Providers should also encourage healthcare professionals to develop coaching and shared decision-making skills as part of their continuing professional development with a quality indicator set against which performance can be benchmarked.

Supporting people to navigate services

NHS structures and systems can be complicated to navigate for the people who work within them, let alone for individuals. Individuals may use a range of services, spanning primary, secondary, community and social care and it is essential to get the transition between them right. As a stakeholder at the panel debate put it: “Gaps in services are where faults happen, the fault occurs at the boundaries.”

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In addition, healthcare professionals and individuals with long-term conditions may not be aware of the full range of supportive services that could be available to support their needs. For this reason, the support of a ‘navigator’ can be valuable in helping people understand what may be available to them – including beyond traditional healthcare services.

As with the role of ‘coach’, a range of different professionals can fulfil the role of ‘navigator’.

In secondary care, specialist nurses (for the conditions for which they exist) fulfil the role of patient advocate and navigator. They support individuals and their families by helping them understand their diagnosis, co-ordinating tests and explaining results, identifying holistic needs (for example for counselling or financial support) and acting as a liaison point between services in different settings, as well as patient organisations and other non-medical opportunities such as health and fitness classes.

In primary care, some organisations have employed community health workers, to proactively support people with long-term conditions and elderly patients. Based in general practices, the community workers build a local knowledge of services – both within traditional health and social care settings and beyond them, such as friendship clubs, walking groups or cookery classes. Individuals identified by the GP can be referred to the community worker for tailored information and support.

This latter approach has parallels with the community health worker role which has transformed health outcomes in countries like Brazil.

Case study – community health workers in Brazil

In Brazil, services have been reconfigured over the past 15 years to improve the management of chronic disease. Family Health Partnership teams were established around the multidisciplinary skills of one physician, one nurse, one medical assistant and four to six Community Health Workers (CHWs).

The CHWs deliver most services at a community health clinic, with monthly home visits to all households (irrespective of request or need) and neighbourhood health promotion activities. Each team serves a population of around 3,500. CHWs undertake adult risk assessments for chronic disease, as well as developing health education programmes to promote treatment adherence and group-level interventions to support lifestyle changes.

The scheme now covers half the population of the country and is associated with: reductions in infant mortality; increased uptake of breastfeeding and childhood immunisations; lower levels of adult hospitalisation for chronic disease (particularly asthma, stroke, and hypertension); higher levels of hospitalisation of adults with diabetes (possibly related to detecting more people requiring hospital care); reductions in inequalities in terms of access to healthcare; increased management of chronic conditions by primary care; development of national policy guidelines to diagnose, manage and treat key chronic conditions; enhanced primary care capacity; increased adult labour and increased school enrolment.

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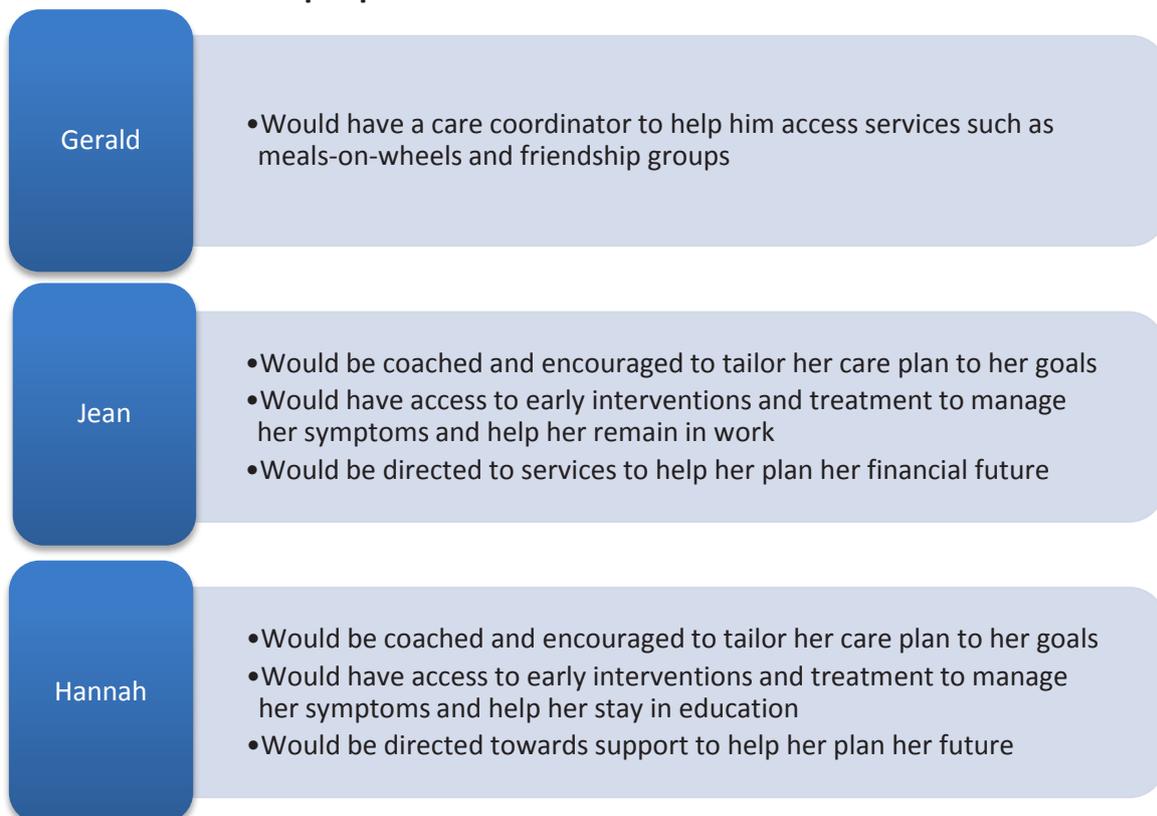
The Sustainable Healthcare Steering Group believes that the community health worker role could help to improve individuals' ability to know about, and access, health and support services locally and would welcome the establishment of additional pilots to assess their contribution and value.

In addition, in some areas the role of navigator can also be performed by lay people rather than professionals. For example, some hospitals use a health information resource where lay members are trained to offer health promotion advice. Such innovative thinking means that great potential resources can be unlocked to support people's care.

Recommendation 12: Commissioners and providers should explore pilot programmes to establish the value of care-coordinators in supporting individuals to navigate the healthcare system. These programmes should include evaluation of the impact on individuals' satisfaction with services, use of resources and wellbeing.

These pilot programmes can help to provide a strong evidence base on how clearly co-ordinated care can impact the lives of individuals and can be used to help influence wide scale programmes implemented both regionally and nationally.

Summary of theme 3: how would expanding coaching and embedding navigators make a difference to people's lives?



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Conclusion

Much more must be done to tap into the underused asset in healthcare: the potential of individuals to become more empowered in actively sustaining their health, while being supported by health and care providers. More must be done to enable and liberate both staff and people with long-term health conditions to take greater control of the management of their condition(s) and consequently, their health.

The vision for a sustainable healthcare system

Our vision is that health and care providers enable people with long-term conditions to understand their abilities, opportunities, rights and responsibilities in actively sustaining their health. By creating an environment in which people are encouraged, empowered and equipped to better support themselves, we can make the whole healthcare system more sustainable.

Features of a sustainable healthcare system

From the discussions and research undertaken, the Sustainable Healthcare Steering Group believes that each of the following areas should be considered in building a sustainable healthcare system:

1. **Primary, secondary and tertiary prevention strategies** – since each can contribute to preventing or delaying the development of long-term conditions or to managing their complications
2. **Early access to evidence-based treatment** – enabling people with long-term conditions to benefit from treatments that, based on shared decision-making, they and their clinician believe offer them the best opportunity to control or cure their condition, and intervening earlier so that individuals receive maximum benefit
3. **Shared decision-making grounded in high quality, impartial information** – supporting people, from the point of diagnosis, to fully understand and be involved in decisions about their treatment and care
4. **Increased use of technology** – making the most of technologies that are already in widespread use and which people already have and are familiar with using, such as mobile phones and Skype, and putting people in control of their own data and giving them access to their records
5. **A coaching approach to enable supportive self-management** – equipping people with the confidence and skills to set their own goals and manage their condition as far as they feel able to
6. **Embedding ‘navigators’ within services** – with local knowledge of healthcare services and allied support services which may be available to individuals with long-term conditions
7. **Equipping the workforce** – shifting the approach taken to management of long-term conditions, whether through coaching approaches or use of technologies – will require support and training for the workforce of the NHS

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Bringing these features together would enable care pathways for individuals to be transformed, in smoothing over the transition points between services and handovers between healthcare professionals and enabling the individual to feel in control throughout the system.

Next steps

The Steering Group has made a number of recommendations for consideration and looks forward to working in partnership with policymakers, commissioners, providers, patient advocacy groups and individuals with long-term conditions themselves, to see them implemented.

Supported by AbbVie, colleagues in other European nations are examining the same questions. This work is being brought together in a pan-European White Paper for publication. The Steering Group looks forward to determining where there are common challenges with other countries and to sharing recommended solutions.

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Appendix a – Additional case study material

In preparing this report, the Sustainable Healthcare Steering Group has reviewed a range of documents, websites and other materials to identify practical examples of approaches to improve the sustainability of healthcare systems, both in the UK and internationally. Summaries of, and links to, some of the most interesting examples are below.

Teams Without Walls, UK – various areas, 2008

The objective of this initiative was to create an integrated model of care, with professionals from primary and secondary care working together in teams across traditional health boundaries to support patients using care pathways designed by local clinicians. A working party from the Royal College of Physicians and Royal College of GPs, together with the NHS Alliance Specialist Network and Royal College of Paediatrics and Child Health, examined the redesign of healthcare and identified (then) current and innovative practice through service redesign including:

- A care of the elderly scheme in Poole, Dorset, which showed that multidisciplinary teams working across hospital and community settings could help people avoid hospital admission and enable enhanced discharge
- Development of an integrated respiratory medicine service in Hull which was supported by patient-centred guidelines, emphasising early treatment and patient education, and an effective community outreach service
- An education programme for people with stable inflammatory bowel disease, run by the gastroenterology service in Barnsley, which also allowed monitoring test results to be sent by email or text to free up outpatient slots, saving both costs and time for patients
- Integrated diabetes and rheumatology services in Bolton, primarily based in GP practices closer to the community, but providing in-reach services to the hospital
- A rapid access one-stop diagnostic clinic to assess patients with suspected heart failure and breathlessness in County Durham, which reduced hospital admissions and improved uptake of evidence-based heart failure therapies

More information can be found at: <http://www.bacch.org.uk/publications/documents/teams-without-walls.pdf> (by clicking on this link you will leave the report)

Family Health Programme (FHP) incorporating community health workers, Brazil, 1994 to date

The objectives of the Brazilian FHP were to provide accessible and comprehensive primary and community care, tackling high levels of infant mortality, and better managing the increasing numbers of chronic conditions associated with an ageing population.

The Brazilian FHP teams consist of one physician, one nurse, one medical assistant and four to six Community Health Workers (CHWs). The CHWs deliver most services at a community health clinic, with monthly home visits to all households (irrespective of request or need) and neighbourhood health promotion activities. Each team serves a population of around 3,500. CHWs undertake adult

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risk assessments for chronic diseases, as well as developing health education programmes to promote treatment adherence and group-level interventions to support lifestyle changes.

The FHP grew rapidly between 1999 and 2007, and covers more than 99 million people (more than half the population of the country). Higher levels of enrolment with the FHP is associated with:

- reductions in infant mortality
- increased uptake of breastfeeding and childhood immunisations
- lower levels of adult hospitalisation for chronic disease (particularly asthma, stroke, and hypertension)
- higher levels of hospitalisation of adults with diabetes (possibly related to detecting more people requiring hospital care)
- reductions in inequalities in terms of access to healthcare
- increased management of chronic conditions by primary care
- development of national policy guidelines to diagnose, manage and treat key chronic conditions
- enhanced primary care capacity
- increased adult labour and increased school enrolments

In the UK, proposals are being developed for the funding of a CHW pilot scheme in North Wales, and a randomised controlled trial to detect changes in individual and population health outcomes, as well as evaluate cost-effectiveness and barriers and facilitators to wide scale implementation. The results of such a pilot and trial would be interesting to better understand the potential for CHWs in the UK.

Relevant documents include:

- Macinko et al. *Going to scale with community-based primary care: an analysis of the family health programme and infant mortality in Brazil, 1999-2004*, *Social Science and Medicine*, 65 (2007)
- Rocha and Soares. *Evaluation in the impact of community-based health interventions: evidence from Brazil's Family Health Program*, *Health Economics* 19.126-158 (2010)
- Macinko et al. *Major expansion of primary care in Brazil linked to decline in unnecessary hospitalization*, *Health Affairs*, 29, no.12 (2010)
- Harris M. *Integrating primary care and public health: learning from the Brazilian way*, *London Journal of Primary Care*, 4:126-32 (2011)
- Giugliani et al. *Effectiveness of Community Health Workers in Brazil: a systematic review*, *Journal of Ambulatory Care Management* 34 (2011)
- Macinko and Lima-Costa. *Horizontal equity in health care utilization in Brazil, 1998-2008*. *International Journal for Equity in Health*, 11.33 (2012)
- Johnson et al. *Learning from the Brazilian Community Health Worker Model in North Wales*, *Globalization and Health*, 9:25 (2013)

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Development of a multi-matrix multi-partner telehealth model in pregnancy care, UK – Sunderland, 2013

Clinicians wanted to use telehealth technology to support home monitoring in women with mild pregnancy-induced hypertension or gestational diabetes. The system needed to monitor blood glucose, blood pressure and proteinuria, and needed to be capable of asking the woman questions and acting on the received patient data.

The clinical team developed safe inclusion/exclusion criteria and the telehealth team configured the NHS simple telehealth system 'Florence' (FLO) to text information to and receive texts from women, and to issue appropriate patient alerts. Additional telehealth technology used to support home monitoring included a Microlife 'Watch BPhone' digital blood pressure monitor and Meditest 'Protein2' urine dipsticks.

The programme recruited an average of five patients per month, and used the telehealth service for a mean of 12 weeks (range 6 to 18 weeks). Results showed high figures for satisfaction, convenience, flexibility with treatment and enhanced understanding of diabetes with all those enrolled. Importantly, there were no adverse outcomes reported during the pilot to mothers or babies. Costs were between £57 and £80 per patient per year, and prevented on average 3.2 hospital visits per pregnancy.

Link to original presentation:

<http://www.networks.nhs.uk/nhs-networks/simple-telehealth/blog/flo-gets-to-grips-with-outpatient-pregnancy-care/KingsFundPresentationTelehealthinPregnancyCHS2ndJuly20131.pdf>

(by clicking on this link you will leave the report)

Who Will Care? Demonstration of five high-impact solutions to prevent a future crisis in health and social care, UK – Essex, 2013

Essex County Council, Southend-on-Sea Borough Council and Thurrock Council set up a commission to take evidence from hundreds of local people of all ages to identify solutions for how health and social care in Essex could be improved and sustained. Five high-impact solutions were identified which set out a new relationship between citizens and the state:

1. [Agree a new understanding between the public sector and the people of Essex](#) – by being up-front and honest about the realities, responsibilities and costs of care
2. [Prevent unnecessary crises in care](#) – by changing the focus of care from treating disease and chronic conditions to supporting individuals earlier
3. [Mobilise community resources](#) – by acknowledging that local approaches and local understanding can deliver care, support, value, and greater independence
4. [Use data and technology to the advantage of the people of Essex](#) – by adopting tools and techniques that better support independent living, self-care, and co-ordination and give more convenient access to good advice
5. [Ensure clear leadership, vision and accountability](#) – by bringing together key partners from the public, private and voluntary sectors to deliver co-ordinated and convenient care for all

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More information about the actions under the five areas can be found at:

<http://www.essexpartnershipportal.org/pages/uploads/%20Howwillcare/130911%20Who%20will%20Ocare%20v.FINAL.pdf> (by clicking on this link you will leave the report)

Florence – telehealth self-management and support through SMS, UK – Stoke on Trent, 2011

The two year project was formed with the objective of identifying and testing cost-effective ways of driving clinically-led telehealth pathways.

The ‘Florence’ (Flo) system – named after Florence Nightingale – allows people to take a more active role in their health care management, managing their condition by sending in details (via SMS) of blood pressure, temperature and pulse readings. These details are analysed by the Flo computer system, which based on the results responds (again via SMS) to reassure them that their results are fine or advise them on action to take.

Flo is also configured to share patients’ information with their healthcare team, who can access the system via the web and mobile apps. Flo can remind the individual to take their tests (or medication) and alert their healthcare team – such as a community matron – if results are not received or if there is a potential problem, for example that their blood pressure is low. This means that their healthcare team can quickly follow up with a telephone consultation or a home visit.

More than 1,000 people in the Stoke on Trent area have been helped by this award-winning service, which runs at around 10% of the cost of previous telehealth solutions. One person said:

“Even though I had never used text before, the system is very easy to use and I don't have any problems sending my readings in. Flo found I had a heart problem and my GP was able to quickly see me and then check on my progress. I'm far less worried about my condition; I am less tired and feel much better now because of Flo.”

Because the system uses mobile technology, it is flexible and means individuals can continue to use it when away from home or on holiday. It is now being used in other parts of the country, including South of Tyne. More information can be found at:

NHS Local: <http://www.nhslocal.nhs.uk/story/more-1000-people-helped-mobile-phone-service-developed-nhs-stoke> (by clicking on this link you will leave the report)

NHS showcase:

<http://www.networks.nhs.uk/nhs-networks/simple-telehealth/videos/nhs-local-showcase-florence-the-nhs-telehealth-system> (by clicking on this link you will leave the report)

Presentation describing the system:

http://www.hee.org.uk/~heeorg/files/4113/6067/7081/Paul_Marriott_Feb_6th_2013.pdf (by clicking on this link you will leave the report)

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Date of preparation April 2014

Co-produced care and next generational health care management, UK – Staffordshire, 2008-9

Staffordshire Hospital funded by UK Preventive Medicine has used a self-care tool for patients for general health improvement to help tackle the capacity challenge which the healthcare system faces, with an ultimate goal of patient empowerment to those with chronic conditions.

People were enrolled in an online health improvement system that was focussed on assisting them through self-care, behaviour change, incentives, coaching and clinician integration. The online system created a personalised profile for each individual with categories that included: my health risks; my benefits; my prevention plan; my preventive testing schedule; my health record; my action programmes; my prevention score; my tracker and my incentives.

The system was available to patients with conditions including: anxiety and depression; asthma; cancer; cardiovascular disease; chronic kidney disease; COPD; musculoskeletal conditions; diabetes; high blood pressure or cholesterol; osteoporosis; sleep problems; and stroke.

Before the scheme was launched a population health picture was constructed which allowed a strategic approach to the study. A percentage chart was created for participants in each risk group (High, Medium and Low) for the diseases assessed, which showed if there were any changes to patients risk within their disease group after continued use of the online self-care tool. Net percentage increase/decrease of patients (number of patients in brackets) within each risk group for all diseases:

- 65.12% (1,697) of patients were low risk in 2009 compared to 55.72% (1,452) in 2008
- 27.44% (715) of patients were medium risk in 2009 compared to 31.04% (800) in 2008
- 7.44% (194) of patients were high risk in 2009 compared to 13.24% (345) in 2008

Net percentage of patients who moved to a different risk group for all diseases:

- 48.7% of High Risk patients moved down to Medium Risk
- 15.67% of High Risk patients moved down to Low Risk
- 46.35% of Medium Risk patients moved down to Low Risk

Further opportunities for similar programmes identified included long-term condition management and screening with risk reduction follow-up in primary care, as well as pre-planned admission preparation and post-discharge support in secondary care.

- Primary care: long-term condition management; screening with risk reduction follow-up; and electronic health record access
- Secondary care: pre-planned admission preparation; and post discharge support

This case study is part of the College of Medicine Innovation Network

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Testing and promoting self-management support (SMS) among people with long-term conditions, carers and healthcare workforces, UK – Cambridge, 2013

Funded by the Health Foundation and NHS East of England, the Centre for Self Management Support (CSMS), Cambridge Hospitals NHS Foundation Trust has been testing the impact of SMS on quality of life and independence for people with long-term conditions including COPD, Type 2 Diabetes, stroke and heart disease. The group has also evaluated the effectiveness of techniques in encouraging behaviour change among people with long-term conditions as well as healthcare professionals.

Projects focus on delivering models of SMS in which people become confident to manage their own condition and take responsibility for their own health, with healthcare professionals supporting them to achieve the goals that matter most to them as individuals. The approach is founded on the “Patient Activation” model (Hibbard et al, 2007), which recognises that people are in different states of readiness, skill and empowerment to take on responsibility for managing their health.

The programmes involve training healthcare professionals in the Patient Activation model and using techniques such as motivational interviewing and shared-goal setting to recalibrate the way that they approach conversations with the patients in their care. Generally, the training takes place over a number of team training sessions.

In COPD, the team has been exploring how web technology (the ‘Prevention Plan’) coupled with nurse coaching can help people with COPD better manage symptoms such as breathlessness and anxiety. In stroke rehabilitation, the team has worked with band 4 practitioners, to develop use structured questions to find out what patients want to achieve from rehabilitation, enabling programmes to be better tailored. In diabetes, SMS is being used to encourage lasting behaviour change, for example around managing and maintaining dietary change, increasing levels of exercise.

Healthcare professionals who have taken part in training have been complimentary about it and have used the skills they have learnt to change their practice. Longer term follow up (6 months) has shown that patients using SMS report improvements in quality of life and exercise capacity. Further research is now needed into the ‘types’ of patients who can benefit most from an SMS approach and on identifying the right time in the ‘life-course’ of the condition to offer SMS services – at diagnosis the person may not be ready.

This case study is part of the College of Medicine Innovation Network

Patient coaching and self-management in HIV, AIDS and Hepatitis C, UK – Scotland, 2013

Waverley Care is Scotland’s leading HIV and Hepatitis Voluntary Sector Service. Life coaching programmes (funded by the Long-term Conditions Alliance Scotland) were initiated to tackle the issues facing people living with Hepatitis C and Blood Borne Viruses (BBV) such as poor mental health; financial hardship; chaotic lifestyles; stigma and discrimination and issues around medication and treatment.

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The programme aimed to support people to gain self-management skills, through: seven weekly sessions (3.5 hours per week); incentives (food and travel); baseline and impact assessments; independent health checks; four weeks post-programme delivery; HIV; Hepatitis C and BBV life coaching; a supportive group environment; expert peer participants.

Both the qualitative and quantitative data collected from participants and the facilitator show that the programmes were successful in achieving their anticipated learning outcomes. These benefits included:

- Raised confidence and self-esteem
- Ability to cope with different emotions such as anger and frustration
- Ability to cope with symptoms such as depression
- Encouraged better health through diet, exercise and lifestyle
- Support to make informed decisions i.e. decisions about treatment
- Encouraged problem solving and building upon strengths
- Increases motivation by building upon realistic personal goals
- Tackled barriers to progress
- Developed new social networks

The programme will seek funding for the continuation and development of the service and to employ an additional worker to focus on the pre- and post-programme development of the service. Additional funding will also enable Waverley Care to train frontline staff to deliver focused one-to-one life coaching interventions and develop and roll out a new training programme for ‘peer mentors’.

More information can be sourced from Waverley Care (David Cameron and Paula McFadgen), *Waverley Care Self Management and Life Coaching Evaluation Report*, July 2011.

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Appendix b - Sustainable Healthcare Steering Group Biographies

Baroness Cumberlege (Co-Chair) – Conservative Peer

Baroness Cumberlege has a wide range of experience in healthcare, holding positions such as Chair of the Brighton and Thames Regional Health Authorities. She entered the House of Lords in 1990, and was made a Junior Health Minister in 1992. She spent five years on this brief, and following the general election in 1997, she was made Opposition Spokesperson for Health.

Baroness Cumberlege has advised Government on health issues, chairing national reviews into community nursing and also maternity services. She is an Honorary Fellow of five Royal Colleges. Baroness Cumberlege is currently Co-Chair of the Associate Parliamentary Group on Health.

Dr Michael Dixon (Co-Chair) - [College of Medicine](#)

Dr Michael Dixon is a GP and has been Chair of the NHS Alliance since 1998. Dr Dixon is a government advisor on GP commissioning and is a strong advocate of preventative medicine, healthy living and integrated care.

The College of Medicine is a charity founded in 2010, bringing together the expertise of patients, scientists, doctors, nurses and other healthcare professionals, redefining what good medicine means to create a more holistic, patient-centred, preventative approach to healthcare. The College is championing a culture of innovation, prevention and patient collaboration in medicine to create a NHS sustainable for the 21st century.

Professor Sir Mansel Aylward – [Public Health Wales](#)

Professor Sir Mansel Aylward is Chair of Public Health Wales, which is responsible for the delivery of public health services at a national, local and community level in Wales. He is also Professor of Public Health Education and Director of the Centre for Psychosocial and Disability Research at Cardiff University. The Centre extends knowledge and understanding of the psychosocial, economic and cultural factors that influence health, illness, recovery, rehabilitation and reintegration.

Formerly (1995-2004), he was Chief Medical Adviser, Medical Director and Chief Scientist at the Department for Work and Pensions and Chief Medical Adviser and Head of Profession at the Veterans' Agency, Ministry of Defence.

Dr Tim Ballard – [Royal College of General Practitioners](#)

Dr Tim Ballard has been a member of the MRCGP Panel of Examiners since 1996. He is a nationally elected member of the RCGP Council. He has been the sustainability lead for the College for the last six years. In 2013, he was elected to be Vice-Chair of Council for the RCGP where sustainability still plays an important part of his portfolio.

The Royal College of General Practitioners (RCGP) is the professional membership body and guardian of standards for family doctors in the UK, working to promote excellence in primary healthcare. The RCGP is committed to improving patient care, clinical standards and GP training. Acting as a voice for primary care practitioners and their patients, the Royal College plays a leading role in the formation of healthcare policy and standards.

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Neil Betteridge – Neil Betteridge Associates

Neil Betteridge is an independent health consultant offering patient insight and expert views as an experienced patient representative. He is Vice Chair of the Chronic Pain Policy Coalition; Patient and Public Voice representative on the Specialised Pain Services Clinical Reference Group for NHS England; Patient Adviser on Enhanced Recovery (NHS England); and International Liaison Officer, Public Affairs, with EULAR (the European League Against Rheumatism).

He was previously Chief Executive of Arthritis Care; Chair of ARMA (Arthritis and Musculoskeletal Alliance); Vice President of EULAR; and has twice been a ministerial appointee, as Patient Adviser to the Department of Health’s 18 Weeks programme; and as Transport and Disability Adviser to the Secretary of State for Transport, as Chair of DPTAC.

Professor Stephen Bevan – [The Work Foundation](#)

Professor Stephen Bevan is Director of the Centre for Workforce Effectiveness at The Work Foundation. He joined the organisation in 2002, as Director of Research. He previously worked at the Institute for Employment Studies.

The Work Foundation is a leading provider of research-based analysis, knowledge exchange and policy advice in the UK and beyond. The Work Foundation is part of Lancaster University – an alliance that enables both organisations to further enhance their impact. Its independent research focuses on health and wellbeing at work, innovation and economic change, labour market disadvantage and how organisational change can promote productivity.

Charles Gore – [The Hepatitis C Trust](#)

Charles Gore is a founding member and Chief Executive of the Hepatitis C Trust. He is also President of the World Hepatitis Alliance, an umbrella organisation for 200 patient groups worldwide.

The Hepatitis C Trust is the national UK charity for hepatitis C. It was founded and is now led and run by people with personal experience of hepatitis C and almost all of the charity’s Board, staff and volunteers either have hepatitis C or have had it cleared after treatment. The Trust’s mission is to reverse the rapidly increasing death toll caused by hepatitis C in the UK until no one dies from this preventable and treatable disease.

Carrie Grant – Broadcaster and patient representative

Carrie Grant has a successful career in entertainment as a TV presenter, singer and vocal coach. She is also an Ambassador for Crohn’s and Colitis UK, having been diagnosed with Crohn’s Disease more than 25 years ago. She has spoken frankly about the impact of the condition on her life, and her experience as a mother to four children who also live with long-term conditions.

Crohn’s and Colitis UK aims to improve life for everyone affected by Inflammatory Bowel Disease (IBD) – the main forms of which are Crohn’s disease and ulcerative colitis. Since its foundation in 1979, the charity has been providing information and support, funding research and fighting for change by bringing together people of all ages who have been diagnosed with IBD, their families and friends, and the professionals involved in their care.

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Phil Gray – [Chartered Society of Physiotherapy](#) and the [Arthritis and Musculoskeletal Alliance](#)

Phil Gray is the Chair of the Arthritis and Musculoskeletal Alliance (ARMA) having recently retired as Chief Executive of the Chartered Society of Physiotherapy (CSP) in January 2014 after more than 15 years of leading the organisation and working in national alliances across healthcare.

The CSP, founded in 1894 has 52,000 members and has grown rapidly over the last decade in response to healthcare demand in the UK. A member-led organisation, the CSP provides a wide range of member services and campaigns on behalf of all physiotherapy staff and the physiotherapy profession.

ARMA is the umbrella campaigning body providing a collective voice for 38 patient charities, professional bodies and research organisations for the Arthritis and Musculoskeletal community in the UK. Together, ARMA and its member organisations work to improve quality of life for all those living with musculoskeletal (MSK) disorders in the UK.

Laura Guest – [British Society for Rheumatology](#)

Laura Guest is the Chief Executive of the British Society for Rheumatology. She was previously Deputy CEO and Director of Commissioning at an NHS Trust, and led on patient choice commissioning at the Department of Health. She is a regular speaker at national conferences on improving outcomes and leading edge service developments.

The British Society of Rheumatology is the professional organisation for rheumatoid and musculoskeletal medical and long-term conditions. Its members include the whole multi-disciplinary team: consultant rheumatologists, trainees, specialised nurses, physiotherapists, podiatrists, occupational therapists, psychologists and GPs with special interest in rheumatology. The Society supports clinicians at all levels to deliver the highest quality rheumatoid and musculoskeletal care in hospitals and the community – in the UK and abroad.

Susan Oliver – Nurse Consultant Rheumatology, Member of the British Society for Rheumatology International Strategy Group, Fellow of the Royal College of Nursing

Susan Oliver has previously worked as Chief Nurse Advisor for the National Rheumatoid Arthritis Society and has published widely with a specific focus on Rheumatic and Musculoskeletal Diseases. She has participated in working groups and advisory boards for the National Institute of Health and Clinical Excellence and Department of Health in the past. She is interested in innovation in the context of improving high quality cost effective care and has been involved in mapping patient journeys through health care and undertaken consultancy roles supporting change with a specific focus on service re-design.

Susan is currently Chair for the European League Against Rheumatism (EULAR) Health Professional Standing Committee. EULAR represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. A pan-European organization; it fosters a multitude of activities in areas of research; patient care; and education.

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Mark Platt – [Royal College of Nursing](#)

Mark Platt is the lead for the Royal College of Nursing’s work on involving and engaging with patients and patients groups on health and social care policy, and works on issues relating to patient experience, including choice and quality. He also co-ordinates the RCN’s Patient Policy Exchange, a group of leading patient organisations which work with the RCN on nursing and care policy issues.

The RCN represents the interests of nurses and nursing, promotes excellence in practice and shapes health policies. The RCN works to develop and implement policy that improves the quality of patient care, and builds on the importance of nurses, health care assistants and nursing students in improving health outcomes.

Matt Regan – [AbbVie](#)

Matt Regan is General Manager of AbbVie UK. He was previously General Manager for Abbott Laboratories in Norway.

Separated from Abbott in 2013, AbbVie is a global biopharmaceutical company working to address some of the world’s greatest health challenges. As a new company, AbbVie is committed to taking a fundamentally different approach to addressing the healthcare challenges of the 21st century. By working in collaboration with stakeholders across the healthcare spectrum, AbbVie’s vision is to help build a sustainable future for the NHS, and health organisations around the world.

Professor John Weinman – [King’s College London](#)

Professor John Weinman is a Professor of Psychology as applied to Medicines, at the Institute of Psychiatry and the Institute of Pharmaceutical Sciences at King’s College London. He is a Fellow of the British Psychological Society and the European Health Psychology Society.

King’s College London is one of the top 20 universities in the world, providing world-class teaching and cutting-edge research. King’s College London is dedicated to the advancement of knowledge, learning and understanding in the service of society. It has 25,000 students (including more than 10,000 postgraduates) from 140 countries and over 6,500 employees. It has a distinguished reputation in the sciences; including health areas such as psychiatry; medicine; nursing and dentistry; as well as in humanities; law and the social sciences.

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**Patient, manager, expert: individual.
Improving the sustainability of the healthcare
system by removing barriers for people with
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